Christine Durham
Paul Ramcharan

Insight into Acquired Brain Injury

Factors for Feeling and Faring Better

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Preface

Brain Injury: Broken Brain, Bones, Body, Life and Spirit

I believe I am in hell therefore I am.

Arthur Rimbaud

My life was broken in a split second in 1991. Driving from a day's teaching to Melbourne University, a car running a stop sign hit my car, spinning it 360 degrees until a power pole in my door finished my flight. The other driver went to get a quote to have his damaged car repaired, leaving me unconscious, choking on my seat belt and having an epileptic fit. Providentially, a passer-by witnessed the accident, ran to my aid, smashed the driver's window, removed the seat belt and stayed by my side for forty minutes while the fire department's 'Jaws of Life' cut my car in two.

Eventually, when I briefly opened my eyes, I was told (but immediately forgot) that I was in intensive care in hospital. In this agonising hell everybody had two heads; they would emerge from the fog to torture me and then fade away. Bewildered and terrified, I did not know if it was normal for people to be two-headed and had no words to express this. Agony from injuries that included multiple breaks to more than half of my ribs took my breath away. A collapsed lung and double pneumonia nearly took my breath away permanently.

That was over two decades ago but ever since that day I've struggled daily with brain injury, pain (I still regularly see a physio), double vision, memory and cognition problems and difficulties with balance. Life has been an exhausting and daunting challenge with difficulty understanding, accessing and comprehending information; mourning the loss of the 'old me', not knowing the 'new me'; ashamed to be a 'bumbling idiot' and terrified that I was insane. For many years, I was frustrated, bored and angry to have to relearn everyday tasks of dressing, eating, walking and talking.

Just recently, I had a 'meltdown' and could not stop crying. This was brought on by vivid flashbacks to my decades ago pain and powerlessness. Back then, I did not understand brain injury and was humiliated and embarrassed at my loss of privacy and modesty (strangers—medical professionals and lawyers constantly tested and judged me leaving me distraught and disempowered as there did not seem to be any hope I'd ever improve). I remember how for several years after the accident I contemplated how I could end my misery. Luckily, my poor memory meant I forgot my plan to end it all.

As Winston Churchill stated: '*If you're going through hell—keep going*'.

After several months in hospital, doctors and nurses spoke of my need to go to a rehabilitation hospital. In my mind, I 'knew' that soldiers had rehabilitation and one thing I 'knew' was that I was not a soldier! I concluded that they all thought I was a soldier. I refused to go to rehabilitation. I longed to go home because perhaps I'd find 'me' at home. But 'I' was not there. The 'new' me did not even know where the tap was or how to turn it on.

I was also aware that I'd damaged the life of my devoted, devastated husband and four children who all tried to support and help me in different ways. But in the 1990s, prior to wide availability of the newly invented pre the World Wide Web, there was little information about brain injury, so they did not understand brain injury, or my needs, beyond the 'care' one would give a close relative who was 'sick'.

After a month struggling to cope with horrific pain, guilt, and limbs that did not obey me (I'd crawl to get upstairs), my wonderful GP explained how rehab would help me with my balance and give me coping strategies for my bewildering double vision. Two half days a week, a taxi would pick me up at noon. As I had no concept of time, I would eat my lunch at 9 a.m. and pace about the drive in panic, waiting for the taxi. I'd be exhausted by the time I got to rehab to do balance classes, occupational training and to complete numerous terrifying tests—tests that proved to me that I was now stupid and dumb. I was overwhelmed with shame: I could no longer do simple arithmetic, the sort that I'd give seven year olds at school.

After my accident I saw many professionals, but not one explained brain injury to me so that I could understand that I had not gone mad, that my difficulties were typical of brain injury—I needed a translation from the medical terms. It was not until several years after my accident that I saw the wonderful late Dr. Maureen Malloy who after giving me one test, remarked with great empathy, 'You must have difficulty understanding conversations in the staff room'. Just writing of Maureen, decades later, tears spring to my eyes because this was the first time someone demonstrated to me they understood how I grappled with life. For several years before seeing Maureen I had felt a like I was living in a plate glass box, separated from the everyday world.

I can't figure where I leave off and everyone else begins.

George McCabee

I had tremendous difficulty comprehending what people were saying to me. It was Rudyard Kipling who stated 'Words are, of course, the most powerful drug used by mankind' and Maureen's words removed a massive weight from my shoulders and from that moment I understood more and could start to forgive myself for being stupid and dumb. For years I had believed all the experts and professionals who told me there was no cure for brain injury, that I'd make the most improvement in the first six months (I was a helpless hopeless mess at six months) and then at two years I'd plateau out (I was an inarticulate, weeping, fearful, dependent, confused lost soul at two years post injury). I'd discovered that their words were true because no matter how hard I tried I didn't 'get better'.

> *Your nightmares follow you like a shadow, forever.*
>
> Aleksander Hermon

As my children cooked the evening meal, I would weep and wish I was dead. I'd be shaking with dread as the nightmare of the long night ahead approached when I'd be overwhelmed by petrifying pain from my smashed ribs.

I struggled to hold on to ideas so I could try to make sense of my predicament. Being like a child again, the words my father used to say to me when I was a child floated to my mind. He used to say 'Chick, a problem stated is a problem half solved'. So, I struggled and wrote a list of things that really upset me and gave it to my occupational therapist (OT). Her reaction was to sternly say 'I'm the expert I know what you need, you need to learn how to cook'. I did not have the words to say 'I've got a fridge full of casseroles from friends! I really need to know what to do when the phone rings because I don't know who is talking—me or the caller'. It scared me. It made me think I was mad. I nearly gave up trying to write after that experience, but somehow I felt compelled to record my experiences with very bad handwriting and even worse spelling on the backs of envelopes or scraps of paper—anything that was handy. I could not say the words or thoughts but I could capture them with a pencil and paper.

Still searching for the 'old' me I thought I would find 'me' at school, so six months after the accident I insisted on returning to school. But the 'old' me was not at school. Ivanhoe Girls' Grammar was wonderful and said I could help in the library for two half days a week. This was a challenging nightmare because of my balance difficulties, double vision and complete loss of the alphabet. My students would hug me, which was rather painful, and I was baffled as I could not follow conversations in the staffroom. The taxi trip to home was frightening. I would then stand under a boiling shower to try to get warm and then collapse in bed, totally exhausted. The following years were spent in a similar way: school, resting, visiting doctors and completing tests for the lawyers. But I kept writing.

> *If there's a book that you want to read, but it hasn't been written yet,*
> *Then you have to write it.* Toni Morrison

Some early mornings when my brain and eye (one was patched) were 'fresh', I tried to record my experience and what I'd learned about brain injury. My sons set up our new computer with bold size 18 point font, and I tapped away with one finger (I still type this way). I was determined that no one else with brain injury should ever be as lost and frightened as I was. I also wanted to show the man who caused my accident what he had done to another human being. I thought about giving him is an a copy of my subsequently published book *Doing Up Buttons* (Durham, 1997, 2005), but did not contact him. ‘*Buttons*’ as it became ubiquitously known as autoethnographical text, a personal narrative exploring my experience of brain injury and my subjective experience of a changed life. It also gives readers insights into their own problems of brain injury.

I discovered that reading can help people find themselves.

I gave my manuscript to a literary agent and within a week I had signed a contract with Penguin Books. *Buttons* immediately struck a chord with many people whose lives had been changed by brain injury or who worked with people with brain injury, because it translated brain injury into something people could understand. For over a decade, letters continued to arrive with positive messages.:

> ……yesterday, I bought it and last night I read it. I couldn’t put it down. I laughed, I cried, I became angry and I read large chunks of it out loud to my husband. At the end I was emotionally exhausted but also astounded…I started reading it during dinner and did not move until I had finished it. I literally could not put it down…For me your book is about a whole lot of things—tragedy, enormous struggle, courage, support, love, loyalty, triumph and a journey that never ends…but most of all it is about guts…

> …As I can no longer rely on my memory to recall, I ‘dog eared’ the pages of your book as I came across relevant information. Would you believe when I came to the end I had ‘dog eared’ nearly every page!…For me it is so confirming of my head injuries…

Over the subsequent years, invitations came to speak at conferences, meetings and workshops for people with brain injury, brain injury organisations and rehabilitation professionals and lawyers in Australia and overseas. Often people had travelled great distances to attend. It was humbling to think that the book had made such a difference to their lives. I formed a speaking business *Talk About Change* and spoke to a wide variety of groups at first assisted by my sons or daughters. Handicapped by pain, memory problems and faulty balance, double vision and difficulty expressing my thoughts, I drew on my teaching experience and used pictures, analogies and stories and Alice from ‘Alice in Wonderland’ to translate information about brain injury so it could be easily heard and understood.

One good analogy is worth three hours discussion.
Dudley Field Malone

At the conclusion to my talk, in order to capture the curiosity of the audience (and give them a take-home message to remember), I’d asked my 20-year-old son to walk down the aisle from the back of the auditorium carrying a mixing bowl and ingredients to make a cake while I donned an apron. As he placed these objects onto a table on the platform, I encouraged the audience to reflect on their previous knowledge of brain injury and what they had been reminded of with pictures, objects and analogies of my presentation.

I'd place the ingredients in a bowl to make a cake, I called it 'The Coping Cake', and I asked the audience to suggest what the ingredients could represent. For example, flour, (the greatest ingredient volume in the cake), what did they think the most important 'ingredient of 'recovery' was? Frequently they would suggest flour could stand for hope, sugar could represent the sweet/good things of life, milk could stand for the milk of human kindness and eggs denoted thinking and talking to bind together information and ideas. Once these ingredients were assembled in the bowl, I would ask the audience if this was a cake. Of course, the answer was 'No'. From the show of hands someone said, 'First you have to beat the mixture, then cook it'.

I produced a giant golden spoon and explained that the job of these professionals was to encourage their patients to *put in the effort and pick up the spoon* to put an *effort* into their own recovery (they, the specialist could not 'give' them 'recovery'). I gave the participants golden spoons with the label 'Changes in life to understand? Remember Alice in Wonderland' as a take-home message.

Using a number of devices like this, I continued delivering scores of presentations over the years and was amazed at the audience reaction. So I discovered that by using learning principles in producing a symbol of a concept, then making connections between the objects/symbols to practical everyday issues, the interest and understanding of the audience could be enhanced. In addition, this use of humour, the unexpected and a twist to make an association, proved to be a powerful vehicle whether I was speaking to professionals or people with brain injury. This was very different to just giving them information—*they* had to put in the *effort* and make connections and understand.

Alice from *Alice in Wonderland*, an analogy I used firstly as 'blurb' on the back cover of 'Buttons', was later used to explain to professionals what it feels like to experience brain injury. This analogy also resonated with people with brain injury. I spoke to one woman who became blind because of her brain injury—she had obtained an audio book of *Doing Up Buttons*. She told me she had had to listen to the reading of the back cover blurb several times because she was crying with relief that, at last, *here was someone who understood brain injury*. Such recognition committed me to listening to people's stories.

> *When people talk, listen completely. Most people never listen.*
>
> Ernest Hemmingway

I spent a decade speaking to groups about brain injury. *Doing Up Buttons* had been out of print for several years when a young man, Harry Troedel, contacted me to get a copy of the book for his friends 'so they would understand'. He said the book should be available for people and he made phone calls and obtained some funding and I put in sufficient money for Penguin Books to reprint 1,000 copies of the book. Together Harry and I gave away the books from the Transport Accident Commission's stall at the 5th Congress on Brain Injury in Melbourne, 2005. I purchased another 100 copies to give to organisations that had supported the publication and to give to Headway, a leading brain injury organisation in Australia.

With the book, we gave out what I called ‘Hope Stones’—beautiful, black polished river pebbles purchased from a garden supply outlet. I attached small gold stars (like I used as a teacher to reward good work) to the stones. The message of this object was that people with brain injury *can* tackle the hard things (like the hard stone) and reach for the stars. Although these take-home messages (like the golden spoons) had been enthusiastically received by audiences after presentations, I was unsure of how they would be received by the delegates of this conference.

But I did not need to fear. The keynote speaker from the USA requested thirty stones to take back to her students. We gave away forty kilograms of these stones! Attendees would come up to me on subsequent days of the conference and pat their pocket saying ‘I’ve still got it with me’—and over the years when I’ve encountered some of these people, they still speak about the influence of their ‘Hope Stone’.

The experience of this conference was remarkable. I met nurses who told me how they had purchased copies of the book to give to people with brain injury, and I learnt that the book was a recommended text at universities from Darwin to Perth to Sydney. It affirmed to me that the book was useful to people with brain injury, their families and professionals. I now faced a quandary, I had put such a tremendous effort into regaining my life and I still experienced so many brain injury and accident-related difficulties that some days I thought to myself, ‘I’m 63, at last now I can put my brain injury experience behind me’. Yet on other days, I felt compelled to speak for all those people who could not speak for themselves and I realised I had discovered a different way to communicate, ‘translate’ the consequences of brain injury.

> *Personally I’m always ready to learn, although I do not always like to be taught.*
>
> Winston Churchill

When I returned to ‘teaching’ for a few hours a week, I progressed from weeping into my eye patch, struggling to be of use in the library, to taking small groups of students for enrichment activities. As a Founding Member of Philosophy for Children, I’d returned from speaking at an International Conference in Mexico a few days before my car accident. I believed it was vital to teach children to think for themselves. This was grounded on my father’s ‘Thinking Walks’ where we’d go for walks along the beach and he’d discuss politics, opera or chess moves with me and ask for my opinion. I frequently did not totally understand the conversation; however, the experience of being treated as an intellectual equal boosted my belief in the importance and power of thinking, and proved to me that through exploring ideas you could find ways to solve problems.

As double vision and memory loss meant that reading was difficult, I used objects similar to the ‘coping cake’ to engage and focus the students’ (and my) attention. I made notes (or the children took the pen from my hand saying ‘I’ll do it, you know you can’t spell Mrs D’), and from these notes I wrote *Chasing Ideas* (Finch Publishing, Jessica Kingsley Publishing) (Durham, 2001, 2014), a book about helping children to think for themselves. I was fortunate that Dr. Edward de Bono endorsed the book, and it has been translated into Taiwanese, Chinese and Arabic.

This book led to invitations to speak about 'thinking' and conducting workshops for Melbourne University, Nan Yang University, Singapore and speaking to principals, teachers and parents. Little did I think that over ten years, teaching part-time I would have the challenge and privilege to conduct 4,000 philosophy/thinking workshops and *my students* would teach *me* how to talk and think again. I adored teaching, however, reluctantly, I acknowledged that the effort of pushing through the pain, double vision and fatigue to teach two days a week consumed most of my energy. I left teaching.

Sixteen years after the accident, every day I felt fortunate to be alive—that I did not die in the accident, or by my own hand. I kept asking myself 'What more can I do to help people with brain injury?' After a presentation to University Disability Liaison Officers, several audience members suggested I should use my experience and knowledge to a Ph.D. About this time, I also heard about the philosophy of phenomenology, and this fired my imagination. At an Open Day at RMIT University, I met Dr. Paul Ramcharan and with his great knowledge he guided me as supervisor of my Ph.D. We both had evidence that although every brain injury is *biologically* different, the way people *feel* about their injury contains many similar themes. The question for the Ph.D. study was aimed at identifying these uniting and mundane themes that negatively and positively affect the life of people with brain injury with a view to identifying factors that help them feel and fare better. I am delighted that Paul Ramcharan agreed to co-author this book.

I have explained how the 'Coping Cake' and the 'Hope Stone' were used to gain the attention and curiosity of audiences and how these metaphors were employed on scores of occasions for a wide variety of audiences. In the search for an engaging, original, non-medical and non-threatening way to connect and communicate with people with ABI, I was drawn to the metaphor of how brain injury 'imprisons the individual'. I thought about symbols that could be used to help participants with memory, cognitive and physical difficulties to focus on their experience in a completely different way with foundations based on Vygotsky's theory of the 'zone of proximal development'.

Sir James Frazer, in 'The Golden Bough', introduces the reader to the book by presenting the vivid picture of the scene and the forest from which a 'golden bough' may be cut by an escaping slave, and be used in self-defence. If victorious, the slave may take the ruler's place. The book then unpacks and expounds on the plethora of issues that explain the reasons for this seemingly strange custom/belief, set in both mythology but also culture.

In similar fashion, borrowing from Frazer's concept of setting out the metaphor which directs, questions and explains concepts, Paul Ramcharan and I now present our own metaphor, one that is employed to provide an explanation and overview of the research approach. 'Keys to the ABI Cage' was developed to address some of the problems associated with brain injury (ABI) while being at the same time, a data collection tool. Below the history, origin and description of 'Keys to the ABI Cage' is given in order that the reader can understand the significance of each part and the nature and relevance of the whole.

I have an ornamental bird cage that has significant meaning for me. For several years following my accident, I wore a black eye patch, like a pirate. Friends gave me brooches and China parrots as a joke, but I longed for a dove, a symbol of peace and freedom. My son Ken located two baby fantail doves, which he presented to me when I was working on the manuscript of *Buttons*. These tame white doves kept me company. I'd wrap them in a towel and they rested on my lap, or they would perch on my shoulder, while I worked at the computer. I would take them outside to let them walk about, and I tried to give them flying lessons. Fantail doves are not like 'proper' birds, as they can neither fly nor walk properly. I felt I was not a 'proper' person as I could neither walk nor talk 'properly'. These doves appear to have lost their head as they frequently position it behind their shoulders along their back. I felt as if I'd completely lost my head—we had a lot in common and we developed a great bond.

Once Penguin Australia published the book, I had numerous media interviews and the doves were often included in the photographs taken to accompany the story. When I went on television, or spoke to groups, I'd take the birds in the fancy travelling cage to remind me to explain how these birds are bred to be like this, so when they are released, they cause a commotion, and flutter in the air, providing a guide to help the homing pigeons find their way home. This provided me with a prompt to say I hoped my book could cause a flutter to help people with brain injury find peace and hope—and to find their own way home too.

Over the years, I've often looked at the cage and thought brain injury is just like being locked in a cage and the key is thrown away. This was how I decided to use the cage, my old walking stick and a wooden pole topped by a wooden flying pig, as an interesting structure to hold cards on which were written words that had been spoken by people with ABI in my fieldwork prior to this study. Thus, symbols and words were combined to assist people reflect on their experience of ABI. The participant-guided interview was a conversation with a purpose—to help participants review things that helped them in a positive way.

The cage was labelled 'The ABI Cage' and once the interview/learning tool was fully developed I called this metaphor-model *Keys to the ABI Cage* to give the process a positive focus. The cage, walking stick and pole held what I initially called 'talking-cards' (after Cameron & Murphy's Talking-mats, 2002) but later changed the name to 'talk-about' cards because the cards did not 'talk', but they did contain information people had talked to me about and the statements were used to invite participants to *talk about their* experiences.

The *Keys to the ABI Cage* is presented on the following page. The assembled metaphor tool is 160 cm high and, 100 cm wide.

It immediately captured the attention and interest of the participants with ABI who did not expect to be confronted with a bird cage, a metaphor-model visually attention-grabbing 'tool' to facilitate reflection, communication and learning. This simplification allowed the participant to reflect and more easily understand how ABI affects their lifeworld.

The ‘talk-about’ cards and other objects in the cage were employed in the interviews to provide interactive prompts for participants to think about and talk about their own chosen concepts and ideas in the three focus areas. The tool was ‘organic’. If people wanted to add categories that did not already exist, they were able to write on a blank ‘talk-about’ card and add to the cards to use in subsequent interviews. The ‘talk-about’ cards allowed participants to ‘wander’ through the concepts as they chose, make connections and change their mind after further reflection. “The tool divides the complicated issues and consequences of ABI into three main themes.”

Theme 1. ‘Our Differences and Difficulties Can PUT us in ‘the ABI Cage’

This sign can be seen hanging on my old walking stick horizontally inserted into the left side of the cage, along with black-backed ‘talk-about’ cards held in plastic pockets. Like the two other themes described below, the choice of ‘talk-about’ cards for this theme was drawn from the literature reviewed, from public information and personal and wider experiences of people with ABI.

Theme 2. ‘How We Feel About Our Differences and Difficulties Can LOCK us in ‘the ABI Cage’

This sign can be seen near the padlock on the cage door. Hanging **inside** the cage were red-backed ‘talk-about’ cards, hung on hooks held by bird-shaped mirrors—to remind people to look and reflect. Words on the ‘talk-about’ cards were drawn as for Theme 1. Additionally, there were objects that were metaphors or symbols—a crushed Solo® drink can (to symbolise a crushed life), a snuffed out candle (a finished life) and a toy snake (people see me as scary).

Theme 3. ‘Keys Can RELEASE us from the ABI Cage’

This sign can be seen on the right side of the cage at the top of the long wooden pole with golden keys attached to it. The pole was crowned with a wooden pig with flywire wings—a flying pig—symbolising achieving the impossible. Hanging on the pole were white-backed ‘talk-about’ cards fixed to a rigid Perspex sheet. These cards had mini objects attached to them (e.g. sun for sunshine, mushroom for nature, tiny cup for coffee, a tiny dog for animals, a ring for love, a rubber band for stretch outside my comfort zone and so forth) to capture the interest and hold the attention of participants, as by the time they reached this most important stage of the interview, participant’s attention might be flagging and they might be experiencing fatigue. These particular cards and objects focused on factors that help to ‘release’ people from the cage. Words on these ‘talk-about’ cards were drawn as for themes 1 and 2.

Chapters 1–6 describe in detail how and why *Keys to the ABI Cage* was developed and used in this study. Participant data obtained from this unique object is then explored in Chaps. 7 and 8. This leaves us to support the reader to see the relevance of the cage to everyday lives and to practice in Chaps. 9 and 10.

Photograph 1. Keys to the ABI Cage

1. Our difficulties and differences can PUT us in the ABI cage.

3. Keys that can RELEASE us from the ABI cage.

2. How we feel about our differences and difficulties can LOCK us in the ABI cage.

Eltham, Australia Christine Durham

Contents

Chapter 1
Acquired Brain Injury

If I have lost confidence in myself, I have the Universe against me.

Ralph Waldo Emerson.

1.1 Introduction

Brain injury is a big problem worldwide.

> Traumatic brain injury (TBI), according to the World Health Organization, will surpass many diseases as the major cause of death and disability by the year 2020. With an estimated 10 million people affected annually by TBI, the burden of mortality and morbidity that this condition imposes on society, makes TBI a pressing public health and medical problem, (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007).

It is difficult to gain a picture of numbers of people affected by brain injury as some sources only report the number of people admitted to hospital. Many people who suffer a traumatic brain injury (TBI) are not admitted to hospital, and the numbers might not include people with acquired brain injury (ABI), where brain injury is acquired through stroke or other medical conditions. In 2003, the Australian Bureau of Statistics (ABS, 2004) reported that the annual incidence rate in Australia, the UK and the US totals some 2.7 million traumatic brain injuries. More recent statistics refer to ABI as the 'hidden disability'. One in every 45 Australians had a brain injury with 'activity limitations' or 'participation restrictions' due to their disability (AIHW, 2007, p. 1).

In the USA, there are 1.7 million new cases of brain injury each year—4000 a day or three per minute—and each year, there are 52,000 deaths due to brain injury (Faul, Xu, Wald, & Coronado, 2010). To put this number in context, it is more than all the American troops killed in the Vietnam War and today up to 20% of US soldiers returning from duty in war-torn areas have mild traumatic brain injury (Hoge, McGurk, Thomas, Cox, Engel & Castro, 2008).

Societies carry considerable financial cost for the lifetime care of people with brain injury. The *Access Economics report for the Victorian Neurotrauma Initiative* (June 2009 p. xiii) identified that for the year 2008, there were an estimated 1493

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new cases of moderate TBI and 1000 new cases of severe TBI in Australia . In this 2009 report, the total cost of TBI in Australia was estimated to be A$8.6 billion:

> The greatest portion [is] born by individuals (64.9%) the State Government (19.1%) and Federal Government (11.2%). The lifetime costs per incident case of TBI were estimated to be $2.5 million and $4.8 million for moderate TBI and severe TBI respectively, across Australia. (p. xvi)

These figures do not take into account the cost of care for people with 'mild' traumatic brain injury.

There are also significant personal costs associated with ABI. An Australian Institute of Health and Welfare Bulletin stated that:

> People with ABI tended to have complex disabilities, they reported more health conditions than the average person with disability, more than one in three people with ABI needed cognitive and/or emotional support, 82% of people with ABI also had physical disabilities, 42% had psychiatric disabilities, 39% had sensory or speech disabilities, 29% had intellectual disabilities, people with ABI report problems including depression and mood affective disorders, 32% of people with ABI received some assistance with cognitive or emotional tasks, but stated that they required more help. (AIHW, 2007 p. 1)

Brain injury can produce issues in solving everyday problems that are highly relevant to a person's welfare. This can mean the person has fewer ways to buffer or deal with external stressors (Lazarus & Folkman, 1984). In a study conducted in the USA, there was a mean loss of 14 points of full-scale IQ from preinjury baseline IQ for people with brain injury (Parker & Rosenblum, 1996).

In the future, with an ageing population, it is estimated that more people will suffer from ABI as a result of falls and other accidents. In an article about ABI among people aged 65 years or over in 2003, it was claimed that 4.7% of this population had ABI (AIHW, 2007), which caused diverse disability causing physical, sensory, speech, cognitive and emotional problems.

However, despite these 'official' statistics, this book directs the reader away from the deficit-based model implicit in the above data that we argue is widely used by medical and health professionals working in the ABI field. Rather, the 'insider's' view of acquired brain injury (ABI) and, given our backgrounds, both educational principles and scaffolding support, underlie our alternative approach. This approach is cursorily laid out below to prime readers as to what proceeds in subsequent chapters.

First, to provide insight into brain injury from an 'insider's' view, the participant's difficulties and needs are embedded in each step of this journey through the employment of van Maanen's concept of 'Headwork' (2011). 'Headwork' shown in figures placed in boxes in Chaps. 1, 3–5 allows the reader to understand the concepts that inform our method, and the development of the new and novel interview and learning tool including the 'Talk-about' cards presented at the end of the Foreword. At the same time, 'Headwork' allows in-depth consideration of those ethical dilemmas that needed to be addressed in our study and, we posit, should represent an ethic that is addressed in all research with people with ABI to make sure that the research 'does no harm'.

The Foreword allowed the reader to enter the private lifeworld of a person struggling with brain injury as Durham shared her personal challenges of a life changed by brain injury as a means of exemplifying what personal experiences participants in the study and studies involving people with ABI might bring.

Second then, this background information explains the reason why the method employed by this study carefully considered ways to take these difficulties into account in order to *do no harm* to the participants: to preserve their rights, privacy, dignity and well-being. The raison d'être and the focus of the present research are discussed.

Third, our focus is on people's everyday life and experiences, and as such, this chapter purposely visits and discusses 'grey' literature, including information from brain injury support organisations. Doing this allows the reader to enter the life-world and rehearse the learning journey or information gathering most likely to be carried out by the person with brain injury and their family; it prepares the reader for the focus of this book where the primary researcher is a collaborator, an 'insider' with the participants, rather than being a study 'about' or 'on' brain injury; it acknowledges the voice of people with brain injury and demonstrates that weight will be given to their words, rather than only looking at input from professionals.

Many studies propose that people with brain injuries lack self-awareness. In this chapter, information written by people with brain injury demonstrates that some people do have awareness and understanding of the phenomena of brain injury and highlights issues they consider important. 'Grey' literature is therefore examined to allow the reader to compare and contrast the person's experience of brain injury with concepts of people who care for and support people with brain injury. More formal analysis of the underlying assumptions of these different discourses is considered in Chaps. 2 and 3 as quantitative body-object models and paradigms and in Chap. 4 as the qualitative body-subject model or approach.

1.2 Acquired Brain Injury(ABI)

Brain injury is the single greatest cause of permanent acquired disability in our society (Rees, 2005, p. xi). It affects body, brain, life, status and future of one in 45 persons (Australian Institute of Health and Welfare [AIHW], 2007). It is said that these people do not 'get better', 'recover' or 'return to a normal state of health, mind or strength' (Oxford Dictionaries, 2010)—they cannot be cured or restored to health by operations, medication or 'treatment', although millions of dollars have been invested in studies that strive to discover ways to help people with brain injury make 'progress', or at least to maximise biological function.

Independent of what is 'known' about the prevalence of brain injury, far less attention has been paid to self-awareness of those with brain injury. Rees (2005) argues that 'Recovery for people with brain injury is relative, and in this context means learning again and developing skills and behaviours that enable the person to enjoy and achieve, irrespective of brain injury' (p. 8). The person's knowledge and beliefs about their impaired abilities (their self-awareness) are important components of their recovery and adjustment (Cicerone, 1991; Medley & Powell, 2010; Medley, Powell, Worthington, Chohan, & Jones, 2010). But their motivation to participate in rehabilitation, or to adopt compensatory strategies, may be affected by impaired self-awareness (Bogod & Mateer, 2003; Fleming & Strong, 1999).

To obtain self-awareness, the person needs to have both the will and the way—the will to concede they *do* have difficulties (this requires courage, confidence and hope that they can *do* something about their difficulties). The person also needs to find a way to learn about their difficulties, to understand *how* they have been affected by brain injury and *what* they can do to deal with, compensate for or cope with their deficits (Durham, 1997).

The present study endeavoured to find an approach to help people with brain injury discover 'their will' and 'their way' because poor self-awareness after brain injury can cause low motivation, non-compliance, minimal engagement and lack of progress in therapy (Ownsworth, Desbois, Grant, Fleming, & Strong, 2006; Fleming, Strong, & Ashton, 1998; Fleming, Winnington, McGillivray, Tatarevic, & Ownsworth, 2006). When a person's life is shattered by brain injury, they need to be motivated and actively engaged to make progress. But studies have demonstrated that increased self-awareness can result in increased emotional distress (Fleming et al., 1998; Wallace & Bogner, 2000) and higher levels of depression (Fleming, Lucas, & Lightbody, 2006; Fleming et al., 1998).

Here is the problem. How can people acquire better insight into brain injury in a positive and beneficial way?

> *We are confronted by a condition, not a theory.*
>
> Grover Cleveland

The journey to self-awareness is complex. The person may be aware of physical difficulties (e.g., they cannot move their limb) one moment, but 'forget' the next; a result of impaired memory might be that many times a day they have to 're-acknowledge' this fact, and additionally, the 'intense effort' required to form a word or to move a limb may be expressed as 'anger, depression, anxiety or fear', (Yudofsky & Hales, 2008, p. 630). Cognitive and emotional difficulties may only become apparent when the person discovers an inability to understand a question or 'find the words' to answer, when they cannot tell the time or work out what to do, or uncharacteristically lose their temper, or feel defeated when they labour to complete a 'test' in rehabilitation.

The rehabilitation practitioner generally obtains information about the person's self-awareness by comparing the patient's self-report of their function, with reports from family members and the rehabilitation staff's more objective measures (Silver, McAllister, & Yudofsky, 2011) using methods such as structured interview questions scored according to a rating scale, which rely on the patient's verbal ability (Silver, McAllister, & Yudofsky, 2011). These methods may not be the most helpful way for the individual to learn about their difficulties, differences and deficits (Durham, 1997). The very act of turning acts, behaviours and emotions into 'scores' and 'ratings' denudes personal experience as will be detailed later.

Indeed, it will be argued in later chapters that assessment testing (and data collection) has the potential to negatively affect the self-confidence and self-esteem of people with brain injury rather than to benefit the person.

Durham has faced the daily struggle to find the will and the way to make ‘progress’ since her brain injury. And as an educator, she has queried whether educational and learning principles could be employed to empower people with brain injury to reflect upon, and better understand themselves—obtain greater self-awareness—so they can learn to feel and fare better. This study aimed to find a method to ask ‘new questions to illuminate “blind spots”, areas in which existing theories, methods and perceptions (might) actually keep people with brain injury and their families and professionals ‘from seeing phenomena as clearly as we might’ (Wagner, 1993, p. 16)—to find ‘What we don’t know well enough to even ask about or care about ... our “blind spots”’ (Wagner, 1993, p. 16). This approach contrasts to the assessment tests, scales and questionnaires used to find answers to what Wagner terms ‘blank spots’, where enough is known about an issue to pose questions, to gather data to fill in the blank spot, as is used by quantitative research. In this volume, these blind spots will be hypothesised in the theoretical form (*see* Chaps. 2–5), identified and characterised more fully from the data collected (*see* Chaps. 7 and 8) and then described more fully in discussion and recommendations (*see* Chaps. 9 and 10).

For now, it is sufficient to emphasise that the present study aimed to help people explore their lifeworld (*Lebenswelt*) as described by Husserl (*see* Husserl, 1952, 1962), the founder of phenomenology: the world of their lived experience since they acquired their ABI. Using the Cage, this was undertaken in a constructive way in spite of participants potentially feeling fragile and vulnerable and in a way that employed principles of education and learning to support greater self-awareness.

Models and metaphors were employed to assist the participant to reflect their lifeworld in a positive way. Nietzsche wrote that ‘One must employ models and metaphors drawn from whatever resources are available’ (Nietzsche, 1995, p. 622). Data collected was analysed using interpretative phenomenological analysis identifying factors that negatively and positively affected the lifeworld of the person with brain injury and in a manner designed so that they discovered *for themselves,* through participation, things they could do to *help themselves*.

1.3 Introducing Brain Injury Through Experience

Damaged brains produce damaged bodies, damaged cognition, damaged emotions, damaged behaviour, damaged interactions, damaged people and damaged lives. Or so, we argue, it is assumed by many medical and health practitioners. Chapter 3 will examine literature from some of the innumerable body-object quantitative studies that examine specific issues to do with brain injury in order to exemplify our arguments in opposition to medical model assumptions that primarily focus on pathology and ‘mending bodies’.

As this research inquiry posits, this body-object approach is not the only possible approach to assist people with brain injury. Social model of disability theorists speculate that the reliance on the medical model leads to a model of pathology and obscures how society itself can be disabling in its approach to individuals, (Barnes, 1990; Barnes & Mercer, 2004; Barnes, Oliver, & Barton, 2002; Finkelstein, 1980, 1993; Oliver, 1983, 1990, 1996). Chapter 4 will examine literature from the body-subject qualitative studies that examine issues such as quality of life and coping, yet it is surprising how little research has been undertaken to examine how the individual, as a *whole person,* attempts to 'reconstruct' themselves and their lives.

When people with ABI, family, friends or others look at information about ABI, much of it may come indirectly from such models. But what is the information available to people with ABI and others who undertake such searches to help them to feel and fare better? This chapter will provide an introduction to brain injury from publicly available information to illustrate the stated characteristics of brain injury, supply an example of information available about brain injury and assess its ability to meet their needs and to present a catalogue of the types of problems participants in this study might be contending with.

To accomplish this, the chapter will explore some of the information from support organisations in official Web-based material. Included will be books and blogs written by people with brain injury, which attempt to explain how the whole person goes about understanding themselves. By the end of this chapter then, the reader will be aware of some of the effects of injury to the brain and the complexity of this phenomenon we call brain injury, at least from the grey literature used by many in their attempts to make sense of themselves and their lives after brain injury.

In concluding this chapter, the aims, purpose and structure of this study will then be explained.

1.4 Gaining Information About ABI

When a person leaves hospital or rehabilitation with ABI, they may be looking for information and perhaps their family and friends may also have been looking for information on ABI prior to them returning to the family home and to the community. What can they find out? What information will support them? The following review of publicly available information has been approached from the perspective of a person with ABI who has recently left hospital.

How does the individual with brain injury, or their family or friends find out about brain injury? Initially, information is provided by hospitals, medical practitioners and health professionals, but the person with ABI may not be in a fit state to understand any more information than 'You've been in a car accident' and 'You've had a stroke'. Their family members ask the medical practitioners questions, as they have many 'blank' spots about ABI to fill in, and as time goes by, 'blind' spots become apparent. They search intently for information, but as they move from the sender–receiver model, which characterises the period under health and medical care, to the seeker–finder model, their approach can be a hit and miss exercise.

When the person leaves hospital and they seek to re-engage with everyday life, they may be in a state of trauma contending with pain from physical damage, or they may appear to be undamaged, but be experiencing difficulty understanding and talking so that information can be overwhelming, difficult to translate and understand, and deeply disturbing. They may try to digest information from pamphlets given to them at the hospital, and then, they may search for more information on the World Wide Web.

1.4.1 Information from the World Wide Web

The person with brain injury, and their family, would most likely turn to the World Wide Web for information provided by brain injury support organisations to try to find out about brain injury. In this search, they may locate information published in academic journals, but this information is not in a form that they can readily interpret and understand.

There is a plethora of brain injury support organisations' Websites, and readers will be informed that the impairments, deficits and psychological and emotional effects of brain injury vary according to the cause and severity of the injury. It is difficult to identify effects of brain injury because many problems are initially not obvious, or it requires a certain circumstance to highlight a specific difficulty. Thus, it is not easy to search for relevant information, and organisations cannot possibly impart information that is relevant to every situation and every circumstance. The reader becomes aware that there are many 'unknowns' and 'variations' in brain injury, so that the information may initially accentuate the sense of confusion and bewilderment.

In order to get a more detailed view of the information available in the public domain, a review of Websites was undertaken in 2009 in order to examine what information was being provided for the person with ABI and their family. The data below needs to be read with some caution given the exponential growth of Websites in recent years. To exemplify this, consider the following comparisons of the same Website between 2012 and the present time (January 2017). The most obvious difference is the added narratives and input from people with ABI. For example, 'Acquired Brain Injury a Web Portal for and by Brain Injury Survivors', 2017 (The Rehab Group), supplied online a manual, video library, a section in which people with ABI tell their story, and there is a 3D brain to explore the structure of the brain. This user-friendly form of information was not available in 2009 at the commencement of this study. Additionally, it is now possible to easily increase the size of the print to make reading available to people with vision difficulties. Compare statements on one Website between 2012 and 2017:

> Acquired brain injury refers to any type of brain damage that happens after birth. Causes include disease, substance abuse, oxygen deprivation, infection or a blow to the head. http://www.betterhealth.vic.gov.au.bhcv2/bjcarticles.nsf/pages/acquired_brain_injury?open (2012)
>
> Versus
>
> Acquired brain injury (ABI) refers to any type of brain damage that occurs after birth. It can include damage sustained by infection, disease, lack of oxygen or a blow to the head.
>
> https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/acquired-brain-injury (2017)
>
> From the same web addresses five years apart came the following.
>
> Traumatic brain injury (TBI) is an injury to the brain caused by external trauma such as in car accidents, sporting injuries including concussions and assaults. TBI (ABI) can cause long-term physical disability and complex neuro-behavioural effects which disrupt quality of life, including neurological impairment (e.g., motor function impairment and sensory loss), medical complications (e.g., spasticity and post traumatic epilepsy), cognitive impairment (e.g., memory impairment and problems with planning, language and safety awareness) personality and behavioural changes (e.g., impaired social and coping skills) and lifetime consequences (e.g., unemployment, difficulty maintaining interpersonal relationships and loss of independence.) (2012)
>
> Versus
>
> Traumatic brain injury (TBI) is not the same as head injury, since a person can sustain damage to the face, scalp and skull without necessarily injuring their brain. TBI is considered a form of acquired brain injury, and refers to brain damage caused by an impact to the head.
>
> When the head is struck hard, the brain slams against the inside of the skull, causing physical injuries such as bruising, swelling, bleeding, twisting or tearing of tissue. There are degrees of injury, ranging from a momentary loss of consciousness (which can happen from a punch to the face, for example) to a long-term bout of unconsciousness or coma, (2017)

These lengthy quotes have been included because they provide an exemplar of information available for people with ABI covering the majority of categories across sites. The earlier definitions in particular demonstrate the use of language and vocabulary that might be unfamiliar to the individual (motor function, cognitive impairment and so forth). They also present ABI terminology and definitions that are 'problem-based' and biological. The more recent definitions replace some terms with more understandable words (e.g. 'oxygen deprivation' becomes 'lack of oxygen', and 'external trauma is re-translated to 'When a head is struck hard…'.

However, at both dates, there is very little, if any, information about 'getting better', 'faring better' or re-engagement with everyday life. Indeed, in the 2017 version, the site suggests the following:

> The consequences of a person having an ABI are far reaching. Coping with any loss of functioning and going through rehabilitation can be difficult. The person with an ABI will have great distress. Family, friends and partners will also experience difficulties as they deal with emotional and practical challenges, interruptions to family life and role changes. (ibid).

It states 'problems' for family members and carers, concluding that 'Coping with the consequences of acquired brain injury can be difficult for everyone, including family members'. Once again though there is no information on how to manage these and in the 'Where to get help', section doctors, neurologists, BrainLink and rehabilitation units are the only ones mentioned.

Both the information, and the 'voice' or tone by which the information is presented, can play a role in the expectations of people with ABI and their families.

This book recognises brain injury as ABI—encompassing both TBI where the injury was caused by an external traumatic event and ABI where the injury to the brain was caused by a stroke, tumour or other medical condition (an internal traumatic event). However, as will be seen, the lack of information about how to address the everyday needs of persons once they return home is clearly a 'blind spot' even in contemporary Websites. Remember such blind spots describe where existing theories, methods and perceptions (might) actually keep people with brain injury and their families and professionals 'from seeing phenomena as clearly as we might'.

To exemplify this blind spot further, look at the Websites first reviewed in 2009 and presented in Fig. 1.1.

The first six Websites were chosen for a more detailed review that involved assessment of whether the information was suitable for a person with physical,

1. Headway Victoria (Australia) Changed Lives Modules.
2. The Children's Hospital at Westmead, NSW, Australia.
3. Child Brain Injury Trust Oxford, UK. 4. CBIT (UK) Factsheets.
5. Brain Injury Association of Queensland (Australia) Facts Sheets.
6. Monash-Epworth Rehabilitation Centre, Victoria (Australia) : Information about Mild Head Injury or Concussion.
7. Brain Injury Society Brooklyn, New York, Brain Injury Resource Centre, Seattle.
8. Traumatic Brain Injury (TBI) website of the American Speech-Language-Hearing Association.
9. Bethesda Hospital, Melbourne website, Steps Project: Skills to Enable People.
10. Communities Health Queensland Government.
11. Acquired Brain Injury 'The Facts' from Brain Injury Australia.

Fig. 1.1 Websites reviewed in 2009

cognitive and emotional difficulties associated with ABI. The review looked for potential difficulties a person with ABI might experience and included identification of the intended audience (the person with ABI and/or a family members) and the relevance of the information included the writing style and language used (formal medical language, or everyday language including jargon), print size, the manual dexterity required to negotiate round the site and presence of any distracting amount of information on the Web page (if there were distracting flashing advertisements to join the organisation or make a donation).

The scope of information on the Websites was also examined. Issues covered by the six Websites were information about the brain, causes of brain injury, minor brain injury, rehabilitation, the law/guardianship, balance, sensory problems, headaches, hearing, speech and swallowing, sexual problems, poor concentration, poor problem-solving, lack of initiative, inflexibility, impulsivity, visual disorders, memory and anger, socially inappropriate behaviour and emotional irritation. Detailed strategies to cope with these difficulties were not available in all Websites. Panic attacks, post-traumatic stress and pain were not covered in any of the Websites; information about depression, epilepsy, self-centredness and hospital was only to be found in three of the Websites.

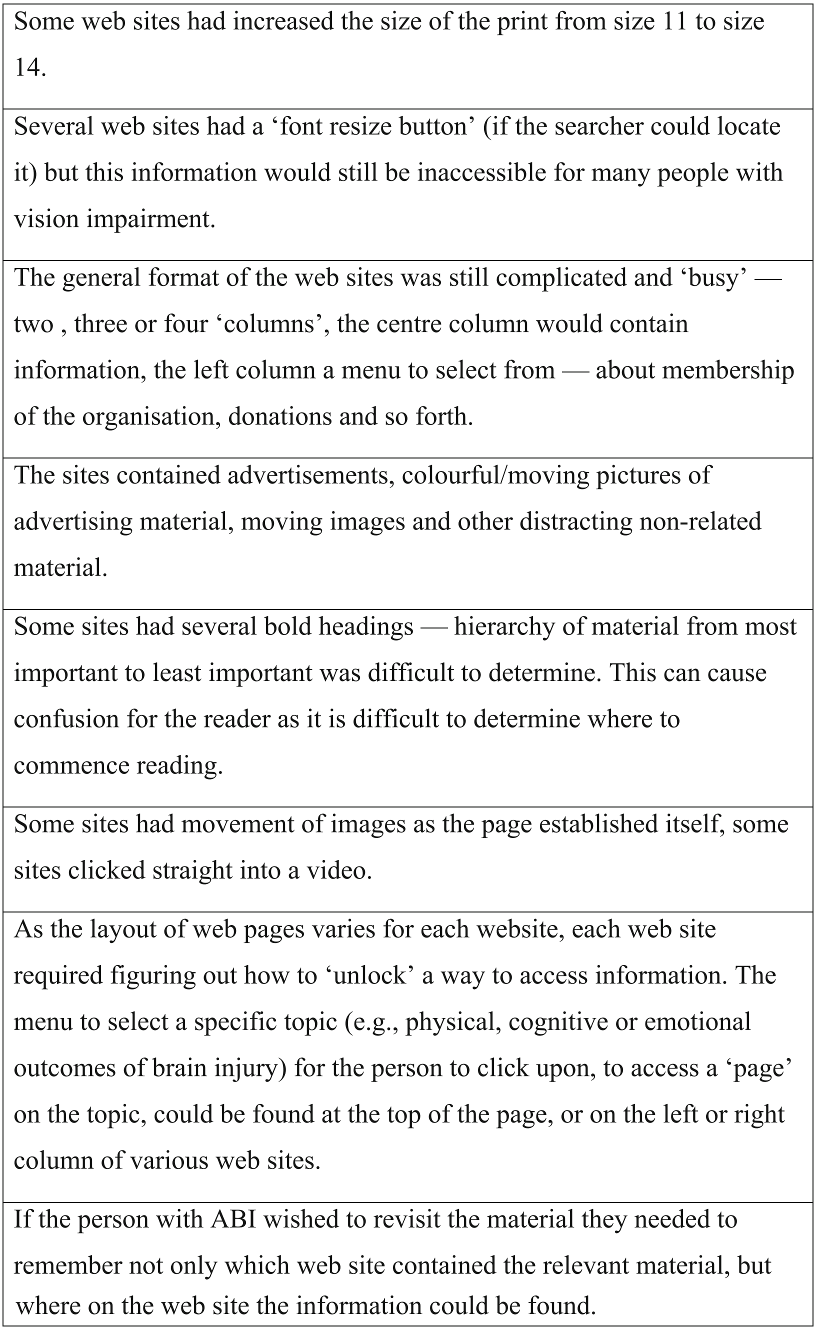
The Websites were also evaluated to ascertain whether educational learning theories were used in their construction and delivery. They were not. Websites were ‘seeker’ models of information. They contained ‘factual’ information, and educational learning theories (discussed in Chap. 5) did not appear to be employed.

Three years following the above search of Websites in 2009, a further review of the World Wide Web elicited from Google (the most obvious search engine a layperson or person with ABI would use) using the search terms ‘Information about brain injury’, for the first 20 Websites listed. These were prepared by health services, brain injury support organisations, doctors, lawyers, rehabilitation hospitals and national institutes, and observations about their content are shown in Fig. 1.2.

This review revealed that it can be still be tricky for a person with memory, sight and other difficulties to access and use Web-based information and to revisit the site and highlight main areas for future reference as might be possible in a book where pages can be marked with paper or post-it labels and main information highlighted in text.

Over the past three years on numerous occasions, Durham has embarked on a search for helpful material about ABI. Each search has produced nausea (due to double vision—moving images, memory difficulties) and frustrations at the complexity of searching through this material. Seeking meaningful information can be messy, complicated and difficult and leave the seeker with ABI frustrated and overwhelmed; it can be assumed that many other people with ABI would have similar experiences.

In order to learn, people with ABI require information *when they are ready* to *hear and understand* it. Relevant information must be presented in a *form* they can *understand,* at a *time* when they are ready to *absorb* and *act upon* it. The way the person with ABI is *motivated to engage* with learning can be affected by a plethora



Some web sites had increased the size of the print from size 11 to size 14.
Several web sites had a ‘font resize button’ (if the searcher could locate it) but this information would still be inaccessible for many people with vision impairment.
The general format of the web sites was still complicated and ‘busy’ — two , three or four ‘columns’, the centre column would contain information, the left column a menu to select from — about membership of the organisation, donations and so forth.
The sites contained advertisements, colourful/moving pictures of advertising material, moving images and other distracting non-related material.
Some sites had several bold headings — hierarchy of material from most important to least important was difficult to determine. This can cause confusion for the reader as it is difficult to determine where to commence reading.
Some sites had movement of images as the page established itself, some sites clicked straight into a video.
As the layout of web pages varies for each website, each web site required figuring out how to ‘unlock’ a way to access information. The menu to select a specific topic (e.g., physical, cognitive or emotional outcomes of brain injury) for the person to click upon, to access a ‘page’ on the topic, could be found at the top of the page, or on the left or right column of various web sites.
If the person with ABI wished to revisit the material they needed to remember not only which web site contained the relevant material, but where on the web site the information could be found.

Fig. 1.2 Observations of 20 Websites reviewed in 2012

of problems—memory, cognition, processing information, applying knowledge, making choices and making informed decisions.

In spite of numerous searches for helpful material on the Internet, Johnson's (2010) online book *Traumatic Brain Injury Survival Guide* stands out as a recent narrative of hope. Johnson states that he wrote the online book because

> Nearly all of the survivors of traumatic head injury and their families with whom I have worked have had one complaint: There is nothing written that explains head injury in clear, easy to understand language. Most say the available material is too medical or too difficult to read. (Johnson, 2010, p. 1)

The format of this Website was easy to follow; the user simply clicked 'next' at the bottom of each page, and the information was presented in clear everyday language, in large print, with obvious headings and had no distracting other material on the page. It contained explanations, examples and advice presented in a friendly, positive and empathetic tone.

Web information indicated that participants in the study might be challenged by a number of issues. The World Wide Web search revealed that Web pages generally isolate problems and classify them accordingly as physical, cognitive, behavioural and emotional, with smaller areas on social consequences and improvement, even though the effects of these problems overlap and influence each other (*see* Fig. 1.3). Note these Websites have been updated as described later, so the references are historical and no longer active.

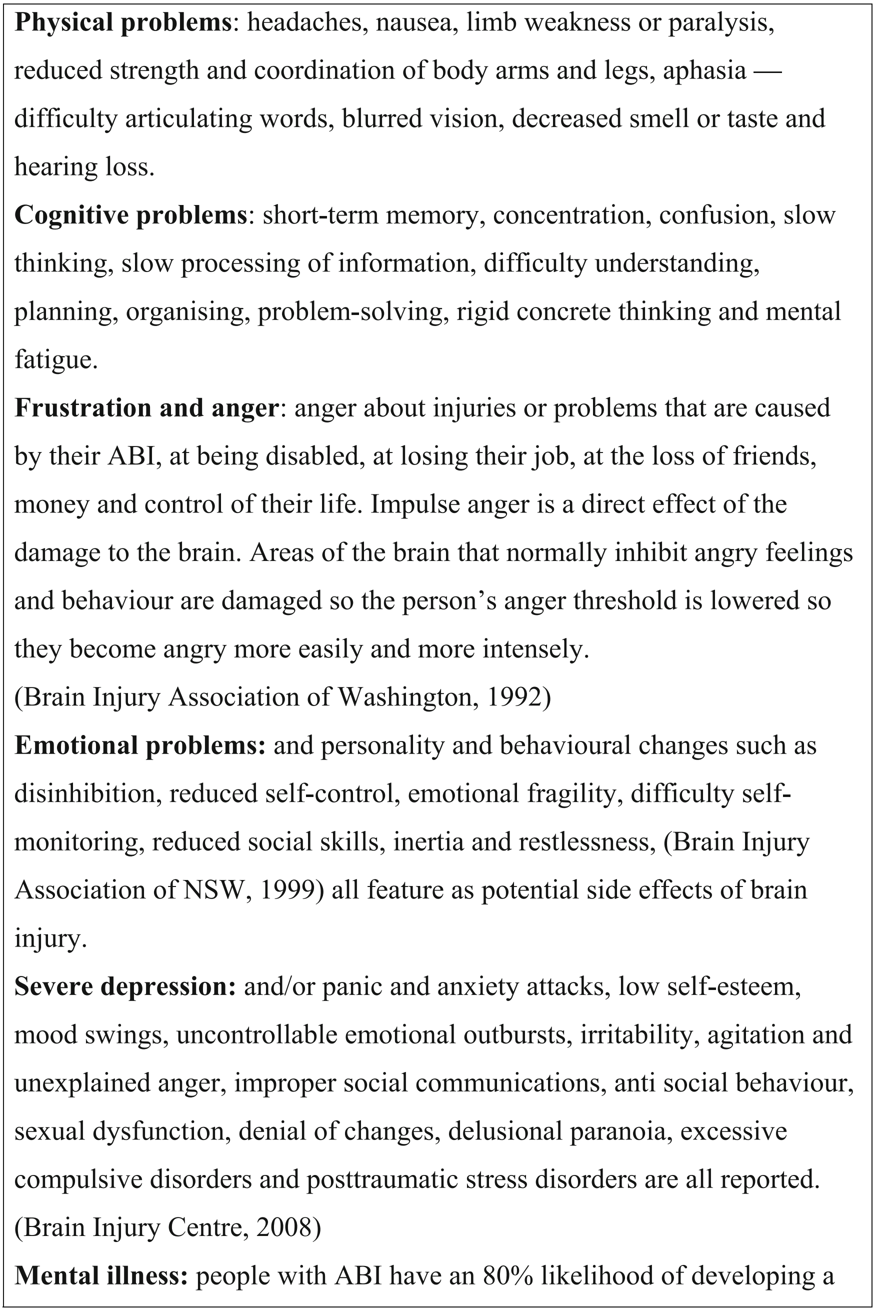
As will be seen in Chap. 3, much of this information is translated from body-object and medicalised views of ABI. The overview above provided a background to the problems study participants might be experiencing, but failed to identify how the person might progress to learn to fare better, and the negative issues described could seem overly pessimistic to people with ABI.

An additional search for relevant literature resources was conducted on the basis of what other areas a person with ABI, recently out of hospital, would seek out. An established library, which houses valuable resources covering ABI, was approached, but this specialist library did not appear to be widely used by people with ABI or their families.

A more recent trend on some brain injury support sites includes first-person narratives, stories of hope and courage, which talk about the trauma of ABI, but also provide a positive perspective on living with ABI as a 'whole' human being. These are explored below.

1.5 How Narratives Provide Another Way to View ABI

There is a broad array of books and blogs that use narrative (*see* Chap. 4) to provide valuable insight into the lifeworld of people with ABI. These narratives explain *what it's like* to have ABI and contrast with the medical '*facts*' about ABI. Narratives facilitate understanding of the emotional and psychological needs of people with ABI by highlighting the way people endure and cope with ABI.



Physical problems: headaches, nausea, limb weakness or paralysis, reduced strength and coordination of body arms and legs, aphasia — difficulty articulating words, blurred vision, decreased smell or taste and hearing loss.

Cognitive problems: short-term memory, concentration, confusion, slow thinking, slow processing of information, difficulty understanding, planning, organising, problem-solving, rigid concrete thinking and mental fatigue.

Frustration and anger: anger about injuries or problems that are caused by their ABI, at being disabled, at losing their job, at the loss of friends, money and control of their life. Impulse anger is a direct effect of the damage to the brain. Areas of the brain that normally inhibit angry feelings and behaviour are damaged so the person's anger threshold is lowered so they become angry more easily and more intensely.

(Brain Injury Association of Washington, 1992)

Emotional problems: and personality and behavioural changes such as disinhibition, reduced self-control, emotional fragility, difficulty self-monitoring, reduced social skills, inertia and restlessness, (Brain Injury Association of NSW, 1999) all feature as potential side effects of brain injury.

Severe depression: and/or panic and anxiety attacks, low self-esteem, mood swings, uncontrollable emotional outbursts, irritability, agitation and unexplained anger, improper social communications, anti social behaviour, sexual dysfunction, denial of changes, delusional paranoia, excessive compulsive disorders and posttraumatic stress disorders are all reported.

(Brain Injury Centre, 2008)

Mental illness: people with ABI have an 80% likelihood of developing a

Fig. 1.3 Web-based information revealed problems that people with ABI experience; i.e., participants in this study might have these problems diagnosable mental illness, and are 3-4 times greater risk of death by suicide. (Brain Injury Australia: Policy Paper – *Falls related Traumatic Brain Injury* April 2009).

Grief: the vast majority of people experience grief and find it much harder to deal with stress after a brain injury resulting in very little ability to cope with the normal stresses of everyday life. (Brain Injury Association of Queensland, Inc., 2007)

Behavioural problems: provide challenges for persons engaged in rehabilitation or attempting to successfully re-enter their communities, these problems affect not only a person's success in rehabilitation, but also his/her social relationships, educational or vocational pursuits, safety and the ability to live happily and independently. (Brain Injury Association of America, 2007)

Social consequences of brain injury indirectly contribute to the rising divorce, suicide, violent crimes, illicit drug and alcohol dependency and unemployment in society. People with brain injury are overrepresented in jails 25% to 87% of prisoners suffer from TBI depending on measurement compared to 8.7% in the general public having brain injury (United States Department of Health and Human Sciences)

Improvement. Many medical opinions state that people with ABI make the greatest improvement in the first six months following injury, this is followed by slow progress for two and up to five years. Then improvement levels out with some experts stating that people with brain injury don't get better beyond a certain point.(Kay & Lezak, 1990)

Fig. 1.3 (continued)

Narratives provide information and personal insight for people with ABI and their families. In searching for books and blogs about ABI, search terms used included brain injury autobiographies, personal narratives, memoirs, brain injury books, brain injury blogs, recovering after brain injury and brain injury—children's books.

Because the information is in story form, narrative may not be as confronting as reading aggregated information. Additionally, these narratives illuminate 'blind spots' (Wagner, 1993) that are not the focus of medical studies. Reading narrative accounts of other peoples' ABI experiences can allow the person to reflect and make connections to their own experiences.

There are now many books that can help people understand and deal with ABI, including self-help books. The books and narratives in the following review include those written by people with ABI, books co-authored by people with ABI and their family carers, and books written by family carers, professional writers and rehabilitation professionals. Some of these books are published by mainstream publishers and others by self-publishing organisations.

1.5.1 Books Written by People with ABI: Narratives from the 'Emic' (Merleau-Ponty, 1962) 'Insider's' Perspective

Personal narratives are important in all societies (Linde, 1993; Peterson & McCabe, 1992; Widdershoven, 1993). People with ABI portray themselves as fully rounded complex human beings, with distinct personal histories, a wealth of experiences to talk about and similarities and differences to other people in their books. The following section includes examples of narratives to put the experience of brain injury in terms of individual experience and to contrast with the 'medical model' approach of isolating deficits.

Many books written by people with ABI echo the belief that telling their story is important. Garrison (2007) wrote about how she woke up in hospital after a substantial stroke and thought that she had survived for a reason or a purpose. Recording the experience of ABI is a powerful step in healing. Bruner (1990) contends that people make sense of their experience as they impart it to others.

Books written by people with ABI contain an explanation that 'I am not who you see' and 'I am really a combination of who "I was" and who "I am"'; they tell the story of how this calamity happened—black ice, fall, car accident, stroke—the *story* is important (if this happened to me, it could happen to you too). They are written in a readable conversational style using easy-to-read words, and they speak with authority and genuine understanding and knowledge. They express the struggle, the complexities and the difficulties of ABI; they reiterate again and again that understanding and knowledge is power to the brain-damaged person. They seek to motivate people with ABI and their families to never give up, they comfort and guide by passing on their discoveries, and they bring hope.

Like mountain climbers, or solo sailors who have circumnavigated the globe, many authors are now motivational speakers. They have had an epiphany, an insight to life. They are examples of Niezsche's statement:

> If we manage to achieve some measure of understanding of the kind of world in which our human reality has emerged… but if we cannot do much more than comprehend ourselves and things human, this will at least be something — and something quite significant and well worth achieving at that, (cited in Honderich 1995, p. 623).

Explaining the lived experience of ABI is the focus of the narratives that deal with many issues about ABI that Durham wrote about in 'Doing Up Buttons'. They focus on the day-to-day frustrations of living with brain injury. For example, Osborn's *(*1997) narrative leads the reader to contrast her pre-brain injury life as a medical doctor, to her post brain injury life where she has difficulty showering and dressing. Nine years post-injury, Osborne (1997) believes that she is still improving due to learnt strategies. Not only does she tell about what it is like to have ABI, she gives hope as we read of her progress from confusion, grief, loss, dysfunction and alienation to a happy life.

Some narratives focus on the loss of identity. Becker (2004), author of a *New York Times* bestseller, grapples with the question of identity as she provides insight into creativity, identity, love, relationships and the elusive something that makes us, us. These could be classed as 'blind spots' of medical research.

A thread that runs through some stories is the importance of acceptance. Skloot, an author of seventeen books, a novelist, poet and essayist wrote his book to tell how he came to accept his injury.

> I used to be able to think. My brain circuits were all connected…I had a memory and an intuition I could trust…. now [14 years later] I can say that I've become adept at being brain damaged. It is not that my symptoms have gone away: I still try to dice a stalk of celery with a carrot instead of a knife…Along the way, though, I've learned to manage my encounters with the world. (Skloot, 2004, p. 196)

Some books focus on how the person is treated by other people. Calderwood's (2003) book tells of her struggle to discover her identity and come to terms with her disability and her sense of loss, grief and rage as she'd been labelled a 'hypochondriac, a liar and a junkie'(p. 32) and was bullied in the nine months it took to be diagnosed. Calderwood points out 'blind spots' of how undiagnosed people can be treated very poorly by medical professionals and the public. Mason's (2009) book narrates her struggle to independent living from a vegetative state after being hit by a drunk driver while cycling. This is another 'blind spot'—how people with ABI can struggle to live independently.

Another issue written about by people with ABI is their rehabilitation experience. Strand (2004) wrote how the controlled and structured environment of rehabilitation reminded him of elementary school. Because he was not informed of the reason for doing certain tasks, he believed he was expected to agree to complete the task and he resumed the outlook and behaviour he'd had when he was at school. He did not realise he was completing tasks to benefit himself. Rather, he thought it was his duty to please the rehabilitation professional, which resulted in learning very little. He realises that if he'd understood the reason for completing tasks, he would have been more engaged in his learning experience.

Strand used metaphors to reflect on the importance of being engaged in the learning process. He uses the analogy of feeling as if he is trapped under ice of a frozen lake, that no one can see or hear him, he can not get a message through to the outsiders: it is ‘cold, dark and lonely’. He chronicles his achievements so that others can use his experiences to ‘forge their own tools to chip through the ice’.

Meili’s (2003) book, written fourteen years after she was assaulted and raped as she jogged in Central Park, New York, identifies many of the reasons why people with ABI write books: she was looking for a way to turn what was truly horrible into something positive; the attack, meant to take her life, gave her a deeper life, one richer and more meaningful than it might have been (Meili, p. 7). She writes about the capacity of the human body and the human spirit to heal and the power of touch, of the mind. She believes that the heart is as important as medicine in healing, and even though she still suffers from her injuries, her experience has let her find her own humanity, kindness and love.

Other first-person narratives take slightly different lines. For example, in his book Winslade (1998), a professor of philosophy and medicine argues for increasing the amount of rehabilitation available for people with brain injury. Kelley (2010) queries whether he will ever heal from the terrible injury and whether his family will ever enjoy quality of life. Mason (2009), Fairclough (2002), Long (2005) and Carey’s (2006) books tell of the importance of love, faith, acceptance, gratitude, humility, compassion, hope and beauty.

The most immediate, but easily missed, point is that these writers have achieved a great deal simply through the process of writing a book that is published. Their work is an accomplishment in itself and points to a significant degree of resilience and a commitment and motivation to connect with other people with ABI and society at large, often under very difficult conditions. It indicates that the person has also re-engaged with life, and significantly, many talk about their struggle to re-learn both who they are (the new me) and the simple practical tasks required to be a writer. This theme of re-learning is vitally important as will be seen.

Moreover, in comparison with the formal information content of many Websites, the stories convey hope, determination and a positive view that life can be good, despite their changed identity and circumstances.

1.5.2 Dr. Mark Sherry’s Book

Perhaps the most significant book encompassing both an academic view and a true insider’s perspective of ABI is Sherry’s doctoral thesis, published as a book *If Only I Had a Brain: Deconstructing Brain Injury* (2006). Sherry’s research is ‘insider research’, which is well established in anthropological, feminist and disability research (Barnes, 1990; Morris, 1991). He used a cross-disciplinary theoretical approach that includes social and medical models of disability, lessons from feminism, queer theory, and post-colonial and postmodern literature in his thesis, which examines ABI in terms of impairment, identity and embodiment, and his research draws on his own circumstances as well as that of others.

Sherry states that ‘many disabled people find traditional research methods oppressive’ (Sherry, 2006, p. 15) and concludes that ‘there is a need for important, practical revisions in the way we understand and respond to the experience of brain injury’ (p. 212). He writes of domestic violence and brain injury, young people in nursing homes and the charity approach of the service delivery system, which came under a great deal of criticism from his participants (p. 212). He also writes about the alarming misdiagnosis of the ‘vegetative state’ and that inability to assess any culturally appropriate information or services is particularly alarming. He states that ‘What has kept me going is knowing that there are many brain injury survivors and allies who are prepared to fight for an alternative vision, where we have rights, choices and respect’(p. 212).

This brief overview has provided the insiders’ views of issues considered of importance to people with ABI, and these issues informed the study. The following section briefly identifies books written by the person with ABI in conjunction with their family members to detect topics they consider important.

1.5.3 Books Written by People with ABI with Their Family Members

Narrative themes from books written by people with ABI are related to themes written by family members. They have been included here to allow the reader to observe issues considered to be important by people with ABI and their family. Bob and Lee Woodruff’s (2008) book tells of Bob Woodruff’s experience since he was injured by a roadside bomb while an anchor of *ABC News* in Iraq. Bob and Lee Woodruff have established the Bob Woodruff Foundation to raise money to provide resources to the estimated 320,000 service members who have sustained TBI and estimated 300,000 service members who have probable psychological wounds.

Some books aim to help the person with ABI to obtain power, by helping them to understand ABI. Jameson and Jameson’s (2008) book contains advice to others with brain injury, and they assert that for the brain-injured person that knowledge is power. Kelley (2010) describes the effects of brain injury, his denial and the deficits that will not go away, techniques that help him manage and his legal battle for compensation. This book identifies that the emotional fallout from legal battles could be termed another ‘blind spot’. Brennan, (2002), a professor of English with special interest in memory, ‘jump-started’ the memory of her daughter who had ABI by constantly retelling her story and fostering creativity and humour (traits she had before her brain injury). She states that the book is ‘a collaborative effort bound by love, recovery and re-invention’ and that ‘we’ve showed these doctors how much of you remains, my darling’ (Brennan, 2002, p. 162).

1.5.4 Narratives Written by Family Members

A number of books have been written by family members of people with ABI (Biagioni, 2004; Brennan, 2002; Camp, 2005; Koenig, 2010; Cohen, 2007; Crimmins, 2000; Cromer, 2010 ; Johansen, 2002; Johns, 2005; Lash, 1993; Morningstar, 1998; Rocchio, 2004). These people have written accounts to tell of the experience of a family adapting to life with a brain-injured person, to give hope and motivation to others with ABI and to raise awareness of ABI. Themes include grief, loss, love, hope, acceptance and adaptation.

The books introduced in this section are available to be read by people whose life has been affected by ABI as well as the general public. They raise awareness and understanding about the consequences of ABI.

For example, writer Thomas's (2006) book about her husband who sustained ABI was selected as one of the best books of 2006 by the *L.A. Times* and the *Washington Post*. The book demonstrates how tragedy can bend, but not break some relationships. Thomas writes of grief and guilt as she shows that a new life can be built upon tragedy. Visiting her husband in the nursing home, where he now lives, he cheerfully said to her 'if I wasn't with you and we weren't getting food, the dark would envelop my soul' (Thomas, 2006, p. 6). This statement exquisitely expresses what was in Thomas's husband's mind at that split second—his appreciation of his wife (and also his need for food)—a good example of what Medved and Brockmeir (2010) would term a story presented in a 'weird fashion'.

1.6 Narratives Presented on the World Wide Web

ABI support organisations now publish the stories of people with ABI. Brain Injury Australia has a Website 'Your Stories' (http://www.bia.net. Au/index.php?option = com_content&view = category&layout = blog&id = 14&Itemid = 32) from which the following are drawn. Some narratives simply tell a story. Lersher tells of how he had a brain abscess and he is still reclaiming the life that he nearly lost, 'it's a long road back, and I'm not there yet'. Jess's story tells about how a fungal chest infection spread to her brain and she was given a 5% chance of survival—she states that she now has 'a second chance of survival'. Ross Cottee's story about his fall-induced ABI uses the word 'fall' in an imaginative way. 'Brain injury is a tragedy? Or a new beginning? Like any piece of art, it is what you make of it how will you view "fall"? The onus falls on you'.

The purpose of some stories is to pass on words of warning: Gladys's story (Australian Broadcasting Commission, 2006) about her daughter Quita encourages all horse riders to wear a hard hat. Brad Schmitz wanted to pass on advice to others with ABI—'It's going to be hard, get organised, take photographs (to help memory) set goals and have dreams'. (http://www.bia.net.au/index.php?option=com_content&view=article&id=269:bbrad-schmitzs-story&catid=14:your-stories&Itemid=32) Kimberly Carnevale's blog (http://www.canineandabledgorving.blogspot.com.au/) is a campaign to prevent ABI and promote awareness. She makes a very significant statement: 'I do expect compassion and acknowledgement that something life-altering has happened to me'. Ralph Perrin's story is 'dedicated to all the people who were about to give up but never did'.

Blogs by people with ABI appear to have a common theme of never giving up, the importance of hope and trying to express what it is like to live a changed life. Indeed, there is an inherent recognition that self-help can be an important part of the process of adaptation and coping, as discussed below.

1.7 Self-Help Books

There are an increasing number of self-help books being published, and these can provide valuable information and strategies—many involve workbooks. These kits and books are most helpful and worthwhile for the person who acknowledges their difficulties and understands the consequences and ramifications of their ABI. The person who actively pursues knowledge to help them deal with grief, memory organisation and other challenges, and can read and understand words, can benefit from these publications.

But some individuals with ABI may not understand or acknowledge their ABI, they may be stuck in a 'dark place' where they feign they are alright, and they ignore or dismiss their difficulties. Their reading, writing and spelling difficulties might make engaging with written material a daunting experience, and memory difficulties might mean they do not retain a lot of what they have written. Additionally, if they do not have a positive memory of school, they may not engage with a workbook-type format as it might seem too much like their memories of school, too much hard work. Not all products are suitable to all people with ABI.

This section about narrative commenced with Bruner's (1990) contention that through talking people can make sense of experiences. A hypothesis is posed that if people with ABI can become involved in a meaningful conversation about their experiences, they can, with dignity, be led to understand and acknowledge their challenges. A premise is made that understanding about ABI could help people to become more involved in the rehabilitation process; choose to complete a workbook, or write a journal (as suggested in some self-help books) and in so doing discover for themselves things that affect their lifeworld, their life, their well-being or quality of life—positively and negatively, and choose a way forward.

1.8 Developing a Focus for the Current Research

1.8.1 Application of van Maanen's Fieldwork, Textwork and Headwork

Public information about ABI and books written by people with ABI simultaneously informed the research methods, principles that guided research methodology, the choice of methods and the 'talk-about' cards (see later) were employed in the interviews in this study. This review also established difficulties/differences/deficits that participants in this study might have.

Listening to and observing people with ABI produce stories and narratives about ABI which could be viewed drawing upon John van Maanen's (2011) conceptual distinction between 'Fieldwork' (collecting data) and 'Textwork' (reading accounts). The authors' long-term engagement in education has further influenced this study.

In order to synthesise the literature reviewed, van Maanen's 'Headwork' will be identified in the boxed figures in following chapters. Headwork verifies how knowledge gained from literature was analysed, evaluated and applied to inform the method used, and 'translated' into everyday language on 'talk-about' cards. These are a carefully developed group of cards, in easy to understand English, used in the study to support people to choose areas of relevance to speak about their experiences. The cards appear in the 'Keys to the ABI Cage' presented at the end of the Foreword as a list simple statements on the walking stick, the 'flying pig' and inside the Cage.

It will be appreciated that many issues recorded on the 'talk-about' cards fit several themes, they overlap and do not fit one topic alone, and the Headwork recorded below identifies how information from this chapter informed the method. In later chapters, quantitative and qualitative studies also identify these and other issues.

Figures 1.5 and 1.6 lay out how the 'talk-about' cards drew from the review carried out above. The 'talk-about' cards were split into three categories: 'Difficulties and differences that PUT me in the ABI Cage'; 'How I feel about the difficulties and differences LOCK me in the ABI Cage'; and 'Keys that RELEASE me from the ABI Cage'. These appear on the green cards in 'Keys to the ABI Cage' (Fig. 1.4).

These are populated from the literature, from consequences of deficits/difficulties 'translated' into everyday language (statements on the 'talk-about' cards can be easily identified by the shaded boxes below).

These are populated from the publicly available information about ABI from consequences of emotional problems. And, in stark contrast to the public information available about ABI, a group of positive cards with themes once again are drawn from the narratives written by people with ABI or their family (Fig. 1.7).

This chapter will conclude by setting out the aims of the study.

1. The participant may be fragile and be contending with many challenges. The way participants engage with this study may be influenced by a plethora of issues: physical problems (headaches, nausea, dizziness, visual, hearing, paralysis, epilepsy, sleeping problems, swallowing, sensory, speech), cognitive problems (intellectual, memory, concentration, inflexibility, lack of initiative, impulsivity, day-to-day difficulties, problems with time, money, problem-solving, confusion, an 'old me' and a 'new me') and posttraumatic stress and emotional problems (depression, suicidal thoughts). The method of data collection must be user friendly.
2. In reviewed books and blogs people revealed many important elements that helped them: understanding, knowledge, hope, love, courage, acceptance, faith, beauty, nature, and determination. This information must be made available to participants.

Fig. 1.4 Headwork 1: The data collection must address these issues about ABI

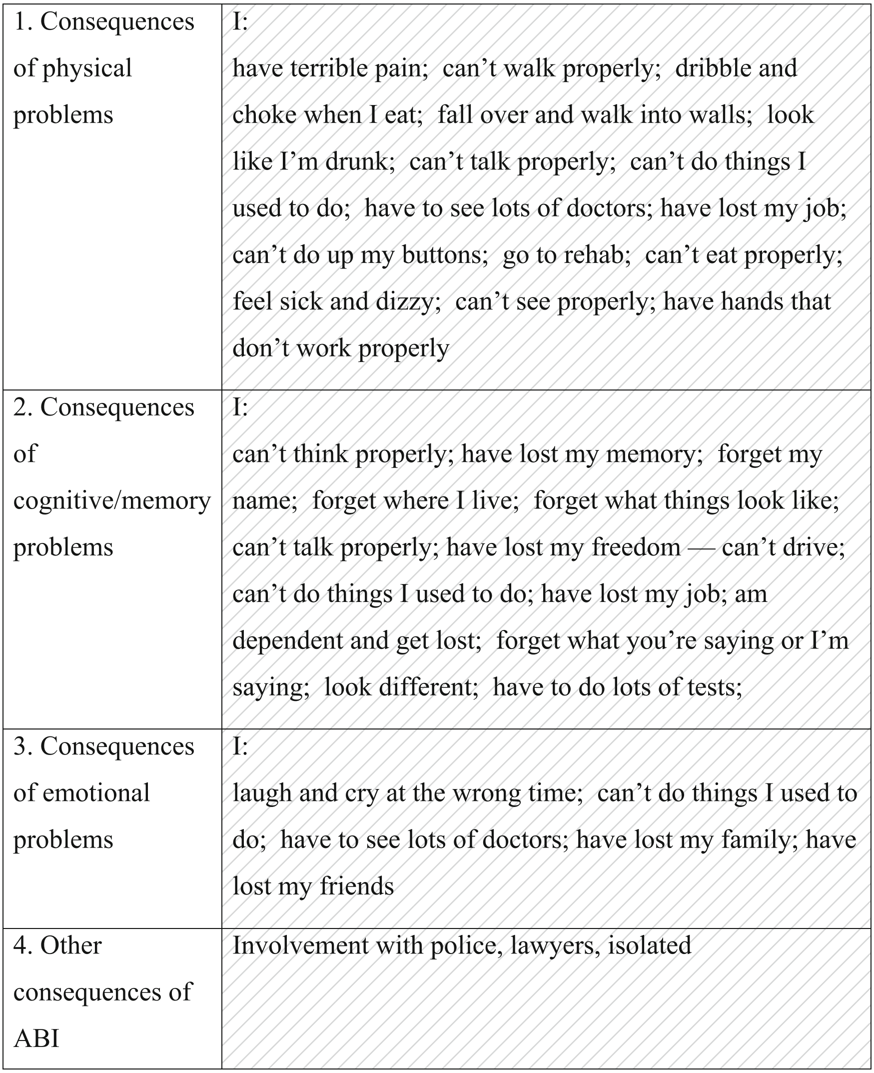
1.9 The Aims of the Study

Gaining self-awareness is imperative for people to make progress. To gain self-awareness takes time. Durham's personal experience and the experience of a significant number of people with ABI indicated that there is a very big gap when people leave the focused body-mending, therapeutically orientated practical task learning they are likely to receive in hospital or rehabilitation hospital.

Mending broken bodies can only go part way to mending broken lives.

The complexities of re-engaging with everyday life, becoming self-aware, often pose problems so complex as to further undermine the person's confidence, and there are seldom sufficient support services available at this time to bridge this gap. Moreover, much of the information that could help the person become aware of their differences, difficulties and deficits provided in Websites is factual, describing problems the person faces without telling them how to address them. This information may lack positivity and hopefulness.

A first theme taken from the initially reviewed publicly accessible literature for people with ABI was that the study must be a *positive experience* for the people involved, both in the process of being engaged with it and also in terms of what they can take away with them. While the negatives, challenges and struggles with life are identified, they must at all times be counterbalanced by positive encouragement and an approach that leads participants to focus on the positive.



1. Consequences of physical problems	I: have terrible pain; can't walk properly; dribble and choke when I eat; fall over and walk into walls; look like I'm drunk; can't talk properly; can't do things I used to do; have to see lots of doctors; have lost my job; can't do up my buttons; go to rehab; can't eat properly; feel sick and dizzy; can't see properly; have hands that don't work properly
2. Consequences of cognitive/memory problems	I: can't think properly; have lost my memory; forget my name; forget where I live; forget what things look like; can't talk properly; have lost my freedom — can't drive; can't do things I used to do; have lost my job; am dependent and get lost; forget what you're saying or I'm saying; look different; have to do lots of tests;
3. Consequences of emotional problems	I: laugh and cry at the wrong time; can't do things I used to do; have to see lots of doctors; have lost my family; have lost my friends
4. Other consequences of ABI	Involvement with police, lawyers, isolated

Fig. 1.5 Headwork 2: 'Talk-about' cards 'My differences and difficulties can PUT me in the ABI Cage'

Participants will not only reflect on their challenges but also on things they find helpful in their day-to-day lives. The methodology chapter will deal with this issue in greater depth.

A second theme taken from the above initial review of information is the importance of *the learning process* as a precursor to obtaining self-awareness to re-engage successfully with everyday life. The study was therefore also interested in the extent to which (re)learning can support adaptation, resilience and ultimately a satisfying life after acquiring ABI. In the words of Freeman (1998) (see below boxes):

> ‘Long term recovery from brain injury is not a medical problem…Medicine has very little to offer in this direction. The way forward lies in education… in fact the medical model… is also often counterproductive to follow. The medical model sees the patient as subservient to the professional. It sees the power of recovery lying in the hands of the physician, whereas the power for recovery lies within the injured person as they relearn their daily living skills. Education is the key’, (1998, p. 14).

I:

feel sad; feel depressed; feel distressed; feel disappointed; feel bad because I say and do the wrong thing; feel mad: feel frustrated; feel angry; feel nuts or crazy; feel scared; hate myself; feel unlucky; feel hopeless (the experts can’t fix me).

Fig. 1.6 Headwork 3: ‘Talk-about’ cards ‘How I feel can LOCK me in the ABI Cage’

1. People who love me	Love - My family; My friends; Animals; Encouragement;
2. Faith and hope	Having hope; Religion
3. Things that make me feel better	Sunshine; The sea; The country; A cup of tea/coffee; Going out; Staying home; Talking books; Flowers; Sport; Talking; My sense of humour
4. Things I can do to feel better	Being useful; My garden; Exercise; Doing things I couldn’t do before; Doing hard things; Achieving hard things; Stretching my comfort zone; Making things; Saying ‘I can try to do it’; Books
5. People who help me	My health professionals; My OT; my counselor; my doctor; What other people with ABI have done;
6. Time to heal	Time passing

Fig. 1.7 Headwork 4: ‘Talk-about’ cards ‘Keys that can RELEASE me from the ABI Cage’

A third theme for the study examined the hypothesis that *people with ABI can be empowered in a positive way* to reflect upon their lifeworld, to identify and to consider things that negatively and positively affect their life experience. They can then acquire better insight into their own ABI experience and things they can do to feel, and learn, to fare better.

Through this enquiry, it is strongly argued that people with ABI benefit from drawing on their own inner resources and their personal support networks, rather than relying solely on external-or expert-driven interventions and treatments. This underpinning assumption has been formed through Durham's personal experience, feedback from books and speaking about the lived experience of ABI and books written by people with ABI and their family members. Acceptance, understanding and hope are of vital importance for the person to make progress.

The study aimed to test these ideas to see whether they held true for participants of the study and, if so, what particular things help people with ABI.

The research question was:

- What issues need to be considered to design and trial a method that employs educational/learning principles in order to empower the person with ABI to constructively reflect upon their ABI experience, to better understand themselves (gain greater self-awareness), so they can feel, and learn, to fare better?

The complexity of the research question was to be unpacked through the following subquestions:

- What factors positively affect the lifeworld of the person with ABI?
- Can an individual gain something, 'be deepened', by the experience of ABI? If so, can this be used to help others experiencing similar life challenges?
- What factors negatively affect the lifeworld of the person with ABI?

Because of the significant weight of data from the 'outsider's' professional perspective in the research area, this study attempted to address the imbalance by employing the binary insider/outsider approach through purposefully examining the issues predominantly from the insider's perspective. Some outsiders, people who care for and support people with ABI and health professionals, were interviewed and their data used for the intended purpose of data triangulation.

From an ethical stance, it was important that the method used in the study also aimed to:

- Do no harm to participants, to give them 'rights, choices and respect' (Sherry, 2006, p. 213).
- Build on a foundation, view, model or belief that the well-being of the individual with ABI is the most important element to consider. Indeed, building from that strength is more important than any pretheorised model of disability, the medical or indeed the social models.
- Assist understanding about ABI, the personal construction of knowledge and identification of things that could assist them to tackle the challenges of ABI.

- Engage participants in a positive, empowering manner by developing and using an ABI learning resource that supports people to learn about the ramifications of ABI, express their frustrations and difficulties and also allow them to reflect upon things that help them and things that they could apply to help themselves live with ABI.

1.10 Recapitulation

This chapter has introduced the raison d'être for the study by reviewing publically available literature likely to be available to people with ABI and their relatives and carers. The findings provide background to the contents of 'talk-about' cards in the 'Keys to the ABI Cage' tool developed for the study. It explains the research was grounded in an understanding of the difficulties that would be faced by participants and the care that would need to be used in order to encourage and facilitate them sharing and learning from their experience. The following three chapters will allow the reader to understand how the information informed the developed method by looking in more depth at more formal academic paradigms, research and findings from empirical studies.

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Chapter 2
Understanding the Assumptions of Major Models of Disability Theory

Everything is vague to a degree you do not realise till you have tried to make it precise.

Bertrand Russell.

2.1 Introduction

The Foreword introduced ABI through Durham's personal experience. The co-author, Ramcharan, has been involved in funded disability research for 25 years. He was involved in research of the All Wales Strategy for the Development of Services to Mentally Handicapped People [*sic*] 1983 (see Felce et al., 1998) and co-directed the Learning Disability Research Initiative, a two million GBP strategy involving thirteen projects designed to support implementation of Valuing People (2001), a national intellectual disability government policy in England (see Grant & Ramcharan, 2007). Paul's work for over a quarter of a century has melded an interest in the everyday life experiences of people with a disability (Ramcharan, Roberts, Grant, & Borland, 1996), and advocacy and voice (Goodley & Ramcharan, 2010). The interest in everyday lives and the everyday struggles faced by people with disabilities was a key basis upon which this exploration of the life experiences of people with ABI was both interesting and, at the same time, challenging. Durham's work was, therefore, immediately of interest leading to both his supervision of her Ph.D. and his contribution to this volume. Both share the passion to seek to change lives for people whose struggles are grounded in their social circumstances as much as their biology.

Chapter 2 provided a review of Websites, books and blogs written by people with ABI, supplemented by a consideration of the information and resources most readily available to people with ABI.

The period over which mending bodies and re-establishing basic skills take place can be variable. One guide to TBI suggests written by a neuropsychologist using 'psychological tests' suggests that

C. Durham and P. Ramcharan, *Insight into Acquired Brain Injury*,
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> research on these tests indicate that for two years following a head injury, there is evidence of improving scores. After this period…I can no longer see large changes in scores (http://www.tbiguide.com/getbetter.html)

More importantly, many people with ABI recount this as an early inpatient response to the question of how long it would take them to get better. From the perspective of the professional (the outsider), this time frame is 'golden' insofar as the greatest recovery is presumed to happen within this time, and it attracts the greatest professional input designed to mend bodies and re-establish basic skills. It is analogous to the 'golden hour', directly after a traumatic injury when there is greatest likelihood that prompt treatment will prevent death. Although recognising its limitations, we shall for brevity, therefore, use the term 'golden period' to refer this two-year period, or thereabouts, directly after the person acquires their brain injury.

We also use this term to contrast with the views of people with ABI. As shall be seen, from the perspective of the person with ABI (the insider), this period is far from golden—it is the 'dark hole period'—the time of greatest pain, loss and despair as Durham has found in her continued engagement with people with ABI over the years.

Depending on the cause of the brain injury, for example, a car accident or a fall causing broken bones some people with ABI are hospitalised. Others suffer brain injury and it is not diagnosed, and/or they are not hospitalised. Some spend a short time, others months or years in hospital depending on their injuries and/or severity of the brain injury. Except for people with severe brain injury, at some time during the 'golden period/dark hole period' of medical and rehabilitative attention, most people with ABI go home to their communities where they have to mend their 'fractured lives'. Examples of information and resources that are typically available for people with ABI and their families have been examined, but from what source does this information come? Upon what assumptions is it based? This is the question that preoccupies us in the following three chapters.

We show that many of the categories of understanding in the information on Websites are drawn from what might collectively be termed a biopsychosocial model encompassing a majority medical model input. We also argue that this more formal academic engagement around ABI has significant blind spots, that it is preponderantly negative, that it predisposes to only certain professional interventions and that in so doing it misses solutions to the everyday support required once a person moves home from hospital or rehabilitation. By exploring the underlying theory, models and information, this review seeks to re-frame the approach on sound alternative assumptions, and to further inform and populate the methodological tool *Keys to the ABI Cage* that is used in this study.

In the first section of this chapter, some of the theoretical frameworks around disability are discussed and two broad categories are identified, the body-object view of ABI and the body-subject view of ABI. The dominance of the body-object view, it is argued, is not inconsequential. The results of such a view continue to objectify people, to obfuscate any interest in the complexity of their everyday lives and, as a result, to miss what is most important—the person behind the theory and behind the actions consequent to the theory when applied. The remainder of this chapter will then examine features and assumptions of the body-object view, including research into ABI, leaving a focus on building the body-subject view for the chapter to follow.

2.2 Differences in Perspectives of Disability

> Man has become less rational than his own objects, which
> now run ahead of him, so to speak, organising his surroundings
> and thus appropriating his actions,
> Jacques Baudrillard.

As already mentioned, it is all too easy to slip into a view that damaged brains produce damaged emotions, damaged behaviour, damaged communication, damaged interaction…damaged people…disabled people. The following introduces philosophies and ways a person with ABI can be viewed.

2.2.1 The Body-Object Model

> *'The body is our general medium for having a world'*
> MauriceMerleau-Ponty, *Phenomenology of Perception.*

The roots of the distinction upon which we draw in this volume have a significant past, lying in broader philosophy, at least since the Enlightenment.

Naturalism and idealism as competing epistemologies have been in contention since Schelling, Kant and the later phenomenologists starting with Husserl who questioned Descartes proposition about the measurement of the object world through science. The competing traditions pit the pursuit of the factual world in the capacity of science to intercept, define and hence find meta-theory, against the idealist view that the reality of external objects cannot be subject to proof. The idealists' world is mediated by our consciousness, and it is only through such consciousness and intention that the world comes into existence.

In this way, even the hard fact of a 'stone' is not, for the idealist, defined through its scientific properties, its physical properties, chemistry and origin (igneous formed from fire and sedimentary formed from the compacting of layers). Rather, the stone may be the object of an aesthetic interest, and it may be a weapon in certain circumstances, evidence of the likelihood of a particular presence such as oil or gold, and so forth. In this way, the stone exists only by the intention of its use, by the conscious intention of the actor.

From one point of view, what is important for the purposes of this volume would be the external and defined fact of acquired brain injury. From another point of view, what is important is how we come to know acquired brain injury through consciousness and experience. The result of our epistemology is consequential to our understanding of the world, our ontology and, more importantly to the choices we make in intercepting and working upon that world. As Merleau-Ponty (2002) argues 'to understand is to experience harmony between what we aim at and what is given, between the intention and the performance—and our body is the anchorage in the world' (Merleau-Ponty, 2002, p. 167).

According to the French phenomenological philosopher Merleau-Ponty (2002), the view we have of the body plays a foundational role in the way we understand and engage with the world. He wrote of difference between the 'body-object', as determined and predicted by medical science, as the outsider's perspective, and the 'body-subject', as the body as we experience it, the body that gives meaning to the world around us, as the insider's perspective. An outsider or etic (Pike, 1954) description of an observed behaviour or belief often holds a different perspective or philosophy to that of an 'insider' (emic) (Pike, 1954). Just as body-object proponents rely upon Cartesian dualism and the separation of the body as an external object from its observation, so the body-subject proponents see object and subject as one and the same, i.e. as people see things, so they are.

However, even within the bifurcated category, body-object or body-subject, which is used to structure this and the following chapter, there are many different philosophies, 'models' or belief systems that have evolved, define and fundamentally affect the way in which the individual with ABI is viewed and treated. Perception of ABI is dictated by the dominant belief, model or 'lens' through which the individual, the medical or rehabilitation professional, family member, friend or the general public views, considers, assesses, or judges the person with ABI. These different beliefs can affect the way outsiders regard and behave towards the person with ABI.

Disablement models that developed in the twentieth century 'defined the meaning of terms we use every day, and that do not always exert a positive effect upon the people to whom such terms refer' (Masala & Petretto, 2008, p. 1242). So before reviewing the ABI literature, it is essential to discuss the place of theoretical systems in research. As a researcher, do such frameworks dictate the approach and limit what I want to observe or measure? Should a theory be used as an apparatus to interpret a person's world? Or should we be looking in our data for the ways in which people themselves construct their own realities and mould something out of these accounts? These questions are not inconsequential because they have a bearing upon how interactions take place between people, one party to this interaction being a person with ABI. It is, therefore, also relevant to the method employed in any study of people with ABI including the present study.

Below, we demonstrate the points made above by exploring and considering varying theoretical views of disability and their corollaries and consequences.

2.2.2 The Moral Model

The first and oldest model of disability is the moral model. In this view disability is a defect caused by a moral lapse or sin.…it brings shame to the person with the disability, (Olkin, 1999, p. 25)

> "*Macbeth: How does your patient, doctor?*
>
> *Doctor: Not so sick, my lord, as she is troubled with thick-coming fancies that keep her from rest.*
>
> *Macbeth: Cure her of that! Canst thou not minister to a mind diseased, pluck from the memory a rooted sorrow, raze out the written troubles of the brain, and with some sweet oblivious antidote cleanse the stuffed bosom of that perilous stuff which weighs upon her heart.*
>
> *Doctor: Therein the patient must minister to himself."*
>
> —William Shakespeare, Macbeth

People with disabilities have been recognised as 'different' and treated according to such differences for many centuries. Recognition and veneration through the ages, of 'gifted' savants with prodigious abilities beyond the population at large (Treffert, 2014) and, since Athenian times[1] (Penrose, 2015) a consistent recognition and support for those disabled in the military service of their country, represent but a small minority of cases resulting in 'positive regard'.

More often than not the effect of such 'difference' has resulted in treatments that have produced troubled lives, impoverishment and a life quality for which none of us would choose to queue. Through the ages, people with disabilities have, *inter alia*: been seen as 'possessed' or 'children of the devil' (leading to exorcism, bloodletting and being burnt at the stake); subject to infanticide (and death); treated as freaks (leading to fair game for circus sideshows, commodification and humiliation); perceived to belong to the class of 'moral degenerates', (such as prostitutes, criminals and beggars who have traditionally attracted the interest of the corrective services); argued to be a threat to the national gene pool (leading under a eugenic argument to both mass murder in Nazi concentration camps and to enforced separation of males and females in institutions); rated as 'unemployable' (leading to their occupancy of poor houses and later institutions); and, latterly, accepted to be legitimate beneficiaries of welfare (having to declare their disability to access additional support services), (see e.g. Thompson, 2010; Metzler, 2013; McClimens & Richardson, 2010; Nielson, 2012; Bogdan, 2014).

For most of history, humanity has perceived the trouble as lying with the person with a disability whether by possession, incapacity to work, moral degeneracy and

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[1] Penrose, in his interesting comparison between the Athenians and Spartans, shows how much more sympathetic the Athenians were, than the Spartans. He argues that '…in Sparta, the failure to recognise the disability caused by impairment was a harsh form of prejudice…The Athenians allowed disabled veterans and others to be exempted from military service and to collect a pension, whereas no consistent record of exemption is extant from Sparta' (Penrose, 2015, p. 522).

more recently in their biology. How might we better understand this sad history, through which the morality of public and Government views have separated, labelled and denigrated one significant group of humans? One way is to consider the links between Government, economy, knowledge and public sentiment (McClimens & Richardson, 2010).

The lack of engagement of Governments and people with disabilities prior to the middle ages meant that the treatment of people with disabilities was likely to be a product of community sentiment. Such sentiment would have been diverse across regions, but would almost inevitably have included issues around systems of religious belief on the one hand and economic security on the other. Given the unpredictability of agrarian modes of production and technology, capricious climates and insecure tenancy, the economic circumstances were often highly testing.

The confluence of living on the edge of survival, alongside religious views of possession might, in the absence of other options have led to people with disabilities being left to die or to infanticide or exclusion, e.g. being treated as possessed. The very survival of people with disabilities was, therefore, at issue and exacerbated by very low levels of medical proficiency. Often, the family mediated the experience of relatives with a disability by controlling interaction with the rest of the community. Families, it should be noted, have consistently been a vital support mechanism through the ages. But for people with disabilities, life was tough and, for many, all too short.

The emergence of new nation States in Europe in the middle ages saw the protection of land for the nobility, giving rise in 1325 to *Prerogativa Regis* (in the prerogative of the monarch) in which land was held for ‘idiots and natural fools’ for the land-owning classes, though no provision was made for those without land. In the absence of such support from families, people with disabilities were likely to be driven to vagrancy, prostitution or shelter in the monasteries from which they were ‘sent to beg “cap in hand”—the source of the term Handicap—for charity’ (Ramcharan, 2016).

The moral model of labelling views the person with a disability as being responsible for both disability and the treatment accruing given the adopted moral position. The religious model has, in the past, been an extreme model where disability is viewed as punishment by God, or a supernatural force and was common in the Middle Ages and particularly during the Inquisition. It was often seen as resulting from their immoral actions the person or those of their parents. Although the moral model of viewing ABI can be seen as ignorant, some insiders privately still hold onto this perception (Durham, 1997). This influences well-being and self-efficacy for people with ABI. Some outsiders behave towards insiders, people with ABI, as if they are being punished by God, or because they had ‘asked for it’ by engaging in reckless behaviour, driving dangerously or taking drugs, for example (Durham, 1997).

It was not until the Elizabethan Poor Laws in the UK in 1601 that the roots of welfare can be identified. The landed gentry now operated in smaller identified areas termed parishes. Since taxes were essential for parishes to thrive, it became necessary to identify the ‘impotent poor’, i.e. those unable to be economically productive.

The resultant laws represented the first recognition of the State's responsibility to support the deserving poor. To be deserving of 'alms' or handouts, it was, therefore, necessary to be defined or to self-define as disabled, a welfare model that lasts in some shape or form to the current day. By doing so, the government social policy and administration of disability separated people with disability from the population at large providing a serviced existence for those eligible.

The alms offered from the earliest times were not enriching but based on the principle of less eligibility, i.e. that they would not match the level of wages for employment (Claeys, 2000). Furthermore, this 'economic model' distinguished between the 'employed, unemployed and unemployable' (Scull, 1989, p. 219). In this model, the person's inability to work and the consequences of this for the individual, employer and Government are established as a basis for social policy. This model was used primarily by policymakers to assess distribution of benefits and to counter fraudulent claims, but this model can lead to confusion and lack of coordination in disability policy. Another important dimension of this model is that by declaring themselves disabled, the person effectively declares themselves unemployable, the result of which means they are more likely to be confined to the financially disadvantaged sectors of society or, later, institutions.

More particularly, from a social policy perspective, the person with ABI is seen as a victim of circumstances, deserving pity and the recipient of charity due to the tragedy of their disability. The emergence of the Poor Laws in the UK, for example, demonstrate how the tragedy/charity model of the 1800s involved the transfer of the responsibility of giving alms from the Church to the government. Workhouses run by local governments housed the unemployable and in some cases the unemployed. The charity model views the disabled including those with ABI as having a tragic, negative and miserable existence. Through raising money and resources, somehow the suffering and sadness of the disabled person's lives would be reduced (Oliver, 1990, p. 1; Swain & French, 2004). This model lasted for nearly two centuries, although both the Enlightenment and industrialisation played a significant role in once more changing the living circumstances of many people with disabilities.

The advancement of science as the Enlightenment unfolded, heralded longer working hours and progressively harder manual labour in the industrial sector, as well as the growth of bureaucracies and more 'brain work'. Agriculture was increasingly mechanised and people moved in droves to cities to provide industrial labour. States too, were changing. Having established the place of alms or welfare, there was now a gradual extension of suffrage, i.e. voting rights. The Poor Laws in the UK from 1834 reflected this widening suffrage and the need to cater for more than just the landed classes led to a focus on the interests of the wider citizenry. Since all men would vote[2], it was necessary to appeal to all groups including people with disabilities.

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[2] In the late eighteenth century, the western USA and some northern European countries gave women the vote. The full right to vote in Australia came with Federation in 1901. In the UK, it was not until 1928 that women had the same voting rights as men and in Switzerland, not until 1971.

While the workhouses provided temporary and low-quality housing for those temporarily out of work, people with disabilities and mental illness posed a problem for Governments and were expensive to house on a continuous basis. For example, as Richardson (2005) argues

> Capitalism therefore sought to remove, control and discipline those who would not or could not conform to new working practices by introducing new secular controls…Between 1720 and 1825, 150 hospitals were built in England to cater for the rising numbers of sick poor (p.71).

These asylums were seen to be placed where the concentration of residents allowed scientific discoveries to be applied more systematically. The seminal work of Seguin and later others on how education could achieve change in the behaviour and abilities of people with disability was revolutionary. While the emergence of modern medicine and psychiatry saw medical staff placed in control of such asylums, Dykens (2006) argues that Seguin's idea of the training school which through education delivered people with disabilities back to community life was adopted quickly but that,

> ..over time these schools changed dramatically. With the realization that students were not being cured, schools became less educational, larger and more custodial..institutions became places to keep persons away from a less forgiving and accepting society, (2006, 185).

McClimens and Richardson (2010) posit that up to and during the mid-1900s many people who had disabilities either died when they were young or lived their lives hidden away in institutions or their homes. In the first half of the twentieth century, both the moral and the early medical models were firmly entrenched in western culture and people with disabilities remained segregated from society (Mackelprang & Salsgiver, 1999). 'Segregation was considered a caring policy in a society which did not care about disabled people…. but World War 1 produced hundreds of thousands of people with disability—who took on the role of the worthy poor' (British Broadcasting Corporation, 1999, cited in Mackelprang & Salsgiver, 1999, p. 7).

Large institutions situated 'around the bend' (and out of sight, the source of this euphemism describing the insane) now operated to cure and to train the lunatics and mental defectives, at least those who did not remain with their families. Bracken and Thomas (2001) argue that in some ways, having been given positions of leadership within the institutions, that psychiatry was borne out of the institutions, rather than the other way around.

The early period in the emergent leadership of the medical profession was also influenced towards the end of the 1800s by Mendel and Darwin in relation to heredity and Binet in relation to intelligence. It may have seemed at the time that the

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(Footnote 2 continued)

Prior to that age restrictions applied (making their voting numbers smaller than men) and various property or rate paying requirements which prevented their suffrage.

potential of biological science was limitless and that, almost inevitably, the source was individual deficit or pathology. Consequently, the eugenics movement argued that people with disabilities were weakening the national gene pool. Separation of the sexes in the institutions and mass sterilisations followed and continued in some places up to the 1960s (Stubblefield, 2007).

However, the most egregious of the eugenics policies under Nazism saw many hundreds of thousands of people with disabilities gassed in the concentration camps. The repercussions of the Second World War for disability cannot be underestimated. The 1948 Universal Declaration of Human Rights emerged in large part as a response to the experience of Nazism. Not long after, Goffman's (1961) work on asylums and Barton's (1959) on institutional neurosis changed public sentiment and pointed to the regimentation, Spartan conditions and cruel treatment experienced in the asylums. While survival rates improved, inmates' experiences are widely recognised as being extreme and catastrophically damaging. Not surprisingly the latter half of the twentieth century has seen deinstitutionalisation and resettlement in the community under a series of 'community care' initiatives hand-in-hand with normalisation theory.

While normalisation proposed (Wolfensberger 1973; 1983) that people should lead as normal and socially valued lives as others in society, it remained difficult to establish among such diversity what represented a norm and, indeed, what was socially valued. More fundamentally, the welfare model continued. To be able to qualify for welfare payments, people had to declare themselves as a person with a disability in order to access services. That many of these policies were exclusive and segregated meant a 'parallel' existence for those so labelled. Thus, while being on a disability register accorded them rights to welfare, it also separated them into a system of off the shelf disability—only services which kept them segregated from the community, leaving the exhortations of normalisation unfulfilled.

Normalisation had observed the application of a host of stereotypical labelling over the ages: 'perpetual child' 'an object to be pitied' 'brave but pitiable', 'objects to raise money for'; 'a menace or threat to society' or 'people to be feared' (Wolfensberger, 1973). People with disabilities have often been portrayed as deviant in the literature, films and television. Bogdan and Biklen (1993) suggest that most monsters are in fact persons with disabilities. Mary Shelley's Frankenstein published in 1818, for example, portrays such monstrosity as a reflection of the potential of the possibilities of science. People with disabilities have been perceived as: 'sick', 'needing special treatment for which they should be thankful', a 'burden to society—they never quite fit in', 'ugly and sexless', 'incompetent', 'freaks' 'cursed by God', or in terms of disability was a 'gift or test from God' (Gill, 1993, pp. 12–15).

It is easy to see that the fundamental view held by persons within society will lead to actions that reflect such views. People act rationally, but do so in a way that reflects the premise upon which that rationality is based. The perception of the person with a disability being a menace or threat would lead to the persons so labelled being distanced from society. The view that the disabled person's body and biology are broken and need to be mended would lead to the primacy of the medical professions in their lives. For the person on the receiving end of such views, the effect of such labels cannot but affect their own self-concept and their reaction to it.

2.2.3 The Medical Model

> For too long a time–for half a century, in fact–psychiatry tried to interpret the human mind merely as a mechanism, and consequently the therapy of mental disease merely in terms of technique. I believe this dream has been dreamt out. What now begins to loom on the horizon is not psychologized medicine but rather those of human psychiatry.
>
> —Viktor E. Frankl, Man's Search for Meaning

The emergence of the medical model alongside the large institutions noted earlier had established a significant medical leadership by the turn to the twentieth century. Rollin (2003) usefully reviews a plethora of treatments for those illnesses recognised by the profession in the UK at the time. Rollin argues dominant treatments to be abstention and 'cold turkey' for alcoholics, hypnotism for the neuroses (i.e. neurasthenia, a 'ragtag' of symptoms causing lassitude and, hysteria) and 'moral treatments' for the insane designed as 'palliatives for symptoms'. Such palliation was likely to encompass systems of physical restraint such as padded cells and straitjackets, chemical restraints available at the time and a number of exploratory approaches such as music, cycling, 'hypodermic injection of brain extract',[3] Indian hemp[4] and opium.[5]

Rollin asserts 'The composite picture of psychiatry in Britain at the end of the Victorian era and a little beyond is chiefly one of unremitting gloom' (2003, p. 298). Certainly, the effect on inmates would have been nothing short of catastrophic to their lives and freedoms. The early testing of treatments seems to have been based upon trial and error more than science, and institutional inmates were the guinea pigs for new treatments. A more systematic approach to the classification of diseases and to treatment was to emerge in the two decades that followed.

Bracken and Thomas (2001) point to the seminal work of Karl Jasper's highly influential *General Psychopathology*, first published in 1913, and to its phenomenological backdrop. Jaspers built his work on the seminal phenomenological writings of Edmund Husserl who had argued that by the process of 'bracketing out' surrounding contextual issues, it was possible to access the phenomenon at issue.

Unlike the vast majority of major phenomenological writings that came later, Husserl, who had started as a scientist, maintained a Cartesian view of the world in which mind and matter remain separate. Most later writings in phenomenology posited that the subject and object world were one and the same, that 'as I see things so they are'. This latter position allows an explanation of the meaning of behaviour in terms of the contextual social, environmental and other factors, making these central to understanding explaining human behaviour and the impact on the person. But Husserl's adoption of a Cartesian position was to have a profound effect on Jasper's work.

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[3] Lancet 3 February 1891.

[4] BMJ, 4 July 1890.

[5] BMJ, 18 March 1893.

In Jaspers' view, the bracketing out of contextual factors led to a focus upon the 'form' rather than 'content' of the individual psyche. So, for example, hearing voices is not of interest in terms of content of those voices but, rather, that there is no stimulus (form) that accounts for the voices. In many ways, phenomenological reduction here ironicises the patient's experience. That is to say, although the medic uses their experience as reported, the model of 'science' is still used to judge whether there are grounds for hearing such voices. In the absence of such grounds, the conclusion is that the cause must be organic and, indeed, faulty.

Despite this, Bracken and Thomas say that Jaspers's comprehensive work on 'form' established the groundwork for the Diagnostic and Statistical Manual used in the USA to date. More importantly, the underlying assumption of form is that it is disordered individual cognition that must be addressed—that the fault lies in the biology of the individual. Importantly, in making a case for a new direction for mental health they argue that,

> Both supporters and critics of psychiatry agree that the discipline is a product of the European Enlightenment and the movement's preoccupations with reason and the individual subject. Although a critical, postmodern position does not mean rejecting the Enlightenment project, it demands acknowledgement of its negative as well as positive aspects. It means questioning simple notions of progress and advancement and being aware that science can silence as well as liberate, (Bracken & Thomas 2001: 724).

As shall be seen, it is these silences that are those being attended to through this study.

The traditional medical model, therefore, places the source of the problem with the person with the disability and stresses the importance of finding a cure or, by taking a moral position on what is 'acceptable' behaviour, helping the person be more 'normal' (Mackelprang & Salsgiver, 1999; Olkin, 1999). Disability was seen as a medical problem, as a

> defect or failure of a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible and rehabilitation…persons with disability are expected to avail themselves of services offered to them and to spend time in the role of patient or learner being helped by trained professionals, (Olkin, 1999, p. 26).

More importantly, the engagement of the medical profession with what is now termed ABI was about to take on a particular urgency. The links between the emergence of medicine and the Great War 1914–1918 cannot be underestimated as the crowds of injured returned from the fronts in Europe, 'the earliest disability policies of the twentieth century around ABI were entrenched in a medical model primarily focused on the physical restoration of individuals who had suffered some sort of physical trauma or impairment as a result of war' (Blessing, Golden, & Bruy'ere, 2009, p. 2).

Prior to the twentieth century, there was a high mortality rate of people suffering from ABI but improvements in care made during World War 1 reduced the death rate (Boake & Diller, 2005). As argued below, the Second World War also produced significant leaps forward in classifying and treating such head injuries.

Even more recently the Iraq and Afghanistan conflicts, blast injuries caused by war have led to significant new research into brain function (Belanger, Kretzmer, Yoash-Gantz, Pickett, & Tupler, 2009; Jones, Fear, & Wesseley, 2007).

The medical or biomedical model of disability has had dominance in the public's perception of disability. The medical model has regarded disability as a defect or sickness that must be cured through medical intervention. It focuses on, for example, training the body to walk and limbs to work again, in order for the person to be able to accomplish everyday tasks; therapy to assist speech; and training to be safe, inside and outside the safety of home or a rehabilitation hospital.

Although ABI does not feature in the early disability literature, it was perhaps seen in those times as manifested in physical impairment and mental impairment. It was not until the mid-twentieth century that it began to have an identity of its own. After 1948, under World Health Organisation auspice the International Classification of Diseases (ICD) and a significant number of reclassifications have taken place since. Similarly the USA, which also had its own history of classification, launched the Diagnostic and Statistical Manual (DSM) with an additional focus on clinical use in 1952, at the same time WHO published ICD-6. This new classification drew on classification work by the Veteran's Administration working with World War II veterans. A vital turn at this point was the move to a biopsychosocial model on the basis of the work of Adolf Meyers who saw mental disorders as individual reactions to biological, psychological and social factors.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) which complements the ICD classification plays a similar role in grounding the biopsychosocial model. While the recognition of ABI as a medical issue first and foremost came at the turn of the twentieth century, it was not until much later that it was formally incorporated within a disability model. In 1980, the World Health Organisation described:

> Impairments as any loss or abnormality of psychological or anatomical structure or function; disability as any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being; and a handicap as any disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal for that individual. (WHO, 1980, p. 14)

Looking at the history of professions and their legitimacy, it may be that the capacity of medicine to work on the brain and the injured body together gave the category of ABI a life of its own. In a useful editorial of the *American Journal of Psychiatry*, for example, Yudofsky and Hales (2002) speak of three classifications addressed by psychiatry (mood, affect, thought and behaviour), neurology (motor and sensory) and neuropsychiatry (attention, alertness, perception, memory, language and speech, intelligence, cognition and motivation). People with ABI may fit under the disability or handicap classification, but it was not until 1993, at a meeting on ABI held in Oxford (UK), that the International Brain Injury Association was formed to encourage global exchange of information, to support research, provide training and to advocate for brain injury (International Brain

Injury Association, 2011). But the move to clarity around the classification of brain injury has been slow.

ABI itself has really only recently been adopted in the DSM and ICD classifications. Wortzel and Arciniegas (n.d) review this history. The DSMIII (American Psychiatric Association, 1980) spoke of ‘post-concussional syndrome’ but not traumatic brain injury or head injury; traumatic brain injury like acquired brain injury however when using initials TBI and ABI DSM II-R (American Psychiatric Association, 1987) identified only ‘head injury’ as an etiologic factor for delirium and organic personality syndrome; DSM IV (American Psychiatric Association, 1994) and DSM IV TR (American Psychiatric Association, 2000) use the term ‘head trauma’ in narratives describing delirium, amnestic disorder, dementia, cognitive disorder (not otherwise specified) and personality change. DSM V (American Psychiatric Association, 2013) TBI and neuropsychiatric sequelae are detailed and criteria for diagnosing an injury event as TBI are offered. This is considered within a framework of neurocognitive disorders and includes a long list of behavioural disturbances (delusions, hallucinations, mood disturbance, affective lability, agitation, disinhibition, wandering, apathy) and the co-occurrence with neurocognitive symptoms (depression, irritability, fatigue, headache, photosensitivity, sleep disturbance).

Wortzel and Arciniegas (n.d.) usefully summarise the DSM approach. In this model, they use the preinjury, injury and post-injury time frames to consider the focus of rehabilitation professionals in four key areas.

- **Cognition**—including impaired arousal or attention, slow processing, memory disturbance, communication issues, apraxia, visuospatial and executive dysfunction.
- **Emotion**—incorporating pathological effect, depression, anxiety, irritability and anger, agitation and aggression;
- **Behaviour**—including disinhibition, apathy, sleep disturbance, fatigue and headaches;
- **Sensorimotor function**—including pain, visual problems, dizziness/vertigo and seizures.

The classifications in the DSM as described above perhaps give a clue about the focus of the current model. It remains unclear whether this approach is biopsychosocial in that many of the social aspects of lives are ignored. First, even were the focus to have a social dimension, this seems to be likely to be in the hands of the medical and rehabilitation staff to establish and to work upon. Secondly, the model is based on a normative framework of cognition, emotional behaviour and sensorimotor function. This means some interpretation is required to assess what is (the person presenting) and what ought to be (the ‘normal’ person). Thirdly, the focus on what ‘ought to be’ implies efforts to use all medical and rehabilitative efforts to achieve this norm, a largely de facto biomedical approach. Fourthly, the body-object approach—the biomedical model—imposes power differences between professional and client (Sherry, 2006; Smart, 2009).

> There may be important weaknesses and limitations of the Biomedical Model which are less visible and rarely acknowledged, but have far greater implications…prejudices and discrimination towards people with disabilities has developed not in spite of but because of it, (Smart, 2009, p. 4).

The ‘golden period/dark hole period’ of which we spoke in the introduction to this chapter, that two-year window in which such change is taken to be possible, therefore establishes a focus premised upon pathology. In this volume, as will be seen, life after that ‘golden period/dark hole period’ now needs to be similarly transcended to engage with the latter end of a ‘recovery model’, that is, with re-engaging in everyday life.

2.2.4 The Social Model

Some models have sought to provide grand or all-encompassing theories around disability. In recent years, the social model of disability has posed a significant challenge to the medical model as a global theoretical framework for understanding disability (Barnes, Oliver, & Barton, 2002). The social model thesis separates the impairment from disability.

> Impairment—lacking part of or all of a limb, or having a defective limb organism or mechanism of the body.
>
> Disability—the disadvantage or restriction of activity caused by contemporary social organization which takes no account of people who have physical impairments and thus excludes them from mainstream social activities. (UPIAS, 1976, quoted by Oliver, 1990, p. 11.)
>
> Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS, 1976 p. 4)

In this model, the impairment is seen as a characteristic, feature or attribute that affects an individual’s mind or body function as a result of an injury, genetic make-up or disease. In contrast, disability is seen as socially constructed. Society is built for the able-bodied, and so it discriminates against people with impairments. It creates disadvantage through attitudes and culture (e.g. negative images in the media) that reinforces stereotypical views of incapacity, inaccessible environments (e.g. homes, businesses, transport, workplaces, education) and organisations that do not question discrimination nor provide accessible environments. Since these barriers are socially produced, they are subject to socially produced solutions.

But there are some limitations to the social model. For example, Shakespeare and Watson (2001) argue that the social model has not so much as replaced the medical model but has simply placed a higher emphasis on addressing disability as a social issue. They go on to explore the background to British academic and political debates over the social model and argue that the time has come to move beyond this position. Three central criticisms of the British social model are presented and focus on the issue of impairment, the impairment/disability dualism and the issue of identity. It is suggested that an embodied ontology offers the best starting point for disability studies, and some signposts on the way to a more adequate social theory of disability are provided.

Indeed, the impairment/disability distinction remains unresolved and fails to establish an embodied ontology (i.e. the disability identity itself). In reflecting this embodied ontology, common identity and action through disability pride has been proposed (Morris, 1991), while intersectionality, the combination of excluded identities (disability, ethnic minority, LGBTI among others) has been a focus for others (Caldwell, 2010). Looking at the history of labelling by others, as discussed above, the embodied ontology or body-subject view is potentially hugely important. Shakespeare (2006) suggests that the way forward lies in a combination of the medical and the social model and new ways of thinking. The issue of impairment, the impairment/disability dualism and the issue of identity are included in the criticisms of the British social model and echo the breakdown of Shakespeare's relationship with the UK disabled people's movement as disability studies became too reliant on political rhetoric and ideology (Shakespeare & Watson 2001). Shakespeare states that 'there is no qualitative difference between disabled and non-disabled people because we are all impaired in some form, some more than others' (2002, p. 27).

However, the very act of saying the word 'disability' may not be helpful. If there is no qualitative difference, as Shakespeare suggests, then why is it we still recognise a group of people with disabilities versus the rest of society? The issue is borne out in the tone and focus of disability studies literature. Longmore (2003), Garland-Thomas (1997a) and Sherry (2006) argue that the social model of disability focuses upon physical disabilities, while cognitive impairments such as brain injury are overlooked. Chappell posits that ABI is marginalised within the social model and states 'some of the arguments emanating from within the social model are assumed to refer to all disabled people, when in reality they do not' (1998, p. 212).

Oliver (2004) acknowledges five common criticisms of the social model (of which he was the main architect): it ignores or is unable to deal adequately with the realities of impairment, it ignores the 'pains' (Oliver, 2004, p. 8) of both impairment and disablement, it is unable to incorporate other social divisions, disabled people are viewed as 'other' (Oliver, 2004, p. 9) and it is inadequate as a social theory.

More recently, the social model has generated a number of radical critiques posing various alternative terminologies around people with a disability. Abberley (1999) asserts 'a liberative theory' of disability requires the posing of values counter to the classical sociological and revolutionary consensus, the assertion of the rights of the human 'being' against the universalisation of human 'doing' (p. 14). Finkelstein (1980, 1993) argues that 'the predominant factor contributing to the disablement of different groups is the way in which people can participate in the creation of social wealth' (Finkelstein, 1993, p. 12).

Oliver (1990) posits that the comprehensive materialistic account of the creation of disability places ideology at the centre of arguments about disability. In the above models, the assumptions underlying the role of the State/society and the body-object, even though not a medical model, are no less likely to have huge ramifications on the persons so-defined.

The problems of many of these attempts to distinguish groups of people with disabilities are that they rely on prior meta-theoretical categories. Moral classification supports the treatment of people as sinners; medical classification establishes the grounds for medical intervention; the social model establishes the grounds for access while failing to explore limitations to the accessibility argument for some. The arguments around 'embodied ontologies' are vital for they fire off the quotidian narratives of day-to-day life and experience, and the collective and synthesised narratives these represent.

For example, Nussbaum (2001) argues that over time people adapt to deprivations which despite best attempts, they fail to escape. In such circumstance, there is an 'adaptive preference' to a life denuded of the potential many of us would continue to fight for, leaving the person 'satisfied with their lot'. Bourdieu's seminal work on the ways in which societal structures rub up against human agency is useful to this debate on ontology, disability, identity and adaptive preference (e.g. Bourdieu and Wacquant, 1992; Bourdieu, 1994). It was established earlier that the principle of less eligibility in which welfare is always lower than employment income and that many of the services to people with disabilities run parallel to generic services for the population as a whole. Each of us brings a number of capitals to bear in our struggle to flourish, and this is true for all humans.

In the absence of additional support from family or others, the economic capital wielded by people with disabilities under a welfare model is likely to be severely limiting; in services that are often still closed, social capital for people with disabilities is limited to those in closed services. Such capital does not afford an expansive network of reciprocal support out of which to build a flourishing community. Moreover, the person has very little symbolic capital (power) given their place within the systems of power (field) operated by staff within such settings.

The structure of State welfarist policy, therefore, bears down upon the person in such a way as to limit the extent to which their combined capitals, their habitus, can be used in pursuit of their life's ambitions. Over any protracted period, such limitations produce a way of being, what Bourdieu terms a 'disposition' which is reflected in the ways in which people act. This establishes their ontological view of the world and of their identity. In the face of additional discriminatory, hectoring and rejecting behaviours by the community, people with disability begin to embody their social practices as what they have come to expect from the world. Such embodied practices may come to reflect Nussbaum's adaptive preference behaviours in which the loss of hope that there can be change for the better is exemplified in limited personal choices and ways of being.

For people with ABI, the challenge to the person's ontology and identity can be particularly important. From the start, there is an additional potential struggle with the embodied practices of life's disposition to date, compared with the need to establish one that is new. It is, therefore, absolutely essential that from the start those interactions, those services, those relationships in the person's life are formed to establish the embodied practices of inclusion and of dignity. It was one of the necessary features of this research to draw upon what we know about people with ABI to structure the research approach to do no harm at minimum, but to work in an inclusive way that treats participants with dignity.

2.3 Recapitulation

In this chapter, we have summarised a number of assumptions underlying major models of disability and demonstrated that in all disability theory models there can only but be assumptions. It has been seen that such assumptions are the basic premise upon which social action is based: assume possession by the devil, then treat such possession; assume biological cause, then address the biological cause; assume social exclusion through inaccessible environments, then create ones that are accessible. Two further points are necessary to make in relation to the discussion above.

First, since the introduction of welfarist models disability theories may have characterised differences across a range people with disabilities, but the administration of disability under welfare policy still means that to access services, it is necessary to declare or be declared as a person with a disability. This is true even under the radical National Disability Insurance Scheme in Australia in which access to those assessed as having 'significant and enduring' disabilities makes available individualised funds that, at least theoretically, can be used to purchase services of people's choice.

It should be noted at this point that at any one time 19–20% of the population of any country may have disabilities, more in countries where there has been conflict. Many of these people live full lives, are employed, home owners and live in relationships of their choice. So, not all people with disabilities are registered for the provision of disability services. Systems of rationing, therefore, still mediate those who are 'deserving' and those who are not. For those that are, lives are dictated by the availability of health and social care services and by other defined rights to services.

For many years, such services have almost inevitably been segregated and run parallel to the policies and services available to other citizens (e.g. in terms of schooling and employment) maintaining the long discrimination between those who work, as independent from those who are deemed to be unable to do so. Redefining people with disability as 'citizens' with rights to a minimum level of outcome or in some other way that affords them as humans a fundamental right to a good life could have huge impacts. This relates to the second point.

In all the models considered above, the medical model has perhaps provided a classificatory system that separates out ABI most. As shown above, many of the arguments within the social sciences seek broader theoretical formulations of disability that are all inclusive. Importantly, also all the models reviewed take the behaviour of others as a predicate to the theory of disability. Having defined the disability, the consequences of mundane interactions are seldom linked back to the theory itself. Disability theory has as yet to systematically explore the behaviours of professionals or members of the community as the subject of understanding. So, for example, what would be the point of making roads and buildings accessible if those around still treated you with disdain? Of what use would it be to mend a body if the professionals treat you in an undignified manner? Even if psychiatry grew from phenomenological roots, even if social constructionism reflects the social model, the everyday experiences and interactions of people with disabilities have been subservient to broader theoretical formulations and this remains a yawning gap, a blind spot, the 'tiger hidden in the foliage'.

It is now time to focus on the everyday and mundane life experiences of people with ABI. In phenomenological terms, a move to the lifeworld (Lebenswelt) rather than that of the bracketing Husserl recommended is required, an engagement with the natural attitude (Schutz & Luckmann, 1973), and the inter-subjectivities of everyday life and experience are necessary. But, as already established, to do so requires at the very least to ensure the approach does no harm and takes into account as much as is known about people's experiences in such a way as to engage in a research process that is at once positive, based on dignity and which helps participants to engage with the reconstruction of ontologies, identities and embodied practices, of hope. This study seeks this path.

Nevertheless, there is knowledge from each of these perspectives that is useful. In what follows, we seek to draw upon the collection of body-object knowledge in Chap. 3 and body-subject knowledge in Chap. 4 to further instruct us as to how the Cage should be populated. Once again, in these chapters we separate out these instructional findings into shaded Headwork boxes that inform Keys to the ABI Cage and to the processes used to engage people with ABI as research participants.

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Chapter 3
Body-Object Knowledge and Its Relevance

> *In nothing do men more nearly approach the gods than in giving health to men.*
>
> Cicero

3.1 Introduction

Having laid out assumptions of disability models in the last chapter, we are nevertheless convinced that these models can contribute something to our interest in focusing on the lives and experiences of people with ABI. As such, in this chapter, we explore some of the significant findings from the medical and biopsychosocial models and then translate these into concepts that informed and which helped us to populate our methodological tool, 'Keys to the ABI Cage'. We follow up in Chap. 4 by undertaking a similar review of literature and its relevance around the body-subject approach.

It should be observed that huge research resources are committed to biopsychosocial model research and treatments over the 'golden period/dark hole period'. Moreover, we shall see that the 'deficit', broken bodies, broken minds focus has fed into Web resources as reviewed in Chap. 1.

Seeking to maximise people's capacity to function through medical means is essential, but there are other issues that need to be considered for the person to learn to feel and fare better in the community. Significantly less research takes place in this domain, a place where, after leaving hospital or rehabilitation, they must spend the rest of their lives. A cursory review of medical model research, its focus, nature, character and its effects is undertaken below. This literature will focus upon the physical and emotional issues that the medical model seeks to address. At relevant points grey textboxes are used as Headwork, to demonstrate how the information informed the Keys Study methodology.

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3.2 ABI and the Medical Model Findings

Millions of dollars are spent on research into ABI, and millions of dollars are spent on rehabilitation programs. The professional has a potentially vast array of data at their fingertips as there are a plethora of tests they can administer to people with ABI, as will be demonstrated in the following section.

Truism though it be, it needs stating that most practitioners function in the way in which they have been educated and trained (Smart, 2009, p. 3). A search of major medical, rehabilitation and nursing journals demonstrates that the majority of ABI studies follow quantitative approaches. In undertaking this review of the literature, a number of Web engines were used that included: Informa Healthcare; PubMed; ProQuest; Wiley Online Library; Taylor & Francis online; ScienceDirect; Google Scholar; Web of Science; Ovid Medline; Ingenta Connect; SAGE Journals online. The search strategy entailed using the following fundamental words: quantitative studies, brain injury, ABI, traumatic brain injury, TBI, and these in combination with each other and with IQ loss, memory loss, depression, fatigue, coping, pain, cognitive rehabilitation therapy, self-awareness, post-traumatic stress disorder, learning disorders, tests, scales, measures and questionnaires.

A review of the above journals was undertaken by looking at ABI-specific studies in the past twenty years (between 1991 when Durham sustained ABI and 2011, when the original Ph.D. study was being undertaken). It is 20 years since Durham suffered ABI and the authors therefore held a keen interest in developments made over that period of time. The review also examined articles in the *Journal of Sociology and Social Welfare, Journal of Poverty, Journal of Social Work* and the *International Journal of Intercultural Relations*, which were more social science-orientated journals but when searched were found to carry ABI-relevant studies.

Quantitative journal articles were reviewed to establish an objective perspective of difficulties/differences and deficits of ABI to (a) provide a background to problems participants may experience, in order to inform the method employed and the tone of this study; (b) examine issues identified by professional studies, which could inform the 'talk-about' cards; (c) identify issues that could be addressed in the ABI learning resource and (d) to look for similarities and differences to issues identified in qualitative studies and books and blogs written by people with ABI. As neither Durham or Ramcharan are rehabilitation professionals, a review of studies involving specific rehabilitation programs was not taken.

The assessment of ABI and its associated co-morbidities were found to occupy a significant number of studies, many of which replicated Website contents presented in Chap. 1. However, the co-morbidities themselves were a significant proportion of the literature and they fell into a number of categories. Ten of these categories, the main ones identified, are used as subsections in the review that follows, and they fall into areas relating to psychiatry, neurology and neuropsychiatry. It will not have escaped the reader's attention that these very much mirror the pathological and negative approach and cover areas set out in the neat summary of medical interests presented by Wortzel and Arciniegas (n.d.) in the last chapter. Where relevant, some of the methods of individual assessment are also mentioned because they are part and parcel of the approach that turns the ABI into an object, the body-object, to be more precise. Needless to say, some of the more established assessment approaches have a longer history than the 20-year search dates.

3.3 Some Categories of Body-Object Research

In what follows, consideration of each area of literature is supplemented by Headwork boxes to inform the Keys Study, our study of everyday lives, in a way that was likely to support people to feel and fare better.

3.3.1 IQ Loss After ABI

Intelligence quotient (IQ) loss represents one of the primary tools through which the medical and associated professions have estimated the effect of ABI. Not surprisingly, a significant number of assessment methods were found in the literature review, though we do not explore these in detail here. Rather, findings are reviewed and include, inter alia: people with ABI have a mean loss of 14 points of Full Scale IQ from estimated preinjury baseline and they show no evidence of recovery 20 months later (Parker & Rosenblum, 1996); performance IQ score on the Wechsler Adult Intelligence Scale-Revised emerged as the most significant predictor of return to work/school following brain injury (Ip, Doran, & Schentag, 1995). Kay and Lezak (1990) posit that traditional intelligence tests, devised using artificial tasks that emphasise old learning, are not an indication to how the person will function with everyday tasks. An average IQ score can mask severe differences—the person can be performing in a superior range on some tasks, but be severely impaired on others and have trouble with memory, planning and self-monitoring (Fig. 3.1).

I can't understand; I can't do things I used to; I can't think properly; I've lost my job;

Fig. 3.1 Headwork 1: 'Talk-about' cards relevant to the literature on IQ loss

3.3.2 Memory Loss After ABI

There were numerous studies around *memory* and ABI in the literature reviewed—working memory, prospective memory, deficits in attention and memory, bilateral damage to important structures of the brain and ways to improve prospective memory (Fleming, Shum, Strong, & Lightbody, 2005; Gil, Caspi, Ben-Ari, Koren, & Klein, 2005; Raskin & Sohlberg, 2009; Roche, Fleming, & Shum, 2002; Roche, Moody, Szabo, Fleming, & Shum, 2007; Sunderland, Harris & Baddeley, 1983). Memory impairments are among the greatest impediments to people returning to work, but may be one area of cognition that can respond to restorative intervention (Raskin & Sohlberg, 2009), a point we shall rely upon and which is further discussed in Chap. 6 in relation to learning.

Findings from these studies highlight difficulties people with ABI experience with encoding, performance and executing phases of prospective memory, which is the foundation of an intention and remembering to perform the intention. Evaluation of the effectiveness of rehabilitation methods, the frequency of memory lapses and working memory difficulties were identified. Schacter and Slotnick (2004) state that memory can be 'distorted' while Schacter, Chiao & Mitchell (2003) posit that '…not only is our sense of self based on memories of past experience…but our retrieval, recollection, and reconstruction of the past is, reciprocally, influenced by the self' (p. 227). The authors conceptualise this with a metaphor of 'The Seven Sins of Memory' or 'flawed memory experiences' (Schacter et al., 2003, p. 227) which include, transience (refers to forgetting over time), absent-mindedness (refers to lapses of attention), blocking (temporary inaccessibility of stored information), misattribution (attribution of memories to incorrect sources or believing you have seen/heard something you haven't—distorted misinformation), suggestibility (distorted or invented including bias) and persistence of memories (unwanted recollections for example with post-traumatic stress disorder).

If memory cannot be relied upon (Schacter et al., 2003) how reliable are the test results of people with brain injury? Could their assessment results differ on another day, or another hour of the day? For the purposes of this study, all these factors were considered (Figs. 3.2 and 3.3).

Data collection must assist participants to access memories by:

- Having an in-built way to help them focus on remembering.
- Developing a new strategy to assist them to discuss their memories or their experience in a positive way.
- Engaging sensory, short-term, long-term and prospective memory.
- Ensuring participants do not feel foolish: they will need prompts to help them to remember issues and also some way to prompt them so that they will remember what they are talking about.

Fig. 3.2 Headwork 2: The memory difficulties of the participant should be considered in the method of data collection

I forget my name; I forget where I live; I've lost my memory; I've lost my friends; I've lost my job; I can't talk properly; I forget what things look like; I'm dependent; I get lost; I have to do lots of tests;

Fig. 3.3 Headwork 3: 'Talk-about' cards relevant to the literature on memory loss

3.3.3 Depression/Suicide After ABI

Depression and suicide were also well represented among the articles reviewed. Clinical studies have reported high rates of suicide attempts (18%) and clinically significant suicidal thoughts (20–21%) (Simpson & Tate, 2002). The prevalence, symptoms, significance of cognitive impairment and depression and suicide have been widely reported (Fann, Uomoto, & Katon, 2001; Hoofien, Gilboa, Vakil, & Donovick, 2001; Jorge, Robinson, Moser, Tateno, Crespo-Facorro, & Arndt, 1993; Jorge, Robinson, Moser, Tateno, Crespo-Facorro, & Arndt, 2004; Kreutzer, Steel & Gourley, 2001; Rapoport, McCullagh, Streiner, & Feinstein, 2003). These studies employ a range of formalised objective assessment measures (Figs. 3.4 and 3.5).

Data collection must help participants feel comfortable by:

- Taking place at a location where the participant feels comfortable — a local library, coffee shop etc.
- Helping them feel 'safe' by explaining several times what they will be asked to do
- Allowing them to take their time
- Letting them lead the discussion
- Allowing them privacy — they must not be 'pushed' to divulge private things
- Having ways to redirect negative thinking by reviewing positive things they have achieved
- Demonstrating understanding about their challenges
- Making it a positive process by not 'threatening' their self confidence by pointing out their deficits
- Giving them positive ideas to think about as they remember their difficulties

Fig. 3.4 Headwork 4: The depression and emotional fragility of the participant should be considered in the method of data collection

Sad; Depressed; Distressed; Frustrated; Angry; Have to do lots of tests

Fig. 3.5 Headwork 5: 'Talk-about' cards relevant to the literature on depression

3.3.4 Fatigue After ABI

A large number of scales have been developed that attempt to measure the nature, severity and impact of fatigue. Dittner, Wessely and Brown (2004, p. 157) report details of 30 scales and recommend that scales are selected to suit the clinician's needs and that existing and new scales are developed and validated.

Fatigue greatly influences the post-ABI life of the person, and there have been innumerable studies employing different ways to measure and compare fatigue between people with and without ABI. There were many surveys, interviews, questionnaires and scales for the researcher to employ. Once again though these are subject to comment, it is the findings that preoccupy us here. Findings of these studies, which include those conducted with people who have ABI, report significantly greater levels of fatigue than the general population, increased daytime sleepiness, lack of energy and exhaustion (Borgaro, Baker, Wethe, Prigatano, & Kwasnica, 2005; La Chapelle & Finlayson, 1998; Olver, Ponsford, & Curran, 1996; Ziino & Ponsford, 2006a, 2006b) (Figs. 3.6 and 3.7).

Interview/data collection must be of a suitable length of time so participants are not distressed by fatigue.

- Opportunity for participants to take a break – a coffee break.
- Interview broken into segments – each segment discussed so they can see progress.
- By using objects/cards/pictures and words they obtain input not just in words.

Fig. 3.6 Headwork 6: The fatigue of the participant should be considered in the method of data collection

I can't do the things I used to do; I've lost my job; I've lost my friends; I have to do lots of tests

Fig. 3.7 Headwork 7: 'Talk-about' cards relevant to the literature on fatigue

3.3.5 Coping Strategies of People with ABI

Studies around emotions and coping (Bornhofen & McDonald, 2008; Pagulayan, Hoffman, Temkin, Machamer, & Dikmen, 2008), emotional and executive functioning (Douglas, 2010; Garcia-Molina, Bernabeu, Guitart, & Roig-Rovira, 2010) have examined ways people cope with ABI. During rehabilitation, and post-rehabilitation, studies have been conducted into community programs (Vander Laan, Brandys, Sullivan, & Lemsky 2001; Ylvisaker, Feeney, 1998), intimacy

(Aloni, Keren, Cohen, Rosentul, Romm, & Groswasser, 1999; Gill, Sander, Robins, Mazzei, & Struchen, 2011), assessing care and support needs (Ladanyi & Elliot, 2008; Turner-Stokes, Williams & Johnson, 2009). Studies into peer support suggest that peer support can enhance coping and can also help offset loneliness and the disruption of social support that can be associated with brain injury (Hibbard et al., 2002; Struchen, Davis, Bogaards, Hudler-Hull, Clark, & Mazzei, 2011).

There have also been studies of people with ABI that have investigated coping strategies and relationships between coping, apathy, depression, denial and avoidance and emotional adjustment (Anson & Ponsford, 2006a,b; Curran, Ponsford & Crowe, 2000; Ownsworth, Desbois, Grant, Fleming & Strong, 2006; Ownsworth, Fleming, Strong, Radel, Chan & Clare, 2007).

High levels of emotional distress have been shown to affect coping; higher levels of depression were associated with coping strategies characterised by worry, wishful thinking and self-blame; strategies that focus on problem-solving and having a positive outlook were related to lower anxiety levels. Major coping types identified include emotion-focused, problem-focused, perception-focused and avoidance coping. Once again inventories with good statistical properties were widely used in these studies (Fig. 3.8).

Coping strategy identified in literature	**Examples of 'talk-about' cards**
Avoidance coping	Going out, staying home
Problem focused	Doing hard things, achieving hard things, Seeing some progress, Doing things I couldn't do before
Emotion focused	Talking
Peer support	My family, my friends, what others with ABI have done
Health Professionals	Doctor; Occupational Therapist; Counsellor; Health Professionals

Fig. 3.8 Headwork 8: 'Talk-about' cards relevant to the literature on coping

Chapter 4 will review qualitative studies around coping, resilience and quality of life.

3.3.6 Pain Following ABI

The incidence of pain following brain injury shows that chronic pain is a significant problem in mild, moderate and severe TBI (Lahz& Bryant, 1996); that shoulder pain after TBI is a clinical issue that has not been well researched or recognised (Leung, 2006) and that pain is quite common because the nature of many ABIs being the result of accident (Sherman, Goldberg & Bell, 2006) (Fig. 3.9).

I have terrible pain; I've lost my job.

Fig. 3.9 Headwork 9: 'Talk-about' cards relevant to the literature on the consequences of pain

3.3.7 Self-awareness After ABI

Self-awareness is another important area that has been the focus of studies examined in the review. Fleming, Lucas and Lightbody (2006) posit that self-awareness is a complex phenomenon that impedes the rehabilitation process and outcome. Their study provided an individualised program to improve self-awareness. These programs were successful but, in all four cases, were accompanied by anxiety. Ownsworth et al., (2007) studied awareness and long-term adjustment, and different awareness typologies were identified. Individuals with good self-awareness and high defensiveness demonstrated the most favourable outcomes. Ownsworth, Desbois, Grant, Fleming and Strong's (2006) study of the associations between self-awareness and emotional wellbeing empirically supported the theoretical view that an increase in self-awareness is associated with improved employment status. Fleming and Ownsworth's 2006 review of awareness interventions in brain injury rehabilitation was conducted because '…unawareness related to brain injury has implications in rehabilitation, functional outcomes, and the emotional well-being of clients' (Fleming & Ownsworth, 2006. p. 74).

Lam, McMahon, Priddy and Gehred-Schultz (1988) posit that self-awareness increases participation in rehabilitation and Ezrachi, Ben-Yishay, Kay, Diller and Rattok (1991) link self-awareness to successful community and vocational reintegration. A correlation has also been found between self-awareness and emotional distress (Fleming, Lucas, & Lightbody, 2006; Fleming & Ownsworth, 2006; Fleming, Shum, Strong & Lightbody, 2005; Fleming & Strong, 1999; Fleming, Strong, & Ashton, 1998; Lezak & O' Brien, 1988; Roche, Moody, Szabo, Fleming & Shum, 2002).

Research has shown that clients with better self-awareness of their impairments have better participation or involvement and compliance in rehabilitation (Fleming

Interview/data collection must be allow for participants to become aware of the difficulties they experience, explore how they feel because of their ABI and coping strategies they use successfully.

- Opportunity for participants to see what some people with ABI have experienced
- Interview needs to be divided into sections to focus upon before moving to another sections.
- Objects/cards/pictures and words utilized to assist them to reflect.

Fig. 3.10 Headwork 8: Participants may lack self-awareness therefor the method should assist them to reflect et al. 1998, 2005). Thus, there is a complex interaction between self-awareness and compliance. Self-awareness and compliance will be issues to address in the Keys Study (Fig. 3.10).

3.3.8 Post-traumatic Stress Disorder After ABI

Studies also evaluate the relationship between acute stress and post-traumatic stress, memory and amnesia (Bryant & Harvey, 2000; Harvey & Bryant, 1998 1999; Gil, Caspi, Ben-Ari, Koren and Klein, 2005). There are other studies about persistent post-concussive symptoms and post-traumatic stress disorder (PTSD) as a consequence of war by Schneiderman, Braver, and Kang (2008); Hoge, McGurk, Thomas, Cox, Engel and Castro (2008) and Ohry, Rattok and Solomon (1996). Bryant, Marosszeky, Crooks, Baguley and Gurka (2000) investigated the effect of PTSD on rehabilitation after severe ABI. Once again scales with strong statistical properties were adopted in all these studies (Fig. 3.11).

Interview/data collection must be take into account the participant may be suffering prom PTSD – they must be treated with respect, kindness, they should direct the interview with what they wish to talk about, they must be put at their ease, the interview must be non-threatening..there must be no right or wrong answers – they must feel success

Fig. 3.11 Headwork 9: Trauma can play a part in how participants react in interviews

3.3.9 Learning Difficulties After ABI

Studies suggest learning difficulties can result from ABI through the combination of cognitive, memory, sight, hearing and understanding impairments that result from damage to the brain. There are many studies in regard to such learning disabilities: Siegal (1989, 1999), Sternberg and Spear-Swerling (1999), Stanovich (1991), Swanson (1993a, b), Wagner and Garon (1999) and Wong (1996). This topic will be examined at length in Chap. 5, which focuses upon education and learning (Fig. 3.12).

Interview/data collection must be take into account the participant may have comprehension and learning difficulties therefore learning principles must be employed

Fig. 3.12 Headwork 10: Participants may have comprehension and learning difficulties

3.3.10 Cognitive Rehabilitation Therapy

Perhaps one of the closest links between therapeutic intervention and re-engagement in everyday life was in the area of cognitive rehabilitation therapy. Several articles were found in the review of this area. Cognitive rehabilitation therapy is a process of re-learning cognitive skills that have been changed or lost because of damage to the brain cells or chemistry. It involves education about cognitive weakness and strengths, process training—practicing cognitive skills, strategy training and functional activities training. Harley et al. describe it as 'reinforcing, strengthening, or re-establishing previously learned patterns of behaviour, or establishing new patterns of cognitive activity or compensatory mechanisms for impaired neurological systems' (1992, p. 63).

Giles (2010) conducted one of the largest randomised controlled trials of rehabilitation after traumatic brain injury to examine the theoretical relationships between cognitive and functional rehabilitation. The study added to the evidence base supporting neurofunctional intervention in addition to standard care in improving independent living skills in people with moderate or severe TBI.

Schoenberg et al. (2008) compared outcomes of patients who received computer-based cognitive therapy with participants who received face-to-face speech–language rehabilitation and established that similar outcomes at a similar cost were the result. Carney et al. (1999) ascertained that specific forms of cognitive rehabilitation reduce memory failures and anxiety and improve self-concept and interpersonal relationships. Cernich, Kurtz, Mordecai, and Ryan (2010) explain current treatment options, and Grealy, Johnson and Rushton (1999) used exercise and virtual reality to improve cognitive function. They concluded that exercising in a virtual environment offers the potential for significant gains in cognitive function. Yet Kay and Lezak (1990) warn against 'The Rehab Wizard'—where people with brain injury and their families feel let down by the belief that cognitive retraining would be the answer to behavioural and cognitive difficulties.

The links between cognitive function and re-engagement with everyday life are obvious. The objective measurement, based upon pre-established understanding of cognition, establishes an important framework through which to maximise cognitive functioning. However, the objectification of the person's cognitive skills can miss the connections between cognition and other aspects of the person's life, and the person's view is an important feature as a focus for re-engagement in everyday life. Cognitive rehabilitation therapy involves professional intervention, and there are computer-based programs that can be used by the person once they have returned home. In Chap. 5, more will be said of the links between cognition, learning and ABI.

3.3.11 Other Areas of Focus in Studies

Studies of the 'effect of ABI on the family' of people with ABI examine the needs of the family members of patients with severe TBI. Bond, Draeger, and Mandleco and Donnelly (2003) concluded that ‘the need to know, the need for consistent information and the need to make sense of the experience was vital’ (Verhaeghe, Defloor, & Grypdonck, 2005).

There are also studies that touch upon social identity and social support, which have been viewed from different perspectives with various discoveries. These include the following: cognitive deficits have been found to bring the person closer to family (Haslam, Jetten, Postmes & Haslam, 2009); identity crisis and disruption associated with ABI (Teasdale & Engberg, 2001) and social isolation and a relaxed way of living in rural areas has been found to accommodate the fatigue of the person with ABI (Jones & Curtin, 2010). Community integration involving relationships with others, independence in one’s living situation and activities to fill one’s time have been recommended in McColl et al.’s (1998) study.

3.4 Some Reflections on Quantitative Body-Object Research

More needs to be said about the body-object literature as a collective body of knowledge and its relevance relationship to the present study.

The studies above show particular foci, most of which are based around deficits. Another indicator of the breadth and depth of interest was the range of topics investigated in research articles in the *Journal of the Australian Society for the Study of Brain Impairment* in the two years following the above literature review: memory (23 articles), communication (10), cognition/motivation (9), community rehabilitation support (8), rehabilitation outcomes (5), residential care (4), executive function (4), anxiety (4), social behaviour (3) and family (3). Two or less articles were found on: neural cells/genes, physical fitness/leisure activities, behavioural change, goal setting, depression, dementia, emotional adjustment, emotional impact hospital to home, occupational issues, early recovery rates, reasoning and positive psychology. The authors understand that approximately 90% of articles published in this journal have been quantitative studies.

As demonstrated by information under the ‘Headwork’ headings, the development of *Keys to the ABI Cage* drew upon this literature. The literature review was used to inform the process through which to engage people with ABI so as to do no harm. It was anticipated that they might be suffering from IQ loss, memory impairment, depression (even suicidal thoughts), fatigue, lack of self-awareness, post-traumatic stress disorder, difficulty coping and pain. Thus, it was acknowledged that we would be approaching and engaging fragile, vulnerable people to reflect upon their ABI experience.

The ‘talk-about’ cards, which were a central part of the process, ‘translated’ difficulties participants may be experiencing, and the differences between their pre- and post-ABI life into everyday, colloquial comments upon which they could choose to reflect if they wished.

However, the approach of the medical model is that ‘defects or failure of a bodily system are detected and … goals of intervention are cure, amelioration of the physical condition to the greatest extent possible’ (Olkin, 1999, p. 26). The literature reviewed has demonstrated how specific difficulties/differences/deficits have been separated for specific examination by experts in various fields. But it is the *combination* of the *total* of the overlapping difficulties/differences/deficits that affect the lived experience or lifeworld of people with ABI. Moreover, these must be set against the positive aspects of their lives, which are seldom if ever mentioned.

The importance of the difficulties/differences/deficits (IQ and memory loss, depression, cognitive rehabilitation therapy, fatigue, lack of self-awareness, post-traumatic stress, coping and pain) cannot be ignored. These topics focus upon and consider answers to blank spots, areas that have been identified as some of the things that are more likely to be found among people with ABI. However, these studies above are largely second-order accounts, which may fail to establish the self-reported impact and meaning from a person-first perspective.

Tests for IQ or memory loss are *not the same* as the initial medical tests conducted in the acute hospital stage to determine the damage to the person’s brain (e.g. magnetic resonance imaging; computed tomography or computerised axial tomography; electroencephalogram; position emission). These medical tests are used to ‘prove’ the physical brain has been damaged.

It is more difficult to prove ABI through IQ and other tests, and tests may not identify how the person feels because of their ABI. Some people feel uncomfortable about others judging and knowing about their difficulties, and there are many reasons why a person may perform a test badly or well at the time of these tests. These reasons might include, inter alia, motivation, whether or not they are having a good or bad day, time of day the test is given and so forth, but test results are taken to be of great importance when used in legal proceedings. The body-object perspective investigated by these studies ‘filters down’ to be reported in Web-based material, as the basis for information in many brain injury support Websites. For the person with ABI, reading about possible difficulties/differences/deficits can be valuable because they provide information so they realise they are not imagining things and that they are not alone, but there may be little information to aid or help the person adapt, cope and re-engage in life, and the reporting may reinforce the view that they are ‘more damaged’ and ‘less normal’ than the rest of society. A positive approach would at very least address the issues of coping and adaptation more systematically as well as listing and describing deficits.

Viewed from the ‘body-object’ perspective, ABI leads to the assumption that a formulaic piece-by-piece response by medical and rehabilitation practitioners is all that can be done. But, as will be shown, this perspective is problematic as the approach is one based on defining problems and not about examining the positive aspects of the person’s life.

The nature of data collection, where the person with ABI may be treated as ‘the object’ of professional and professionally shared expertise, may further disempower the individual. Most importantly, this medical model of research is transposed into the rehabilitation setting, where the issues of the inequality of power between the professional and the client are taken as a given. The professional (the expert with all the knowledge) administers a test or questionnaire (that may have been trialled and developed in studies), and the client, the person with ABI, is required to comply and answer the predetermined test questions. Because, for example, injuries from of a motor vehicle accident may involve compensation, the client may feel under additional pressure to comply to complete tests.

There are, then, further issues that inform the present study which are informed by the processes involved in research and practice adopted by the body-object approach (Figs. 3.13 and 3.14).

- Because of the number of ‘tests’ given to people with ABI, the method employed in this research should *not* be like a test.
- The method should give the interviewee the power to choose issues to discuss and whether or not to disclose information.
- The participant should hold the power, be in control.
- The method should focus upon things the interviewee does to help themselves.
- Engagement with the method should have a positive outcome.
- The method should acknowledge that the interviewee has many challenges, and acknowledge that having ABI is difficult.
- The method should foster hope and empower people to share with others the ways they tackle their difficulties.
- The method must be user friendly, easy, use non medical language and be nonthreatening.
- Participants must not feel they ‘have’ to participate in this study, they must not be bullied or coerced to participate.
- Participants will be the ‘expert’.
- The possible emotional fragility and fear of new situations will need to be addressed.

Fig. 3.13 Headwork 11: Reflecting on body-objects tests and this study

Participants must be comfortable being engaged in this study by:

- Helping them to understand what is required of them.
- Helping them to understand why they are participating – the purpose.
- Ensuring they don’t feel foolish: they will need prompts to help them to remember issues and also some way to prompt them so that they will remember what they are talking about.
- Ensuring that they can reflect upon their experiences (including their deficits) in a way that does not upset them.

Fig. 3.14 Headwork 12: Participants should feel comfortable

Chapter 1 pointed to other important issues (love, hope, courage, determination, etc.) that affect the lifeworld of people with ABI, both in hospital and once they leave the hospital or rehabilitation setting. These could be regarded as blind spots. These factors are not generally the focus of quantitative research (nor rehabilitation); indeed, they may not be issues that can be addressed by medical professionals, but that does not mean that these issues are not vital to the individual as they re-engage with life. Indeed, as suggested earlier using the notion of 'embodied practices', it is vital to ensure that the life experiences from the earliest stage prepare the person for a life of hope and not of resignation. The Keys Study intended to identify things that had helped people with ABI to learn to feel and fare better and to share these collective concepts.

One more point should be made. The focus of literature reviewed above predominantly covers the 'golden period/dark hole period' when the person with ABI has most contact with professionals who can 'make a difference', the period over which it is believed that body can be 'salvaged' and 'repaired'. But, to reiterate, the consequences of ABI remain with the person for many years, or a lifetime, not just the 'golden period/dark hole period'. In spite of the tremendous advancement in knowledge gained about ABI, there is little information available about the way people with ABI understand their new situation, or how they feel about rehabilitation, or being involved with research studies or how they regain their sense of identity, or things they can do to help themselves.

3.5 Recapitulation

Quantitative body-object literature provides empirical data about particular difficulties/differences/deficits for people with ABI. The systems of classification established in the medical model have been criticised because of their focus on 'mending' bodies and brains while missing the everyday and mundane lives produced by the recurrent and prolonged engagement with the medical and rehabilitation professions. The empirical studies reviewed have, like the assessments of clinical professionals led to the development of questionnaires, standardised measures, scales, tests and collateral reports to determine deficits in order to identify the impairment of the person with ABI, and to assess areas for improvement in a time-controlled manner with results that can be shared and understood by other professionals. But 'learning to improve' or 'learning to live again' does not cease for the person with ABI once their engagement with the professions has diminished or ended. Indeed, it might be argued that the importance of re-learning in situ, where they re-engage with their everyday lives, is important as well as the initial professionally dominated period.

From the literature reviewed in this chapter, it has been found that people with ABI are known to lack self-awareness, and they can experience memory difficulties and can become distressed when they become aware of their difficulties and limitations. These issues were considered in the development of *Keys to the ABI Cage* method, which aimed to provide a positive experience for participants as 'Headwork' in this chapter has demonstrated. Examples of 'talk-about' cards informed from the quantitative, body-object literature, allowed the participant to reflect upon their own experience, by exploring both the positive as well as the negative aspects of their life world. Involvement in the Keys Study was not as confronting or challenging as an IQ test for example as participants had seen the Cage model, been shown a Power Point presentation explaining what they would be asked to do to reflect upon and speak about their experience.

The Keys Study was designed to access the first-person experiences of people with ABI. Participants were not obliged to understand and answer questions. As it presently stands, the quantitative, outsiders', body-object, medical model may not fit the needs of the fragile participant experiencing multiple challenges.

The period of re-learning for people who acquire an ABI lasts a lifetime, yet few studies examine the period post-professional input. The Keys Study focused on the period when people were learning to re-engage with the complexities of their relationships and home lives after the 'golden period/dark hole period', implying that the methodology sought to adopt an approach in which there was a learning element. Chapter 5 will examine literature about learning.

Finally, the approach adopted did not accept that body-object-based information exhausts the information that should be publicly available. Indeed, such information may be counterproductive to personal identity and the views others have of relatives with an ABI. In his study, Sherry (2006) suggests:

> … a need for the theoretical revision of both the medical and social models of disability. Issues of rights, inclusion, respect, and diversity are often marginalized within the medical model, where the focus is on labelling the 'deficits' of an impaired body. Likewise, issues of identity, embodiment and human agency are often sidelined in the social model, where the focus is on identifying disabling barriers, often from a structuralist or materialistic perspective, (Sherry, 2006, p. 203).

Taking into account Sherry's recommendation, the following chapter will examine the body-subject, qualitative literature.

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Chapter 4
The Body-Subject Perspective of ABI—A Literature Review of Qualitative Studies

> People create reality and their lived experience as they reflect on, interact with and respond to others; thus reality is fundamentally inter-subjective. Only theories that take into account this inter-subjective nature of human experience can understand, explain, and illuminate how people create their social and personal realities.
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4.1 Introduction

Thus far, we have created Headwork boxes that inform the content and processes of 'Keys to the ABI Cage' by reviews of information on Websites and body-object literature. Unlike some of the personal narratives reviewed in Chap. 1, the predominant focus of Websites and the body-object approach was found to be deficit-based. The blank spot (Wagner, 1993) was that these approaches were blind to anything outside of the syllogism that starts with 'mending broken bodies' as a premise.

We argue there is a need for a 'paradigm shift' (Kuhn, 1962) to supplant present theories because they no longer speak to the concerns of practising scientists (Terre Blanche & Durrheim, 1999, p. 4) and practitioners, and those who live every day of their lives with ABI. As Sandberg and Alvesson (2011) say, there is often a need to 'reframe' a research area rather than simply to point to 'gaps in the literature'. The body-object perspective, the medical model, focuses on mending deficits and does so by isolating different aspects of the person affected by ABI as shown in Chap. 3. Saxe, in the nineteenth-century poem 'The Blind Men And The Elephant', points out that the beast was more than the sum of its parts that people think they can 'see' when in fact they are 'blind' or unaware, and they speak knowledgeably about that which they do not know. This poem articulates how the person with ABI and indeed professionals may view the way they are treated as just isolated 'bits' of themselves, rather than taking them as a whole person. This poem could be viewed as a metaphor for the body-object view—it does not see the person as a whole person.

C. Durham and P. Ramcharan, *Insight into Acquired Brain Injury*,
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The Blind Men and the Elephant: John Godfry Saxe (1816–87) (see Saxe, 1995)

It was six men of Indostan
To learning much inclined,
Who went to see the Elephant
(Though all of them were blind)’
That each by observation
Might satisfy his mind
The First approach’d the Elephant,
And happening to fall
Against his broad and sturdy side,
At once began to bawl:
“God bless me! But the Elephant is very like a wall!”
“….like a spear!” “….like a snake!” “….like a tree!” “….like a fan!”
So oft in theologic wars,
The disputatants, I ween,
Rail on in utter ignorance
Of what each other mean,
And prate[1] about an Elephant
Not one of them has seen.

Elephant: Christine Yvonne Durham after John Godfry Saxe

The outside of an Elephant
Is made up of different parts
But that’s not all Elephant is, Elephant has mind and heart
Elephant’s more than leg and trunk and hide and eyes and meat.
Elephant’s more than tail and ears and side and tusk and feet.

In circus, zoo, and forest too
Elephant works in fields and more
A family pet, a faithful friend,
He can run amok and gore.
Carrying tourists, logs or heavy loads, his attributes are many

But rogue and wild, and strong and huge, Elephant’s very scary!
Why, oh why, I ask you,
Does this massive wrinkly beast
Disobey his master

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[1] Prate—to talk foolishly or at length about something.

Or sit upon a seat?
He sways and dances (it is true) when tethered to a stake
When looking into all of this, of sense we cannot make

The essence of the Elephant
Is mighty hard to find
It’s not locked up in books or film
Or held in someone’s mind
If only Elephant could speak, and tell us what he knows
Then, and only then, could we discover how he goes.

In this light, ‘mending bodies’ is not the *only* way to perceive ABI, nor treat people with ABI, and as will be demonstrated in this chapter, the body-object approach misses a large portion of the phenomenon that is of importance to the insiders, to people with ABI who question ‘Will I *ever* feel better?’ ‘Will life *always* be this awful?’ ‘I’m lost, how can I find myself?’ (Durham, 1997).

This study was approached from the insider’s perspective and author Durham placed herself as a ‘visible researcher’ (Denzin, 1997), exploring the insider’s, body-subject, emic view introduced in Chap. 1. As joint authors, we will commence by considering the person with ABI as being *more* than the sum of their parts. Subsequent to introducing phenomenology in Chap. 3, the concept of ‘intentionality’ will be revisited and its links with qualitative academic literature and with feminist perspectives drawing upon personal narratives and insider’s views will be explored as an alternative.

This chapter will establish the place of this study within the body of work of qualitative body-subject research: research that focuses on ways people experience ABI. The review of qualitative studies, together with the perspectives discussed in this chapter, informed the methodology employed in the ‘Keys Study’. Chapter 5 will continue to provide a background to the methodology by reviewing relevant learning theories and concepts from educational literature.

4.1.1 Intentionality: Another Way to Consider ABI

In Chap. 3, the place of phenomenology as an alternative ontology to those grounded in a scientific or the hypothetico-deductive model was introduced. Two requirements for a study methodology follow. First, if phenomenology is a suitable ontology (philosophy of being), then what is its epistemology—its philosophy of knowledge? Secondly, and subsequently, how can such an epistemology be operationalised?

Phenomenology, a philosophical movement of the early twentieth century, had immense influence on continental Europe. Developed as a theory of knowledge by Edmund Husserl (1859–1938) in his book *Ideas: A General Introduction to Pure Phenomenology* (1913), it offers a descriptive analysis of ‘essences’ in general. ‘Essences’ (from the Greek *eidos* ‘form’—exceptionally vivid visual or auditory images that allow detailed recall of something previously perceived) were not only objects (such as an object of sense-perception) but also acts of consciousness. The phenomenologist must 'bracket', suspend judgment or perform an 'epoché', the 'natural attitude' to the world. Phenomenology asserts that through 'eidetic' or 'intuitive' approaches we have knowledge of the *essential features* of the lifeworld, which phenomenologist's term 'essences'.

One of the major presuppositions of phenomenology is that people have an intention to an object. As already argued, the seemingly hard fact of a stone might, given differing intentionality, for a physicist a series of atomic and subatomic forces —for a petroleum prospector, a focus for analysis of hydrocarbon presence—for an artist, its aesthetic—or for a person being attacked, a source of defence. The intentionality towards the stone is defined in its usage. The phenomenological researcher tries to find the essence of a phenomenon from a particular perspective—in this case from the experiences of people with ABI. This does not involve an hypothesis or preconception but focuses on the 'how' and 'why' of everyday intuitive lived experience—again, in this instance of the experience of ABI—rather than the 'how much' or 'how many' of the scientific positivist position.

Since the second century, when problems of brain injury were first recorded, people were searching for a way to make 'broken heads' 'better'. The old nursery rhyme 'Jack and Jill' (1795) tells the story of two children who went up and fell down a hill—Jack fell down, and broke his crown, and went to bed to mend his head with vinegar and brown paper (an old remedy used to treat wounds, bruises and other injuries). This study aimed to find a new way to help 'mend' broken heads.

An alternative and more sinister origin of this rhyme, suggests another theory about the head, and offers another way to view brain injury. 'Jack and Jill' is claimed to tell the story of King Louis XVI's (Jack's) beheading (lost his crown) followed by Queen Marie Antoinette (Jill) whose head came tumbling after. The executioner held Louis XV1's severed head aloft, by the hair, to allow the head to gaze on its body as consciousness was believed to remain for at least eight seconds after beheading until lack of oxygen caused unconsciousness and eventual death.

For many people, ABI is akin to 'losing their head'. Like King Louis's eyes gazing at its own body, they can observe their own body and life, but they are quite disconnected from it. In a split second mind, memory, movement and hope can vanish leaving the individual with ABI profoundly damaged, unable to understand, unable to call on prior knowledge, unable to find a way forward. It is as if they have 'lost' their head, 'lost' themselves, and 'lost' their life as they knew it. Over time, they can spiral down feeling discouraged, desperate, humiliated, worthless and disorientated (Durham, 1997) because to improve cognitively and physically is a long, slow process.

Phenomenology is a philosophy in which a person reflects and speaks about their interpretational narrative of their experience (Giorgi, 1985a, b). Each person is unique and they can engage in personal understandings and discovery and explore the meaning of that experience. Above we can see two competing narratives in relation to Jack and Jill. Neither may be wrong—each differs given how we intentionally engage with the rhyme, whether an historical allegory or as a narrative on the contemporary treatment of the day.

The contention in this book is that, like the blind men approaching the elephant, ‘mending bodies’ by adopting a singular and biomedical intentionality misses the whole and ignores the experiences of people with ABI as they seek to re-engage with their everyday lives.

This study posed the question: Given new understandings of the experiences and intentioned actions of people with ABI, can we find a new or different way to reconnect head, body, life and dreams for people who suffer from ABI?

We have sought to show above how a phenomenological ontology (a philosophy of being) gives rise to a study epistemology (a philosophy of knowledge) and an alignment has been established between these in opposition to a positivist stance. However, for an empirical study, a philosophy of knowledge has to be operationalised—to be translated into a methodology. Van Maanen (1990), writing about phenomenological research in education, relates ‘experience’ to our direct acquaintance of things, the intuitive qualities, impressions of, description of and interpretation of the everyday. But this leaves open how we ask about this experience. What questions and approaches should be used? Giorgi (2009, p. 122) argues that ‘What one seeks from a research interview in phenomenological research is as complete a description as possible of the experience that a participant has lived through’. Furthermore,

> Asking for a situation is vital since the discovery of the meaning of the phenomenon (later in the data analysis) needs to have been connected to a specific context in which the phenomenon has been experienced (Englander, 2012, p. 13).

The present research benefited from Durham’s experience of ABI both personally and as discussed previously her long engagement with people with ABI over many years. The research questions therefore reflected this prior understanding of ‘context’ as a basis for the development of a research approach and ‘questions’ capable of understanding the experience of ABI among the study sample. They also drew upon the systematic study of literature grounded in a supervisory relationship with Ramcharan for the purposes of gaining a doctoral degree by research.

As with all other humans, our actions as writers and researchers are therefore themselves intentioned. If first-person ontologies are given primacy, it is not only to fill a gap and to achieve paradigm shift. It is also to hear the voice of people with ABI and to ensure our research conduct achieved dignity and respect, and did no harm.

In this respect, it has been argued that ‘only qualitative analysis can accurately capture the complex pattern of an individual life without violating the integrity of life or dehumanizing the individual’ (Kotre, 1984, p. 3).

Renzetti and Lee (1993, p. 6) assert that ‘extreme sensitivity is needed in the conduct of research that intrudes into the private lives or deeply personal experiences of the research participants’. Feminist advocates of qualitative methods have argued that ‘individual women’s understandings, emotions, and actions in the world must be explored in those women’s own terms’ (Jayaratine & Stewart 1991, p. 85). ‘Such methods are consistent with the ways in which research participants are treated and the care with which researchers attempt to represent the lived experience’ (ibid., p. 90). For feminists, this involves being cognisant of issue of power and patriarchy.

The majority of participants in this study—those with ABI and people who care for and support other people with ABI—were 'vulnerable', 'difficult to access', 'invisible' 'hidden' and 'hard to reach' (Stone, 2005). From previous chapters, it has been demonstrated that this was to be 'sensitive research' (Wellings, Branigan, & Mitchell, 2000, p. 256) with vulnerable people (Liamputtong, 2007). Their 'invisibility' could have included their marginality, lack of opportunity to voice their concerns, fear of their identity being disrespected, stigma attached to their social conditions, heavy responsibilities and scepticism about being involved in research (Birman, 2005; Fisher & Ragsdale, 2005; Stone, 2005). The present research therefore aimed to provide a time and place for conversations, described by Robertson and Webber (2000) as 'deep and meaningful conversations about life experiences, many of which have not previously been voiced' (pp. 531–532) and research with '…potential consequences or implications, … directly for the participants…' (Sieber & Stanley, 1988, p. 49).

Oakley (1981) suggests the 'goal of finding out about people through interviewing is best achieved when interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship' (p. 41). A rapport and understanding of the individual participants was developed over the period of contact, the phone calls and the interview. Specific encounters were particularly upsetting and are etched in memory for the interviewer Durham, and Ramcharan who had access to the data transcripts. The powerlessness, frustration, perception of being 'taken advantage of' or being 'ripped off' by 'the system' affected some participants profoundly. This was one issue in this study that was underestimated.

Feminist studies also point to experiences of oppression (Mies, 1983: Peter 2000; Fraser and MacDougall 2016) within the research process and the importance of reflexivity or recognition of self in the research process. This is the opposite of Milgram's (1974) famous study of 'obedience' that relied on the abstract authority of the 'scientist', which is an example of research design that depends on *maximising* the hierarchical distance between researcher and research participant. Moreover, in line with arguments by Jayaratine and Stewart (1991), the research topic was selected to have potential to help people with ABI; the Keys Study aimed at specifically determining information that would be most useful and have positive impact; the method was designed to be appropriate to ask questions of vulnerable people; and the answers and data collected would be to assist people with ABI.

The Keys Study was sensitive research into vulnerable people, and to reduce the power differential between researcher and researched, a research approach capable of achieving this was needed. As such, we adopted a narrative research method involving principles of motivational interviewing, which is a directive, client-centred counselling style for eliciting behaviour change by helping clients explore and resolve ambivalence (Rollnick & Miller, 1995). Using this method, the participant was placed in control to speak about what, from a plethora of potential topics, they considered important. The relationship between the interviewer and interviewee was more like a partnership rather than expert/non-expert interaction.

In the Preface to this volume, the 'Keys to the ABI Cage' was presented. It will have been noted from Chaps. 2 and 3 how we used Headwork boxes to guide the relationships between researcher and participants during the development of the data collection method. “Keys to the ABI Cage” as presented in the introduction to this volume is the result. However, there is one further set of literature which informs our approach, the qualitative, body-subject, emic or insider’s perspective which is reviewed below.

4.2 ABI from the Qualitative Body-Subject, Emic, Insider’s Perspective

Having explored some phenomenological assumptions, we now explore how a view grounded in experience was created for the Keys Study.

Rees (2011), in his book “Out of Calamity”, depicts people with ABI as whole people with many facets. In his narratives about people with ABI, Rees tells the story of Phillip, a young man whose parents are delighted when they come across notes that he has scribbled: in their eyes this is an indication of improvement. But

> his mother’s claims about his improvement has raised a few eyebrows among the more prescriptive and sceptical professionals…(who said) anyway his mother is not objective and doesn’t know what she is talking about (Rees, 2011, p. 60).

From the perspective of the insider, ‘those professional gainsayers, and there are many of them…’ (Rees, p. 64) can impact upon the individual. In considering Joe, another person with ABI, ‘few (professionals) if any gave Joe any hope’ (Rees, p. 79); fortunately Joe received kindness and understanding from the hospital cleaners. ‘Joe’s serious injury, isolation, lack of hope, let alone activity had drained his strength’. These quotes provide an example of how some people with ABI and their family perceive their treatment by professionals; their need to be listened to, their point of view taken into account, even small positive issues to be considered and their need for encouragement and hope.

As explained in Chap. 1, one reason for undertaking this study was conversations with hundreds of people with ABI who have attended Durham’s presentations or workshops, told her that they felt, and still feel powerless. They lacked encouragement and hope. Simon (all names in this volume are pseudonyms) stated: ‘They (the professionals) thought I was stupid but I’m not, I’m just slow.’ Mark remarked: ‘The medical viewpoint is that people with ABI don’t have insight. This is not true…we do have insight…we have to re-assess our own lives’. But the body-object perspective can take away hope and further disempower the person with ABI, who, with ‘King Louis XV1’s gaze’ (or the gaze of the decapitated head surveying the person they once were) may see themselves as no longer an individual, as a ‘retard’, ‘object of pity’ among many other disparaging labels.

The body-object language such as ‘physical problems’ does explain the consequences to the person, who may feel unintelligent and dumb: Jo-Anne said: ‘I can’t walk normal and I fall over. I feel stupid’. Jo-Anne, together with the majority of people with ABI would not have used the word ‘cognition’ before their ABI, so terms such as ‘cognitive impairment’ need ‘translation’ so that people like Jo-Anne can understand how having cognitive impairment can impact on their everyday life. Terms such as ‘behaviour impairments’ or ‘personality dysfunctions’ may not explain that a person with ABI might feel out of control and do crazy things that they would not have done prior to their ABI.

At writing workshops, Peter made the observation: ‘When I get mad I do mad things: I threw my new typewriter in the river because the Keys weren’t in alphabetical order!’ demonstrating, in a humorous way, that later he had insight into what was normal/not normal and the affects of anger and frustration. Max remarked ‘When I was mad I chased an emu’, indicating he also had insight into ‘foolish things’ he could do when he was angry. Phillip said: ‘I need a “cone of protection” like Maxwell Smart, to keep out my anger’, showing he had considered his anger problem and found a ‘socially acceptable’ way to describe it. Martin divulged that ‘I’m not mad. I just pretend to be’—demonstrating he was aware of ‘what’s what’, and ‘who’s who’ but that he could only accomplish his ends through extreme behaviour. These comments support the findings of Egan et al. (2006)’s study, who found that people with ABI are capable of greater insight, reflection and humour than indicated in previous research.

Lack of ‘Choice’, lack of ‘Being in Control’ and lack of ‘Power’ may not feature in lists of impairments, but people with ABI are acutely aware that ABI brings with it loss of choice, loss of power to have a say in what they want to do. Poignant statements such as from Atticus: ‘The moment my stroke hit me in the back paddock I lost my choice’; Adrian, ‘I felt disempowered in rehab. If you stay disempowered they keep their jobs’. These statements about the predicament of powerlessness of people with ABI have been expressed at a number of ABI support meetings.

People with ABI listen to other people with ABI; there is understanding and a bond. Felicity said: ‘It’s helpful to know others have the same experience’; Pip remarked: ‘It’s good to know someone understands’; Ian thought: ‘There’s a lot of wisdom in this room full of people with brain injury, a lot of experiences’; John explained by saying: ‘I can feel what you say mate’; Pru commented: ‘I want to be seen as me, an individual, regardless of any disability’.

The research tool Keys to the ABI Cage demonstrated empathy with the ABI experience.

The body-subject view which would support such voices also fits with the seminal ideas of phenomenology offering ‘an interpretative approach to social reality and the lives experience of human beings’ (Holloway & Wheeler, 2010, p. 3).

Qualitative research comes in many forms, but data has priority; it is initially broadly focused, process orientated, context-bound, and involves getting close to data (Holloway & Wheeler, 2010, p. 10). The focus is on the emic; ‘thick descriptions’ (Geertz, 1973) which are detailed portrayals, interpretations and the uncovering of feeling and meaningful behaviours; the researcher–researched relationship is based on the concept of equality as human beings; the researcher is visible and is the main research ‘tool’.

The use of qualitative research has only recently begun to populate the literature around ABI, but is quickly growing (see, e.g. Sample & Darragh, 1998;

Albrecht & Devlieger, 1999; Darragh, Sample & Krieger, 2001; Levack, McPherson, & McNaughton, 2004; Howes, Benton & Edwards, 2004, 2005; Jumisko, Lexell, & Söderberg, 2007; Lorenz, 2010a, b; Uprichard, 2010; and Lloyd, Gatherer & Kalsy, 2006).

4.3 Qualitative Academic Research: The Insider's Experience from the Outsiders' Perspective

A formal literature review up to the time of the study in 2011[2] was undertaken using 12 web search engines. Main terms qualitative studies, narrative, lived experience, quality of life, coping, resilience and brain injury yielded 24 studies many of which revealed blind spots not covered in conventional quantitative approaches. These blind areas contributed to the method of *Keys to the ABI Cage* and the 'talk-about' cards that populated the cage and offered participants focal points for their narrative.

This literature, produced largely through open-ended and semi-structured interviews and narrative first-person accounts, illuminate the person with ABI's own perspective and lifeworld. Gelech and Desjardins (2011, p. 62) posit that although concepts of the personhood of the individual as 'lost' or 'shattered' have dominated discussions in the literature, this 'perspective is a crude representation of the post-injury experience of self, and the aspects of stability, recovery, transcendence and moral growth are also involved in this process'. Like Rees, they show how the complexity of 'personhood' cannot be subsumed under a single concept and is dynamic as opposed to being fixed and, as such, must develop during and post the rehabilitation experience.

This involves *relational* concepts of self: comparing the present self with the past self, the self in relation to others or the self as improving over time (Nochi, 2000). Nochi's categories of the positive self include the 'self as better than others' with ABI; the 'grown self' in which the new ABI self is seen as having grown in relation to their past self; the 'recovering self' in which progress is being made; the 'self living in the here and now', in which people see themselves as normal; and the 'protesting self' who find ways to function best given life's challenges. Nochi demonstrates how, using these categorisations, the person can come to terms with their new self.

Kendall and Muenchberg (2009) suggest that there is a significant process of grieving for the loss of the old identity and the construction of a new identity. In the examination of 52 biographical accounts by people with ABI, they isolated a number of coping strategies: personal discovery (learning about self), goal-directed (practical problem-solving), control and independence, purpose (believing their

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[2] The more recent literature will be explored further in the discussion chapter later and any new findings interpolated with the recommendations for practice.

injury had a purpose), spiritual, social coping (using support networks), focusing on each day and not long term, persistence and hard work and use of emotional coping and seeing the lighter side. The strategies are not mutually exclusive and focus on an ‘opportunity structure’ for rationalising the new self in a new environment. In some ways, both Nochi and Kendall and Muenchberg’s strategies are generic in that they have relevance to us all. What is different is that acquiring an ABI may change the distance for accomplishment. As argued of Borudieu in Chap. 3, new circumstances require a person to find new personal and social, economic and symbolic resources to pursue lives they choose. Linge (1990) usefully argues that a focus on small achievements helps in this regard.

Indeed, the study by Jumisko et al. (2009), in their examination of ‘what it means to feel well’, points to the importance of becoming familiar with the new self, together with showing strength and resolve, re-establishing a sense of control, being close to someone and feeling ‘good enough’. This work mirrors the salutogenic theory first posited by Antonovky (1979). Antonovky argued that a ‘sense of coherence’ was essential to the management of stress and to coping and as a precursor to better health. However, it is not just health that is as issue for many people with ABI. Levack et al. (2010), in their meta-analysis of 23 studies, also emphasise areas of the new self. They point to disconnects between mind–body, the pre- and post-injury identity, social situations and emotional supports. These factors test the reconstruction of self-identity and reconstruction of both personhood and ‘place in the world’. For Levak, Kayes and Faydl (2010), it is the internal and external resources on which people with ABI can draw, that is vital. Yet discovering these new resources may be problematic too without additional support.

Examining coping themes not present in quantitative coping inventories, Karpmann et al. (1986) identify a number of characterising features that are largely about personal qualities and values: hope and optimism, determination, self-evaluation, new attitudes to life, new support networks and religion. But, as pointed out by both McColl et al. (1998) and Turner et al. (2007), people need to find solutions in their own peculiar and individual circumstances. Turner et al. (2007) suggest that this means a need to work with individual experiences as a focus for rehabilitation. But if this focus on the individual is important to the rehabilitation professional, it must be *more important* to the person as they seek to re-enter life without professional input. Even more importantly, Kendall and Terry (2008) found that while coping produced benefits in short- and long-term functioning, it did not necessarily contribute in the same way to wellbeing and faring well. This significant finding represents a blind spot in the literature, especially for people after the ‘golden period/dark hole period’.

The focus on adaptation and coping styles in the literature reviewed in Chap. 3 focused around professional practice, and how the professional orientates towards delivery of care and support. The collective work around personal accounts speak of the place of love, hope, faith, of the importance of nurturance, social and support networks, of knowledge and personal skills in engaging with the practicalities of everyday life challenges. They speak of relational thinking of the new and old self, the self as changing and of the connection of the self to others. These and many more feature as the internal and external resources and personal qualities that can be drawn upon from an everyday repertoire, so the person can learn to cope and learn to feel and fare better.

By exploring the subjectively meaningful experience of people with ABI, the qualitative studies establish a multitude of perspectives with a dominant focus of coping, adaptation and recovery. Some of the studies have an interest in further clarification of conceptualisations that might contribute to professional practice in varying ways. Featuring in this way are the elucidation of coping themes that can be operationalised using coping inventories (Karpmann, Wolfe & Vargo, 1986); coping styles that allow professionals to orientate towards different responses by people to the acquisition of brain injury (Kendall & Muenchberg, 2009); coping styles that go hand-in-hand with people feeling ‘at ease’ with themselves—successful styles of coping (Nochi, 2000); coping and adaptive responses in targeted areas such as community inclusion (McColl et al., 1998), employment (Oppermann, 2004) and in the transition from hospital to home (Turner et al., 2007).

On the basis of the reviewed studies, a number of points informed the development of *Keys to the ABI Cage* and to the methodological procedure used in this study. The boxes are at times repeat concepts previously discussed, these important concepts that apply to ensuring the wellbeing of participants as they (a) engage with this study and (b) return home to continue to struggle with their ABI (Figs. 4.1 and 4.2).

Taking place at a location where the participant feels comfortable — a local library, coffee shop etc.
Helping them feel ‘safe’ by explaining several times what they will be asked to do.
Allowing them to take their time.
Letting them lead the discussion.
Allowing them privacy — they must not be ‘pushed’ to divulge private things.
Having ways to address ‘Faulty Thinking’ to redirect negative thinking by reviewing positive things they have achieved.
Demonstrating understanding about their challenges.
Making it a positive process by not ‘threatening’ their self confidence by pointing out their deficits.
Giving them positive ideas to think about as they remember their difficulties.
Making interview/data collection must be of a suitable length of time so participants are not distressed by fatigue.
Giving opportunity for participants to take a break — a coffee break.
Breaking Interviews into segments — each segment discussed so they can see progress.
Using objects/cards/pictures and words they obtain input not just in words.

Fig. 4.1 Headwork 15: Strategies in the method employed to help them feel better/cope better

1. Difficulties and differences:
I've lost the 'old' me; I don't 'know' the 'new' me; I forget my name; I forget where I live; I've lost my memory; I've lost my friends; I've lost my job; I can't talk properly; I forget what things look like; I forget what you're saying or I'm saying; I've lost my freedom; I'm dependent; I get lost; I have to do lots of tests; I can't understand; I can't do things I used to; I can't think properly.
2. How I feel can LOCK me in the ABI Cage:
Sad - Depressed; Distressed; Disappointed; Mad - Frustrated; Angry; Nuts/crazy; Bad - Guilty, Bad - I say and do the wrong thing; Bad - I don't understand; I feel crushed; I feel scared; I hate myself; I feel hopeless (the experts can't fix me).
3. Keys that can RELEASE me from the ABI Cage:
Love, Having Hope, My family, my friends, what other people with ABI have done, encouragement, animals, talking, sport, flowers,going out, exercise, sport, staying home, cup of coffee, doing hard things, achieving hard things, stretching my comfort zone, seeing some progress, doing things I couldn't do before, my doctor, my occupational therapist, my counsellor, health professionals.

Fig. 4.2 Headwork 16: 'Talk-about' cards allow participants to reflect on issues

4.4 Narrative as the Insider's Perspective of ABI

> By words we learn thoughts, and by thoughts we learn life.
>
> Jean Baptiste Girard

> For me, words are a form of action, capable of influencing change. Their articulation represents a complete, lived experience.
>
> Ingrid Bengis

Life stories are important to everyone as they provide an opportunity for the person to express who they are, their sense of self and they also allow others to understand who we are and how we got that way (Linde, 1993; Widdershoven, 1993). Narratives can reveal the personal, situated and practical aspects of coping and show that coping with ABI is not a single event but 'coping as inseparable from their existence' (Marshall, 2009, pp. 137–138). When writing about life stories of people with learning disabilities (*sic* intellectual disabilities) Atkinson (2010) states that stories can help us trace an otherwise hidden history, treat people as 'expert witnesses', enable people to represent themselves as fully rounded human beings, show the beginnings of a resistance movement, encourage historical awareness and reflexivity (Atkinson, p. 7). Atkinson suggests life stories are particularly important 'because often people have been silent, or silenced, while other people—families, practitioners, historians—have spoken on their behalf' (2010, p. 9). People with ABI have similar experiences and by telling their stories they gain a voice.

The books written by people with brain injury and their families (Chap. 1) demonstrated the need of people to tell of acquiring their injury, to show they have gained wisdom from their experience, helped others by passing on advice, encouraged them and offered an uplifting story about the importance of love, courage and hope. These three words are the insiders' perspectives of the important issues that help people endure/cope with brain injury. But these are metaphysical words, not recorded on medical reports, government documents or quantitative research papers. Yet such concepts lying within a humanist frame are as crucial to a person's life as a mended body. These concepts are also both positive and powerful and are the antithesis to the negativity of the fixing broken bodies approach characterised by much of the body-object writing.

There is a saying 'beauty is in the eye of the beholder'. We argue that in a similar way a blind spot is in the eye of the beholder. People with ABI and family who write books about their experience do so in order to illuminate issues, thoughts *they believe that other people do not see*; in other words blind spots. They bring to light things they perceive to be hidden issues of the ABI experience.

However, research into ABI narratives is not straight forward as asserted by Tidwell et al. (2009). Making sense of and organising information from narrative is not easy. 'Quite unlike its pristine and logical presentation in journal articles…real research is often confusing, messy, intensely frustrating and fundamentally non-linear' (Marshall & Rossman, 1999, p. 21).

Some of this complexity has been addressed in the professional and academic literature as discussed below.

4.4.1 Narrative to Reveal the Insider's Perspective: Books Written by Professionals

Accounts by professionals have commonalities to the books, web articles and blogs as discussed in Chap. 1 and as outlined by Atkinson above.

Brain injury professionals use narrative as a powerful method to confront the reader with the realities of life for the person with ABI. Rees (2011) expresses the bewildering world of the person with brain ABI illuminating the blind spot that positive interactions with others are important.

> Negative interactions, or perceived negative interactions, increase the person's perception of threat and can turn simple frustration into aimless rage. Alternatively, sustained positive exchanges between the environment and brain can help the person develop awareness and socially acceptable behaviour. (Rees, 2011, p. 107)

Rees also demonstrates their intelligence, feelings and awareness of their difficulties, inter alia:

> I am well aware that they regard me as intellectually inadequate compared to them p. 17.
>
> My fear of rejection isolates me p. 17.
>
> She talks in riddles although there is a consistent theme of her 'quest for the elusive true self' p. 21.
>
> Progress is a balancing act p. 64.
>
> The visiting psychologist or social worker who just wants to test Michael and produce a report which is invariably negative. Because they identify his deficiencies as they call them…it's the lack of positive input which fosters ignorance. Ignorance leads to lack of understanding and being ignored p. 141.
>
> Sometimes we were advised that Ben was 'plateauing'. That's another expression that defies accurate definition and is not helpful for someone striving to recover p. 151.

Rees has shone a light upon blind spots that are not the focus of medical model research. The main themes that have come out of his work are:

> people with ABI can be aware of their own perceived deficits and aware of how other people view them
>
> being brain injured can cause shame and frustration
>
> people with ABI want to be the same as other people
>
> people with ABI are isolated and lonely
>
> recovery may involve good and bad days, one step forward, one step back
>
> definitions such as 'plateauing' are not helpful
>
> it is not easy to remain positive.

Mason (2008), an ABI Case Manager, writes of the courage of people with ABI as they 'put the pieces together', their perseverance, everyday struggles, search for help and hope for recovery. He writes of the harsh realities endured by the mounting number of ABI survivors whose lives may be unravelling. Here again, we read of the importance of hope, courage and the importance of giving people a voice to tell their story to restore their dignity.

Laskowski (2003) wrote his book after hearing poetry written by a man with a severe ABI and felt 'stunned and ashamed', to find he was surprised by the 'intelligence and feeling' expressed in the poetry. His fictionalised journal focuses upon the everyday struggle to communicate and be intimate with others, the person's efforts to free himself from chains of his caregivers and return to normal life.

Driscoll and Straus's (2009) stories of American soldiers with TBI and PTSD present us with yet another set of blind spots. Military personnel train so hard they may cut off their emotions to do what they are told, which can come back and haunt them. They can feel like they are 'stained' by their war experience that they have 'blood on their hands' (Driscoll & Straus, 2009, p. 68) and this can affect their progress. Several of the issues identified by military personnel could be applied to other people with ABI—low tolerance of things other people did and telling it as they saw it. They Driscoll and Strauss write of a man with TBI in a supermarket remarking 'Lady, if you hit him (small son) again I'll break your arm and shove it up your ass. You should spend less time on the phone, and more time taking care of your kid'. Driscoll and Straus identified that one of the biggest challenges of ABI is mustering 'the courage to allow others to help you even when you feel unsafe' (2009, p. 73).

References to children with ABI have been purposely omitted, but because a story book for children was to be written as a component of the final ABI learning resources—for Henry Stewart Talks UK and the book 'Unlocking My Brain Through the Labyrinth of Acquired Brain Injury' (Durham, 2014), a search was conducted to locate books that use narrative to explain ABI to children. Picture story books for children included Snyder's (1998) '*Elvin, the Elephant Who Forgets*', Leaf and Widucki's (1988) '*Susan's Dad: A Child's Story of Head Injury*' and Moulton's (1986) '*My Friend Lucy*' and Parker's (2005) '*The Get Well Soon…Balloon!*'.

4.5 Recapitulation

This chapter has shown that intentionality is central to this study, which is based on the premise that meaningful behaviour is best grasped through the person's narrative, through their own voice being heard.

It was likely that participants would express widely varied everyday experiences and respect for this diversity was vital. It was important to assist the participants to express how the challenges they faced could be offset by positive factors in their lives, particularly in their lives after the 'golden period/dark hole period'.

In order to learn to feel better, learning to cope and adapt are essential. The review of qualitative studies and material written by people with ABI proposed that it was important to incorporate metaphysical concepts (love, hope, support and courage) in order to fully encompass the phenomena of coping. These factors have a knock-on effect on the methods and procedures to be adopted and more of these are considered in Chap. 6.

Through the examination of body-subject or emic perspectives, qualitative studies and narratives, another picture has emerged of the way the person with ABI can place their lives in the light while themselves growing in the process. From the insider's perspective, involvement in qualitative and quantitative studies involves issues of power, control and opportunities to speak about what is deeply meaningful. Participant experience for those involved in quantitative studies where tests, scales and questionnaires are used differs from those involved in qualitative narrative studies, where the person would have the opportunity to express their opinions and reflect on their experience. It can be seen that some of the research topics discussed in the quantitative studies in Chap. 3 (e.g. depression, self-awareness, coping, peer support and social identity) have also been identified in qualitative studies, where the studies reviewed, focused upon coping, rather than deficits.

This review has also shown there is a large amount of information from the insider's perspective not readily available to people with ABI or their families, unless they subscribe to academic journals that report on findings of studies. Tragically, the insight, wisdom or blind spots identified in this literature are not readily available to assist the person with ABI to have hope and understanding. This material does not appear to be translated nor does it trickle down to ABI support organisations' Websites to the same extent as data obtained from quantitative studies. Additionally, like the insiders' perspective information in Chap. 1, this information is available only for 'seekers'. Many people with ABI would not have the computer or other skills or resources to sift through and find the resources that would help them. Indeed, some people with ABI do not have computers and remain isolated from the communities in which they live.

The findings from the qualitative studies echo Durham's experience about the importance of love from family and friends, a hope and belief that life for people with ABI had been spared for a purpose, to help others with ABI as was the case with author Durham. The findings from these studies also provide positive encouragement and hope for the person with ABI.

The Keys Study set out to determine whether there was a way to assist participants with ABI to reflect and 'discover' these perceptions/beliefs/strategies *for themselves*, to join the metaphysical with concepts and ideas that support them to feel and fare better.

Given the changes to identity, circumstance and context, the interface for reflection and learning becomes absolutely essential to the Keys Study and warrants further attention. The joining of metaphysical concepts with everyday life experiences is a product of lifelong learning. But for the person with ABI who is challenged to relearn (and to do so with as a new identity, with changed personal and social resources) as quickly as possible, they need a learning tool to assist them to reflect and learn. Based upon the difference between what a student can learn without help and with help, the Keys Study therefore essentially drew upon Lev Vygotsky's seminal work on the 'zone of proximal development'. Under this conception, different resources are used as scaffolding to support learners to independently find their own solutions. The case of re-learning for people with ABI represents a unique problematic challenge and requires the study to address learning principles in its approach to data collection.

In conclusion—How can people with ABI and their families learn of the good news—all the data about things that can positively affect their endurance/coping/recovery? How can people with ABI construct their own knowledge about ways of coping with ABI? This question will be explored in Chap. 5, a chapter devoted to learning principles.

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Chapter 5
Reflection, Understanding and Insight from the Educational/Learning Perspective

> *Every function in the child's cultural development appears twice: first, on the social level, and later, on the individual level; first, between people (interpsychological) and then inside the child (intrapsychological). This applies equally to voluntary attention, to logical memory, and to the formation of concepts. All the higher functions originate as actual relationships between individuals.*
>
> Lev S. Vygotsky

5.1 Introduction

Responses from people who read *Doing Up Buttons* (Durham, 1997) and *Unlocking My Brain through the labyrinth of ABI* (Durham, 2014) demonstrated firstly that people could *learn* and reflect upon their own life by reading of the physical, emotional, social and metaphysical things that affected the quality of life and well-being of someone else, as they adapted and adopted coping strategies to re-engage in their new life. Additionally, there is a need for material that deals with the reconstruction of the 'whole person', or self, following ABI. This implies the particular relevance and importance of learning in the lives of people with ABI during rehabilitation and after leaving hospital when support and resources may be withdrawn. This is an area yet to be fully researched and in which much remains to be done.

Several authors who write about ABI state the need for people with ABI to 're-learn' (Durham, 1997; Freeman, 1998; Lewis, 2004; Rees, 2005). As has been shown, it can be difficult to locate 'easy to read' information that employs educational principles to inform, motivate and encourage people with ABI to *learn* to understand their lifeworld. Their quality of life and well-being is affected by the physical, emotional, social and metaphysical things (existence, cause and effect and possibility). Certainly, the predominant messages in the grey literature (e.g. ABI support Websites) have previously concentrated on the medicalised diagnostic 'problems' identified in Chap. 1.

C. Durham and P. Ramcharan, *Insight into Acquired Brain Injury*,
DOI 10.1007/978-981-10-5666-6_5

Much of the seeker information on Websites provides information that is of this banking type, providing ‘the facts’ about ABI. But, as we have demonstrated, facts are uni-dimensional in perspective and can lack connection to people’s realities. Only recently have the stories of people with ABI demonstrated that encouraging people to write of their ABI experience, not only helps the writer ‘sort out their thoughts’ but can help people learn about vital issues as they reflect and reconstruct themselves and their lives.

In terms of learning, Freeman (1998) usefully states that:

> Medicine has very little to offer (to help the person function as independently as possible) in this direction. The way forward lies in education… in fact the medical model, as well as being superfluous in many cases and at most times in a person’s life, is also often counterproductive to follow. The medical model sees the patient as subservient to the professional. It sees the power of recovery lying in the hands of the physician, whereas the power for recovery lies within the injured person as they relearn their daily living skills… Education is the key, (Freeman, 1998, p. 14).

Durham yearned for a book to help her learn about, and understand, some of the ramifications of ABI, the consequences of injury to her brain. She was terrified when she could not figure out what to do, and when she found herself intentionally doing something senseless. She did not understand why her head instinctively told her body to react in a certain way. An example is one day, crossing the railway tracks on her way to school, the boom gate came down to signal an approaching train. She did not know what to do and was astonished to find herself running across the tracks in front of the oncoming train. It sped past with only a whisker to spare. ‘You stupid idiot’, she told herself ‘Why on earth did you do that?’ It took days of puzzling before she figured out an explanation of why she had done such a dangerous thing. She realised that she had been frantically searching her mind for what it meant when a horizontal barrier was placed across your path. Somewhere in her subconscious, she remembered the ribbon at the finish of a running race when she was a child at school. She must have thought that a boom gate was like a finishing line of a race and this is the reason she ran. Other examples such as the ‘drop your handbag’ when traffic lights turn green were equally as puzzling though less dangerous. But when ‘wires are crossed’ thinking about ‘what is normal’ becomes a real issue.

Frequently, cognition problems only surface once rehabilitation has been completed, when the person moves into a re-engagement with their social, familial lives and within their localities. The person may not have the words to explain problems, or they may feel too ashamed to confess that they feel either stupid or crazy. For Durham, shame played a role when not knowing what to do and where to get information about doing crazy things. The logic was ‘Crazy people do crazy things, I do crazy things therefore I must be crazy or insane’. If only there were narratives about the experiences of other people with ABI, and the strange things they did (in books or blogs that now exist), Durham would have seen the connection between her actions and the man who stopped at a puddle because he did not know what it was, or the person who chased emus, or the man who threw his typewriter in the creek because the Keys were not in alphabetical order. Similar narratives would convey some comfort and recognition that others had these problems. But education is more than information; it involves the learner *doing* something—engaging, making sense of, making connections, applying and considering how they can use their new understanding.

Vygotsky's'(1978) 'zone of proximal development' where a learner can achieve learning with the assistance of scaffolding from the teacher or a peer, and where the scaffold is slowly removed (as scaffolding is removed from a building when construction is complete), offers potential. As explained below, the Keys Study, therefore, drew upon a number of educational and learning principles to provide scaffolding to support learning, and to apply this learning to action, and thus achieve more autonomy and independence.

Once again, as the discussion unfolds, relevant Headwork will point to how the literature informed the methodological approach and procedure. As in the previous chapters, this will be highlighted in separate shaded boxes.

5.2 Scaffolding Learning: The Place of, Educational Theories, Motivation and Flow

In order to discover, realise or understand, children, adults and people with brain injury, all need to be absorbed and actively engaged in their learning. This study developed *Keys to the ABI Cage* with the aim of motivating participants to reflect and learn more about ABI and things that helped them to learn to feel and fare better. Mirroring the arguments in Chaps. 3 and 4, philosophies/models/beliefs or paradigms in education are changing from those focusing on 'being taught', the analytic-empirical-positivist-quantitative paradigm (where the person believes that a separate material reality exists apart from the beliefs of the individual, group or societies—similar in concept to the medical model) to 'learning on your own with guidance', the constructivist-hermeneutic-interpretativist-qualitative paradigm (Schubert & Schubert, 1990). In this latter paradigm 'Truth is a matter of consensus among informed and sophisticated constructors, not correspondence with an objective reality.' (Guba & Lincoln, 1989, p. 44).

In the constructivist model, there is a significant critique of what Freire (1974) calls 'the banking model' in which education becomes an act of depositing knowledge, in which the students are the depositories simply memorising and repeating what has been deposited and teachers the depositors of the knowledge. Rejecting this model has led to different positions. For example, critical-theory, neo-marxist and postmodern-praxis focus upon 'questions of power, control, and epistemology as social construction with benefits to some and not to others' (Muffoletto, 1993, p. 4).

As Freire goes on to say:

> They (students) do, it is true, have the opportunity to become collectors or cataloguers of things they store. But in the last analysis, it is men/women themselves who are filed away

> through the lack of creativity, transformation, and knowledge in this (at best) misguided system. For apart from inquiry, apart from the praxis, men/women *cannot be truly human* [our emphasis]. Knowledge emerges only through invention and reinvention, through the restless, impatient, continuing, hopeful inquiry men/women pursue in the world, with the world, and with each other. (Freire, 1974, p. 58).

Others argue for modes and tools to better understanding and more effective problem-solving (Reeves, 1996), a point premised on seminal authors such as Kolb (1984) and Lewin (1890–1947). This is an important point that fits well with the more constructivist approaches to contemporary learning theory. In their seminal work, Bloom (1956) developed a taxonomy exemplifying the process of learning through stages: from remembering, to understanding, to applying, then analysing, evaluating and then creating once again. Learning must be tied to actions ultimately, but must, too, be open to change.

So the question arose as to how the research could incorporate learning that had the potential to change how each person acted as a result of engagement.

In summary the study, which employed *Keys to the ABI Cage* as a method, was firmly positioned within the experiential learning theory: learning is a process grounded in experience, where learning is a holistic process of adaptation to the world (Freire, 1974; Kolb, 1984). From within such a paradigm, learning is a process of creating knowledge through the transformation of experience. The success of the Cage would recognise the importance of internalising knowledge and learning in pursuit of social activity, life transformation, and would attempt to scaffold learning (Vygotsky, 1978) and have implications for practice.

But in what does such scaffolding consist? This is discussed below.

5.2.1 Motivation and Engagement as Crucial Elements in the Learning Process

Engaged students want to learn. Many people with ABI are not ready to learn for many reasons. For example, they may not acknowledge that they have ABI, they may still want to be (and pretend to be) as they were, or they may feel there is stigma attached to having ABI (e.g. they feel they are different and 'dumb').

Csikszentmihalyi (1990, 1997) posits that 'flow' happens when the person becomes so absorbed in an engaging and interesting task that action and awareness merge. According to Wlodkowski (2008) in order to foster flow, firstly the goals must be clear and compatible, allowing the learner to concentrate even when the task is difficult. This links to 'negotiated curriculum theory', where goals are negotiated with the person. Secondly, the feedback is immediate, continuous and relevant so that the learner is clear about how well they are doing. Thirdly, the challenge carefully balances skills and knowledge while stretching the learner's capacities (Wlodkowski, 2008, pp. 267–268). These concepts were incorporated into *Keys to the ABI Cage* tool to establish flow.

If students are to work through Bloom's taxonomy as described previously (Shulman, 2002; Coates, 2005, 2010; Krause & Coates, 2008), 'motivation is the portal to engagement' (Barkley, 2010: p.15).

So how is it possible to support such motivation? As early as 1932, Piaget (1932) stressed the importance of experiences as the learner makes connections in an atmosphere of play with the teacher's role as facilitator, mentor, consultant and coach. The notion of 'playfulness' is at the heart of many contemporary learning approaches as exemplified in scaffolding using enhanced online and computer-simulated learning environments (Delen, Liew & Willson 2014; Duffy & Azevedo 2015). These studies demonstrated more engagement with learning resources and particular improvements for students assessed as being less motivated prior to the intervention (Duffy and Azevedo 2015).

However, such engagement is often influenced by self-perceptions and expectations as shown in Fig. 5.1.

Keys to the ABI Cage

- captured the attention and curiosity of people with ABI.
- provided an example of what it's like to have ABI.
- showed them their input was important.
- simplified the complexities of ABI into three themes reflecting the 'talk-about' cards.
- adopted a method that was an unexpected, fun and different way to examine a serious issue.
- was used in a way that participants received constant feedback that they were doing well.
- was implemented such that participants received constant feedback that they were doing well.

Fig. 5.1 Headwork 17: How Keys to the ABI Cage addressed the issue of motivation

5.2.2 Engagement Is Influenced by Expectations and Self-perceptions

From educational theory, we learn that in order for the learner to engage in learning, they need to believe that success will result from their effort. '[People] need to have confidence that, if they put in the effort, they can succeed. If there is no hope, there is no motivation' (Barkley, 2010, p. 11). Motivational theories that address student expectations include self-efficacy theories, attribution theory and self-worth models (Cross & Steadman, 1996). Self-efficacy theories state that the learner's belief about their ability to succeed has *greater importance* than either skill level or task difficulty (Bandura, 1971, 1997; Corno & Mandinach, 1983). If the person has confidence in their ability to perform a task, they will be motivated to engage in it. This theory holds an important message for professionals working with people with ABI.

In the present study, participants were introduced to *Keys to the ABI Cage*, with a PowerPoint presentation explaining the three-step way of looking at ABI. They then examined the *Keys to the ABI Cage* model—looking at the different 'talk-about' cards and the numerous different objects. This process showed the participant how ABI can affect people, how people feel about ABI, and factors that help people cope using everyday (non-medical) language.

By rehearsing the method with the participants in several different ways (seeing and touching) and reviewing the PowerPoint introductory digital storage disc, participants could see that they could contribute and succeed in sharing their thoughts. As the participants identified issues that affected them, they were led to discover factors that had helped or could help them in the future. They isolated strategies through which they could help themselves. This approach assisted them to have success in their own learning. On many occasions participants said 'You'll understand…you have brain injury'. There was relief that they could open up and voice their issues and not feel ashamed (Fig. 5.2).

However, as argued below, perceptions of success and failure are also important particularly for people with ABI given their circumstances. The person with ABI may have experienced failure in every attempted task—in many things they *do, inter alia*—they cannot walk, talk or even eat properly. The individual may also face failure in everything they *think,* they do not know what day it is, they forget names (including their own name), they do not know what a cup or a hairbrush is and they cannot follow conversations. They attribute failure (and the resultant

Keys to the ABI Cage:

- recognised the importance of involvement and participation for learning to take place.
- was devised to assist the participant to become involved and participate, and think about their experience.
- gave everyday examples and used everyday things to show that the task was not difficult or complicated.
- used simple structure (1. Difficulties and Differences, 2. Feelings and 3. Keys) that could be used for further reflection not only in the 'classroom' (the research location), but also outside the parameters set for the research study.
- ensured participants were not coerced to answer specific questions but to simply tell the parts of their story they wanted to share using the tool as a prompt.
- engaged the participants because it was interesting and different.
- gave participants control over the direction of the interview.

Fig. 5.2 Headwork 18: Keys to the ABI Cage addresses the issue of engagement feelings of being dumb or stupid) to nearly everything. It was recognised that having such attributes could affect their willingness to engage with *Keys to the ABI Cage* and the study.

Weiner's (1985) attribution theory states that students attribute success or failure according to their perceptions of why they might have succeeded or failed in the past. Weiner suggests that success or failure of tasks can depend on factors that include ability, effort, luck, fatigue, ease or difficulty of the task. If 'success' depends on attributes over which the person believes they have control, such as putting in an effort, a hypothesis was made that students (people with ABI) would be more likely to have confidence to be involved with the task rather than when success depends on external conditions over which they have no control, such as the difficulty of the exam (test, questionnaire).Weiner's attribution theory suggests that the person with ABI, whose cognition, emotions, memory and confidence is damaged, may believe that failure is most likely because they attribute the situation to be dominated by *external (outside the person)*, *unstable (the outcome is not as intended)* and *uncontrollabl*e factors. They are not 'in control'.

In order to counteract these factors, the persons with ABI involved with this study were informed in the advertisement, and during the preinterview phone conversations, that their personal insights were important, their comments were valuable and that they would be able to choose what they said. Barkley (2010) has

Keys to the ABI Cage:

- used an original method so that participants would not think 'last time I did a test/questionnaire I failed, or I felt a failure.'
- employed many different ways so the person could feel successful — from putting a card in a box to discussing their experiences.
- was implemented to encourage and praise participants for their wisdom/personal insights.
- had no right or wrong answers.
- was developed so that success was built into the tool.
- placed participants in control of what they wished to talk about.
- looked interesting and fun thing to engage with;
- helped the participant understand what they were asked to do;
- provided constant positive reinforcement that they were doing well;
- did not ask difficult questions;
- made easy requests about what to do (place a card or talk about an issue) and, gave them choice about the topics they wished to talk about.

Fig. 5.3 Headwork 19: Keys to the ABI Cage addresses the issue of attribution of success also shown how ‘success’ is built into a task: when there is no right or wrong answers, the person is encouraged and praised for their wisdom and the person has the power to control the discussion (Fig. 5.3).

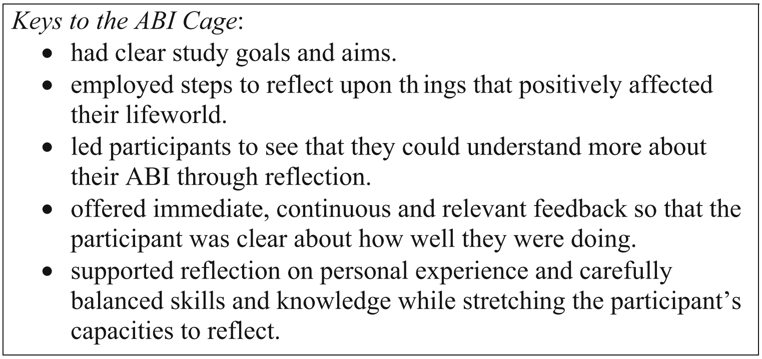
Associated with promoting success in learning as described above is the fear of failure. Evasion can be a powerful strategy to maintain control for students who do not feel it possible to gain from learning. In the absence of personal control, Barkley (2010) posits that these students have a ‘low level of confidence and expectancy of failure [that] have placed them in a state of almost chronic disenchantment’ (Barkley, 2010, p. 14). These learners recognise the value of learning to accomplish a task, but feel incapable because they ‘aren’t certain of what to do or how to do it or they doubt they can do it’ (Barkley, p. 14).

The interview aimed to have participants involved in reflection, not involved in trying to figure out how to evade questions they did not wish to speak about.

The importance of preserving the participants’ self-worth was essential to all discussions relating to failure, success and having control. Cross and Steadman (1996) describe ‘failure-accepting students’ who are resigned to failure. They feel hopeless and respond to learning tasks with indifference (Cross & Steadman, 1996). To cope with failure in daily life, people with ABI need to accept failure as a minute-by-minute, hour-by-hour occurrence rather than as defining who they are.

When some students do not succeed, they would rather let people think they are *lazy* (question their effort) rather than think they are *dumb* (question their ability). Some students do not even try because they believe there is a low possibility of success—Covington (1993) refers to these students as ‘failure avoiders’. Similarly, people with ABI have to overcome their abhorrence of admitting they do not know how to do up their buttons or tie their shoelaces and their self-worth and self-esteem is affected by their differences and difficulties. Fear of failing and being seen as dumb can block and inhibit learning.

Keys to the ABI Cage method was developed to allow the participant to preserve their self-worth because the tool acknowledged their enormous challenges in an



Keys to the ABI Cage:

- had clear study goals and aims.
- employed steps to reflect upon things that positively affected their lifeworld.
- led participants to see that they could understand more about their ABI through reflection.
- offered immediate, continuous and relevant feedback so that the participant was clear about how well they were doing.
- supported reflection on personal experience and carefully balanced skills and knowledge while stretching the participant’s capacities to reflect.

Fig. 5.4 Headwork 20: Keys to the ABI Cage addresses the issue of self-worth empathetic way and asserted that they had special insight and wisdom, which they were invited to share with others with ABI. Self-worth models put forward the hypothesis that people are strongly motivated to preserve their self-worth (Fig. 5.4).

5.2.3 Active or Experiential Learning

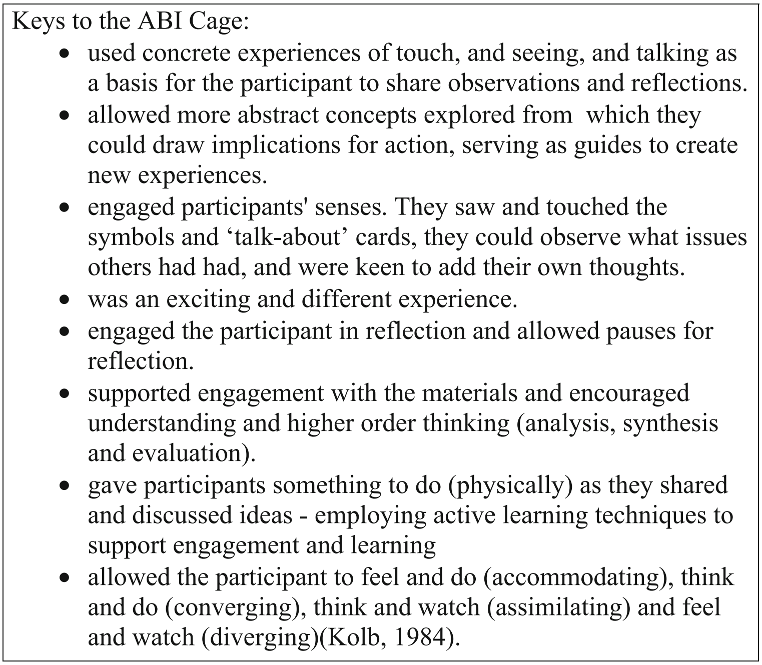
'Active learning' principles were used in *Keys to the ABI Cage*. Learning is taking an idea or concept and making it part of the personal knowledge and experience of the learner. This is done by connecting concepts and 'accommodating' (Barkley, 2010)—fitting or altering the existing structure to accommodate the new learning and action as a result.

People grasp new information in different ways: some 'through experiencing the concrete, tangible, felt qualities of the world', relying on their senses and 'immersing themselves in concrete reality'; some through 'symbolic representation or abstract conceptualisation—thinking about, analysing or systematically planning'; some through watching others and reflecting on what happens—reflective observation; some 'jump right in and start doing things—active experimentation' (Kolb et al., 2000, pp. 3–4).

Coulson and Harvey (2013) propose a model of scaffolding reflection for experience-based learning: over four stages students need to be 'supported to reflect', to 'reflect for action', to 'reflect in action' and then to 'reflect on action'. This model links learning to change through reflection and offers maximum agency to the person to convert thoughts to actions over time—to explore the 'dropped handbag at the traffic light' and to apply new forms of action to see what works.

The plasticity of the brain, may, over time, offer new neural pathways that create a learned behaviour or a recognition, and there is a need to stop and think, or provide a new cue for the person's actions. For the purposes of this research, *Keys to the ABI Cage* offered an innovative tool with recognisable metaphors (crushed cans, pigs that fly) and a series of 'talk-about' cards that reflected common experiences from which each person could reflect, and then through reflection, formulate new ideas about their lives and how they act. The approach also fits with Vygotsky's idea of the zone of proximal development, leading to more independent and autonomous change based on reflection and learning.

People with ABI who may have an unreliable memory might panic when they forget what they were told or instructed to do. But having the Cage in front of them and 'talk-about' cards in their hands, they had a way to review the issues that led to certain conclusions as they figured things out for themselves. Additionally, people with ABI may become paralysed when trying to judge if they did give the correct answer, so they needed to know that it was okay to revisit their ideas (Fig. 5.5).



Keys to the ABI Cage:

- used concrete experiences of touch, and seeing, and talking as a basis for the participant to share observations and reflections.
- allowed more abstract concepts explored from which they could draw implications for action, serving as guides to create new experiences.
- engaged participants' senses. They saw and touched the symbols and ‘talk-about’ cards, they could observe what issues others had had, and were keen to add their own thoughts.
- was an exciting and different experience.
- engaged the participant in reflection and allowed pauses for reflection.
- supported engagement with the materials and encouraged understanding and higher order thinking (analysis, synthesis and evaluation).
- gave participants something to do (physically) as they shared and discussed ideas - employing active learning techniques to support engagement and learning
- allowed the participant to feel and do (accommodating), think and do (converging), think and watch (assimilating) and feel and watch (diverging)(Kolb, 1984).

Fig. 5.5 Headwork 21: Keys to the ABI Cage addresses the issue of active learning

5.2.4 ‘Flow’

Keys to the ABI Cage was also devised to encourage what Csikszentmihalyi (1990, 1997) terms ‘flow’. Flow happens when the person becomes so absorbed in an engaging and interesting task that action and awareness merge. According to Wlodkowski (2008) in order to foster flow, firstly the goals must be clear and compatible, allowing the learner to concentrate, even when the task is difficult. This linked to ‘negotiated curriculum theory’, where goals are negotiated with the person. Secondly, the feedback was immediate, continuous and relevant so that the learner was clear about how well they were doing. Thirdly, the challenge carefully balanced skills and knowledge while stretching the learner’s capacities (Wlodkowski, 2008, pp. 267–268). These concepts were incorporated into *Keys to the ABI Cage* tool to establish flow (Fig. 5.6).

Keys to the ABI Cage:

- had clear goals.
- used cards to help participants concentrate even when thinking about hard things.
- gave control about what they want to talk about.
- offered immediate, continuous, and relevant feedback.
- challenged the participant and carefully balanced between what the participant kneow while stretching them to think more about issues.

Fig. 5.6 Headwork 22: Keys to the ABI Cage addresses the issue of 'flow'

5.2.5 The Theory of Association

No single teaching and learning strategy is applicable to all people. It is necessary to differentiate sufficiently to allow differing engagement styles. de Sousa's (1987) theory of association was implemented in *Keys to the ABI Cage* where a combination of pictures, symbols, objects and words was used to provide a framework to support the participant's ideas. The participant was assisted to emotionally respond to the process by the purposeful use of humour and *Keys to the ABI Cage* being 'different' and eye-catching and a unique way to revisit their ABI experience in a safe space. Emotions were acknowledged as an important element in the whole ABI experience, as emotions can influence transfer and obtaining attention.

Brain scans have shown that retention can be improved when new learning makes sense and it can be connected to experience (Barkley, 2010). Memory difficulties affect every aspect of learning new information. By embedding strong emotional context, repetition and visual imagery learning was more likely to become part of long-term memories. Pictures and objects were used to help the participant make connections so they could make sense of and retain more than by simply reading or being told information.

As retention of the learning needs 'adequate time to process and reprocess information so that it can be transferred from short-term to long-term memory…this requires time and usually occurs during deep sleep' (Barkley, 2010, p. 23). By allowing participants to reflect further upon their concepts, they were given 'Some Further Thoughts' sheets so that they could record any further thoughts they had in the days following the interview (Fig. 5.7).

Keys to the ABI Cage:

- allowed the participant time to think/understand.
- repeated information to allow time for assimilation.
- engaged the participant by allowing them to examine the association between difficulties or challenges and how they felt.
- used pictures/objects/symbols so the participant could put the concepts together.
- added 'Some Further Thoughts' sheets to allow time for further reflection.

Fig. 5.7 Headwork 23: Keys to the ABI Cage addresses the issue of theories of association

5.2.6 Learning in a 'Community

Many people with ABI feel as if they are the only person to experience what they experience. Knowing others in the community share common experiences can help them to feel less isolated. Barkley (2010) writes about the importance of promoting synergy between motivation and active learning through creating a sense of classroom 'community'.

In this study, a sense of community was used—not in a classroom, but with connecting the participant to the ideas and thoughts of other people with ABI—a 'Community of people with ABI'. Much of what has been written about learning communities was applied to this study to develop a group of connected people with shared interests, goals and responsibilities towards one another (Brophy, 2004); the words on the 'talk-about' cards were from other people with ABI, and they were helping to develop material/resources to help others with ABI (Fig. 5.8).

Keys to the ABI Cage:

- gave them a sense of belonging to a group of people facing similar challenges.
- established a 'community' feeling, a resource from people with ABI for people with ABI.
- emphasised the values of the participant's insight to help others with ABI.
- allowed the participant to come to the conclusion that they are not alone or isolated with their issues.
- supported self-reflection in a malleable way to allow any issue the person wanted to 'get off their chest' to be talked about.

Fig. 5.8 Headwork 24: Keys to the ABI Cage addresses the issue of participants feeling they are part of a community of people with ABI

Howe (2013) provides a useful argument that scaffolding should be presented as a 'support for the reconciliation of conflicting perspectives' and we have seen, how for people with ABI, such conflicts may seem pervasive. In this light, each person struggles for meaning through their interactions with peers, networks and with formal learning. For many people with ABI, there are significant 'conflicting perspectives' at a time when they are more likely to have fractured social networks and peer groups. Consequently, people with ABI have found through Durham, and with excitement, that others have similar experiences, that there is some possibility of alliance and of empathy. Slovak et al (2016) show how sharing the scaffolding across the students and the home can support socio-emotional learning by reinforcing new skills and actions. The relevance *of Keys to the ABI Cage* may, therefore, not just rest with this study. As argued in Chap. 9, its relevance and the relevance of other scaffolding underscores the vital learning that should be central in the lives of people with ABI in their homes, networks and, as importantly, within services.

We have considered above the 'motivational factors' that contributed to the development of *Keys to the ABI Cage*. But there are also vitally important aspects to cognition and learning which also needed to be taken into account. These are set out below.

5.3 Educational Theories About Cognition and Learning

In order to engage with *Keys to the ABI Cage*, 'cognitive' skills are required. The participant needs to think about concepts, reflect and express their opinion. But as covered earlier, people with ABI may have cognitive problems that include difficulty with short-term memory, concentration, confusion, slow thinking, slow processing of information, difficulty understanding, planning, organising, problem-solving, rigid concrete thinking and mental fatigue. We also learnt that impairment of memory is a significant impediment to people with ABI who are returning to work; however, memory can help through programs designed to assist memory (Raskin & Sohlberg, 2009). *Keys to the ABI Cage* was developed to support the individual whose slow thinking and poor memory may limit their understanding and problem-solving.

5.3.1 Cognition

In the following sections, different approaches to cognition are used to inform the further development of *Keys to the ABI Cage*. Given different approaches, this section is meant to draw upon leading paradigms within learning and rehabilitation practice.

5.3.2 Cognitive Rehabilitation

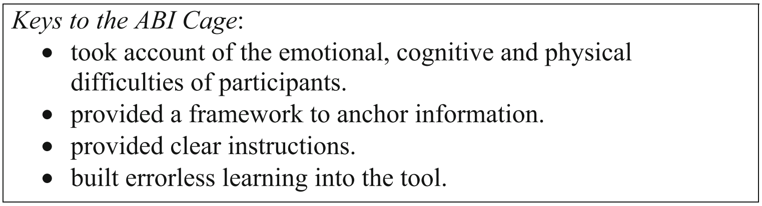
Cognitive rehabilitation is an established branch of rehabilitation where the individual practices various cognitive tasks to help attention, memory and other problems with thinking. This may include doing arithmetic, solving logic puzzles and working on concentration and communication skills and executive functions.

Sohlberg, and Mateer (2001) explain that just as cognitive abilities overlap each other they are also influenced by emotional difficulties such as anger, anxiety or depression, behavioural difficulties such as impulsivity, frustration and physical problems such as impairments to movement, sensory changes, headaches and pain. The authors suggest that the artificial distinction among cognition, emotion and motivation has been steadily ‘eroded’ but

> it is still common in rehabilitation texts to see box diagrams in which cognitive problems are dealt with in cognitive rehabilitation and/or speech therapy, emotional and behavioral problems are dealt with in some sort of affective rehabilitation therapy (e.g., group counselling, individual psychotherapy); and physical problems are dealt with through medical management and occupational rehabilitation specialists…. Although the notions of inter-disciplinary or even trans-disciplinary treatments attempt to bridge and coordinate various approaches, there has been very little written on or investigated with regard to how to practice this philosophy in patient interactions and not just in a paper trail, (Sohlberg & Mateer, 2001, p. 9).
>
> This, they argue, should not simply be the domain of collaborating professionals.

More recently, we have begun to reap the rehabilitation benefit from collaborating and forming partnerships with families and caregivers, (Sohlberg & Mateer, 2001, p. xi).

See Fig. 5.9.



Keys to the ABI Cage:

- took account of the emotional, cognitive and physical difficulties of participants.
- provided a framework to anchor information.
- provided clear instructions.
- built errorless learning into the tool.

Fig. 5.9 Headwork 25: Keys to the ABI Cage addresses issues from cognitive rehabilitation

5.3.3 Cognition/Thinking Involves Steps and Skills

Compared with cognitive rehabilitation, education views cognition within a framework of providing a scaffold or framework for learning. Anderson and Krathwohl’s taxonomy (2001) seen in Fig. 5.10 is a revised form of Bloom’s Taxonomy of Learning (1956) introduced earlier. While it is tempting to view or treat the following taxonomy as a linear process for learning, this should be avoided. For example, inquiry or problem-based learning approaches often start at the complex end of the taxonomy (‘create’) to stimulate learning, and then work ‘backwards’ to examine the issue and deepen learning.

Learning involves:

- *'Remembering'* involves recognising (identifying) and recalling (retrieving) information. This starting point can prove to be difficult when memory is affected.
- *'Understanding'* involves the person constructing meaning from information: interpreting, illustrating, classifying, summarising, inferring, comparing and explaining.
- *'Applying'* involves using the knowledge or procedure to a new situation or event.
- *'Analyzing'* involves breaking the material or concept into parts by differentiating, organising and attributing.
- '*Evaluating'* involves making judgments based on criteria and standards by checking and judging.
- '*Creating'* involves putting elements together to form a functional whole; re-organising elements into a new pattern or structure — generating ideas — hypothesising, planning — designing and producing — constructing.

Fig. 5.10 Anderson and Krathwohl's learning taxonomy (2001)

It could be generalised that good thinking involves gaining insight of an issue in order to have foresight to tackle similar issues. Thinking back to Durham's experience with 'drop your handbag' reaction to a green traffic lights or 'running in front of an oncoming train' reaction to a boom gate, she needed to understand by remembering, understanding, applying, analysing, evaluating and creating to develop ways to talk to herself next time she saw a traffic light or boom gate, and when she was confused about what to do.

Keys to the ABI Cage used a cognitive process*:*
Remembering: Start by obtaining simple remembering and recall of information.
Understanding: Lead participant to make show they understand a concept by telling a story to illustrate the point.
Applying: Use the concept to make connections and apply the information to another idea. Explore and analyse the consequences of the information, and select other issues to distinguish a point.
Evaluating: helping participant make a judgement about the issue by checking and judging.
Creating: generating ideas about how the information could be used in the future, hypothesise, and plan for a further time.
Encourage synthesis where information gained can allow insight and foresight into problems.
Involving different ways of engaging with the material, recalling, talking about, applying a concept to something else, connecting, comparing and analysing the material until the person can talk about possible issues for the future and what to do about them.

Fig. 5.11 Headwork 26: Keys to the ABI Cage provides steps for participants to engage in higher order thinking

People with ABI need to learn to strengthen their cognitive skills across the lower order and higher order thinking spectrum. In using tools that are underpinned by such principles, people with ABI can then begin to engage with the variety of cognitive thinking levels (Fig. 5.11).

5.3.4 *Learning Styles*

There are various approaches or ways of learning (Kolb, 1984). The way that a person concentrates takes in, understands and stores and remembers new information is defined as their learning style. Honey and Mumford (1982) posit that students learn best when they have an experience, they review the experience, they draw conclusions from the experience, then plan the next step. This draws upon the concept of the student as 'activist', 'reflector', 'theorist' and 'pragmatist'. Such a learning style approach was employed in *Keys to the ABI Cage*. Participants created their own knowledge by exploring the ideas drawn from other people with ABI and the ABI literature (Fig. 5.12).

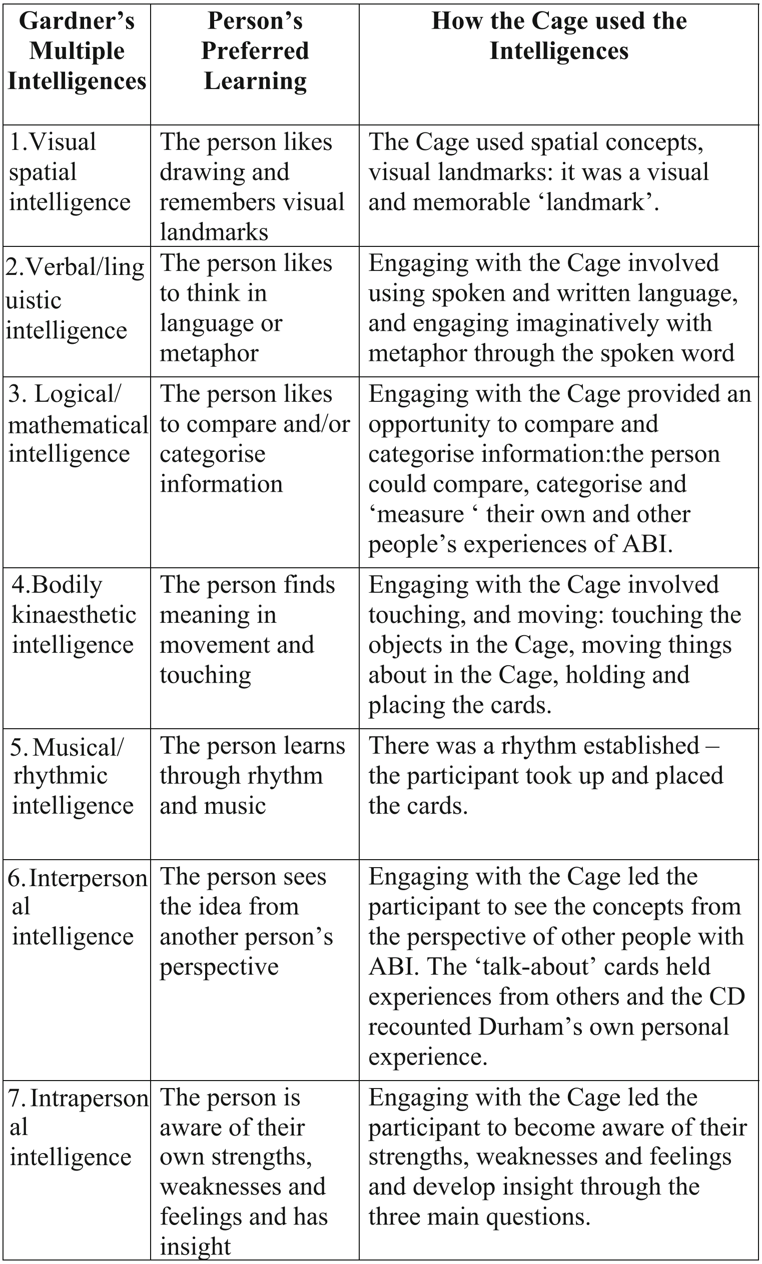
Keys to the ABI Cage.

- gave participants the experience of seeing the Cage, and watching the digital storage disk.
- helped them to review from their personal perspective.
- encouraged them to draw conclusions from the experience and then plan how they could deal with issues and emotions in the future.

Fig. 5.12 Headwork 27: Keys to the ABI Cage provides an experience for participants to review

5.3.5 *Multiple Intelligence*

Multiple intelligences are a theoretical framework for defining/understanding/assessing/developing people's different intelligence factors. In his seminal work, Gardner (1983) conceptualised multiple intelligences as a framework that defines how we think, how we come to understand our world or how we generate knowledge. With Gardner's hypothesis in mind, *Keys to the ABI Cage* addresses many of these 'intelligences' in helping participants understand and generate knowledge (see below) Fig. 5.13 employment of Gardner's Multiple Intelligences in Keys to the ABI Cage.



Gardner's Multiple Intelligences	Person's Preferred Learning	How the Cage used the Intelligences
1.Visual spatial intelligence	The person likes drawing and remembers visual landmarks	The Cage used spatial concepts, visual landmarks: it was a visual and memorable 'landmark'.
2.Verbal/linguistic intelligence	The person likes to think in language or metaphor	Engaging with the Cage involved using spoken and written language, and engaging imaginatively with metaphor through the spoken word
3. Logical/ mathematical intelligence	The person likes to compare and/or categorise information	Engaging with the Cage provided an opportunity to compare and categorise information:the person could compare, categorise and 'measure ' their own and other people's experiences of ABI.
4.Bodily kinaesthetic intelligence	The person finds meaning in movement and touching	Engaging with the Cage involved touching, and moving: touching the objects in the Cage, moving things about in the Cage, holding and placing the cards.
5. Musical/ rhythmic intelligence	The person learns through rhythm and music	There was a rhythm established – the participant took up and placed the cards.
6. Interpersonal intelligence	The person sees the idea from another person's perspective	Engaging with the Cage led the participant to see the concepts from the perspective of other people with ABI. The 'talk-about' cards held experiences from others and the CD recounted Durham's own personal experience.
7. Intrapersonal intelligence	The person is aware of their own strengths, weaknesses and feelings and has insight	Engaging with the Cage led the participant to become aware of their strengths, weaknesses and feelings and develop insight through the three main questions.

Fig. 5.13 Summary of Garner's multiple intelligences and how they were used in the Cage

8. Naturalist intelligence	The person has a keen interest in the world of nature	The photos of the Cage outside involved the world of nature.The bird, rocks and other contents were part of an 'eco-system' and used this as a metaphor for their experiences.
9. Spiritual/ existential intelligence	The spiritual meaning of life is important to the person.	Engagement with the Cage provided an opportunity for the participant to discuss their spiritual meaning of life. Metaphor was used.

Fig. 5.13 (continued)

As shown, 'multiple intelligences' present a panoply of vehicles through which learning can best be accomplished rather than a single theory reliant upon a limited range of learning styles. In this sense, the approach offers a means through which people can meaningfully engage using the learning style they find most appropriate to their own engagement with knowledge. It is argued that the concepts of learning styles and multiple intelligences can be helpful when working with people with brain injury because the person may have difficulty comprehending words, they may be suffering from aphasia to some degree and memory difficulties may limit their ability to remember the topic under discussion. By holding the 'talk-about' cards in their hands, they had a prompt for what they were talking about.

Applying the concept of multiple intelligences to this study, a hypothesis is made that some people might find the physical presence of the Cage and handling the artefacts (symbols) more helpful, while others might participate better with the digital storage disc, visual version in which the written word is required to express their response. *Keys to the ABI Cage* appealed to and sought to engage all of Gardner's multiple intelligences.

The models of disability outlined in Chap. 2 established pretheorised versions of reality which, it has been argued, imposed, as a priority, a framework of meaning. These assumptions would guide us to ask only certain questions that come from the premises of these theories and reflect their assumptions. The phenomenological stance allows the data from people with ABI to 'speak for itself', to establish their meaning and, from this, to ground our understanding in those areas that have meaning and relevance to those with ABI rather than a theory imposed by 'experts' without consultation.

5.4 Recapitulation

This chapter has identified the literature in the field of education that was considered when devising *Keys to the ABI Cage*. A foundation of this study was that people are different, they learn in different ways and that different things can affect their learning.

Keys to the ABI Cage was devised to address people who are logical, critical, realistic and accurate by using structured activities, allowing them to deal with the information sequentially, analytically, logically, factually and verbally. *Keys to the ABI Cage* was also devised to address the learning needs of people who learn through intuition, imagination, seeing the big picture, trying to understand and by discussing and sharing ideas. It is acknowledged that the issues discussed in this chapter may not be a prime consideration of ABI research, nor may the issues be the foremost focus in rehabilitation. This may be because of pressure of time constraints, limited funding, lack of resources, an absence of guidelines and the absence of appreciation of the significance of motivation and educational and learning principles.

But it is nevertheless essential that learning is seen to be particularly important to people who have to build new lives, build new identities and discover actions that help them cope on a day-to-day basis.

The aim of the Keys Study was for the individual to achieve understanding and insight into ABI, so they can learn to feel and fare better and make the best of living with ABI. This study aimed to access the lifeworld of people with ABI by inviting them to talk about their life in terms of a 'commonwealth of concepts' displayed visually in the tool, *Keys to the ABI Cage,* or, indeed to add to these concepts. It also offered a model for thinking through lives in terms of actions to adopt that would support them to fare better. Learning is, as pointed out early in this chapter, vital to humans choosing how to act.

Finally, this chapter has brought a constructivist learning theory into alignment with a phenomenological and constructivist epistemology as outlined in Chap. 3 and how this has informed Keys to the ABI Cage, the study methodology. It has shown how, all of us—families, friends, or human service professionals—can listen to the lifeworld and experiences of people with ABI and **WE CAN LEARN FROM PEOPLE WITH ABI**, how to help them and others with ABI feel and fare better. Chapter 6 will explain the methods used for this study, synthesising information about education from this chapter with information about ABI obtained from the literature reviews in Chaps. 2–4. Interpretative phenomenological analysis (IPA), the method used to analyse the data, will be explained, and an example of how IPA was used will be provided. Chapters 7 and 8 will then present the analysed findings.

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Chapter 6
Capturing Insights

> *The doctor may also learn more about the disease from the way the patient tells the story than from the story itself.*
>
> James B. Herrick.

6.1 Introduction

We have identified in previous chapters difficulties and problems associated with ABI from the literature. We have also emphasised the blind spot relating to a positive model of ABI which seems all but absent from the literature to date. In adopting a method that supports people to feel and fare better, and which is itself ethical in its approach, we have adopted van Maanen's concept of 'Headwork' to provide a catalogue of important issues and statements that informed the 'talk-about' cards and that 'did no harm'. A number of criteria therefore needed to characterise this study:

- to preserve the rights, privacy, dignity and wellbeing of participants.
- to approach brain injury from the insider's body-subject perspective—Durham's role was as a *person with brain injury and a visible researcher*.
- to adopt *a constructivist paradigm* of education, where the individual themselves 'constructs' knowledge, with guidance. Knowledge produced was of *direct benefit to people with brain injury*, to adopt a *positive* as well as a negative focus.
- to respect participants as 'whole' human beings and acknowledge their courage and perseverance (they would not be defined only by their difficulties, differences and deficits).
- to select adults at least two years post brain injury who are no longer in the rehabilitation setting.

Below, we make a formal introduction to the study methodology.

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6.2 Keys to the ABI Cage—Contents of the Method

Keys to the ABI Cage was displayed at the end of the Foreword. The Cage itself was used in face-to-face meetings but, for people in rural areas, a PowerPoint version was created and distributed on a DVD. The PowerPoint presentation included slides with Durham's voice-over. Additionally, three orange-coloured slides were situated after each of the three topics on the 'talk-about' cards. When the participants came to an orange slide, they were asked to pick up the 'What ABI means to me' sheets and answer the question that corresponded to the 'talk-about' cards (Themes were as follows: Difficulties and Differences, Feelings and Keys). For both groups, the face-to-face group and participants living in rural areas then, three themes about issues were addressed as shown in Fig. 6.1.

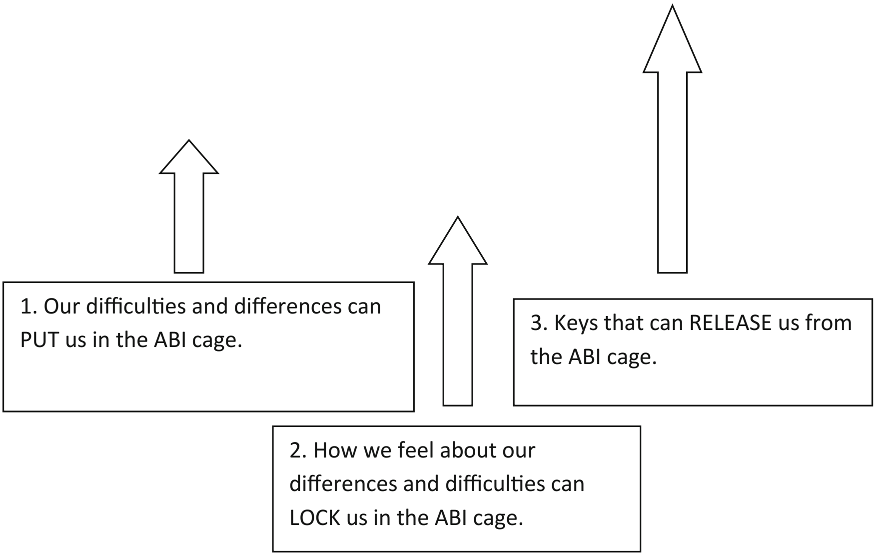


Fig. 6.1 Three research themes Keys to the ABI Cage

6.3 Alternate Ways to Conduct the Interview

'Handy Thinking Tools' were prepared to provide an alternative structure for the interviews for participants who did not appear to understand or enter into the spirit of 'Keys to the ABI Cage', and/or for participants who became 'stuck' on a particular problem or issue. Both 'Handy Thinking Tools' and 'Keys to the ABI Cage' are learning/discovery tools to assist the unpacking of the many facets of ABI: to provide a structured framework to build a discussion, to jog memory (before answering open-ended questions) to encourage reflection, self-discovery, thinking what coping strategies are used and could be used in the future, to provide a positive interesting experience, to lead the participant to learn new tools to use in their daily activities to understand issues and problems.

All participants responded well to 'Keys to the ABI Cage' except one participant who became stuck on the words on one 'talk-about' card part way through the interview using 'Keys to the ABI Cage'. Handy Thinking Tools was also used in discussions along with 'Keys to the ABI Cage' at a second meeting with ABI support groups. Professionals were introduced to Handy Thinking Tools and found them a valuable resource for discussions.

Method B: Handy Thinking about what it is like to have ABI

Handy Thinking Tools are tactile, tangible, mnemonic devices that utilise senses of touch, sight and hearing to reinforce analytical, practical, creative thinking about an issue or problem. Participants can learn to 'count on their fingers'—digits of the hand can be used as symbols to prompt specific questions. Handy Thinking Tools can help in brainstorming and understanding of issues, and lead to the individual finding solutions and making informed decisions (Fig. 6.2).

Fig. 6.2 Handy Thinking® Tools

1. THUMB: Pigeonhole it: Ask 'What is it like to have ABI?' (Sort, organise and group the problem or issue).
2. POINTER FINGER: Point out the facts: Ask 'What are some facts that you know about ABI?' 'What facts would you like to know about having ABI?' 'What do you do/say to yourself to help you cope with your ABI?'
3. MIDDLE FINGER: Find the Feelings: Ask 'What are some of the feelings you have about having ABI?' 'What do you do/say to yourself to help you cope with your feelings about ABI?'
4. RING FINGER: Judge the issue: Ask 'What are the Good, Bad and Curious things about having ABI?' 'What are the bad things about having ABI?' 'Is there anything good that has come out of you having ABI?'

5. LITTLE FINGER: (this finger needs GROWTH—Great Original Wise Thinking) Ask ‘What have you discovered?’ ‘What has helped you cope with your ABI?’ ‘What could you do to help yourself in the future?’ ‘What advice would you give to someone with ABI?’

Method C: Advice to a friend with ABI

If the participants do not become engaged with either ‘Keys to the ABI Cage’ or ‘Handy Thinking Tools’ about what it is like to have ABI, they might be having difficulties with one of the following issues or problems, or another similar problem. Their problem could be written on a ‘talk-about’ card and then they could talk about the issue. This method was prepared but not used in the Keys Study as Keys to the ABI Cage was readily adopted by the participants.

Once they had unpacked the issue, it was anticipated that participants might wish to engage with ‘Keys to ABI Cage’ or talk about ABI using ‘Handy Thinking Tools’.

The following issues have been identified in workshops with people with ABI over the past 15 years. If the participant did not want to talk about their own issues of ABI, they may be happy to give advice to one of the following ‘people’. ‘Talk-about’ cards could be looked through and a problem tackled to break the ice and get the participants talking.

Using ‘Handy Thinking Tools’, the participant could choose one of these problems or issues to unpack:

1. Crushed
   Sally: ‘I hate myself, I’m a waste of space’. Paul: ‘I don’t think I’ll ever feel better. Will I?’
2. Temper
   Sean: ‘The OT kept telling me I wasn’t trying enough. It made me mad’.
   Jim: ‘How can I deal with my temper?’
3. Sad
   Sam: ‘I can’t stop crying. I’m so sad’.
   Phillipa: ‘How can I deal with my sadness—I’ve lost myself and my life!’
4. Bad thoughts
   Dean: ‘I can’t let go of awful thoughts’.
   Brian: ‘My thinking—sometimes I think I’m crazy. I don’t understand’.
   Heidi: ‘I keep jumping to conclusions. I was convinced my husband was having an affair—I saw it in a dream’.
5. Understanding
   Mark: ‘How can I learn to understand again?’
   John: ‘I can’t understand what people say. I feel stupid’.
6. Memory
   Christopher: ‘I can’t remember what day it is or even my own name. What can I do?’ Mary: ‘I’ve forgotten how to tell the time, what money is and how to work change out in a shop. What things could help me?’

6.4 The Sample

6.4.1 *Sample Sizes*

This study was primarily about the experiences of people with ABI at least two years post acquiring their brain injury. These people were engaged in their everyday lives once again. Confidence in the findings of the study was enhanced by triangulation of data—the employment of three different types of participants (sources) and two methods of data collection.

Participants were to include 30 people with ABI, five people who care for and support people with ABI (Note not referred to as carers—as the word carer implies unequal power) and five professionals. The latter two groups were included for the purposes of data triangulation (Denzin, 1970) and the different methods established methodological triangulation (Lincoln & Guba, 1985) to test the tool in different formats.

Data saturation was sought by the selection of the number of participants with ABI (Glaser & Strauss, 1967; Strauss & Corbin, 1998). This saturation ensures trustworthiness since no new concepts are obtained from additional interviews once saturation is reached. Various arguments have been made about what size sample achieves saturation (Mason, 2010; Morse, 1994; Creswell, 1998; Bertaux, 1981; Smith, 2004; Smith & Eatough, 2008). Given our wish to exemplify diverse experiences as well as collective experience, we established a sample size of 30 as noted above.

However as Durham still experiences difficulty with counting, in error, 36 people with brain injury were interviewed for the study, (in this case much to her supervisor, Ramcharan's, satisfaction and mirth).

6.4.2 *Type of Sample (Inclusion Criteria) of Participants with ABI*

As the main aim of this study was to do no harm to participants, ethical considerations informed the inclusion criteria: participants with ABI and people who care for people with ABI needed to be willing to reflect on the ramifications of ABI without becoming too distressed; if a person with ABI was taking part in the study, the person who cares for and supports them could not take part in the study, or vice versa. Participants needed to be able to understand the Plain Language Statement about the study, and be able to participate meaningfully with words or actions; they needed to be between the ages of 19 and 60 years; they should not be in a fragile state, stressed or in the midst of a crisis, nor awaiting a court case related to any accident associated with their ABI in 2009 (the year the interviews were conducted). Participants needed to be willing to have the interview tape-recorded. In order to reassure participants that their privacy would not be invaded, they were specifically *not* asked their age, occupation and so forth and all data was deidentified and circumstances sufficiently disguised so as not to give away their identity. The participants with ABI were to be between 2 and 14 years post-injury. The majority of participants with ABI were in their 20s and 30s, their brain injury was caused by a motor vehicle accident (i.e. brain injury acquired from the year 2000 plus), and they acquired their brain injury between two and eight years previously.

Participants were recruited from information placed in a broad range of brain injury support group newsletters and websites in both city and rural areas. A major feature of this research is that it had no connection to ‘traditional’ sources of participants where the participant may have felt services/support could be compromised by their statements.

We have decided not to follow convention and detail demographic and disability characteristics of the sample. Disability (what impairments each person has), under a social model, is considered less important than the experiences they related around their struggles with everyday life. Given the analysis undertaken, we considered ex post facto what role demographics would have played in our analysis. The answer was that they would have played very little part—the focus was on the recurrence of themes in their experience which they guided in the choice of ‘talk-about’ cards which were selected from the ABI Cage. The small study sample would also have made it difficult to make sense of causation or even influence sufficient to satisfy a scientific critique. In some senses the gratuitous use of data not used later seemed to us an unusual approach for these reasons.

The sample was therefore a non-probability sample and was purposive, requiring participants with particular characteristics to participate in the study. The sample might also be categorised as a *criterion* sample in that only a specific group, a group that met the study criteria from among the ABI population, was recruited for the study.

The sample resultant from the above approach is summarised in Fig. 6.3 in which we identify the data collection strategies used across each participant group.

Group	**Method**	**People with ABI (*N* = 36)**	**Family carers**	**Professionals**
A	Interview only	10	5	5
B	Reflection Kit plus Interview	10		
C	Reflection Kit only	16		

Group A = Interview only — 10 people with ABI, five people who supported and cared for other people with ABI and five professionals.

Group B = Reflection Kit plus an interview — 10 people with ABI

Group C = Reflection Kit only — 16 people with ABI.

Fig. 6.3 Methods of data collection

6.5 Interviews and Their Importance

It will be noted that the data collected from the PowerPoint Reflection Kit came in written form and this did not allow the same detail nor discussion that might have been used in a face-to-face interview. The approach therefore allowed some comparison of the two approaches. Ideally interviews would have been preferred and the opportunity to engage in narrative and life story discussions. As argued previously, learning often takes place in interaction and discussion with others through a process of reflection and then safe testing out of ideas and actions.

Life stories are important to everyone as they provide an opportunity for the person to express who they are, their sense of self and allow others to understand who we are and how we got that way (Linde, 1993; Widdershoven, 1993); therefore, *Keys to the ABI Cage* was developed to scaffold the person's thinking to tell the story of their experience.

Such interviewing involves unpacking and exploration of the participant's experiences and lifeworld and led to greater understanding. Creswell's (1998) 'qualities of caring' was adopted: which the participant was viewed as a valued person, their comfort and security was paramount. The interviewer gave freely of themselves in conversation (Creswell, 1998). The researcher listened carefully, to 'hear' data, to have an 'ear' for what the participants were saying and focused on what they found to be important or unimportant in their search for meaning (Hermanowiscz, 2002). The interview was limited to one hour rather than a maximum of 90 min (Seidman, 2006), because people with ABI may be experiencing fatigue, emotional, cognitive and physical difficulties, and difficulty travelling to an interview. Pre- and post-interview phone calls allowed rapport to develop, and 'Some Further Thoughts' sheets gave the participants time to reflect on issues after the interview. Seidman's tips to direct the interview (2006, pp. 81–93) were followed. These included: Respond to the interviewee, but do not lead the response to the question; Do not interrupt the participant while they are speaking; Ask them to tell a story about a particular part of the experience. Be patient; do not fill the silences—give them time to think and respond.

6.6 Keys to the ABI Cage—The Study Procedure

Brain injury support organisations were contacted by phone and asked to place an advertisement in their newsletter. People with ABI, family carers and professionals were all invited to ring and register their interest, and they were then contacted by phone. If they fitted the inclusion criteria, they were sent a letter that set out the inclusion/exclusion criteria and Plain Language Statement which detailed the research, and two Informed Consent Forms to be witnessed (one to keep and one to send to Durham). Once the signed consent sheet was received, Durham phoned and negotiated a time for the interview or discussed sending the Reflection Kit. In the case of interviews, a telephone call was made the day before the interview to make sure it was still suitable and to remind them of the time and place of the meeting.

Interview procedure:

If a face-to-face interview was being undertaken, the following were taken by car and assembled at the interview location if possible (on several occasions, the cage was assembled on the footpath or car park as it was too bulky to be assembled in a coffee shop):

- *Keys to the ABI Cage*, complete with walking stick, pole and 'talk-about' cards.
- Two boxes (one labelled 'Do' and the other box 'Don't') and a second set of the 'talk-about' cards.
- A laptop computer with the PowerPoint® presentation 'Introduction to 'Keys to the ABI Cage' ready to use.
- The recording device.
- The signed and witnessed Ethics Consent Form returned to Durham.
- The evaluation form.
- A 'Some Further Thoughts' sheet and self-addressed stamped envelope.
- Take-home information about who to contact if the participant was upset by revisiting their past experiences.

When the participant arrived, Durham introduced herself and her husband Edward who drove her to each interview. Edward then moved to an area out of the way but within sight of (but out of hearing range). The interview commenced with a brief chat about previous phone conversations, and the participant was put at their ease. Coffee was ordered (if in a location where coffee was available).

Consent and permission to audio record the interview were then confirmed, and the voice recorder was switched on. In the face-to-face interview setting, Durham introduced the participant to the *Keys to the ABI Cage* model as they viewed the digital storage disk on a laptop computer. This described the three-step process (Fig. 6.1) of the interview to familiarise them with the concept and what they would be asked to do.

They participant then examined the cage and 'talk-about' cards to further become familiar with the concept and with what they would be asked to do.

Reflection Kit procedure:

In the first contact once interest had been registered by a prospective participant, Durham asked the participant if they had a computer, if they knew how to insert and use a digital storage disk and if they were willing to participate in this way (with or without an interview). After they had read the Plain Language Statement and returned the signed, witnessed Consent Form, a package was assembled and sent by mail. This included an instruction sheet for using the Reflection Kit, the digital storage disk, 'What ABI means to me' sheets and a stamped addressed envelope to return the completed sheets.

Having established rapport in the interviews or by phone with those who were sent the DVD Reflection Kit, the data collection began around the three themes.

Theme 1. ‘Our Differences and Difficulties Can PUT us in ‘the ABI Cage’

This sign can be seen hanging on Durham’s old walking stick horizontally inserted into the left side of the cage, along with black-backed ‘talk-about’ cards (black symbolising the negative) held in plastic pockets (Fig. 6.2). Like the two other themes described below, the choice of ‘talk-about’ cards for this theme was drawn from the literature reviewed in Chaps. 3–5 (and summarised in shaded Headwork boxes across chapters), from public information and from personal and wider experiences of people with ABI.

Participants were invited to pick those cards relevant to them (either in interview or in the Reflection Kit) and place them in a ‘Do’ and ‘Don’t’ box. Participants could talk about the comment, or something the words reminded them of, *if they wished to do so*. The cards and other objects in the cage were employed to provide interactive prompts for participants to think about and talk about their own chosen concepts and ideas.

The tool was ‘organic’. The ‘talk-about’ cards allowed participants to ‘wander’ through the concepts as they chose, make connections and change their mind after further reflection. In the first section, ‘Our Differences and Difficulties can PUT us in the ABI Cage’, participants added the following statements to those already provided, which were turned into ‘talk-about’ cards over the period of the 30 interviews: ‘I don’t know “new” me’; ‘I’ve lost “old” me’; ‘Police’; ‘Lawyers’; ‘Isolated’; ‘Very, very, very cold’ (Fig. 6.4).

Theme 2 ‘How We Feel About Our Differences and Difficulties Can LOCK us in ‘the ABI Cage’

Hanging **inside** the cage were red-backed ‘talk-about’ cards (red for emotions), hung on hooks held by bird-shaped mirrors—to remind people to look and reflect. Words on the ‘talk-about’ cards (Fig. 6.5) were drawn from the literature (see Headwork in previous chapters). Additionally, there were also objects that were metaphors or symbols—a crushed Solo® drink can (to symbolise a crushed life), a snuffed out candle (a finished life) and a toy snake (people are scared of me). The same procedure applied to choosing cards and discussing their meaning. Titles on the cards used are shown in Fig. 6.5.

Theme 3 ‘Keys Can RELEASE us from the ABI Cage’.

This sign can be seen on the right side of the cage at the top of the long wooden pole with golden keys attached to it (Fig. 6.6). The pole was crowned with a wooden pig with flywire wings—a flying pig—symbolising achieving the impossible. Hanging on the pole were white-backed (white symbolising the positive) ‘talk-about’ cards fixed to a rigid Perspex sheet. These cards had mini-objects attached to them

Fig. 6.4 'Talk-about' cards—Theme 1: Our differences and difficulties that PUT us in the ABI cage

Fig. 6.5 'Talk-about' cards—'How we feel about our difficulties and differences can LOCK us in the ABI Cage'

(e.g. sun for sunshine, mushroom for nature, tiny cup for coffee, a tiny dog, 'stretching my comfort zone' had a rubber band wound around it). This captured the interest and attention of participants and caused a lot of smiles. These particular cards focused on those factors that help to 'RELEASE' people from the cage.

This list contained a wide range of things in order to show participants that there were *many* things that can help us feel better, or factors that have a positive effect

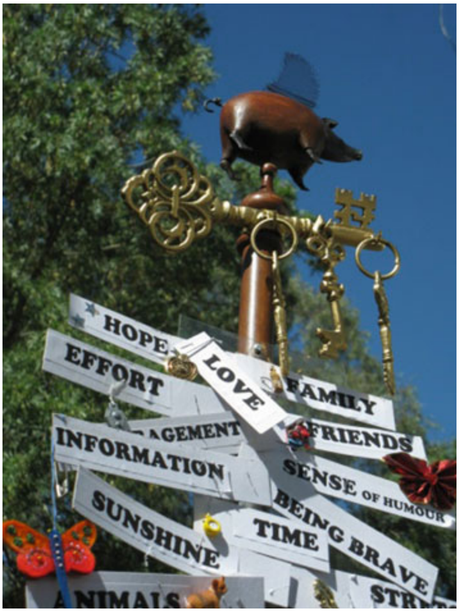


Fig. 6.6 'Talk-about' cards—Keys can RELEASE us from the ABI Cage'

on our lives (Fig. 6.6). When participants held the stack of cards denoting *Keys to the ABI Cage* that could release them from the cage, they became aware of the large number of 'Keys' that could help them feel and fare better, shown in Fig. 6.6.

Figure 6.7 shows the approach used in both interviews and in the Reflection Kit.

At the conclusion of the interview participants; completed a brief evaluation sheet; were given the 'Some Further Thoughts' sheet, and a stamped self-addressed envelope; a sheet of phone numbers of people to contact if they became upset as a result of participating in the study; and 'Hope Stone', This was a black polished river stone with a star affixed to, This was a meaningful symbol of the hard things (the stone was a hard thing) people with ABI can tackle and a coloured message that they can find ways to reach for the stars.

Participants were contacted by phone on the day following interview, or when Durham received 'What ABI means to me sheets', and again one week later to make certain that participants were not troubled by their participation. A thank you card was sent. This contained two coloured photographs—one of the 'ABI Cage' and another of the 'Pole of the Flying Pig'—showing some of the Keys that can release us from the ABI Cage, and additionally a bookmark of coloured paper with the phone numbers of professionals for them to contact in case they were/became upset as a result of their participation in the study.

Eight participants returned 'Some Further Thoughts' sheets and had put an effort into relating issues they had previously forgotten to mention. Two others just wrote a few words, ten did not return the sheets. There was a great variation in the quantity and quality of data collected in the interviews and Reflection Kit. This will be discussed in Chap. 9.

***Keys to the ABI Cage* Acquiring better insight into what it's like to have ABI**

*The words on these 'talk-about' cards are things people have talked to me about (and I've experienced myself.) You are invited to talk about these things. 1. How you are **different** to how you were,and the **difficulties** you have**.**

2. How you **feel about your differences and difficulties.**

3. Things that have helped you **cope** with your ABI**.**

*I had my world turned upside down when I had a terrible car accident.

*Every day I still struggle to live with pain from my injuries, ABI, double vision and memory problems. So I do understand what life is like for you.

*I felt frightened and bewildered. I didn't want anyone to ever feel as lost and scared as I was. So I wrote *Doing Up Buttons*.

*Here are my doves Lovey Dovey and Cloud. They couldn't walk or fly properly so they weren't proper birds. I felt wasn't a proper person — I couldn't even do up my buttons!! We were a good team!

*When I went on television to talk about my book I would put them in a cage to take them to television studios.

*ABI is just like being put in a cage. It feels like the cage is locked and the key is thrown away. There seems to be no way out.

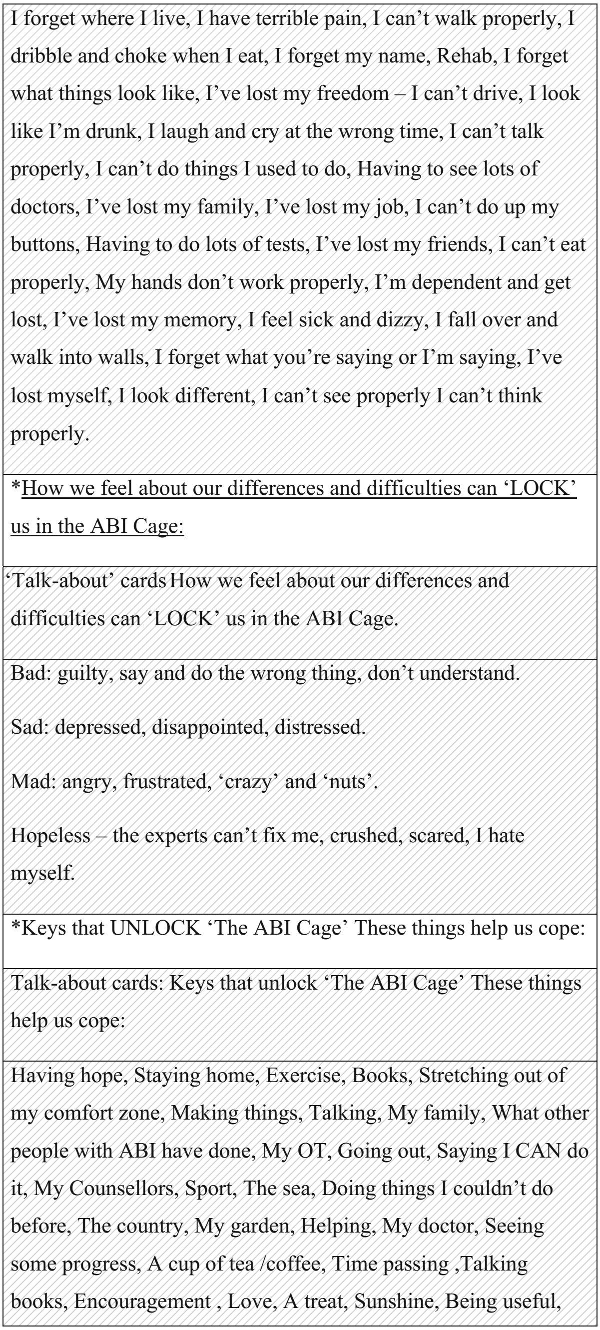
*But pigs can fly! I have tried to stay hopeful! I decided to use (1) My old walking stick, (2) Lovey Dovey's Cage, (3) A flying pig, to help you explain what living with ABI is like for **you.**

*Picture of the Cage

*Our Differences and difficulties can PUT us in the 'ABI Cage'

'Talk-about' cards:Our Differences and difficulties can PUT us in the 'ABI Cage'

Fig. 6.7 Introductory digital storage disk and Reflection Kit: *Stars* indicate individual slides and the words on the slides



I forget where I live, I have terrible pain, I can't walk properly, I dribble and choke when I eat, I forget my name, Rehab, I forget what things look like, I've lost my freedom – I can't drive, I look like I'm drunk, I laugh and cry at the wrong time, I can't talk properly, I can't do things I used to do, Having to see lots of doctors, I've lost my family, I've lost my job, I can't do up my buttons, Having to do lots of tests, I've lost my friends, I can't eat properly, My hands don't work properly, I'm dependent and get lost, I've lost my memory, I feel sick and dizzy, I fall over and walk into walls, I forget what you're saying or I'm saying, I've lost myself, I look different, I can't see properly I can't think properly.
*How we feel about our differences and difficulties can 'LOCK' us in the ABI Cage:
'Talk-about' cards How we feel about our differences and difficulties can 'LOCK' us in the ABI Cage.
Bad: guilty, say and do the wrong thing, don't understand. Sad: depressed, disappointed, distressed. Mad: angry, frustrated, 'crazy' and 'nuts'. Hopeless – the experts can't fix me, crushed, scared, I hate myself.
*Keys that UNLOCK 'The ABI Cage' These things help us cope:
Talk-about cards: Keys that unlock 'The ABI Cage' These things help us cope:
Having hope, Staying home, Exercise, Books, Stretching out of my comfort zone, Making things, Talking, My family, What other people with ABI have done, My OT, Going out, Saying I CAN do it, My Counsellors, Sport, The sea, Doing things I couldn't do before, The country, My garden, Helping, My doctor, Seeing some progress, A cup of tea /coffee, Time passing ,Talking books, Encouragement , Love, A treat, Sunshine, Being useful,

Fig. 6.7 (continued)

Growing things, My sense of humour, My health professionals, My friends, Flowers, Religion, A picnic, Books, Stretching out of my comfort zone.

*Now we are going to look at **your** experience and things that have helped **you** turn a piece of poo into a rose.

***HOPE= Help Other Possibilities Emerge"**

Fig. 6.7 (continued)

6.7 Ethics

Ethical considerations were of implicit in the study design as emphasised in preceding chapters. The Keys Study sought to establish a balance between risk and benefit, both in the process of doing the work, and in terms of the long-term gains (i.e. means and ends). We sought to achieve benefit for study participants and public good by making the study findings relevant to the wider population of people with ABI. We also sought to ensure the benefit produced was at all times as high as could be managed within a research process which the RMIT Human Research Ethics Committee would approve.

Ethics may also apply to the researchers too.

As a person with ABI, Durham still experiences difficulties with double vision, memory, understanding time, numbers, juggling a number of tasks at the same time and fatigue. Organising just two interviews a week, packing the car, arranging driving support from Durham's husband for trips of up to two hours to the interview, conducting the interviews, and all the administrative work such as transcribing and organising interviews were emotionally and physically draining and took their toll.

All-in-all significant difficulties were experienced by Durham in juggling so many different tasks at the same time.

Halfway through the interviews, an ethical issue arose, which required attention, and the study was suspended for a period of three months while this was resolved. The suspension of the interview programme meant some people were already in the 'pipeline'. It was important to honour the agreement to involve them in the study.

Unfortunately, the issues that involved the suspension of the study led to reluctance to make contact with participants at the conclusion of the study or at the time of writing this book in case there could be another incident. This is unfortunate as it was intended to present the findings of the study to participants and send them a copy of *Unlocking My Brain* to ask for their comments.

6.8 Analysing the Data

In total, over 150,000 words of transcripts of data were transcribed from the recorded interviews, Reflection Kit 'What ABI means to me' sheets and 'Some Further Thoughts' sheets that were returned after the interview. The most data recorded was from the interviews. The breadth and depth of data from both the Reflection Kit 'What ABI means to me' sheets and 'Some Further Thoughts' sheets reflected the individual and their understandings, i.e. some interviews and Reflection Kits and sheets obtained amazing insights but others did not.

A software programme was not used for analysis to be true to phenomenology. This phenomenological study had been about 'humanness': the method that data was gained through interviews and conversations, with Durham's role as a subjective actor, rather than a detached and impartial observer (Moustakas,1994; Plummer, 1983; Stanley & Wise, 1993). Participants had freely shared their deep metaphysical suffering, and Durham was concerned that a software programme might not capture the pain, shame and hope expressed by the participants.

6.8.1 The Phenomenological Approach to Data Analysis/Understanding

In phenomenology, 'Meaning is central, and the aim is to try to understand the content and complexity of those meanings… through a sustained engagement with the text and a process of interpretation' (Smith & Osborn, 2003, p. 66). The analysis therefore searched through dialogue to uncover connections between issues and emotions, issues and insight, and issues and how people coped or survived.

Phenomenological reduction involves leaving theoretical speculation behind and 'bracketing', cutting through the taken-for-granted and conventional wisdom about what it is like to have ABI—the blank spots. Instead, it focuses on the participant's personal perceptions, understandings and knowledge—blind spots. Data analysis moulds 'meaning from narrative' (Moustakes, 1994) from the 'clay' of the words participants used to describe their everyday, mundane, quotidian experiences.

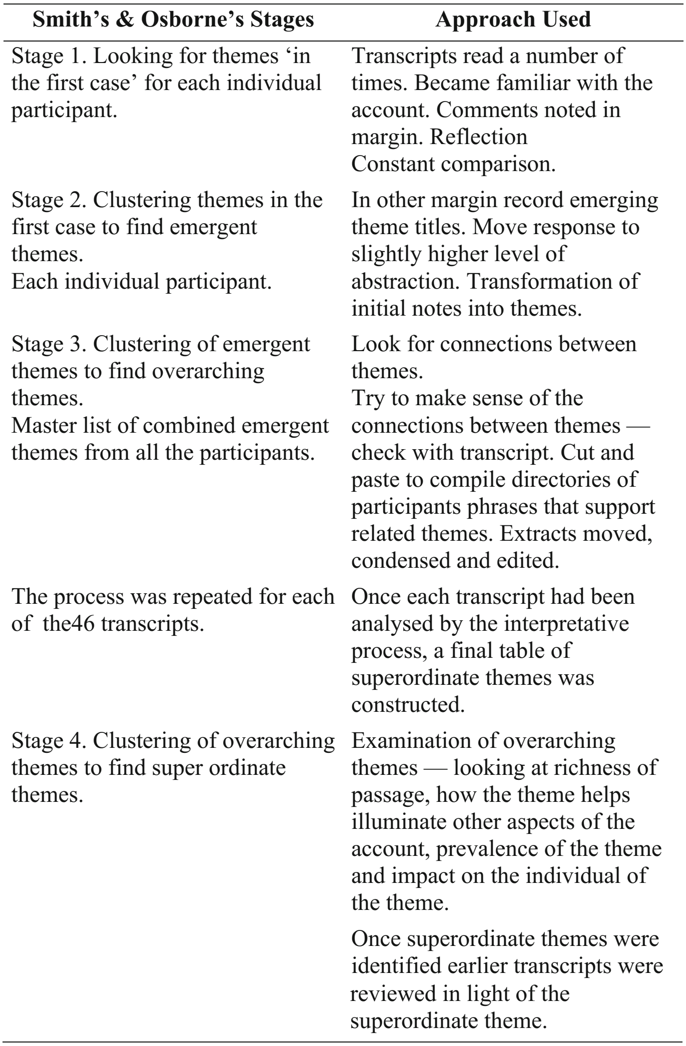
Several approaches to analysis of the data were trialled but rejected. Colaizzi's (1978) seven-stage model proved too unwieldy and confusing; The approach of Diekelmann et al. (1989) was rejected given it was formulated for use by a research teams; Giorgi's (1985a, b) four stages of reading to make sense of the whole, failed sufficiently to explore meanings behind the expressions. This brought us to the interpretive phenomenological analysis (IPA) of Smith (1996).

Smith's (1996) interpretative phenomenological analysis (IPA) was eventually selected for several reasons. First, the interviews themselves were from an insider's perspective and IPA is concerned with a person's *personal perception and account* of ABI (an event), rather than attempting to make any essentialist statement about ABI (the event itself) (Smith, 1996). IPA involves interpretation. As an insider, Durham was in a good position to interpret statements: ‘explain the meaning, bring out the meaning, act as an interpreter’.

Secondly, IPA focuses on the *narrative* and involves formulating the connections between issues, emotions, insights and survival.

Thirdly, IPA allows flexibility of approach and delves deeper than quantitative measurement, thus enriching the ABI literature.

Finally, Smith’s method encompasses many methodological translations of phenomenology, those that were rejected as described previously.



Smith’s & Osborne’s Stages	Approach Used
Stage 1. Looking for themes ‘in the first case’ for each individual participant.	Transcripts read a number of times. Became familiar with the account. Comments noted in margin. Reflection Constant comparison.
Stage 2. Clustering themes in the first case to find emergent themes. Each individual participant.	In other margin record emerging theme titles. Move response to slightly higher level of abstraction. Transformation of initial notes into themes.
Stage 3. Clustering of emergent themes to find overarching themes. Master list of combined emergent themes from all the participants.	Look for connections between themes. Try to make sense of the connections between themes — check with transcript. Cut and paste to compile directories of participants phrases that support related themes. Extracts moved, condensed and edited.
The process was repeated for each of the46 transcripts.	Once each transcript had been analysed by the interpretative process, a final table of superordinate themes was constructed.
Stage 4. Clustering of overarching themes to find super ordinate themes.	Examination of overarching themes — looking at richness of passage, how the theme helps illuminate other aspects of the account, prevalence of the theme and impact on the individual of the theme.
	Once superordinate themes were identified earlier transcripts were reviewed in light of the superordinate theme.

Fig. 6.8 Smith and Osborne’s stages and approach used

Transcripts of participants with ABI, then transcripts of mothers and wives who care for and support family members with ABI, finally professionals' transcripts were analysed to support data triangulation and to demonstrate different ways people perceive factors that influence the lifeworld of people with ABI. The analysis followed the staged process described in and Smith and Osborne (2008), first for one transcript, and then repeating the procedures for each transcript; identifying themes in the first case which were revisited and clustered together to form *emergent themes* if they repeated across participants. These themes were further clustered together to form *overarching themes*, which were finally clustered into *superordinate themes*. An example of this process is shown below as explained previously in.

6.8.2 *Applying Smith and Osborne (2008): A Worked Example*

The approach used is summarised as previously explained in Fig. 6.8.

The following short example relates to things that negatively affect the lifeworld of participants with ABI. The same approach was used in relation to all data across each of the three study focus areas and each of the three participant groups.

Stage 1 **'Words in the first case' (the participant's direct words)**

Sally's transcript was read and reread to identify factors that had a negative impact on her lifeworld. These were underlined and notes made.

> It was many months…I think it was my GP, that actually diagnosed me. I think she said 'are you angry?' and that was one of my biggest problems. Cause I couldn't control my anger (9). I don't think I realised that, because I didn't know what was going on those first few months. But then I ended up getting referred to do rehab, so I was there for 6 months.

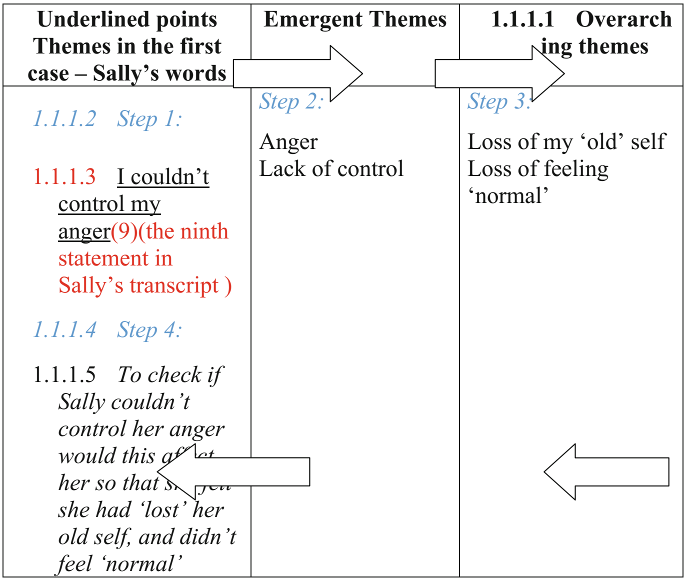
Among all the underlined passages was one statement 'I couldn't control my anger' (Sally statement 9), and this example will now be used. This statement is shown in Fig. 6.9 with an emergent theme shared by other participants—'anger' and 'lack of control' and an overarching theme that seemed to hold all of these themes in the first case.

Stage 2 **Clustering of emergent themes**

Sally's emergent themes of 'Anger' and 'loss of control' were now cut and pasted onto a master list of emergent themes of all the participants with ABI (Fig. 6.10).

Stage 3 **Clustering of emergent themes to make overarching themes**

Sally's statement demonstrated that her inability to control her anger had a negative effect on her lifeworld. Implicit were several comparisons—between the 'old' Sally, who could control her anger, and the 'new' Sally who could not control her anger; and between Sally who could not *trust herself* to control her anger versus

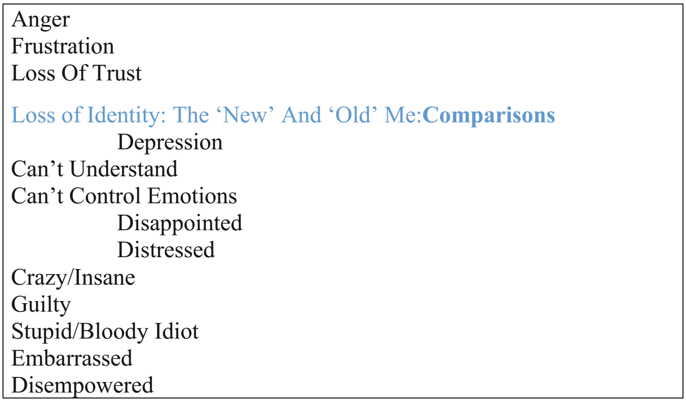


Underlined points Themes in the first case – Sally's words	Emergent Themes	1.1.1.1 Overarching themes
1.1.1.2 Step 1: 1.1.1.3 <u>I couldn't control my anger</u>(9)(the ninth statement in Sally's transcript) *1.1.1.4 Step 4:* 1.1.1.5 *To check if Sally couldn't control her anger would this affect her so that she felt she had 'lost' her old self, and didn't feel 'normal'*	*Step 2:* Anger Lack of control	*Step 3:* Loss of my 'old' self Loss of feeling 'normal'

Fig. 6.9 Themes in the first case, emergent and overarching themes

the one that did. It might be assumed that she felt this loss of control and anger was not 'normal' and that, as a result, she did not feel normal. Clustered with similar statements from other participants with ABI, the consequences of Sally's inability to control her anger therefore clustered together to form the emergent themes:

(i) Loss of identity: the phenomena of the 'new' and 'old' me.
(ii) Loss of understanding.
(iii) Loss of trust—I can't trust myself.



Anger
Frustration
Loss Of Trust

Loss of Identity: The 'New' And 'Old' Me:**Comparisons**
  Depression
Can't Understand
Can't Control Emotions
  Disappointed
  Distressed
Crazy/Insane
Guilty
Stupid/Bloody Idiot
Embarrassed
Disempowered

Fig. 6.10 Emergent themes from several participants, including Sally's 'Anger'

The transcripts of other participants were then revisited using a constant comparative approach, and similar themes were clustered together to make the overarching theme ‘Loss of self’ ‘loss of the ‘old’ me’. Figure 6.11 shows themes at the varying levels.

Stage 4 **Clustering of overarching themes to make superordinate themes**

This process was repeated as the clustered overarching themes were cut and pasted together to form the superordinate themes, umbrella themes capable of holding several overarching themes together under a single category. In this case, Sally’s frustration and concern about her inability to control her anger contributed to the Blind Spot ‘Syndrome’ or ‘Conglomeration’. The consequences of ABI can result in the person with ABI being (not just feeling) Afraid, Ashamed and Isolated. This belief is in their ‘blind spot’. They are not aware of these as factors, that they are feeling afraid, ashamed, isolated.

The ‘essence’ of the lifeworld of people affected by being unable to control their anger is very complicated and through reflection, as seen in this example, people engaged in the interview had the chance to reflect and to learn through the process.

Superordinate Themes ⇦	**Overarching Themes** ⇦	**Emergent Themes** ⇦
1. ‘The Blind Spot Conglomeration’. Consequences of ABI can result in the person with ABI being (not just feeling) Afraid, Ashamed and Isolated but this is in their ‘blind spot’ and they are not aware of these factors that influence their wellbeing.	1. Loss of ‘self’ loss of the ‘old’ me	(i) Loss of identity:the phenomena of the ‘new’ and ‘old’ me: Comparisons
		(ii) Loss of understanding
		(iii) Loss of trust: Can’t trust myself, other people, the experts, fate/God/luck
		(iv) Loss of faith/Religion/ being punished by God

Fig. 6.11 Superordinate, overarching and emergent themes

6.9 Recapitulation

This chapter has discussed *Keys to the ABI Cage* metaphor/tool and has pointed to the three themes focused upon in the interviews and a number of ‘talk-about’ cards that variously populate both the physical cage and the Reflection Kit. Data collection, sample size, type of sample, the interview procedure, the Reflection Kit procedure, ethical considerations of this study and the method employed (IPA) to interpret and analyse the data have also been considered.

The analysis of the resultant data illustrated using a worked example how one comment from just one of the 46 participants could, using a constant comparative method of data analysis, be placed in emergent and overarching themes through the process of analysis

It is now time in the following two chapters to present a summary analysis of all the transcripts in relation to the three study themes and from the point of view of the three sample groups—people with ABI, their carers and professionals.

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Chapter 7
Understanding What Negatively Affects the Lifeworld of People with ABI

I cannot conceive of a greater loss than the loss of one's self respect.

Mahatma Gandhi

She took a step and didn't want to take any more, but she did.

Markus Zusak

7.1 Introduction

We have demonstrated that many accounts of ABI place theory as subject and experience as a predicate. The medical privileges mending broken bodies and on occasions some psychological help, however for many people, very little more than what can be done to practically mend such bodies is considered; the social model privileges how disability is socially constructed under the banner of 'accessibility' and hence limits its interests to these premises.

We have asked an alternative question in this book. We have asked participants, more than two years post-acquiring their brain injury about how their experiences, can help us understand how best we might respond to assist people with ABI to re-engage with the social world and environments of their everyday lives.

We have shown how "Keys' to the ABI Cage' was borne out of Durham's wide-ranging experience with people with ABI, from what is known in the literature and from an educational perspective which scaffolds learning and motivates engagement. We have shown how in this study all of this was achieved in a way that helped people to feel and fare better and in a way which conferred dignity and respect on those who participated.

This chapter and the following chapter will use interpretative phenomenological analysis (IPA) outlined in Chap. 6 to examine factors that negatively and positively affected the lifeworld of a person with ABI, where the place of intentionality is a vital component of the process. Others might choose to cluster or collapse the data in a different way. This interpretative analysis did not focus on every theme that emerged from the data, rather, themes were purposefully chosen because of their relevance to the research question—to discover factors that had a negative effect on

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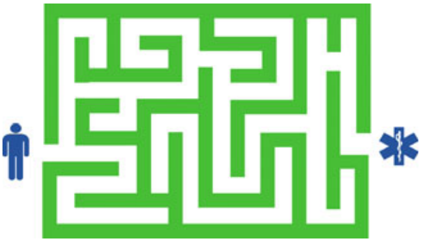
the lifeworld of people with ABI, and to discover what the data suggests about their learning experience.

In what follows we present the lifeworld, the everyday experience, of people with ABI for a sample of people post-rehabilitation to exemplify the lives, the struggles and the successes that characterise their existence.

However, a note should be made about the narratives of participants. Despite the focus being post the ‘golden period/dark hole period’, the affect of rehabilitation on their lives was considered and shown to have a huge impact on their later experiences back in the community. ‘Rehab’ was just one of 60 ‘talk-about’ cards, which many participants chose and placed in the ‘Do’ box—it was yet another way their life might have been ‘different’ since their ABI. While this study had no intention of critiquing or analysing rehabilitation, most participants had a plethora of comments to make and stories to tell about ‘rehab’ which amounted to it being, for them, more a ‘dark hole’ than a ‘golden period’.

This chapter will demonstrate that people with ABI can learn to have self-awareness, not in a linear straightforward way, but by a process of ‘learning’, or ‘constructive circumambulation’- by being supported through scaffolding to circle (or visit and review their experience) and recircle themselves: to reflect upon, build upon and learn from their experiences.

A labyrinth—a winding, twisting path walked to aid reflection—explains the right brain, creative process of “Keys’ to the ABI Cage’. The process involves imagery, imagination and intuition and an opportunity to vew and review an issue form several directions in several time frames. A labyrinth is different to maze as a maze has just one solution. A labyrinth presents a puzzle to be solved—requiring logical, sequential analytical left brain thinking where memory is vital to emerge.



Keys to the ABI Cage method provided the ‘path’ like a labyrinth for participants to ‘walk’ to tell stories to aid them to reflect on things that had a negative and positive effect on their life. Insiders (people with ABI) and outsiders (family members and professionals) were included for the purpose of triangulation.

This chapter will commence with the superordinate (main) themes and summarise how these were populated by giving examples from the overarching and emergent themes identified in participants' narratives (see Chap. 6, Fig. 6.6). This is the reverse to how the analysis was achieved, i.e. it started with words in the first case, clustering them into emergent themes, clustering these into overarching themes and finally superordinate themes. It should be noted that neither the superordinate nor overarching themes were on the 'talk-about' cards rather the findings from using these cards could be clustered into these themes.

While we cannot say that the themes exhaust all narratives from all people with ABI, we can propose that for this sample of 36 people with ABI the themes derive from their narratives and, that as the work continued, fewer and fewer new themes emerged. This provides some confidence that the data was becoming saturated for this sample and that we can confidently report the recurrence of experience of study participants.

7.2 Factors that Negatively Affect the Lifeworld of Participants with ABI

> Long term recovery from brain injury is not a medical problem…Medicine has very little to offer in this direction. The way forward lies in education…the power for recovery lies within the injured person as they relearn their daily living skills. Education is the key, (Freeman, 1998, p. 14).

The arrangements and methods for this study have been premised on these words. Two superordinate themes were eventually identified as characterising *overall*, the things that negatively affected the lifeworld of people with ABI:

- 'ABI damages not only the person's brain, body and beliefs, it also damages their hope, honour, trust, safety and security';
- And 'Learning with ABI is hard labour—it is a struggle to learn when the person is afraid, ashamed and isolated'.

In the remainder of this section, these emergent themes and their relation to the four overarching themes are explored. The superordinate and overarching themes are shown in Fig. 7.1.

7.2.1 Loss, Lost and Trapped

The majority of participants told stories to illuminate the overwhelming effect of being a 'different' person as they struggled to function. They were overcome not only by physical, mental, communication and emotional difficulties and pain but they were also overpowered by a sense of loss.

Superordinate Themes	⇦	**Overarching Themes**
ABI damages not only the person's brain, body and beliefs, it also damages their hope, honour, trust, and safety and security. Learning with ABI is hard labour		1. Loss, lost and trapped 2. No longer a 'normal' human being 3. Damage from emotional fallout 4. The rehab experience didn't suit me

Fig. 7.1 Study superordinate and overarching themes

> I wish I could have one more day without a brain injury just to be the person that died once more — to be with my family the way I used to.

In their struggle to make sense of themselves, most participants told stories about how they constantly compared their old and new self: how they thought they deserved to be treated by people including by their family, friends, health and legal professionals and how they perceived that they were actually treated; and their slow recovery progress compared to the effort they were making. Many stories demonstrated that life prior to their ABI seemed 'more fair' than their post-ABI life, where they had no choice and little power. The complexity was in many ways, therefore a product of comparing a *new with an old me* as shown in Fig. 7.2.

The difficulties expressed in Fig. 7.2 also cut the person off from normal people, isolating them, making them feel like an alien. Without a personal identity and clarity over their own self, the presentation of self becomes impossible and the self becomes constructed to reflect and respond to the ways others treat them. This 'looking-glass self' was not a self with which the person felt happy! A sense of bewilderment, loss and confusion because of what people said and of the 'stranger' who had taken over their body and life was complicated and demanded all their attention.

> When I don't understand what people are saying I feel frustrated … embarrassed

Self-doubt was common with self-trust a casualty as well as trust in other people, experts, fate or luck.

> I'm frightened because I can't trust myself and I can't trust other people and I can't trust health professionals.

Indeed a third of participants felt 'scared' or had 'lost trust' in their families. Fred was 'physically attacked…smacked by my wife'. Melissa was distressed that her parents would accuse her of being lazy but she was trying hard and suffered

‘Old Me’	**‘New Me’**
1. I could walk, drive, work, go out, socialise, travel. I could chose to do anything I wanted to	I can no longer do these things. With my loss of physical, cognitive skills difficulties I’ve lost my choice — I have no power
2. I could talk, listen and understand	I can’t talk, listen understand and I have great difficulty communicating
3. I could eat easily	I don’t know when I’m hungry, I have difficulty chewing, swallowing — I can’t smell or taste my food
4. I could see	I can’t see properly
5. I could cope with life	I can’t cope with life and fatigue plagues my day — I get exhausted trying to cope with all by difficulties. This limits my life
6. I could control my emotions	I can’t control my emotions I make a fool of myself crying when I shouldn’t

Fig. 7.2 Comparisons to the ‘Old’ and ‘New’ me taken from the data

from ‘bad fatigue’. A majority lost trust in their friends who said they ‘seemed OK’—Pete wished he could reply ‘Oh yeah. Swap places with you, then.’

Distress was expressed at the perceived lack of understanding from professionals and at the pessimistic prognoses they delivered. Their stories inferred that they thought professionals would be ‘the one group of people who would understand’. More is said of the professional group later.

For those who had religious beliefs, this had both a negative and positive impact on their lifeworld. Some participants had *lost trust in God,* and many were struggling to make sense of why God was punishing them, or they queried whether God had caused their ABI to teach them a lesson, or if they could trust God to protect them in the future.

> Man plans — God laughs.

The loss of trust (in themselves, others, God and the future) negatively affected their lifeworld.

As we proceed in this chapter, we shall highlight the inherent forms of learning that can be identified in the narratives as exemplified in Fig. 7.3.

To query, to ask questions about trust and fairness, to remember the 'old me' and make comparisons with the 'new me'

These demonstrate how participants were employing cognitive processes ..interpreting, comparing, explaining and making judgments. They show how they circle around discussion of their reality to make sense of it. They are circumnabulating on the basis of their construction of their reality.

Fig. 7.3 Examples of people with ABI 'learning'

7.2.2 No Longer Like a 'Normal' Human Being

Statements from participants indicated a degree of insight into the changes they were grappling with and the ability to compare themselves to a 'normal' human being. But none of the participants referred to themselves as disabled, although Goodley's (2011, p. 1) statement 'to be disabled evokes a marginalised place in society, culture, economics and politics' could be applied to them. However, as they told stories and compared themselves to other 'normal' people, this comparison had a negative effect on their lifeworld.

The four emergent themes: 'Can't function normally', 'Can't understand and communicate normally', 'Can't control my emotions normally' and 'weird and abnormal issues' clustered together to form the overarching theme 'I'm not like a 'normal' person any more'.

Having balance problems and being 'clutsy', 'dodgy' and 'fineline' made activities such as walking, driving, socialising and travelling a problem with impaired vision accentuating these issues for some. Several participants described how in the early months after their injury, they were 'freaked out', frightened and disturbed when they lost the basic 'normal' ability to know how and when to eat.

> I forgot to eat. I didn't have any appetite; I didn't know when I was hungry and when I wasn't.

They found themselves dribbling and choking, because their 'brain had forgotten how to tell the throat how to swallow'. Meg still felt like a 'freak' as she still had to put her fingers down her throat to help herself swallow. Loss of smell and taste was further proof that they were no longer 'normal'. Despite fatigue, many participants had difficulty sleeping at night or, as one participant expressed it, her brain 'could no longer go to the place of sleep'.

The inability to speak so that other people could understand was very upsetting.

> I have a great deal of trouble enunciating words — people find it hard to understand me

Holding the 'talk-about' card with a topic in their hands helped some participants to *hold* a conversation about how they had difficulties speaking, listening and understanding. Several participants discussed their puzzling inability to use the telephone, yet they did not remember this or 'have the words to ask for help' at an appropriate time.

> It's weird telling you … because you understand what I'm talking about … But then you forget that you couldn't remember to use the phone, so you couldn't actually get any help anywhere, because you couldn't remember what you couldn't remember. I think, looking back now, I thought there was something really bad, wrong, and that I'd better not tell anyone. No, not that I shouldn't tell anyone, but that I was embarrassed, ashamed … I don't know, I think I was terrified.

The perceived 'lack of normality' also stretched to controlling emotions, a category sufficiently large and important to stand on its own. Emotional outburst, uncontrollable laughing or crying was referenced many times:

> I cried all the time…at the drop of a hat. I was very emotional

> I went sort of the opposite, I just found everything hilarious. I was really extreme. I'd sit there and just laugh at everything. Well, I couldn't help myself.

The participants spoke of perplexing 'invisible' issues—'left neglect' where they ignored the left side of their body; double or distorted vision; and not knowing who was talking.

> If I was granted a wish today, it wouldn't be to have my sight back. It would be 'can I have my left side back, to make me whole again'. But the loss of sight I can overcome, workaround. The left loss…

> If a person was in the blind spot, I didn't know that they were there…I couldn't see them, but my body could sense they were there and I'd move away, so I was forever falling over. So I'd say … "walk over there, you're on top of me, get away from me", and she couldn't understand.

The overarching theme 'Not like a normal person anymore' therefore encompassed everyday functions, understanding and communicating, emotional control and weird issues and had a significant impact of their everyday lives. When taken together as a complex, these issues produced lives in which, without support and understanding, it became difficult to move forward with even the day-to-day decisions much less those pervasive choices that one makes to seek a better life (Ramcharan et al. 2013). Once again learning took place during the interviews (Fig. 7.4).

7.2.3 *Grappling with Emotional Fallout*

All participants identified with the 'Sad', 'Mad' and 'Bad' 'talk-about' cards and their subsections. The employment of these three small everyday words provided a 'softly softly' approach, a non-psychological, non-professional way to broach profound, personal, serious matters. Participants 'got' the way the words were used, and the words got them talking. Several participants requested the cage door be

Fig. 7.4 Examples of people with ABI 'learning'

n/learning: participants demonstrated a depth of recognition about their lifeworld and they could understand things were not 'normal'(a comparative approach) and they made judgements, checked and evaluated, classified and came to conclusions about their action (a performative approach).

Reflecting Anderson and Krathwohl's (2001) model, of learning they were seeking to remember, understand, applying, analysing, evaluating and then (re) creating.

unlocked so they could remove and hold the crushed drink can saying 'This is me, my life'.

Many participants expressed *disappointment* with themselves and their lives, because they could now no longer achieve their dreams, the fact that day-to-day survival was difficult, that financially their future was changed for the worse: that they no longer had careers they had loved, marriages had broken down—life was no longer predictable or controllable.

> Disappointed is an interesting word, it's too mild for what I felt. I was probably disappointed with myself, disappointed with the doctors, and disappointed with everyone and everything for a while.
>
> Um, sad, distressed, and absolute abject despair and futility. Because I think brain injury it's the unknown as well.
>
> I'm so disappointed with life — my illness wasn't my fault.

They were ashamed and disappointed. They talked about feeling depressed, hating themselves, having contemplated suicide or disappearing, feeling powerless and the reluctance of professionals, family and friends to discuss their suicidal feelings. Many participants also identified with the 'distressed' 'talk-about' card—that the ABI experience was distressing.

Anger was a big problem for many participants, and they told stories of their terrible anger and rage. Anger was expressed at the way they had been treated by professionals.

> I was very angry, I had terrible anger
>
> I'm so angry at the way I was treated — all professionals, even alternative ones are arrogant.

Another participant explained about their terrible uncontrollable anger where they wanted to put their hand through a glass window, and how they would kick things and hit their partner.

However the majority of respondents reported they had feelings of frustration, they felt annoyance rather than anger—at themselves, at situations they were put in because of having ABI and their loss of choice.

> Probably mad/frustrated — that’s brain injury in a nutshell.
>
> Oh God I was really frustrated.
>
> It drives you to distraction… trying to make your brain work.

All participants placed the ‘Frustration’ ‘talk-about’ card in the ‘Do’ box. ‘Mad/frustrated—that is brain injury in a nutshell’ and their stories told of the struggle of trying to cope with a brain and body that does not obey the person—of when they cannot understand why they behave in a certain way, when they are forced to rely on others, or to complete ordinary tasks when they are blind.

Many participants said that in the years following their accident they had believed they had gone mad or insane that they often questioned if they were crazy, mad or nuts. They thought that everyone else was mad: Sharon said she thought the professionals were trying to make her feel insane on purpose, or, surmised that was what they were doing, was ‘part of a stupid IQ assessment’. These participants were profoundly affected by believing they were insane.

Most participants expressed *guilt* in some story or other—either about pain they were causing their family who they felt they had ‘let down’, for what they had put their family through, because they had not avoided the accident, because they could not make themselves better or because they had ‘let’ their ABI affect their life too much.

> I feel guilty because I can’t trust myself — I’m not dependable — with good and bad days my thinking works in stops and starts.
>
> I feel bad because I’m slow and I can’t concentrate, I can’t understand things.

Over half the participants felt guilty they had not ‘tried hard enough to make themselves better’ as they grappled with the emotional fallout of ABI.

Many male participants expressed feeling like a ‘bloody idiot’ when they did or said the wrong thing, poor balance and unsteady gait led to accusations of being intoxicated, stereotyped as a loser and declined entry to bars. Women felt bad about other issues such as doing and saying the wrong thing; one participant elegantly called this the ‘loss of social graces’; others would query if the inappropriate action was due to their ABI or whether they were ‘just stupid?’ Not being able to complete simple tasks such as doing up their buttons resulted in them ‘feeling pretty stupid actually’, being embarrassed because they were ‘slow and can’t concentrate or can’t understand things’. The participants were ashamed, afraid and isolated as a result of their emotional fallout.

The stories told, when taken together, indicate an unremitting struggle to claim (back) an identity; they speak of the anger and frustrations of seeking to be understood and to understand others; they speak of the unremittingly negative responses and rejection of who they are and how they are; so too do the stories highlight how this reduces their mobility, their social interaction and accessing physical environments. In each life area, the downward spirals which interconnect us to being social and to being human are crushed. The frustrations, the emotion represent a cry of hope against the barrage of negative events in their lifeworld (Fig. 7.5).

Fig. 7.5 Examples of people with ABI 'learning'

Cognition/learning: remembering, understanding, analyzing, evaluation were again demonstrable as THE modus operandum, the very essence of their struggle to square learning and action as acceptable to others and to themselves.

7.2.4 The Rehab Experience Didn't Suit the Individual

As mentioned earlier, this study did not set out to critique rehabilitation. An unexpected outcome of the study was over half the participants expressed opinions about how upsetting they had found the rehabilitation experience.

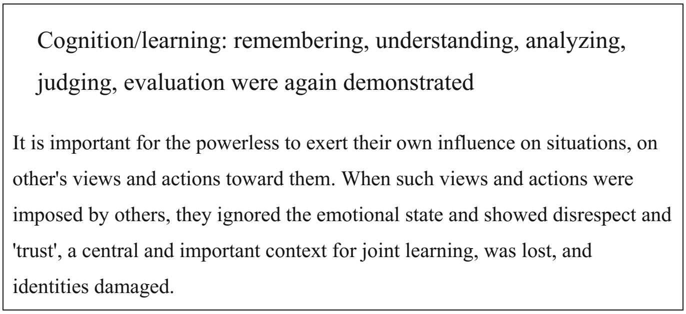
Reviewing the data revealed issues around a perceived lack of understanding of the professional. Use of power, and concepts such as truth, fairness and justice in treatment, had a profound long-term ramifications on many participants' sense of wellbeing. Some participants had forgotten what was *said* and *done* in rehabilitation, but not how rehabilitation made them *feel*. They talked about people and events they did not want to think about, but found they could not forget. This will be further examined in Chaps. 8 and 9.

The following long quote has been included because the perception this participant had about the rehabilitation experience still upsets her years later and it encompasses many of the participants' comments:

> Rehab was so awful actually I don't…it's something I don't talk about, I don't think about, if I do, I cry…I've always believed it was my own fault that I didn't like rehab. In terms of that, I was in a terrible place, so it was always going to be bad…I was suffering…anywhere would be bad…but this was worse. 'Cause it was bad at home, but this was really bad. And I think it's the way, it's a system that… it's a hierarchy, it's really structured, it's really rigid, there's rules, there's no compassion, there's no understanding, it's not about the individual, it felt like you were in a factory…that you were just being pushed through, you were a number…you were just on this treadmill.

The majority of participants were informed that the brain heals for up to two years, and then they 'plateau out'. This two-year rule took away their hope: 'I was told all through my rehab and from other doctors, that the brain will only heal in the first two years, and after that there's not much healing that happens'.

A few participants said they had been damaged twice—firstly by ABI, and secondly by rehab.



Cognition/learning: remembering, understanding, analyzing, judging, evaluation were again demonstrated

It is important for the powerless to exert their own influence on situations, on other's views and actions toward them. When such views and actions were imposed by others, they ignored the emotional state and showed disrespect and 'trust', a central and important context for joint learning, was lost, and identities damaged.

Fig. 7.6 Examples of people with ABI 'learning'

> In rehab I felt like a meal ticket.
>
> … they were just like a Nazi camp to me …
>
> I wanted it to be about me. Well, all our problems were different. And I don't like group therapy.
>
> Some of those experts that I saw…didn't inspire … they made it harder
>
> Rehab was a waste of time.
>
> My OT was hopeless — it just didn't fit with what I felt I needed.
>
> I wasn't wanting an OT and I didn't want to do the exercises.
>
> I didn't like anything done in groups.
>
> [Health professionals]…anyone who has made a difference? Nup sorry
>
> Professionals from rehab centre I don't think played a huge role in my acceptance … They focused on the physical
>
> If all the health professionals were sitting there I'd just (acts holding a gun) blow them away…all fucking useless.

Less than being a 'golden period', rehab as an experience for many was a 'dark hole' the memory which many participants sought to repress. As emphasised in Chap. 10, professional empathy was sadly missing. The struggle to exert their own influence on the process was denied by the system, and they were powerless to change how people treated them.

Note Positive comments about rehabilitation will be identified in the following chapter (Fig. 7.6).

7.2.5 Recapitulation

Most participants 'got it wrong', no matter what they did, many had only limited success and some were worn out with the struggle and were frozen. Chap. 8 will examine factors identified by participants that helped to counteract the paralysing effect of ABI—factors that helped them to live and learn.

Throughout the interviews, many participants modified their statements as they reflected further about an issue. Most surprising were two participants who had stated that they had suffered from depression and been suicidal until recently. But later in the interview, they stated that they now realised that ABI had been the *best* and *worst* thing that had happened to them in their life. As will be seen in the following chapter, great challenges and satisfaction are not mutually exclusive.

7.3 Mothers and Wives': Factors that Have a Negative Impact on the Life of Their Loved Ones

Participants included three mothers of sons with ABI, Molly and Sue (pseudonyms, as for all participants) whose sons were in their twenties. Molly cared for her son at home, Sue's son lived independently and both sons had support from formal carers. Jane's son, a young teenager, was at school. Also included in this group were two wives, Jo whose husband had suffered his ABI several years ago and whose life had established a form and rhythm to accommodate his disability and Liz who was still learning to put in place structures to support her husband. These five women had had their lives totally disrupted by the ABI suffered by their loved one, and they shared the common goal to provide a lifeline, to protect, encourage and support their loved one; and factors that affected their son or husband also affected them. Emergent themes were clustered from the plethora of issues, difficulties and differences they identified. The analysis proceeded in the same way as previously outlined.

7.3.1 Factors that Negatively Affect the Lifeworld of People with ABI from the Perspective of Mothers and Wives

The three overarching themes, the 'lack of understanding and guilt'; 'being judged by others and the stigma of ABI'; and 'sadness for the future', collapsed down to the superordinate themes: 'It's very hard being a person with ABI'; and 'It's very hard caring for and supporting a person with ABI'. This is shown in Fig. 7.7.

7.3.2 Lack of Understanding and Guilt

All the mothers and wives spoke about how medical terms are hard to understand and the difficulty they had obtaining information that they could understand, their need of information for family, friends, and school and sporting groups. They stated that they needed training so that they could learn how to help their loved one.

Superordinate Themes	Overarching Themes
It's very hard being a person with ABI.	1. The lack of understanding and guilt
It's very hard being a carer of a person with ABI.	2.Being judged by others and the stigma of ABI
	3.The sadness for the future

Fig. 7.7 Mothers and wives: overview of findings

> I mean medical terms are hard enough if you don't have a brain injury but if you have an injury it becomes like a second language because I know a lot about medical terminology because I've done a medical receptionist's course but before I did it, if you look at the medical terms… you don't know unless you've studied it …so imagine someone with an ABI it's like hello, I don't know what you're talking about …

They all felt helpless in the early days in the hospital. '*I needed information and training*'. They were not advised what they could or should do; they felt 'thrown in the deep end', and spoke with regret and anguish '[I] didn't know what I was doing'. Some said that they did not understand about ABI and one thought he would 'grow out of it' or 'get better' despite his mother being told 'this is as good as he's going to get'.

> But it's mind boggling, I mean you're there with your loved one and there's all these IVs and everything going on and these machines beeping and you think there really needs to be a non medical way to explain things…

Based on a belief that rehabilitation would make all the difference, these women tenaciously fought for rehabilitation for their loved ones. Molly and Liz even fought for rehabilitation where they were told there would be no benefit, taking extreme measures to learn how to care for them, even getting their private health insurance to pay for some time in a rehabilitation hospital so that they could learn how to physically care for them.

Despite this trust in the system, they reported 'very little rehabilitation of the mind...is this a cup or a toothbrush?… but not a lot'. Sue spoke about how the rehabilitation experience for her son involved too much time with no activity, which led to bad habits such as smoking. If therapies had appealed to her son, his outcomes might have been better. The mothers' emphasis on rehab highlighted that, for them, such rehab would give the person maximum chance to improve or get better. Any mother would want this. But in placing the emphasis here, it identified rehab as a singular hope, one tied just to mending bodies as well as an approach incapable of addressing needs in the social realm subsequent to this phase. Sue, a mother with a son in his early twenties, identified a plethora of issues with which she had to juggle. He was not a child, he had both good and bad days and he wanted his independence: this was a

> 'recipe for disaster… he blew his settlement trying to buy affection and loyalty'. 'Drugs — psychosis — from then on it has been hell — he couldn't cope — life lost all reality — Everything he used to do and his dreams were gone' (Sue).

Liz's problems were becoming more apparent as her husband spent more time at home after leaving hospital.

> I kept asking myself is it behavioural or is it something wrong with his head? Is it going to improve? (Jane).

Jane's son was refusing to attend school, and Molly had fought and won many battles with authorities. Jo had experienced problems with the legal system, and friends were loath to testify in her husband's defence. The five women had coped with and swallowed many 'bitter pills'.

7.3.3 Being Judged by Others—The Stigma of ABI

A further theme related to being judged by others. Here, the stigma of ABI and the distress of loving a person with ABI were found to be fundamental issues.

> I know a lot of people who've never heard of ABI they wouldn't have a clue…
>
> I want people to understand — more education about ABI — it would even be nice to have a TV ad…something about ABI, you know.

All the women had stories that clustered into how difficult it was when people did not understand about ABI. It was particularly upsetting when family and friends could not or would not acknowledge or were in denial about their son's/husband's difficulties. Jane spoke about how she was having trouble getting her son to go to school because of comments made by the teacher who told her son's classmates that her son was just lazy, and the teacher aide she had fought so hard to get, would be sent on errands rather than assist her son. Sue's son had a 'sort of aide' when he tried to go back to university but the aide did not understand about ABI. All the women said they want more people to understand, and they wanted more education about ABI.

Having their son or husband accused of being drunk was a common occurrence. Sue spoke about 'the worst moment of my life' when a neighbour accused her son of being drunk and said to her 'you must be so embarrassed by your son'. Unsteady gait caused rejection, criticism, venom and stigma. Having a stick was seen as a way to show the son had a problem. Jo's husband was told he was drunk at the supermarket, and people had taken advantage of him and short-changed him.

Stories emerged about how friends and strangers perceived them as 'pretending' or 'cheating' to get an advantage. This was very upsetting. Jo's friends, who were to be a witness in her husband's court case, privately told her that there was nothing wrong with her husband now. Strangers had made similar comments when they saw a disability sticker on their car or when they were in disabled seats at concerts.

> We've been to concerts — people say "What's your disability?" And he say's "I've got an ABI" and they say, "You're standing up, you're walking you're talking, you're fine".

7.3.4 *Sadness for the Future*

Mothers and wives spoke about how their life now revolved around the needs of the person with ABI. Some mothers of sons with ABI spoke about the added difficulty of trying to support their husbands as they slowly came to terms with their son's brain injury, cope with the needs of their other children as well as considering if it was possible for them to continue to work perhaps in a part-time capacity.

> Because you're Mum you fall into the habit of treating them as children, wanting to 'fix' them, and that's really difficult not to do. I constantly get reminded by my son now "Mum you're doing it again" (laughter) so I have to stop and think.

The two mothers of the older sons were concerned about what would happen to their sons when they die. They felt pressured to put things in place so that their sons would be supported.

Sue spoke about her son's loneliness, his relationships that have ended in disaster and her sadness at watching him with his brother and his nieces, and she could see that look 'I'll never have this'. She was acutely aware of all the things his life lacked and was saddened to think that he would always be on his own with no love. She said:

> T.S. Eliot — my biggest metaphor for ABI is the Hollow Man … between the idea and the reality, between the motion and the act is the shadow (chasm), and that for me was with my son. He'd agree "I can do that, yes I'll do that" — but the next day — nothing, no memory of it, no motivation no capacity and that becomes incredibly frustrating.

There was a sense of loss for the future and a sadness for the mothers and their sons too.

> No girlfriend — no grandchildren. As a mother it's sad to think he'll be on his own — no love — how do you replace that?

> My son's had a few tries at relationships but they've ended in disaster so I think he's signed off from that…

> On the love angle, we had a little granddaughter born recently … seeing my son with his brother and his nieces you could see that look "I'll never have this" and he doesn't drive

> because he can't, he's got so many lacks in his life comparative with—and I know comparisons are odious but I just wonder….

Another mother had to make the decision to turn off her son's life support. She spoke of her anguish:

> As a mum it was the hardest thing…we told him that we really love him and we'd give him that choice and every one of us did that with him — they turned off the life support and he began breathing for himself … he has fought so hard to be here.

7.3.5 Recapitulation

It is very hard being a person with ABI, and it is very hard caring for and supporting a person with ABI. But once the whole story of the experience of the mothers and wives is considered in Chap. 8—'Factors that positively affect the lifeworld'—this experience will be seen to be not all negative and need to be balanced with positive factors as discussed later.

It will be observed that there were many commonalities of issues identified by people with ABI, and mothers and wives of other people with ABI. These included the difficulty understanding ABI and the need for information in non-medical language. Shame and guilt was felt by both groups, and the stigma of ABI played a role in negatively affecting their lifeworld. The mothers and wives demonstrated that they believed that rehabilitation was vitally important. This belief in the effectiveness of rehabilitation was not identified by over half the participants with ABI, who were disappointed in their rehabilitation experience. The participants with ABI identified problems with rehabilitation that the carers had not identified.

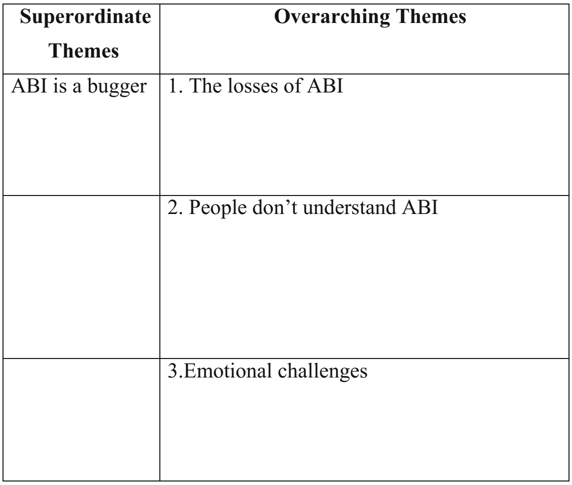
7.4 Professionals: Factors that Have a Negative Impact on the Life of Their Clients

Professionals representing over 70 years of experience working with people with ABI had a wide range of different philosophies. Each person brought the expertise of their training and their experience to the study.

They were interviewed in order to triangulate the data about factors that they thought had a negative impact on their client's life, and also to obtain their feedback about *Keys to the ABI Cage* information/learning tool and if it could be of benefit to their clients.

7.4.1 Factors that Negatively Affect the Life of People with ABI

Following the same approach as previously, the views of professionals' emergent, overarching and superordinate themes could best be expressed by one professional with the simple words 'Brain injury is a bugger'[1] expressing her frustration, and admission of defeat that trying to help people was complicated and difficult, Fig. 7.8.



Superordinate Themes	**Overarching Themes**
ABI is a bugger	1. The losses of ABI
	2. People don't understand ABI
	3.Emotional challenges

Fig. 7.8 Professionals: factors that negatively affect the life of clients with ABI

7.4.2 The Losses of ABI

Professionals spoke about the loss of life as they knew it, including loss of physical and cognitive skills.

> (my client) has been locked up in a secure ward in a rehab hospital for 8 years.
>
> …he forgets things, he laughs, he cries.
>
> He's a very cluey guy, and has lots of embedded knowledge (but can't read)

Kirsten spoke of the losses associated with ABI—that her clients feel they have lost everything.

> Recognise that there is a lot of loss — I think like they feel they've lost everything from relationships to especially work, driving a car, having to start all over again.

---

[1] Bugger is an Australian colloquialism meaning complete frustration in this context.

Mary identified that there was a limitation on understanding, so that clients relied on trust because they had lost the mental resources to raise an alarm if they were being poorly treated and that they had lost the ability to know when they had been diddled or tricked. She stated that no one deals with their distrust of themselves.

> Distrust … they can't trust themselves — others.
>
> They may have a 'chip on their shoulder', but no one deals with that.

7.4.3 People Don't Understand ABI

Professionals stated that, in the main, the general public does not understand ABI. Several professionals spoke of general practitioners who had little knowledge about ABI, and clients with ABI having poor experiences with medical professionals, and the way staff can treat young people like children.

> The person with brain injury may have experienced many people who do not understand ABI.
>
> I know lots of people, lots of GP's who don't understand ABI.
>
> A lot of people with brain injury have had a lot of poor experience with the medical profession.
>
> I've noticed with X over the years that he does have quite a mistrust for medical professionals and I've met other clients like that and that's based on the poor relationships they've had whether it's with GPs, or psychiatrists, psychologists….

Four of the professionals identified that medical jargon is actually useless to people with ABI and their families in the long run.

> It is useful in giving a diagnosis, **but it doesn't explain what it means for the life of the person** [our emphasis] and it's actually quite useless information for families — education is much broader than just information.

Several professionals spoke about the isolation of the person with ABI that there was misunderstanding within families and that people with ABI can lose contact with their friends, they cannot relate to their friends and, moreover, their friends have nothing to say to them and they have nothing to say to their friends. This even occurred with some families.

> There can be a lot of misunderstanding, even within families.
>
> Families split up, divorce…
>
> They need advice to see a counsellor for marital problems: marital counselling but people don't know that stuff and how are they ever gunna know that stuff if someone isn't there to tell them
>
> People with ABI don't want everything all at once— show them (a model of the) brain, take them apart, show them where damaged.

Phyllis said people who had not been involved with the health system before were given too much information all at once and that ‘social workers like to tick boxes and you only have certain amount of time with the client’.

> They (the client) didn’t hear it…they weren’t in the space where they could hear it.

Ben was concerned that some people with ABI fall

> somewhere in the cracks between the criminal justice system and the Mental Health Act, which doesn’t seem to cater for either of them very well.

Once people with ABI are discharged from the health system, unless they have been linked up to some other agencies before discharge, they are left to sink or swim. Phyllis talked about the need to have an agency to support people once they had left hospital.

> Once they’re discharged from the health system, unless they’ve been linked up to some other agencies before discharge they are left to sink or swim.

7.4.4 Emotional Challenges

Professionals identified that people with ABI can suffer from depression and emotional problems.

> I think it’s almost irrefutable…certainly the research shows that if you’ve got an ABI your incidence of depression and other mental illnesses is very high.
>
> They can have very bad weeks this makes them very fragile…emotional problems.
>
> There’s the down side of getting really depressed about the problems, but there’s the up side of these are all the amazing things of how you cope.
>
> ‘We have lots of trouble modulating inappropriate behaviour…he realises…then he forgets…and he says “ooh sorry”.’ ‘There can be a lot of misunderstanding, even within families.’
>
> They can’t relate to their friends because their friends have nothing to say to them and they have nothing to say to their friends.

All the professionals spoke about the incidence of depression and other mental illnesses associated with ABI and how their clients’ bad weeks can make them very fragile. Judy, Kirsten and Mary said that some clients try to pretend they are okay but they slip up; women are concerned that they look different. All professionals spoke about how their clients were isolated from their family and friends.

Not all professionals identified all the losses and difficulties that people with ABI identified; although as a *group,* most of the difficulties were discussed. Areas of expertise were apparent by the comments from the group of professional participants.

7.4.5 *Brain Injury Is a Bugger*

The factors that negatively affected the lifeworld of clients with ABI, the losses of ABI, people don't understand ABI and the emotional challenges collapsed down to the superordinate theme: 'Brain injury is a bugger'.

As mentioned above, the professionals as a collective group identified most of the issues identified by the people with ABI, and mothers and wives. However, this translated into a rather different approach. This approach, the blind spot, was their focus on the deficits and crucially the absence of focus on how these deficits affected the hope and honour of the person or on their ability to learn. There was not a focus on teaching the clients to understand, patience or the motive to recognise the person as a human first and not a subject of their professional practice. Several practitioners focused on 'fixing' and not on issues around fear, shame, trust and power. A blind spot of some professionals was the fear and shame of the person with ABI and how this impacted on their lifeworld, and which they failed to see.

7.5 Recapitulation

By using IPA analysis, this chapter has identified the ways in which ABI is experienced by people with ABI, by family carers and by professionals. The triangulation of data that might confirm the common themes and experiences has actually only partially accomplished this task. Indeed, while there were some common categories of experience between the groups, there were also uncommon categories or blind spots.

Common categories identified were the physical, cognitive and emotional losses and challenges of ABI. The issues were complicated; they overlapped and affected other issues. The collective and catastrophic affect to the person's life was identified by all groups, as was the isolation of the person with ABI.

However, participants with ABI reported their loss of trust and hope, and their shame and humiliation had a profound effect on their lifeworld. It should be noted that a pathological and deficit approach is unlikely to endear professionals to the person with ABI unless that person has accepted and reflected on ways to build upon what skills they have to feel and fare better in their lives. Sadly, the majority focus on such deficits as a basic assumption for professional action is the obverse of what people with ABI need to feel better about their damaged selves. A mindset change is required of professionals to acknowledge the feelings of the person with ABI alongside trying to 'fix' their body and mind—empathy is essential (see Chap. 10). The participants with ABI were aware they had many blind spots. This included being able to understand ABI and the consequences of ABI to them; they needed to understand their emotional reaction to situations, their shame, their belief they were insane, their loss of trust of themselves and others. But in the negative cycle of interconnected events, interactions and emotions, their capacity for hope and their pursuit of a full life became a casualty of the unremittingly negative feedback from many quarters.

One interpreted blind spot was the participant with ABI's belief that it was the 'professional's job was to cure them'—the same way as you go to a doctor to get medication or surgery to 'get better'. A second important interpreted blind spot was their inability to see *they* could play an active, indeed a lead, role in helping themselves.

The statements made by the participants with ABI reported in this chapter demonstrate that they had awareness and insight into things that negatively affected their lifeworld. As demonstrated at various points, the implicit struggles with elements of learning were an essential aspect used by them in seeking to adapt to new lives, identities, relationships and environments. But there was very little technical know-how used to scaffold this learning, nor recognition of its centrality by any of the participant groups. In the face of huge amounts of new information, people with ABI felt swamped by their experience. But some participants had moved from feeling that life was not worthwhile to feeling that life was worthwhile, and a few participants felt enriched by their struggle.

Thus, these negative themes are not the whole story—participants with ABI had also discovered 'Keys' to release themselves from the 'ABI Cage'—these discoveries will be explained in the following chapter. In discovering Keys over time, each was demonstrating the capacity of human will to fight their way through, to reflect, to learn and to formulate new actions which confer upon them a sense of belonging and fulfilment.

This chapter has shown the often catastrophic, always challenging and complicated nature of ABI, and a conclusion could be reached that the story of people with ABI is bleak and hopeless. In Chap. 8, this view is tempered with the positive experiences of data from the three participant groups.

However, looking more closely are other messages.

It can be seen from the narratives in this chapter that participants with ABI were implicitly comparing perceptions, ideas and actions almost continually. For example, comparisons of self and identity:

> I wish I could have one more day without a brain injury…

Comparisons on their metaphysical and moral compass:

> I'm frightened because I can't trust myself and I can't trust other people…

Comparisons of how they are and what they are struggling, through reflection, to be:

> It drives you to distraction…trying to make your brain work

and so forth.

Their statements were not mechanical and unchanging e.g. I am x, I think y and I do z. Rather people explored what x, y and z they were and how they might be x1, y1 and z1 in the context of their everyday spaces and interactions. Their statements were, then, 'constitutionally comparative', comparing options about identity, about social actions and so forth. In being so, it can be asserted that they were *comparing* concepts, ideas and actions. One can see the similarities between this as a form of learning and Anderson and Krathwohl's (2001) learning taxonomy described earlier.

Furthermore, the complex of concepts established '*mini-hypotheses*' about how to feel and fare better in the world. In Austin's (1962) words, the concepts were '*performatives*'—more than just words, but words that implied chosen social actions. This *constructive circumambulation* from the Latin *circum* around plus *ambulātus* to walk is used to describe looking at an issue by reflecting on it from different points of view—moving round the problem and actions taken, then reflecting on the action to redefine issue and further action that could be taken in a circular, not a linear way. This is the very essence of learning and explains its centrality to growth for people with ABI as they re-engage their communities.

Sadly, since trying out new actions often 'goes wrong', the negative feedback of others who do not understand the struggle of ABI leads to criticism and rejection as shown in this chapter. This has a major effect on the person. They may lose the capacity to circumambulate and think: it is better to be me in my isolation than to be me in interaction with others (perhaps leading to depression); or, it is better to express my frustrations in ways in which people pay attention than to remain quiet (often leading to accusations of challenging behaviour); or, it is simply better to be with others who understand (ABI support groups).

What is missing in services is the understanding that is necessary to house this learning safely and in place, i.e. within the networks and supports relationships that constitute the person's interactional life. Making the person safe to try, and to make mistakes, is what establishes the grounds for continued reflective circumambulation. While people with ABI, indeed all of us, may not reach a solution through our efforts, we will reach that one which is best in supporting us to feel and fare better safely without damage to how we define ourselves.

Chapter 8 continues to exemplify these themes but relating to the things that free people from the ABI Cage. The ideas are further discussed in Chap. 9.

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Chapter 8
Factors that Positively Affect the Lifeworld of the Person with ABI: 'Keys' for Change

> *The greater the obstacle, the more glory (or satisfaction) in overcoming it.*
>
> Molliere

8.1 Introduction

It is with relief that at last we come to the heart and purpose of this study—to find the factors that have a positive effect on the lifeworld of people with ABI—love, hope, understanding, empathy and humanity.

This chapter provides some noteworthy information for professionals so they can see the importance of showing their insight and understanding and provide easy to understand explanations so that people with ABI do not feel beaten and broken by the system.

Since these areas are largely unreported, these factors did not draw on academic notions such as quality of life, coping or resilience but drew on the views of people with ABI, the wives and mothers and the professional participant narratives.

As with Chap 7, people with ABI identified a wider range of factors than some of the family members or professionals. The latter groups addressed the issue with directness: they had definite established opinions. Once again participants with ABI did not address the issue of helpful things in a linear straightforward way, but in a roundabout way, by using 'talk-about' cards in telling stories, making connections, revisiting ideas, changing their ideas—a process of 'constructive circumambulation'—circling themselves and reflecting on, changing their mind, and learning from thinking about their experiences.

Chapters 6 and 7 explained the way in which the analysis was carried out. There were 35 'talk-about' cards under the heading Keys to the ABI Cage and these included 'My Doctor', 'My health professionals', 'My OT', 'My Counsellor'. It

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needs to be noted that medical and rehabilitation professionals need to inform their clients that they cannot ‘fix’ them as medical professions can ‘fix’ other ailments like removing an appendix, inserting a pacemaker or prescribing medication that cures cancer.

The person with ABI needs to be enlightened and encouraged to understand that they need to be *actively* involved in learning to live with ABI. They need to learn to understand, accept and adapt from as early a time post-injury as possible. They need to be counselled to understand that many things can bring satisfaction to life, even though at the time they wish they could be the ‘old me’ in their ‘old life’. Stories of how other people with ABI have coped could be useful in this regard.

8.2 Factors that Positively Affect the Life of People with ABI

Chapter 7 identified just some of the perplexities and complexities of ABI for the person with ABI that leads to unsatisfactory lives. Keys are things that help people with ABI to move from being *unsatisfied* in their life after acquiring their ABI, to being *satisfied* (at least to some extent) with their life. Keys to the ABI Cage therefore represent an amalgamation of participants’ perceptions, opinions, emotions and identified factors that positively affected their lives.

This study has established that there are a plethora of Keys that can help people with ABI unlock the ABI Cage and release them from feeling imprisoned.

As the overarching themes, Keys are phenomena that people with ABI can use to play an active role in helping themselves to find ways to cope with or live with the challenges of ABI. Keys are active not passive. Keys require the person to have ‘active acceptance’, the will and courage to accept Keys proffered by family, friends and professionals. Other Keys need the curiosity and effort of the person to find ways to regain their identity and reach some form of new equilibrium.

The data led us to two superordinate (main) themes that positively affect the lifeworld of the person with ABI. Firstly, there are many Keys that open the ABI Cage (help the person with ABI to feel and fare better). Secondly, constructive 'circumnambulation' learning can assist the person with ABI to help themselves to feel and fare better.

At end of Chapter 7 we observed that the narratives collected from participants with ABI were both constitutionally comparative as well as performative. In the narratives, we saw the struggles between ideas and perceptions and concepts that support a person to make choices about how to act in their everyday life. We continue to explore these ideas in this chapter. In this chapter, we also confirm ‘constructivist circumambulation’ as the second superordinate theme. Such learning can assist the person with ABI to learn to help themselves to feel and fare better. Figure 8.1 presents a summary of the overarching themes that dually made up both superordinate themes. We shall use the overarching themes, as before, as subsections to describe these findings.

Superordinate Themes ⇐	**Overarching Themes ‘Keys’**
1. There are many ‘Keys’ to open the ‘ABI Cage’ 2. Constructivist ‘circumambulation’ learning can assist the person with ABI to learn to help themselves to feel and fare better.	1. Hope: Learned optimism/resilience /coping 2. Love 3. Learning to understand ABI and working things out 4. Learning to face the facts (acceptance) 5. Making progress: Brain injury is not all bad

Fig. 8.1 People with ABI: overview of findings of factors that positively affect the life of people wirg ABI

8.2.1 *Hope*

The overarching theme of ‘hope’ encompassed determination, wishful thinking and denial. Participants expressed the importance of believing ABI was not going to ‘beat’ them—they believed they would improve, though of what such improvement consisted was, as will be seen, as much to do with a fulfilled and satisfying life (acceptance and re-evaluating goals), as to do with a mended body.

The consequences of giving up hope would mean they would no longer struggle against their difficulties/differences/deficits.

> Um, I guess I don’t use the word hope, I just think of it as bloody mindedness. Sheer determination, where I’m mad as hell and I’m not going to take this anymore.
>
> Hang on; I’m not going to let this beat me!
>
> Proving professionals wrong—I’ve proved them wrong in a thousand ways.
>
> There is nothing I can’t do. I just haven’t found a way to do it.

Once again the sense of movement, growth and change are encapsulated both successes despite challenges and others’ views as well as hope for the future. They emphasise the constitutional comparison of concepts which ‘define them as learners, doers, and as successful’. These are the basis of the hope we all carry, not just people with ABI.

Wishful thinking including not believing the opinion of professionals was voiced by some:

> They told mum that I’d never be able to walk again or do this or that or have children—Luckily I didn’t believe them—you wouldn’t want to believe would you! (laughter) (drove to the interview, was married with children).

> The doctor was quite adamant that after two years you've reached your peak—it took away all my hope—I was frustrated because I thought I was going to get better… but then I thought I'm going to improve…

Note that the things accomplished and valued were not about mending bodies. In the first quote, the person was married, could drive and had children. These represent the fulfilment of their capabilities, accomplishment despite the challenge or the opinions of medics or others.

Denial also played a role in improving their lifeworld.

> It just went in one ear and out the other,

> I've never thought about these things

Indeed, some found ways to manage despite their difficulties and excused such difficulties by saying 'everyone does silly things'.

For many of these participants, 'hope' involved what we have termed 'wishful thinking', because it involved a refusal to accept the considered opinions of professionals. Their refusal to accept that their life would be spent in a nursing home, in a wheelchair or that they could not have children assisted their recovery.

The majority of participants had refused to accept the 'two-year rule'. They had been informed that the progress will cease or slow down after the first two years but they refused to believe this. Indeed, our proposition is that this is an inimitably medical and rehabilitation view. It ignores all that is required in the social realm. The person's concept of self lies in their social and community lives, emphasising the need for medics to 'leave a space' for this, not to comment upon the body as if it were the world. Fixing bodies is a smaller part of a larger whole. Living lives well in spite of ABI is the key and requires learning and an empathy from professionals about what contributes to setting the conditions for engaging with such learning.

Hope encompassed many characteristics outlined in Seligman's (1998) 'Learned Optimism'—the participants had learned to tell themselves that just because they had failed at a given task this did not mean they would always fail in everything they attempted and they could 'excuse' their failure or blame something else. They coped and bounced back in a resilient way if hope was maintained.

Several participants talked about how they obtained comfort and security from their religious belief and that this was very important to them. However, concern that God was punishing them was frequently associated with religious belief. Nearly one-third of participants said that nature and the environment brought hope and comfort and a few participants spoke about seeking symbols to show they were: 'doing the right thing'. This search to confirm their existence and identity is very well rehearsed in existentialist writings, but clearly featured as an everyday experience for many in the study sample.

8.2.2 Love

Participants with ABI could be divided into two groups—half who spoke about how they were loved, supported and sheltered by their family and how their love for their family also caused them to work harder for the sake of their family—so they could have a life. For these participants, the love was of prime importance.

> Love is extremely important. I believe that if I didn't have my family and husband to come home to, I wouldn't have worked so hard—I don't think I did it for me, I did it so they could have a life…

and, another key releasing this person was,

> The understanding of my oldest and very dear friends and their ongoing support.

The other half of the participants, who did not identify love as a Key, told stories of how they were estranged through divorce, or misunderstanding or lack of understanding. Many in the latter group spoke of animals who loved them unconditionally and who gave their life meaning. Several participants stated that they would have killed themselves but for their love of their animals and the way their animals 'understood' and loved them—animals provided the unconditional love they needed to survive. Several participants identified that taking responsibility and caring for their animals had been very important.

> I could stay in bed but I have a big black muzzle [of her guide dog] nudging me saying get up and feed me.
>
> My dog understood that I was crook [Australian word for unwell] and stayed by my side.
>
> I think if I didn't have my three cats who loved me unconditionally, to talk to, I wouldn't cope at all.
>
> Taking responsibility and caring for something else (my animals)—I think it is very big.
>
> My cats saved my life. I would have 'disappeared' but for my cats.

Most participants identified things they loved doing, things that gave them satisfaction, and a purpose. The way they perked up and became enthusiastic about these things showed they were more than a diversion—they were fully engaged with their 'passion'.

A huge range of such passions were identified: painting, fishing, knitting, going to live shows, writing, going out for coffee or lunch. Some men were very passionate about watching sport, the gym and exercise. Many women participants said they had discovered (or learnt) that doing cross stitch/tapestry/knitting focused their thoughts, calmed them down and they felt productive as they watched their project progress. Several women referred to their craft as their 'security blanket' and they took it everywhere.

Participants could be divided into two groups - those who liked going out and those who liked staying home.

> I love going out—I'm terrified of my armchair
>
> I love going to live shows
>
> Going out to lunch on the weekend made me feel more normal
>
> Writing all my thoughts down—everything… and they say stop this lunacy and I say I can't stop…
>
> Painting—art is very important (couldn't draw before) colour gets me excited
>
> Ah, gardening is a new thing I've taken up that I find a lot of peace, as a therapy… it's a wonderful, wonderful thing
>
> A treat—yes—that's part of the life process—it has to be achieved—a prize at the end of something. You've achieved something so now you can have a treat. Big or not so big—a cup of coffee shared with friends or family
>
> Exercise—Yes so important — I'm convinced the exercise side of things reduced the severity of the damage that was done significantly.

The final category of things people love is things that give people a sense of satisfaction and purpose—helping others—particularly others with ABI. This was most important as it allowed the person to use their sense of empathy and humanity that has been perhaps newly acquired—it is a positive new gift they can give. Participants spoke with pride about their volunteering. May expressed it beautifully:

> I'm a volunteer I have a lovely lady to look after. She's lovely, she loves me, she's like a mum to me and I'm a mum to her.

Others expounded

> Helping people yea…!
>
> I volunteer to help people with disabilities 'cos I know what it's like to be in a wheelchair.
>
> Being useful—yes that's why I do so much—I refer to it as my sense of purpose.

It should not go without notice that what people share, brings people together. People with ABI share an understanding and in doing so understand that rejection by others hurts, that trust between people supports their interaction and growth, that giving of the self produces a sense of accomplishment among many other feelings. If we were to replicate services and relationships that carry similar such features, we might discover the 'pearls of wisdom' people with ABI are proffering to the rest of the world.

Love of people, pets and activities helped most participants belong and feel comfortable about themselves. Love by others and for other carried people from a life that did not seem worthwhile to a life with worth and purpose. Meaningful lives which made best use of capabilities and give life purpose were therefore central to feeling and faring better.

8.3 Learning to Understand ABI and Working Things Out

Learning to understand is at the heart of this thesis. It is not possible to 'give' people understanding—understanding comes from actively taking on board ideas and information, learning to make sense of ABI for themselves and trying out the ideas before once more adapting their understanding.

About a third of the group spoke about the importance of finding out what other people with ABI have done and the value of peer support. An ABI writing group helped people share ideas, learn new skills and express themselves. Some participants in 'seeking to belong' found joining ABI support organisations was helpful, yet others voiced the opinion they wanted to be normal, mixing with normal people.

> Gain as much knowledge as you can about your brain injury to help you understand…
>
> If I'd had the CD (Reflection Kit) earlier on it would have helped me to understand that I wasn't going mad. And it certainly would have given me another way of approaching things too. And perhaps to even ask more questions. Because if I knew that was the situation, then I could relate that to other areas…
>
> What other people with ABI have done—this is massive to me—peer support—my writing group
>
> What other people with brain injury have gotten up to, or survived. Um, it didn't help to start with, because I was too interested in myself. But later on, to read stories of people who've survived was good
>
> Meeting you (Durham) at a conference in Sydney was another moving point for me and the rest of my life, as I feel that it is the survivors who can talk the talk to get others back on their feet after an injury, because we can walk in their shoes.

All participants with ABI had struggled and were still struggling to understand ABI for themselves. Not one participant remarked 'I found this wonderful web site…booklet…I was given information from the hospital', or that 'Dr X explained ABI so that I suddenly understood'. No one spoke about understanding about ABI from information on brain injury support Websites or blogs, although now, eight years after the interviews, more people are searching the web.

All the participants wanted to find out more about ABI. About a third of the participants spoke about reading *Doing Up Buttons* and gaining greater understanding from reading the story—it helped them make sense of their own personal issues. Almost all the participants said that 'medical language' was not helpful in helping them make sense of their experience.

Keys to the ABI Cage helped many participants understand their ABI—one man said that he had ABI for 7 years and he denied it—but the Cage had 'showed him' (he had gained self-awareness) and he now acknowledged his ABI; another said if he had seen the Cage earlier it would have helped him to understand that he was not going mad, and would have given him another way to approach things and ask more questions; another participant commented 'It let me open up my own eyes'. Opening up my own eyes is a wonderful description of 'learning'.

Participants had discovered (taught themselves) a range of strategies through which they could work things out: for example, ‘patience’, ‘minimal stress’, ‘simplicity’, ‘routine/organisation’, ‘structured living’, ‘quietness’, ‘a healthy diet’, ‘exercise’, ‘concentration’ and ‘tracking progress and achievements’. Notable here is that these categories do not differ from those that might benefit anyone let alone people with ABI. Participants also spoke about the effort required to teach themselves to make their body work again.

> Try not to get impatient with myself
>
> Never be afraid to ask for help or get something wrong
>
> The more ‘mistakes’ I made the more I learnt and recovered. Getting as much help from as many people as possible always puts you in the best position possible
>
> Whatever I’m doing gets all my attention
>
> Writing…recording my thoughts, feelings and daily events
>
> Tracking my progress and achievements
>
> Facing the fact I need to rely on my palm pilot diary
>
> Everything is ‘slowly slowly’ and time has changed
>
> ‘I try to be the best I can at everything that I was good at before my ABI.’
>
> ‘My short term memory is getting better… I have always practised my memory with mind games and developed strategies’
>
> ‘Repetition with a new task or learning something different — repetition is the only way to cement it until it becomes part of the fabric of your life’.

The reader should be aware that implicit in these narratives is that participants had already remembered and understood concepts and had then gone on to apply, analyse and evaluate their actions. They were in effect reflecting - circumambulating through both self-reflection and then testing in order to create new ideas to move their lives forward. These implicit concepts so clearly demonstrated above align with Anderson and Krathwohl’s (2001) learning taxonomy presented in Chap 5.

Twelve positive comments about specific rehabilitation professionals were obtained from transcripts of the 35 participants with ABI. Speech therapists, counsellors and psychologists were appreciated, and three men spoke about physical exercises being ‘wonderful’ or ‘brilliant’.

> I did a lot of intensive rehab…. physio exercises at the gym. I devoted all my time to doing that, last year 6 days a week. (man)
>
> Rehab exercises was just brilliant (man)
>
> My balance is a hundred times better with a lot of hard work and physios. (man)
>
> I had a lot of rehab, it was extremely helpful. But taking control of it was… better. I was so determined to get home It was going to take too long to do it their way. It’s a long time to sit, if you’re just in hospital (woman)
>
> The doctor treating me with respect and dignity that I was just like my old self
>
> …but the head rehab doctor, she was excellent.

> …I was starting to realise then that something dire must have happened. Because, she (the doctor) came in and sat on the bed, took my hand and was very emotional. Which for a doctor, I thought was very surprising. She said “It’s so great to see you back here, the way you are now, that’s wonderful” and so on and so forth. And, from that day on, I had all the staff coming into see me, to tell me that they were all there to help me out and so on. Eventually I got up and started walking again, and doing all the rest of it.
>
> …she (the doctor) she thinks I’ve made a marvellous recovery and I think she’s quite proud of that. Probably for her and her skills as well.
>
> I believe in God and I believe in doctors too and I believe in the wonderful kidney guy, and the neurologist I believe in him too and my GP–she’s good.

Empowering the person with brain injury to have a say was important. One man spoke about how ‘Letting me do what I want, and not what they think I want/need. One of my speech therapists used that theory on me and it allowed me to surge forward in my rehabilitation’.

8.3.1 Learning to Face the Facts (Acceptance)

‘Facing the facts (acceptance)’ could be seen as a subset of the ‘Learning to understand ABI and working things out’, but it concerns a cluster of comments from participants about discoveries they had made about identity, self-belief, not giving up, a positive attitude and a sense of humour.

Accepting that the person is not the same as prior to ABI was mentioned often:

> Coming to terms with the fact that I’m not the same person anymore
>
> Redefining who I am and where I want to head to
>
> Admitting to myself I have shortcomings (short-term memory) and learning to employ strategies to assist me with coping with these shortcomings
>
> I now view the word from a changed perspective
>
> I have changed careers/job to a completely different area

Recognising the positive things that have come because of ABI:

> Changed me—learning new things
>
> I have a much greater understanding of life and people
>
> Learning to appreciate life
>
> Believe in yourself
>
> Looking at every part of my life post the brain bleed as a bonus
>
> Focusing on the small goals that achieve bigger goals
>
> It’s like I’m constantly finding new aspects of myself
>
> Talking about things.

Again, just to reiterate, all of these quotes are about changing and reframing concepts and ideas about self and, as such, implicitly linked with (re)learning.

One man said ‘at least I’ve got some sense: a sense of humor!’ Several persons saw a sense of humour as important to their lifeworld, as ‘the best thing I’ve got going for me’, the ability to see the funny side of things or to be a ‘court jester’ to whom people came to share humour. This man had thought about ways he could get attention and prepared humorous things to say. By using their sense of humor, they gained value from being who they were rather than feeling the butt of other people’s mirth or disparagement.

8.3.2 Making Progress—Brain Injury Is not All Bad

The burden of feeling ‘not normal’ and ‘different’ to others weighed heavily on many participants so being able to do normal things again was seen as a symbol of improvement and progress—and boosted their confidence, self-esteem and hope.

Participants spoke about making progress in big and small ways. A handful of participants spoke of the freedom of being able to drive again. It was an exciting part of recapturing their life in any way possible. For Mary, it was wonderful when she was actually able to put her left foot straight into her slipper. Others mentioned

> Being a basketball coach and instilling some of my training into the team
>
> Knowing I am making a worthwhile contribution at work.
>
> Returning to study
>
> Now I’m in a job that I love more than anything I’ve done. So I think this has given me the opportunities to make those sort of decisions, and it’s been a really powerful experience
>
> Getting my license again was freedom!

Achieving or doing hard or challenging things was also found to be a Key to the ABI Cage:

> Doing things I was told that I wouldn’t be able to do
>
> Stretching outside my comfort zone
>
> Being able to do things at work that are beyond my fellow peers
>
> I was proud I could teach therapists a couple of things on the computer.

Being able to work or be a volunteer, being able to make a worthwhile contribution and being able to reuse old skills in their new life led to participants move from feeling life was unsatisfactory to life was satisfactory. Some participants wanted to ‘give back’ to help others in the same predicament, felt they were now wiser as they had thought about and explored their lifeworld and had a much greater understanding of life and people.

> I’m glad this happened to me. My mother is horrified when I say that. But I would say that I haven’t changed as a person, but I’ve learnt something…a little more courageous…I think this has given me the opportunities to make those sorts of decisions and it’s been a really powerful experience and I’m glad it happened.

Some participants expressed how lucky they feel to have survived: it has given them a chance to start their life again, they feel special because they had experienced so many unique and valuable things, they believe they are a newer better person and have become more aware, for example of the environment, pollution, good friendship, humanity, volunteering, service clubs and general sharing. Some have become highly sensitive to many things such as noise, light, people, even feelings. Brain injury has been a really powerful experience for many of the participants.

> What I say to them now is, there are two selves, there's the person I was before, and no matter how much I grieve and think I've lost that person, I have not lost her. She's still here, she's just been pushed back by this new self. There's two selves, and there's this new self, and the two of them have to learn how to get along.

After discussing their experience, many participants described experiencing 'The Survivor's High':

> I am clearly meant to be in this world now and I have a responsibility to work on myself always to be living up to the best me I can possibly be
>
> I am so grateful that physically, thank God, I am OK, my spirit has been damaged, not broken, and it's up to me to make the most of the unpleasant challenge that has happened to me
>
> I have a desire to share my story and feelings with others so they too can appreciate the wonders of life and all the moments they have. If they had a difficult experience which challenged them, I am so happy to come talk to people and let them know they're not alone
>
> I was lucky (to have the right surgeon) I'm not scared, I should be but I'm not I should be dead but I'm not.' (brain tumour)
>
> I have to accept that I am newer better person and I have become more aware of the environment, pollution, good friendship, humanity to mankind, volunteering, service clubs and general sharing, better sailing skills amazing eh?.

8.3.3 'Many Keys' and 'Constructivist Circumambulation'

Participants identified a plethora of factors that helped them to feel and fare better. These are not only their Keys. They are the Keys, as will be described in Chap 9 which need to feature in all forms of professional services and supports.

These 'Keys' to the 'ABI Cage' covered a wide range of factors from humble everyday things, to things that gave their life meaning and purpose. They were pleased to identify 'talk-about' cards that were important to them and to tell stories about other hobbies or pastimes that brought them pleasure. Using 'Keys to the ABI Cage' to talk about their experience helped them to made sense of ABI and construct their own knowledge about things that helped them to feel and fare better. For many, it added to a learning journey that had already begun. But for many others, it represented a revelation which prompted then to think that starting such a learning journey was a Key to their growth.

Posit, if you will, that learning, relearning, seeing things anew, reframing our view of the world is the basis of moving forward in life, indeed growing. If this is accepted, then many people with ABI are required to do so in the most difficult of circumstances, from which there is little escape. If this is true, then it might be argued that the preponderance of people with ABI who struggle to re-learn will be greater than for the population at large. If this is the case, it might be argued they become deepened by their experience, a point to which we again refer later.

Once we recognise that some people with ABI have great insight into the ABI experience, **we** can learn from them. It is not just the case of their learning from us that is important.

8.3.4 Triggers and Turning Points

This study also sought to try to find ‘triggers’, turning points or epiphanies when the participant came to the realisation that life was going to be bearable, that it was worthwhile living. As they engaged with *Keys to the ABI Cage,* participants told stories of such experiences. We will allow the participants to explain:

> Actually it was a flower that told me one day that the world is really worth being in. It was a memorable experience because I was walking around the side of my house and the world had been grey for a long, long time and I saw a red tulip, the bulb I’d put in a pot, and it had flowered red and honestly I stopped in my tracks, and it was like wow, and I’ll never forget that, and the world then had colour.
>
> Yes yes I had a lightning bolt moment, an epiphany—in rehab I was in the ABI unit, surrounded by others—you start comparing yourself and you say “I’m not as bad as them”, and my family was saying “Oh my God, she isn’t really quite with it!” and I knew I could sit back and do nothing, and let people look after me and pamper me for the rest of my life, or I could take another road and have a life that I felt I had achievement in. I felt I was at the crossroads that it was up to me—one was the hard slog the other was the easy road but I don’t think I’ve ever taken the easy road.
>
> I was told all through my rehab and from other doctors, that the brain will only heal in the first two years, and… I refuse to believe that and I feel very lucky that I refused. So that really helped me to think I could keep getting better. I still believe it.
>
> Believing the brain is a muscle—today the new term is neuro-plastic, but I was told all through my rehab and from other doctors, that the brain will only heal in the first two years…. That would be the one big change I would like to see in rehab or ABI treatment. I went for 10 years and I saw people who believed it—it was heartbreaking.

In this last quote, we can see that modern medical discoveries and theories such as arguments about the plasticity of the brain allow us not just to have hope, but also to act in ways that seek to accomplish outcomes through a rewiring of our brains and how they make connections between things, i.e. how people learn. If people with ABI are sentient beings, then they will continue to have this capacity. It is both false and wrong to assert that nothing can change post-hospital or rehab.

Superordinate Themes	⇦ Overarching Themes ‘Keys’
With love, hard work and the ‘right’ attitude his life can improve	1. Love
	2. Understanding — the ‘right’ information
	3. Developing some quality of life for him

Fig. 8.2 Wives and mothers: overview of findings

Indeed, after the ‘dark hole’ of the first two years—the ‘golden period’ and rehab, the main work is still left to do.

8.4 Wives and Mothers: Factors that Positively Affect the Life of People with ABI

In this section, we proceed analysis of transcripts as for people with ABI and identified that love, understanding and developing quality of life were seen as central prerequisites to the superordinate theme that ‘with love, hard work and the “right” attitude, it was possible to feel and fare better, i.e. to improve’ (Fig. 8.2). The form of improvement, as shall be seen is, once again at odds in respect to a medical model only approach.

8.4.1 Love

Family carers identified love as an essential overarching theme: Family, people who love them and people they love and things they love to do, categories replicating the views of people with ABI themselves which were presented at length earlier.

8.4.2 Information They Could Understand

Once again, repeating the narratives of people with ABI, mothers and wives stated that it was vital to obtain information that they could understand, their relatives and schools and sporting clubs could understand—this was not simply information from a 'bunch of booklets' or the Internet as 'they repeat all the negative issues'.

> Information and not just give you a whole bunch of booklets—probably 5 months after his injury I started to read through some of these—my husband wouldn't. Reading them sort of throws you because you think "Oh my God is he going to be like this—like that? Is he going to end up that way?"

Family members of people with ABI thought that *Keys to the ABI Cage* would be a way to explain about ABI 'in a humorous way—with things their family member could relate to, things he could see and touch'.

As one mother put it:

> I've had great support from friends—but I don't think even my closest friends understand ABI or me—some days I'm just ragged; I need info for friends.

Mothers and wives talked about the breakthrough once their loved ones understood about ABI, developed some insight and then accepted assistance. Brain injury support groups and talking to others with ABI was seen as valuable ways to obtain understanding.

> He has developed some insight: He accepts assistance
>
> He accepts he needs to use his mobile phone
>
> [He] accepts it's good to talk to someone else with ABI.

Looking at the things people talked about, it is possible to see a movement away from information about the ABI to consideration of concepts together in interaction which are about how to establish meaning to life and in doing so, how to counterbalance the challenges faced. This is a source of information in the metaphysical realm of hope, love, trust and dignity as well as about the practical helping tasks.

8.4.3 Developing Some 'Quality of Life'

The mothers and wives of boys and men with ABI all identified that it was vital to find 'good' people who could help in different ways—a psychologist, a guardian (who took over managing Sue's son's life—'if she had not intervened he would be dead') who obtained 'proper' medication and accommodation.

Maintaining social ties requires helping loved ones develop confidence and self-esteem. These tenacious women carers spoke with pride about the way their family member coped

> …learning by his own mistakes, but not on tight leash…but supported and shadowed
>
> He works 16 h a week; Sympathetic understanding work is important
>
> You should see him on the phone 'I'm an artist now'… this has helped his self esteem—he feels like he's out there and contributing to society and he's made friends with others who have ABI, [with] similar injuries to himself, [it's] easier when people understand

> Whiteboards, he's only just started to use a diary, he couldn't before, he tried but he wouldn't know what day it was but now…
>
> …he lives with a mobile phone ringing…we just program it in and it rings and tells him what he does at a particular time.

Realisation that the lifeworld of their loved one was affected by their attitude led to comments such as: 'I need patience' and 'Every little thing is a gift'; 'I take it just one day at a time'; 'We're lucky to still have him'; 'Appreciate the small gains and events'.

8.4.4 Recapitulation

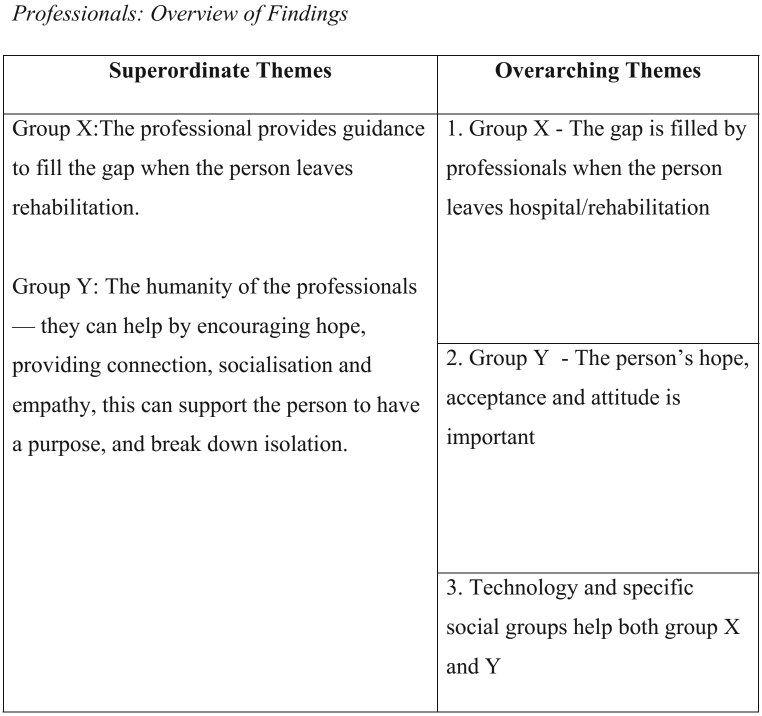
'With Love, Hard Work and the "Right" Attitude, His Life Can Improve'.

Clarity over the importance of love, understanding and developing quality of life, even through small engagements that accomplish change, are what set the conditions for giving meaning to life and are separate from the cold and clinical environments of rehabilitation. They are also a necessary environment through which constructive circumambulation (replication of positive reflection leading to greater insight) can be engaged and which support positive change for people with ABI.

Learning together then was vital in creating new roles, tasks, expectations. These, as will be shown in Chap 9, become the habituated aspects that define new lives, relationships and communities which over time all concerned come to accept. It is true that sometimes these networks break down, but replacement networks which do the same are vitally important to rebuild. Life without a network of support, without love and without empathy is isolating and destructive to any person. But for those whose agency to search out and build such networks is not matched by the resources they have, no such new support networks can be built. This emphasises the need for competence and resources that are distributed to support people with ABI, perhaps more than for others as well as for services able to support such support building.

8.5 Professionals: Factors that Positively Affect the Life of Clients with ABI

As for participants with ABI and family members, we proceeded to interview and analyse transcripts for professionals who each brought to the study their expertise and experience about things that help people with ABI to learn to feel and fare better. They brought valuable insight into this area of the study. Overarching themes identified by clustering of emergent themes provided a new angle on the importance of the family, 'the support team' of the individual.



Professionals: Overview of Findings

Superordinate Themes	Overarching Themes
Group X:The professional provides guidance to fill the gap when the person leaves rehabilitation. Group Y: The humanity of the professionals — they can help by encouraging hope, providing connection, socialisation and empathy, this can support the person to have a purpose, and break down isolation.	1. Group X - The gap is filled by professionals when the person leaves hospital/rehabilitation
	2. Group Y - The person’s hope, acceptance and attitude is important
	3. Technology and specific social groups help both group X and Y

Fig. 8.3 Professionals: overview of findings

It was anticipated that a triangulation of the data between professionals and people with ABI and family carers would lead to confirmation of views. However, divergent views among professionals and in comparison with wives and mothers called into question the use of triangulation as simply ‘confirming themes’. The professional views fell into two groups:

X group focused on the place of the professional; while, Y group focused on the ‘humanity’ of the professional.

As previously, Fig. 8.3 presents an overview of the superordinate (main) and overarching themes.

8.5.1 *Group X: The Professional Fills the Gap After the Person Leaves Rehabilitation*

Professional Group X saw that the most helpful thing for the person with ABI and their family was to have home visits by professionals to fill the gap between hospital and home and have regular contact with the family, to manage or address problems and make sure providers are doing the right thing.

> People with brain injury need help with not the medical needs but follow up needs—I think none of the current models work well that's why they often struggle and their families struggle because the health bit ends at whatever point they think that your rehab is finished…
>
> What we need to start saying is rehab doesn't start till 2 years or 5 years post-injury but we have this system where things have to be very set and very structured, again if you don't fit the pigeonhole you don't get…
>
> We need regular training for family carers. Current training is often just for the professional and service providers.

8.5.2 Group Y: The Person's Acceptance and Attitude Is Important—Hope, Love and Dreams

For Group Y, the person's hope, acceptance and attitude is important:

> People with brain injury need hope when the doctor says you're going to be a vegetable, or that you're only going to improve for 2 years or 5 yrs… people need to have hope
>
> His self worth—there's a light inside him it may be masking other issues but it's still a form of self-esteem
>
> …once you provide situations for people to thrive in, they will do that, and I'm always amazed that how far that can go
>
> Medical jargon is actually useless to you in the long run…not in diagnosis but what it means for life it's actually quite useless information to families—education much broader than just information
>
> Help with the creation of purpose—purpose I think is an absolute key to everything we're doing
>
> The "switch" to get people going again. It's the same things that everybody else does—their kids, their partners, their work it's all those things that we all value—what makes me feel good. What makes me get out of bed every day and come to work?
>
> There's something about recreation… the sense of purpose is so enormous in human beings, that to have lots of time, and nothing to do with it, no sense of purpose, is worse… it's torture
>
> Some people might see it as a wake-up call. Like some people may lose their jobs would lose their self-esteem and would despair, and other people would say I get to spend extra time with my children and I think some people see it as that. It [ABI] can bring you to despair, or it can help you to refocus your life and priorities and there's something about your belief and faith or serendipity or whatever it happens to be… I've spoken to people for example, who have said I can't rush around so much, so I am able to listen more and that has opened huge opportunities for me

We have cited many quotes from professionals in Group Y because they saw the individual with ABI as working with the power to affect their outcome by working with hopes, dreams, understanding and purpose. These professionals identified that understanding the impact of ABI on the individual was an important component and that people needed education and supportive networks. This was much broader than about the getting better, about rehabilitation and overseeing providers. As examined in Chap 7, Group Y said that medical jargon is actually useless, not in diagnosis, but in what it means to life in the long run.

Clients might have information, but they cannot absorb it. They need be able to identify issues to tackle and what they will do to improve.

Some professionals identified how a sense of humour helped their clients and how, as professionals, they needed a sense of humour. Clients needed to think about ‘alternatives to watching television’.

Professionals from Groups X and Y identified that Palm Pilots and mobile phones can be helpful if the person is able to use them. Several professionals stated that there needed to be more groups like Headway, where the person could go to just ‘hang out’. In one country town location, a travel cost of $90 a week meant belonging to an urban group would not be viable financially, especially as a taxi was required to get the client to the centre. On the other hand, some people do not want to be in an ABI group. They want to be out with people in their communities and localities who reflect their interests and aspirations.

8.6 Recapitulation

This chapter has shown in spite of catastrophic, complicated affects of ABI, Keys can help the person move from being unsatisfied with their life during the months or early years after their ABI, to being *engaged* in thinking about the elements of a meaningful life. This study has established that there are a plethora of Keys that can help people with ABI unlock the ABI Cage so they can release themselves from feeling imprisoned and find a satisfaction in their lives.

The Keys exist in the metaphysical world as well as in the world of practical help and clinical attention to getting better. Indeed, the notion of getting better establishes a particular type of opportunity structure for hope that may never be realised. The meaning of hope, love, caring, trust and the warmth in offsetting the challenges lies deep in us all. The Keys are a way of understanding this and a way of beginning to see what is important to people and thus, what should then, also be important to professionals.

Keys ‘open doors’. They are one step in the process of moving from one place to another. Keys involve a complex mix of coexisting perceptions, opinions, emotions and behaviours. Keys can be used by people with ABI so they play an active role in helping themselves to find ways to cope with or live with the challenges of ABI. These Keys can release people from feeling bleak about brain injury and beaten by brain injury, so they can make the best of brain injury. Keys are active not passive; all these Keys require the person to have active acceptance—the will and courage to accept Keys proffered by family, friends and professionals. Other Keys need the curiosity and effort of the person to find ways to regain their identity and reach equilibrium. The personal stories of participants with ABI revealed that, for some, the brain injury brought a fresh appreciation of life, an awareness of their strengths and weaknesses and wisdom.

Mothers and wives of people with ABI believed that love, understanding and patience could assist their loved ones and the development of lasting networks of support. Some professionals suggested professional expertise is valuable in guiding the person with ABI (and their family) on the ABI 'journey', while other professionals identified empathy and compassion as being of prime importance. All participants identified the importance of the person and their family gaining understanding about ABI.

It is thus that we have come full circle to the phenomenological heart of this study. This study commenced by explaining that it was going to look for a way to acquire better insight into ABI in order to find a way to help people feel (and fare) better.

Remembering and then 'understanding' was the common and universal theme that helped people move from feeling that life was not worthwhile to feeling that life was worthwhile. In order to 'understand' people need to work with Keys, *they* can identify and Keys that are meaningful *to them*. As the first step in Anderson and Krathwohl's learning taxonomy, remembering (identifying and recalling information) leads to the second step 'understanding' (interpreting, classifying, inferring, comparing and explaining), then applying the understanding to different concepts, then analysing, evaluating and finally creating (generating ideas and hypothesising).

From this study, a conclusion could be drawn that the usual information about ABI needs to be supplemented by linking in the underlying 'Keys' including the metaphysical concepts in order to support each person to feel and fare better. The metaphysical ideas around love, trust, resilience therefore become a necessary environment and context in which people learn and apply their ideas in interaction with others, in which they fail but come back with lessons that help them try again. The recurrent and endless attempts to 'try again' (Anderson and Karthwol's category of 'creating once again') are what place learning at the very centre of efforts to support people with ABI. Most importantly, 'trying again' represents ***every*** person's struggle to give meaning to their lives, to achieve their capabilities and help them to feel and fare better whatever the circumstances within which they live.

We can therefore now emphatically agree with Freeman's words that 'education is the key' and we shall further formalise this argument in the following chapter.

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Chapter 9
Discussion: Illuminating 'Blind Spots' for the Health Service Providers

> *Long term recovery from brain injury is not a medical problem. What is needed is re-learning… the power of recovery lies within the injured person as they relearn their daily living skills. Education is the key,*
>
> (Freeman, 1998, p. 14)

9.1 Introduction

In this chapter, we will draw together some of the threads of learning **we** have gained **from our study participants**. We shall employ a framework that acts as a heuristic to assemble the blind spots and blank spots that have been discovered. Along the way, we shall emphasise how this research has relevance to people with ABI, family carers and professionals. So, to house the findings in a synthesised manner, our first task is to adopt a heuristic framework that will support this intention.

Let us recall the importance of Edmund Husserl's phenomenology to our study, the importance of listening to the lifeworld of people with ABI and others as they ascribe meaning to their world. In identifying such meaning, we can identify grounds for their social action, i.e. why people act the way they do. Social action presupposes meaning—for example, if I give meaning to my identity as a non-racist, my social actions will reflect this 'reality', and vice versa.

Moran (2011) points to Husserl's 'phenomenology of habitualities' and argues that, 'Habit…for Husserl is intimately involved in the constitution of meaningfulness and forms of sense at all levels'. Once people pursue social action without having to think about the relevant action for that situation, they have formed a habit. Many of these habits are shared with others, making them cultural mores. In our own lives, consider our roles within our family, our work group and among friends.

We are not always 'mind readers', so, with just the smallest action, it is easy to cause offence. For example, not unpacking the dishwasher as our partner has anticipated or not following or showing appreciation for the sport/television

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program/film/food or music our friends value. Much of what we do is habitual, and we negotiate where to 'change expectations'.

We have seen in detail how people with ABI struggle with these habitualities as they re-engage in day-to-day life in their communities. Indeed, when habits cannot be applied by the person they become 'exposed', since they have to make a decision about how to act and respond without relying on that habit; the reactions of others to them in such circumstances, therefore, have a huge impact. The person with ABI becomes the 'looking glass self' seeking affirmation, guidance and information from others to gauge whether their own response and actions have been acceptable. So negative responses, and especially their reoccurrence, can be devastating for the person. Imagine being rejected or told you are wrong constantly. It is soul-destroying!

The notion of habitualities is vital to this chapter in two ways—on the one hand, it has the potential to explain 'blind spots'; on the other, the concept emphasises the importance of learning such habitualities as a precursor to people with ABI living an included life, developing a clear identity and to pursuing future hopes, dreams and aspirations.

Let us look at the relevance of habit to 'blind spots'. It is possible for two groups of people to have different habits. It is only the power one has over the other which allows those with power to define the 'reality' of that situation in terms of which actions are pursued. Any other interpretation is to the powerful party a 'blind spot'—they cannot see, or simply reject, the alternative view as well as those actions that the alternative view would warrant.

Thus, we have argued that a view of 'mending bodies' (tied up with an education drawing on a history of 'established' ideas) misses the vital stage of mending lives which lasts for a lifetime once people move back to their home and community. We have shown how the language and categories explaining ABI in many public information documents draw from the 'habits' of a 'mending lives' discourse. We can, too, see how the negative and pathological labels used in this narrative lead to particular professional actions to 'make the person (as close to) normal' again. All of these actions exist insofar as the professional has rights and authority to define 'the problem', to the extent that what is published on Websites recognises this authority and, insofar as the construction of services is based upon, and consequent to, the authorised professional definition of the 'problem'.

Pierre Bourdieu's work on *habitus* offers a very useful heuristic in this respect (Bourdieu & Wacquant, 1992). They argue that we have capitals (resources) that are economic, cultural, social and symbolic (to do with power) upon which we draw in our everyday lives. These capitals will differ among groups, between an Inuit Eskimo and an urban Londoner for example. In living in these contexts, we draw on the potential of the capitals to create our habits and, pursue our lives within the context of what we learn to be culturally and socially appropriate.

Thus, for example, the many words for 'white' which structure Inuit existence, survival and flourishing, will not be mirrored in the urban Londoner's understanding and culture. Collectively, the habits become a disposition (habituality), a way of being, and all social practices are embodied (i.e. internalised) as Inuit practice and culture. The Inuit use these categories with a great degree of expertise. A Londoner arriving and telling the Inuit they have it wrong and should act in a different way would likely not be taken seriously and left to his or her own devices if she/he continued to insist upon a different way of being or 'seeing whites' in this case. Within any cultural 'field' then, there is what Bourdieu terms symbolic capital, a relation of power that operates to maintain the disposition of the culture within any field of practice (i.e. in this case a tundra environment and community).

Now, apply this to people with ABI. It is likely that their capitals will change once they get back home; it is likely that they will require new supports to live a life of their own choosing; it is likely that their search for the embodied practices of their group will be affected by their injury, and it may be that unlocking their potential to adopt new identities given these changes may be problematic.

For people entering new lives, there is 'anomie' in which the person with ABI is alienated from their usual preinjury social practices, habitualities and moralities. For them, social practices are unknown by virtue of having to redefine their lives, spaces and their interactions with others. In such circumstances, the 'looking glass self' becomes more important. Since actions and relations are unknown, people are looking even more than may be usual for the confirmation and affirmation of others in terms of who they now are (identity)—in order to define themselves and how they act (social acceptance) in the future.

The social practices and identity, unknown to them, become known through others' responses to them. This research has demonstrated 'what is known and experienced' by different groups. In the first section of this chapter, we shall talk about the concomitant blind spots, particularly those which do not see, ignore or reject the lives and experiences of people with ABI. In doing this, we propose to ask the reader, professionals and families to **assume the position of 'the looking glass self'**. Of this, more shortly.

The second pre-eminent aspect of habit relevant to this thesis, and which is further explored in Sect. 9.3, is its relevance to the centrality of (re-) learning in the lives of people with ABI. If, as argued above, social practices are unknown and, if people with ABI have to find new replacement social practices, then inevitably (re-) learning is required to survive and to flourish.

It has been argued above that the disposition and embodied practices of any culture are tied up with an historical lineage of ideas; they are built from a recognition of the powerful (usually government) conferring the right of some people (usually professionals) to act using this established history of ideas; they are sustained around complex guilds and professional societies and complex organisational structures with governance that resists challenge. In short, the disposition and embodied practices of these groups are extraordinarily resistant to change. Foucault has argued that professionals given the power to act turn their clients into objects, i.e. clients become objectified and defined by the professionals' ideas through such 'dividing practices' (Foucault, 1982).

What we have shown in this study is the lack of clarity people with ABI have in relation to their disposition, their habitual and comforting place within family, home and community. We have also shown how this is often related to the struggles to adopt an identity of their own. Writing is now beginning to emerge around identity in a world of post-modernity. Ranieri and Pachler, for example, write that:

> In the fast-changing and uncertain world of late- or post-modernity, individuals need to continuously cope with new challenges; this condition requires them to develop a flexible identity and a dynamic ability of “being-in-the-world” (2014, p. 64).

Adding complexity to this task for people with ABI in relation to learning is that

> …content delivery as the dominant paradigm is no longer appropriate, a point argued by constructivist approaches to learning from Vygotsky (1931/1978) to von Glasersfeld (1995). To face the challenges of uncertainty and change in “liquid” modernity (Bauman 2000), learners require flexibility, and need to develop a dynamic ability to make sense of knowledge so they can deal with perpetual change (ibid).

Since learners are indeed immersed into an ever-changing world, the acquisition of static knowledge transmitted by the teacher or trainer is no longer sufficient for the learner to make sense of their dynamic experiences of the world—if it ever was. In other words, content delivery as the dominant paradigm is no longer appropriate, a point argued by many.

However, in their excellent article on a dialogical conception of habitus, Akrivou and San Giorgio (2014) suggest that Bourdieu’s theory of habitus does not allow sufficiently for such change. They consider that ‘transformative’ learning takes place where trust is established between interlocutors in conversation and as accompaniers in social action.

Moreover, conversation partners gradually become less preoccupied with ‘safe’ habits and engage in reaching a ‘shared truth’ with regard to how to proceed in a shared quest for *die sache*—or the subject matter of inquiry (Gadamer, 1989; Gadamer & Lawrence, 1982; Kelly, 1988). For them, conversation represents the ‘binding “play of persons”’—and this can only happen in trusting relationships since

> The quality of experiencing cognition is possible once a person freely “gives up” the safety of one’s self authorship on the basis of solitary reason….the processual self emerges from a dialogical habitus experiencing an organic way of being complete in situ…This gradually develops a diverse set of the brain’s cognitive pathways…we learn to skillfully *be* with experience (Akrivou & San Giorgio, 2014, p. 2).

Notable in this quote is the notion now gaining recognition from science in relation to the plasticity of the brain.

Post-modernity and identity and research around new identities in new e-media environments have recently been gaining more interest too. This idea of lifelong learning as an ‘ability to see’ draws on Heidegger’s notion of ‘being in the world’ cultivating adult learners’ dynamic abilities to be actively engaged with their thinking, acting and feeling. In doing so, they live ‘authentically’ as well as, flexibly, in the face of change. In this context, personal mobile devices have been viewed by some as suitable means of supporting individuals’ adults’ learning at any time, anywhere and across many contexts (Arrigo, Kukulska-Hulme, Sanchez, & Kismihok, 2013).

However, new technology may be a double-edged sword. Field and Lynch (2015) point to the 'liminal space' (Field & Lynch, 2015) between identities into which many young people now fall, observing of their study participants that,

> …they have in common a current inability to imagine the future; when asked about the future they speak of obstacles and of impossible situations which inhibit choice. They appear bound, immobilised. For some, life is to be coped with (ibid, p. 11).

The authors highlight the importance of learning in formal and informal environments and through 'communities of practice'. Looking at identity and cultural practices among young music learners, Lonie and Dickens (2016) show how some learning environments exclude young people as do some settings and some organisations. They show how by re-appropriating spaces for communities of practice the students in their study were able to encounter and learn new art forms across genres through self-directing social practices. It may not have escaped the readers' attention that some participants with ABI expressed similar sentiments about ABI support groups which they attended. Walsh, Muldoon, Gallgher, and Fortune (2015) in their study of 53 adult survivors of ABI in post-acute community rehabilitation argue the importance of social factors to well-being, a social cure (Jetten, Haslam, & Haslam, 2012). As they say,

> It seems that belonging to groups (affiliative identity) fosters perceptions of social support and that perceiving social support facilitates participation in activities which become internalised as social identities (self-as-doer identity) which in turn impact positively on psychological well-being. Our results suggest that looking to one type of social identity alone may not tell the whole story regarding relationships between social identity, social support and emotional status following brain injury, (Walsh et al., 2015, p. 566)

Stone, Underwood, and Hotchkiss (2012) talk about a 'relational habitus' in which learning is intersubjectively sustained through formal and informal communities. There are several implications from this emergent research for people with ABI. If learning is the key as Freeman argues, then people need to be supported to learn in environments in which they can feel safe and learn to trust those with whom they interact. Learning is based on deep relationships since it is only through encounters of trust that self-reflection ensues and actions change. Moreover, growing is better supported in relationships that last and where habitualities become shared over time. Some approaches since this study was completed begin to recognise these factors even within rehab practice. Sullivan, Gray, Williams, and Green (2014) suggest 'clinical implications for real life activities to be incorporated as part of rehabilitation' (p. 424); Lexell, Alkhed, and Olsson (2013) emphasise group rehab to give patients 'the tools they needed to change their everyday situation, especially in relation to gaining more knowledge and learning new routines and habits' (p. 536) where professionals, family and friends play crucial roles. The place of 'habits' in this proposition should be noted not least since predating any new habit is a lot of learning and a lot of practice!

Habits which have been glued together previously with a range of available resources and capitals are thrown into complete disarray when a person re-enters life in the community where new habits have to form in a coherent way to produce inclusion. The resources that are available are likely to be different and the demands on others similarly so. Amartya Sen, a Nobel Laureate for Economics argues that a person’s capabilities are bounded within his or her circumstances. To live to achieve what one is capable of, to hope, to dream are a function of how the resources that are available will, or come to be, applied.

In these senses, the implications for services must be grounded in a series of principles relating to learning, to identity and to positive change based upon the lifeworlds of those with whom they engage, with whom they explore ideas in a trusted relationships. Moreover, the levels of support to provide the freedoms others take for granted should be designed to work towards situations in which sufficient supports are available not just to manage an austere existence, but to support hope, aspirations and growth.

We now have a framework for exploring blind spots and for exploring the practice relevance of the research findings. This occupies the following two sections.

9.2 Understanding Negative Blind Spots

This section explores the ‘blind spots’ identified in the Keys Study. Instead of presenting them as findings, we ask the reader, given what they have learned, to walk a mile in the shoes of people with ABI; we ask readers to empathise and to weave these new threads of understanding into a strong rope designed to support people with ABI to feel and fare better—to provide new ‘scaffolding’ that holds up the structures, processes and elements of a good life through learning.

It will be remembered from Chap. 3 that one phenomenological approach to the medical understanding of symptoms was that if there were no apparent explanations for their observations that they might be seen by medics as delusions or as hallucinations. Drawing on the phenomenology of Husserl (intended perception) and Merleau-Ponty (embodied perception), Fuchs (2005) writing about delusional mood and perception argues that there is an ‘intimate connection with the world mediated by the lived body’ (Fuchs, 2005, p. 138). Note here that this connection to the world changes if our body changes. For example, experience of stairs will change if, all of a sudden, one becomes blind or unable to walk.

To encounter such new embodiment and perception, we now ask the reader to place him or herself as a novice Eskimo, or, as a new village resident living in high and mountainous terrain, or, as a Bedouin—i.e. as a stranger (Schutz, 1944) in a new world in which movement, social interaction and perhaps language have changed. Flimsy as this metaphor may be, it may provide sufficient analogy to people with ABI, arriving in a new destination with no clear identity, being challenged by the terrain, and struggling to communicate in order to survive and flourish.

Imagine now that you are required to walk from the village to uphill pastures, or to go out and hunt seal in the ice or to successfully mount a camel to follow other Bedouin across a desert—you might struggle with thin air walking uphill, or end up in danger trying to walk on different forms of ice or fail miserably to get the camel to do your bidding and, further, to act in culturally appropriate ways since you have not the habitualities of that culture at your disposal. You may feel shame or loss of status, unable to control your body as you have been used to doing. If your fellow villagers, Eskimos or Bedouin tribesmen, show a lack of empathy and kindness; if they offer no support; if all you get is negative feedback; if you lack the esteem you have once had in your home environment—then you are, over time, likely to become exasperated and even angry.

When Websites and medics talk about challenging behaviours, it may be that these are produced by the reactions of others and are not only a function of the brain injury. It may be that these are wholly understandable as 'behaviours of resistance or protest' (Ramcharan, Nankervis, Strong, & Robertson, 2009). The cause of such behaviours needs to be understood by the professionals and families and others. Such behaviours may be wholly understandable. They represent the struggle to be human, to be accepted and to be treated with dignity.

The first 'blind spot', then, is that ABI damages more than just the brain.

As you employed the looking glass self in the examples above, you may have felt all those things felt by people with ABI in our study sample—fear of different types (being lost, left behind, in danger, unsure of who to turn to and so forth), shame (at the incapacity to know how to act, at gaining recognition and status, at lack of knowledge of practicalities), disappointment, distress, hopelessness (since you cannot yet choose how to act, how to communicate and how to flourish in your new environment) and loss of status (comparing the new you to the one you are now in your new environment and social group) along with anxiety, suspicion leading over time to a sense of hopelessness and even depression.

You may have felt guilt too. William James (1950) in the *Principles of Psychology* wrote about the 'fiendish punishment' experienced if people do not notice us or 'cut us dead'. James suggests that the consequences would be 'rage and impotent despair' (cited in de Botton, 2004), and the person with ABI may daily experience the 'torture' of being a 'nobody', being held in low esteem, invisible or ignored. Like our sample participants, you would be searching to understand what was 'true' in life—and what made you a valued human being at all.

The medical model too has the potential to classify these beliefs/feelings/perceptions in a negative light (see Chap. 3, Diagram 3.1). These symptoms are treated as the cause of the person's cognitive, behavioural and emotional problems.

What this study has shown is that in many cases they are not symptoms, but rather a perfectly reasonable and understandable response to the struggles of life. Adopting these symptoms as a cause leads to a downward spiral since the response is more negative feedback, maybe more medication, perhaps more specialist services trying to rid the symptomatology through regimes that incorporate testing and behavioural programs.

In this way, the medical model treats the effect of these interventions (behaviour, emotions, depression) as the cause of behaviour. What this study shows is that the cause also lies in the social realm, with the impassioned struggle to be human, to be social and to be included.

The second, and associated, blind spot in this study is the negative effects of rehabilitation for over half the participants in this study.

Taking up your 'looking glass role' where you left off, consider, if you will, how much courage it would take to resist the constant negative feedback in your social life only to find you are being subjected to countless medical and psychological tests, being told you are lying about your abilities or cheating to get a better life (monetary compensation). As a new Eskimo, tribe member or Bedouin, you are now subjected to tests to see why you are not 'normal'.

For many people in this study, the rehabilitation experience had been a real problem. It is no 'golden period' at all but a 'dark hole'. The protagonist in Graham Greene's story *The Moment of Truth* reveals that:

> …[he] thought doctors and surgeons are not necessarily good psychologists; perhaps, because their interests are so concentrated on the body that they forget the mind, they don't realise how much a tone of voice reveals to the patient. They say "there's always a good hope" but what the patient hears is "there is very little hope if any", (Greene, 1990, p. 37)

Participants in this study believed strongly that rehabilitation should not solely be about mending bodies, but about helping them understand ABI and themselves and building skills, talents and hopes through education and encouragement. Instead participants reported inter alia: being 'treated like a leper', being 'dumb and stupid'; feeling mistrust having been 'burnt' or 'tricked' when doing assessment tests in particular; feeling terms had been misused.

This feeling of being tricked was revealed very forcefully to Durham during the last stage of the first few interviews. Durham had made two sets of 'talk-about' cards that were very similar: 'Being useful' and 'Helping'; and 'A cup of tea' and 'A cup of coffee'. Durham was astonished that the first five participants all responded in similar vein to the following: 'Being useful is the same as helping!' 'A cup of tea or coffee—what's the difference—did you think I had forgotten I had already chosen one'. They explained that they felt they were being 'tested' and 'tricked', as they had been in rehabilitation tests and it took some time to repair the conversation and convince them that there had been no intention of tricking them. The 'Helping' and 'A cup of tea' cards were removed because the main aim of this study was to do no harm and not to upset the participants. This was the only example where the 'talk-about' cards distressed a participant.

People with ABI also reported being given IQ tests on several occasions and experienced negative emotional outcome from being obliged to complete tests that emphasised their impairments. Is the purpose of such tests to indicate their capacity to cope? If this is so, the people with ABI should have their test results explained to them and different ways of coping with their social networks explored. People need to be able to employ higher order thinking in order to identify strategies they use; however, learning about ABI, (re-)learning about manners and learning about 'faulty thinking' in an engaging way should play an important part of the rehabilitation experience.

Some emergent findings contest the assumptions of this IQ testing model. Gordon and Duff (2016) point out how important it is to learn contextually and with familiar partners (as opposed to IQ which simply tests the individual). They found using collaborative referencing (agreement on the label for novel shapes in their research) that recovering the agreed label reduced each time the task was repeated. One interesting finding was that when just one member of the ABI sample was provided a new partner, they too improved, indicating agreement was not based upon their memory, '…these results demonstrate the important role partners play in the communicative successes or failures of individuals with TBI in everyday interactions' (Gordon & Duff, 2016, p. 1482).

If such new ways of learning are peculiar to setting and interactants (as in your case of being an Eskimo, Bedouin or high plains villager), then there may be potentially limitless ways in which you might learn with and through others to establish you new habitualities, drawing on multiple intelligences, and in everyday settings and interactions. Mogensen (2016) drawing on neuroplasticity argues that the undamaged parts of the brain can be 'reorganised into new algorithmic strategies'… clinical outcomes may be a patient with different but as proficient mechanisms for cognition' (Mogensen, 2016, p. 429), i.e. the brain rewires itself to find a solution. He points to inexplicable and seemingly unimportant matters, such as a finger rather than a cross in a computer-simulated prism adaptation therapy experiment, as producing much better outcomes for no apparent reason. Much remains to be done to explore the potential of neuroplasticity, contexted cognition, new technologies for learning and social action which are anathema to the negative targeting of IQ and other tests which simply point to 'the' problem.

Given the emphasis of this book that 'learning is the key', it is not surprising that Durham and Ramcharan posit that much work needs to be done and that there is a significant need to prioritise research and practice in these areas.

For many people with ABI, their issues in rehab were described as 'minor', 'unimportant' or 'insignificant', while 'plateauing' was used to imply no further improvements were likely or expected. The turn of phrase 'you never will…' was often defeating leading to loss of motivation and hope.

By reason of the blind spots identified above, threats to the self-efficacy of participants, their belief in their capacity to achieve goals, were severely challenged. Verlinden and Brands (2016) have found that 'Control over interfering emotions and developing a sense of control and mastery over brain-injury associated symptoms seem to be of importance in the development of self efficacy…Treatment programmes should focus explicitly on reinterpretation of interfering thoughts and symptoms and the reinforcement of self-beliefs' (p. 604). The present authors would concur.

In the above two blind spots, we have shown how the continuous low level or direct negative reinforcement destroys a person's self-esteem, suspends their identity formation and destroys their trust in others. Participants in our study had 'proof' or reasons for many of their fears that affected their lifeworld, (see Sects. 7.2.1 and 7.2.2). From the perspective of the professional, some of the fears expressed by participants with ABI could be placed upon a sliding scale from extreme sensitivity, to paranoid, to delusional. However, in the same way we saw that avoidance could be a coping strategy (in Chap. 5) or used as a defensive function for retaining self-esteem (McKay, Langdon, & Coltheart, 2007). What can be seen by others as purely negative and/or destructive behavioural issues can be performing a very valuable and protective function for vulnerable people on the long-term road to learning to live with ABI.

Aristotle posits in *Nicomachean Ethics* that how one manages one's fear is a measure of courage. Positive psychologists have pointed to 'endorsed strengths' or 'encompassing virtues' such as wisdom, courage humanity, justice, temperance and transcendence, and how these define bravery, persistence and integrity, i.e. courage (Peterson and Seligman, 2004). It has been argued that a shift is required in terms of how rehabilitation practice produces improvements in well-being by working with such strengths and virtues (Evans, 2011). This is one important lesson for professionals—the need to adopt positive—psychology and strength-based (Connolly & Harms, 2015; Slade, Oades, & Jardin, 2017) models which build on strengths and which recognise causation in personal experience and not in organic abnormality.

Some approaches, suggested since the completion of this study, have started to reflect issues such as those outlined above. Perceptively, Ackroyd, Fortune, Price, Howell, Sharrack, and Isaac (2011) emphasise,

> raising clinician's awareness of the possibility of growth for their clients rather than working solely to "fix a problem". The social network surrounding the person with ABI may also provide an opportunity for the development of post-traumatic growth. Some recent research in people with other neurological illness suggests that growth in patients tends to be best predicted by growth in their partners and vice versa…thus a communal search for meaning seems to be a significant process by which growth may be maintained… building what is strong rather than solely striving to fix what is wrong. (p. 654).

Using 'compassion-focused therapy' Ashworth, Clarke, Jones, Jennings, and Longworth (2014) show how shame, self-blame and other emotional responses can be addressed in rehabilitation to support adjustment, to build trust in staff and to regain control. They speak of 'scaffolding' interventions for those not coping after injury. Fraas (2015) speaks of the growing recognition by clinicians of the importance of listening and responding to personal narratives, while Greenfield (2011) emphasises the need for clinicians to take a more phenomenological approach, to dialogue, explore changes in metaphor so as to support identity development, establish coping and promote advocacy.

The sense of loss you may now be feeling in your role as Eskimo, Bedouin or high mountain villager may be great. If you had been told you would never 'get better' or 'get the hang of your new role' you may lose hope, feel lonely and isolated. Our participants had a real distaste for being delivered such 'messages of doom'. Some studies have found improvements over time for people with ABI through involvement in the 'academy of life' (Bulinski, 2010) through improved self-efficacy (Cicerone & Azulay, 2007) or through attaining healthy and productive lifestyles (Corrigan, Bogner, Mysiw, Clincholot, & Fugate, 2001).

However, for many, the unrelenting negative responses may simply add to the destruction in their lives and of their lives. Moreover, it is a struggle to learn when the person feels afraid, ashamed, isolated and is trying to understand and cope with the ideas discussed above (see Sects. 7.2.1, 7.2.2, 7.2.3 and 7.2.4). Without support how can you get up a mountain where the air is so rarefied? Without support how would you handle the camel and pitch your tent; without support how would you navigate the dangers of different ice-flows and find your food? Moreover, without observing and learning and practice following others, your own identity within the social milieu and environment will remain perplexing if not opaque. You will not learn your place and develop your new identity without such learning.

In their important review summarising applied behaviour analysis and positive behaviour support, Ylvisaker, Turkstra and Coelho (2005) argue for a ‘collaborative contextualised approach’ encompassing: working in highly idiosyncratic contexts, where behaviours will be used (through situational training and coaching), with regular communication partners, ‘so they can interact supportively and do not misinterpret or react punitively to awkward behaviours’ (p. 264) allowing self-reflection and withdrawal if feeling stressed. Vitally, they argue that the ‘application of a person-centred goal formulation framework, so that the individuals understand that their goal is “social success”, not “social appropriateness”, and counselling specifically designed to help the individual develop a personally compelling sense of self that includes positive social interaction strategies as a component’ (p. 264). It seems to us that this represents very apposite advice given our study findings.

Some recent studies are recognising the importance of both positive psychology but also the importance of placing interaction in social contexts of everyday interaction. Martin, Levack, and Sinnott (2015) argue that

> that social identity and social connectedness ought to be primary foci of rehabilitation rather than matters only of secondary concern. Consideration needs to be given to both the environmental contexts and the intrapersonal strategies that support people who require residential rehabilitation services to achieve social connection, and thus their life goals, following a severe acquired brain injury, (p. 1234).

Some studies also recognise that it is important to work with family and friends too. For example, Andersson, Bellon, and Walker (2016) show how for children with ABI returning to school there is a need to support ‘the family to adjust to changes and work towards the positive construction of new roles and identities following brain injury’ (p. 838).

The third negative blind spot is that learning is hard labour.

Resume your Eskimo, Bedouin or high country native role, having now been there for a few days. How is it possible to learn all you need to do when getting mixed messages or being ignored? Through your isolation, shame and fear you may find it hard to learn—self-awareness of your unusual situation is a start and may also help in your understanding of the physical, emotional, cognitive and metaphysical challenges you are facing.

Participants with ABI in this study had a deep understanding of their situation: they could identify issues that affected them when they were provided with the scaffolding and the opportunity to discuss ideas through using *Keys to the ABI Cage*. They demonstrated that they could learn to acquire better insight into ABI using *Keys to the ABI Cage*. Learning theories, then, can be applied to assist each person with ABI to learn about and understand their ABI.

Participants spoke about not being in the right 'headspace' (see Chap. 7) to understand ABI in the 'information' that, in the past, had been given to them because they were 'trapped': swamped by their losses, no longer normal people and damaged from emotional fallout of feeling sad, bad and mad. They were ashamed, afraid and isolated and over half the participants were disempowered by their rehabilitation experience. Maybe at the time of their involvement in the Keys Study, two years or more post-injury, they were in the right 'headspace'; however, an hour spent with a bird cage let them open up their own minds to greater understanding of ABI.

Some participants admitted they had denied that they had ABI. Self-awareness is an important area that has been the focus of studies examined in the literature review in Chaps. 3 and 4. It is a complex phenomenon that can impede the rehabilitation process and outcome (Fleming, Lucas, & Lightbody, 2006; Lamberts, Fasotti, Boelen, & Spikman, 2016). Assisting people to understand and gain self-awareness both positive and challenging around their ABI in a constructive way was an important component of this study and also for learning.

The interviewed mothers and wives felt guilty that initially they were unable to understand ABI and may have done things differently had they such information. Statements made by professionals identified most of the physical and cognitive losses and some of the emotional difficulties. However, most professionals revealed a blind spot: they focused on 'fixing' the deficits of their clients without focusing on how these deficits affected their client's self-esteem and self-belief, their ability to learn, and eschewed discussion of issues of trust and power. Each client's fear and shame was not issues that were readily talked about. Learning could be termed a blind spot of the medical model, and it was not a focus of the professionals, nor the majority of studies about ABI.

The finding herein suggests that the headspace is not only about recognition of ABI and its affects. Trust through relationships where people can feel they can 'get it wrong' safely or 'confront themselves' is vital. Even before the process of learning then, preconditions such as building trust and self-awareness are necessary precursors to establishing a 'headspace' in which the person feels motivated to learn. This may be in short supply where the negative responses leave the person without hope that things can change. In your 'looking glass role', you may not have a common language with which to negotiate, to be heard nor to understand. In that role, you may be dependent upon support and would learn least through a didactic blackboard and chalk approach. As described in Chap. 5, you might fare better by drawing on other learning approaches—visual, kinaesthetic, music/rhythm and other forms of interaction drawing on other intelligences (Gardner, 1983).

Figure 5.1 presented earlier, outlines Anderson and Krathwohl's (2001) learning taxonomy with the fundamental elements being remembering, understanding, applying, analysing, evaluating and creating. In your "looking' glass role', you may already have been imagining the employment of these strategies. From the above, it can be seen that even reaching step 1, 'remembering', can be a problem when faced with the confusion caused by negative reactions, rejection and mixed messages. Embodied practices or habitualities are 'understood' through observing and/or modelling or experiencing the ‘correct’ ways to act in different circumstances within the cultural setting(s) occupied. The motivation to achieve such understanding may also be casualties where no matter what the person tries, they ‘get it wrong’. This is exacerbated where the person is taught in inappropriate ways leading to further rejection.

An important finding of this study was that all participants—people with ABI, mothers and wives, and professionals—identified that there was a need for information in non-medical language that helps people understand and learn about ABI. All three groups stated that people with ABI, their families and the general public and some health professionals do not understand the ramifications of ABI. We have shown that there are presently some significant blind spots in the information that is available and that much of the information is couched in a negative manner which further accentuates difference and abnormality.

Further study is needed to determine different ways to identify suitable information for people with ABI, created in a way that is interesting to them and understandable. *Keys to the ABI Cage* used several metaphors and material objects (crushed cans and flying pigs as well as hope stones) to support reflection and understanding. There is potentially limitless artifice possible to engage people in ways that respect them as humans, that supports their reflections and which builds confidence. As we shall argue later, these must be a key to a ‘positive learning’ approach for people with ABI.

We shall attend to the ‘analysing’, ‘evaluating’ and ‘creating’ elements of Anderson and Krathwohl’s (2001) learning typology in the following section.

At this point, it is sufficient to note that prior to engaging in learning there is a need to: build trust in relationships (prove empathy and understanding); build confidence, self-awareness and adaptation; offer a safe space to ‘get it wrong’; and to support reflection on information that is made understandable and which reflects multiple intelligences.

But this does not explain either the content of a ‘positive learning’ approach or the processes. In the section to follow, we shall explore the remaining four blind spots in the light of our proposition about the centrality of learning to the lives of people with ABI. We shall synthesise findings in such a way as to begin to weave the threads together which will support people with ABI to feel and fare better.

9.3 Drawing on Positive Blind Spots

Above, we established the importance of *learning* to people with ABI faring and feeling better. Further, we have shown how negative blind spots simply reproduce anomie, trauma, difficult behaviours, rejection, isolation and loss of hope, self-esteem and confidence:

> …professionals often do not seem to realise that prolonged small traumas, for example ongoing experiences of failure or cumulative life events, might increase their vulnerability

> of developing PTSD-like symptoms…[trauma] That is, different kinds of problem behaviours can be considered as symptoms of PTSD, such as aggression and anger outbursts, self-injurious behaviour, non-compliance, social isolation, sleeping problems and restlessness…, (Mevissen & de Jongh, 2010, p. 308).

Such blind spots simply exacerbate or reproduce the very things they are supposed to address—they are 'brought forth by the healer'—i.e. are iatrogenic. They contribute to a 'headspace' that does not produce a motivation to learn. Indeed they can, in a worst case scenario, themselves be a source of trauma presaging

> …the effects of assaults on victims' sense of safety, trust and self-worth; their frequent revictimisation; and their loss of coherent self (van der Kolk, Roth, Pelcovitz, Sunday, & Spinazzola, 2005, p. 389)

In your "looking' glass role', you have been tested to see what is wrong with you, and you have been given negative feedback. What are you wishing for from your new friends and 'family'—what services would you choose and why? The participants in our study pointed to a number of things for which they yearned—to a number of blind spots in which the formal literature fails to engage substantively. These are explored below, and they are linked into the learning model being developed out of the findings of this study.

Blind spot 4 is the positive effect of 'humanity'.

People, as we have seen, cannot learn if they are in the wrong 'headspace'. Kirsten, a participant in this study, a professional with many years' experience working with people with ABI, remarked 'What I like about the stuff you are doing—the humanity of it—with all these things it's about humanity…'. She reflected upon the importance of hope and a sense of purpose. In your own new "looking' glass role', your sense of hope, (knowing there is no way back home), is to become part of your group and your culture, to thrive in your new world—to develop loving, reciprocal and valued relationships that make you feel good and make you want to be part of something, 'to get out of bed everyday', as Kirsten put it. Kirsten exemplifies the centrality of family friends, empathy, touch and reassurance.

Rees (2005) writes about 'connoisseurship' people who understand ABI and can assist people with ABI:

> The greater the number of persons who become connoisseurs, the greater is the chance of promoting understanding effective learning, and inclusion…Connoisseurs will have intimate familiarity with the phenomena of people with brain injury. They respect and are committed to their inclusion in society and understand the factors influencing rehabilitation. Connoisseurs typically present narratives that advance community understanding of the difficulties, but also the skills and talents, of people with brain injury, (Rees, 2005, p. 5).

In short, people with ABI require support from those who have sufficient knowledge of ABI, who understand the importance of inclusion and who treat them as equally human.

Put another way, the problem is not solely that of the person with ABI—it belongs to the people with whom they interact and the services and support workers too. Out of such core values comes the support that produces competence. As argued by Booth and Booth (1994), competence, therefore, should not be defined by *individual abnormality* and difference but by the distribution of supports available within family, friendships and society which helps each person to flourish. This ‘distributed competence’ model is about how we all flourish—since none of us on our own have the capacity to ‘do it all ourselves’—we share the necessity of a ‘civic duty’ to share with others.

Consider the businesses and bankers, mechanics, service industries, educationalists, employers and others upon whom all of us rely, but ‘take for granted’, but who help us flourish. This is a hidden distributed competence upon which we rely. Similarly in your “looking’ glass self’, you too will want to rely on this distributed competence and you too will want to find the ways in which you can contribute something to your new ‘tribe’—to be treated with dignity and as a human who has potential to contribute.

There are then, many Keys that open the ABI Cage, which is blind spot 5 as exemplified in so many ways by study participants as described in Chap. 8. The sixth blind spot is Keys that ‘help in coping’ and the seventh blind spot is ‘optimism’. These blind spots are *insufficiently represented* in the literature on ABI. Figure 9.1 sets out the number of areas identified by research participants that act as Keys to the ABI cage relating to blind spots 5–7.

The lists in Fig. 9.1 present concepts at differing levels. Some are about attitudes (being positive, sense of humour); others are about outcomes (success, achieving

- Seeking social support
- Focusing on solving the problems
- Working hard to achieve
- Worrying
- Invest in close friends—engaging in particular intimate relationships—this strategy was not a common strategy
- Seeking to belong
- Wishful thinking
- Social action
- Tension reduction
- Recognising you are not coping
- Ignoring the problem
- Resisting self-blame
- Keep to oneself
- Seeking spiritual support
- Focusing on the positive
- Seeking professional help
- Seeking relaxing diversions
- Physical recreation

Additional Keys identified by participants over the study period were:

- Nature
- Animals
- Symbols
- Helping others
- Further study
- Achieving hard things
- Sense of Humour
- Employment
- Doing ‘normal’ things/feeling a ‘normal’ person
- Success
- Attitude
- Doing things for myself
- Feeling deepened through suffering

Fig. 9.1 Keys to the ABI cage

hard things); some are in the metaphysical realm (spiritual support, love and intimate relationships); activities, environments and sentience feature (nature, environments); personal development and achievement (achieve hard things, working hard to achieve things, further study); others relate to support (seeking social support, seeking professional help); and belonging and identity feature strongly as do the hope for doing normal things and feeling like a normal person.

There are signs that the literature since this study was conducted that is beginning to reflect some of these arguments. Levasseur et al. (2016), for example, use a Human Development Model-Disability Creation Process (HDM-DCP) drawing upon an anthropological model of human development and disability. This model shares the notion of habits that was central to the arguments made earlier on in this chapter. The model sees such habits as the result of the person's interaction with personal (identity, organic and capability factors) and with environmental factors (societal, community and personal). Habits cannot, therefore, form if factors prior to interaction remain confused or unclear, '…illustrating the circular and practical … dynamic and interactive process of disability and human functioning' (p. 638). This cyclical process has its similarities to our notion of 'constructive circumambulation'.

However, the model focuses on the individual without recognising that environmental, interactive, community and other concepts are interactively produced. It is the joint learning and distribution of competencies which makes a difference. Thus, the capacity of those close to create outcomes through interaction and to themselves learn how to do this is placed centre stage as a principle for service provision.

In short, none of the categories is any different from those we would expect of any of us. Why then should such hopes, aspirations and capabilities be so hard to achieve? Think again of your "looking' glass role'. Had you identified any of these as having potential to help you feel and fare better?

A positive approach to ABI would privilege these ideas and would do so among key people in the person's life.

Keys to the ABI Cage allowed people with ABI to easily identify phenomena that contributed to a satisfying life for them—to their psychological wellbeing, happiness and hope for the future. Yet the search for life satisfaction remains unresolved for many and in the literature too (Astrom, Asplund, & Aström, 1992). Participants emphasised the need to grow, to transform. Some were 'deepened by suffering' (Nietzsche, 1995). In the words of Helen Keller

> Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved.

and Martin Luther King,

> Human progress is neither automatic nor inevitable… Every step toward the goal of justice requires sacrifice, suffering, and struggle; the tireless exertions and passionate concern of dedicated individuals.

Several participants felt that their life was enriched by their ABI experience; they now appreciated being alive, they were aware of their strengths and weaknesses and they now felt wise.

These beliefs or understandings also emerged through the interview process as a means of learning about ABI and applying new knowledge to themselves, reflecting on their life and gaining insight. This appeared to be a turning point for some participants in terms of their self-understanding and new pride in what they had achieved and overcome. The study identified that some participants had constructively circumambulated around the phenomena of ABI and worked things out for themselves: they had learnt that there were many Keys to the ABI Cage, that certain things affected their quality of life and that they had different ways of coping with their challenges. The 'powerful experience' of ABI had led them to acquire better insight into life. They felt wise. This is powerful information to pass on to others experiencing the life challenges of ABI.

The participants chose and talked about virtues and strengths such as: wisdom and knowledge, courage (accomplishing goals in the face of opposition), humanity (strengths of tending and befriending others), justice, (fairness), temperance (forgiveness and mercy, humility and modesty, self-regulation and self-control) and transcendence (appreciation of beauty, gratitude, hope, humour and playfulness and spirituality).Thus, subjective well-being is influenced not only by their physical, cognitive or emotional impairments but by their engagement with everyday life and relationships and by a focus on 'what is strong, not, what is wrong'. These findings have subsequently been made available to people with ABI with the publication of 'Unlocking my Brain through the Labyrinth of Acquired brain Injury' (Durham, 2014) to encourage them to reflect and gain insight and have their own 'Eureka moments'.

This process of 'analysing' that knowledge, the next in Anderson and Krathwohl's (2001) stages, was found in this study to be transformative—but maybe not immediate. It takes significant time, rehearsal and re-rehearsal to make sense of what it means in terms of relationships and place. For example, in distinguishing the many words for 'white' in Eskimo culture you may 'make many mistakes' before knowing which white makes igloos, which is a fishing hole, which is unsafe and so forth. This is why safe spaces for applying, evaluating and reviewing that knowledge are required. In doing so, patience is needed for while the brain may be plastic, it will take time for new neural pathways to turn rehearsal into habituality. It is also why in developing new relationships the distribution of competencies between people with ABI, family, services and others needs to be negotiated. But learning new distributions of competence is as much about *the learning of others* as it is about the learning of people with ABI. *Learning together*, therefore, needs to be in context and applied to goals that become agreed over time.

For many, both people with ABI and family carers, this new distribution of competencies requires adaptation and maybe even dealing with grief and loss. For example, the centrality of employment to people's identity and felt sense of accomplishment as well as the source of material comfort may be significantly changed (Sveen, Soberg, & Ostensjo, 2016). In the Keys study, five participants were working in different areas to their preinjury jobs, two participants expressed job satisfaction and four were studying. Some participants wished they could have career opportunities or work longer hours. Others who were not working wished to gain some employment and many had tried with great persistence to obtain work but could not.

Thus, unfortunately, few of the participants in the present study felt they had recovered sufficiently to be able to claim they had a 'healthy and productive lifestyle, or had returned to work'. If only two out of the 36 participants were satisfied with current employment, this is indeed a grim reality for the future of this group of people with ABI if life satisfaction and coping equates to being able to live as they had lived and worked before their ABI. Coming to terms with this and finding positive factors to balance out this part of their identity was clearly one of the harder things to accomplish for many people.

This finding was in agreement with the idea that although concepts of the 'personhood' as 'lost' or 'shattered' have dominated discussions in the literature, that this 'perspective is a crude representation of the post-injury experience of self, and the aspects of stability, recovery, transcendence and moral growth are also involved in this process'(Gelech & Desjardins, 2011, p. 62). Nochi's (2000) categories also show how a person can come to terms with their new self and develops new coping strategies as identified in Chap. 4 (Kendall, Kendall, & Muenchberg, 2009). It is also why Linge's (1990) suggestion to note and focus on small achievements is wise for all of us, people with ABI too.

Keys to the ABI Cage aimed to help people with ABI discover and come to terms with the new self (self-actualisation) by helping them to understand ABI, to feel safe, to belong to the 'brother/sisterhood' of people with ABI, to recognise their achievements and to have their achievements recognised by others. Identification of factors that positively affected their lifeworld assisted them to see their ABI experience with 'new eyes'.

Findings from *Keys to the ABI Cage* indicated few participants mentioned the word coping; however, they could nevertheless identify Keys what could be classified as coping strategies (see 8.2.3–8.2.7). Lazarus and Folkman's (1984) seminal work and Smith and Lazarus's (1990) work centres round the notion that emotions are influenced by evaluations (appraisals) of events that cause specific reactions in different people.

People with ABI in this study wrote about a wide variety of coping strategies—more extensive than those recorded in most coping self-report inventories (see Chap. 4), indicating that self-report inventories may fail to assess the full nature of coping. The problems associated with self-report inventories have been documented extensively in the literature, yet the use of these inventories to assess coping is still widespread (Kendall, Shum, Lack, Bull, & Fee, 2001).

Participants with ABI in the present study identified a plethora of unique ways to cope with multiple challenging situations at any one time; physical danger; emotional spin-offs including their loss of confidence and loss of trust; and their belief that they are sad, mad and bad, afraid, ashamed and isolated and fatigued.

This study unravelled complexity, whereas coping inventories do not. It allowed choice by the person of those things that they could or might use as 'appraisal' devices and buffers against stress. The Keys, therefore, allowed the collection of diverse experiences and provided grounds for choosing how people can engage. By drawing on the 'talk-about' cards, which represent the range of experience, people reflected on strategies and approaches they do not presently use but ones that may be open to them.

In the face of adversity, challenge and exclusion, it is hard to bounce back, to demonstrate resilience (Garmezy, 1991; Luthar & Ziegler, 1991; Masten, Best, & Garmezy, 1990). With the supports implied from our findings, some participants could be said to have displayed 'resilience'. Adversity can be applied to people with ABI, but competence is problematic if you are not competent to walk, talk, think or even eat as you once did. Positive adaptation involves skills, attitudes, awareness, acceptance of deficits and taking steps to adapt. These are not the normal attributes of a person whose life is changed by ABI.

Perlesz, Kinsella, and Crowe (1990) stated that few studies explore the experience of coping well and resilience after traumatic injury, and this still seems to ring true. Curran, Ponsford, and Crowe's (2000) study provided evidence that coping strategies are associated with emotional outcome, and Uprichard (2010), using the person-centred global approach, found that participants felt less valued and judged by society and wanted the focus to be on enablement rather than disablement. This is also a finding of *Keys to the ABI Cage* study.

The Resilience Research Centre (RRC) uses a more ecological and culturally sensitive definition of resilience. 'In the context of exposure to significant adversity, resilience is both the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being'(Resilience Research Centre, 2017). Given this definition and what was said about the use of *Keys to the ABI Cage* in providing a scaffold for coping, the same may be asserted around resilience. The Cage maximises the chance that people may find the resources through which to sustain their wellbeing.

The nature of this scaffolding and a reflection on 'Keys' to the ABI Cage is summarised below.

9.4 Scaffolding Learning—Summary for Readers, for People with ABI, Family Carers and Professionals

Scaffolding learning requires establishing the conditions to create a 'headspace' in which people feel motivated to learn. Building trust in relationships is the key to this as is patience and a safe space to try and to fail. Working on 'what is strong, not what is wrong' is crucial—a positive educational approach. The metaphysical concepts around love, intimacy, hope, beliefs, belonging and support are an essential holding environment in which all thriving is accomplished. Being negative, critical or providing complex or mixed messages or being punitive is counterproductive and is iatrogenic, contributing to loss of hope and, in worst case scenarios, to a feeling of trauma and abuse.

Learning is not a singular thing to make people 'normal'. To create new habitualities means working with people in their natural settings with their everyday relationships, families, friends and others. Normality is defined by the groups through their actions—trying to make the person fit with pre-existing habitualities is likely to fail and to stress all involved. Similarly, competence does not just adhere to the disability. Rather competence is distributed and all parties must learn how this new distribution of competencies will work for the benefit of the group and in a culturally sensitive manner. Whatever each person contributes, no matter how small should be valued as, ipso facto, their contribution to the groups and its identity. Moreover, each situation will be different and so will require a different approach.

Professionals need to plan for diversity and not establish prearranged approaches imposed by authority and without listening to the voices of people with ABI, those which ignore each person's peculiar circumstances, relationships and settings.

Since replicating pre-existing relationships is unlikely to work, adaptation, coping and resilience need to be major mechanisms through which all parties operate. This may also involve dealing with grief and loss.

In all forms of learning, a range of learning styles (intelligences) needs to be catered for in ways which make them understandable. The learning process that follows should draw on some of the concepts and any others that are not listed from this study as a positive mechanism for helping people to explore possibilities, options and their interconnections consistently.

The process of learning may be very slow and so patience is required. Understanding is supported by constructive circumambulation in which by drawing on appropriate concepts and ideas the person begins to test the complex interconnections making up their life. Habituated acts which glue people together in culturally acceptable ways take time to (re-)learn—rewiring the neural pathways may require rehearsal ad infinitum—but the brain has a plasticity the nature of which is as yet not fully tested, leaving hope that things can change.

Once understanding begins the opportunity to apply, analyse and evaluate follows naturally if the understandings have been worked upon in natural settings across the important relationships in each person's life. At this stage, and reflecting back on Bourdieu's concept of habitus discussed earlier, the stage of application, analysis and evaluation will draw upon all those resources—economic, social, cultural and symbolic, that are available and will seek to convert these into positive outcomes for the person and the groups within which they operate. It may be that in this approach the final element of Anderson and Krathwohl's (2001) approach—creativity—may become a function of all parties including the person with ABI as they draw upon, co-ordinate and apply the capitals they have to their best advantage. The role of professionals will be in supporting the *conversion of these capitals into outcomes*.

Finally, since all people are aiming to achieve what they can in life given their own gifts and capabilities, the journey itself is as important as the outcome. What gives meaning to life is that struggle to be all you can be given those capabilities. Even if you do not quite complete the journey, it should have been worth the struggle. Change and movement towards hopes, dreams and aspirations are all important. To bring us back to the starting point of learning, for people with ABI, many of these notions of life's possibilities have to be redefined to give life meaning—this means recognising the ABI and what is possible must be an essential starting point—then people can dare to dream. You may now relinquish your role as Eskimo, Bedouin or high plains native recognising how for you, as for people with ABI, what is left is 'hope'. Then, we can all weave the threads together in ways that help each person including those with ABI, to feel and fare better.

In Chap. 10 to follow, we reflect on some of the policy and practice recommendations for professionals, family carers and people with ABI. This is couched in terms of a message of hope rather than one which produces separation, anxiety, fear and hopelessness.

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Chapter 10
Parting Thoughts: Finding a Balance

It isn't that they can't see the solution. It's that they can't see the problem.

G.K. Chesterton

The diseases of the mind are more destructive than those of the body.

Marcus Tullius Cicero (106-43BC)

> While modern medicines may occasionally have an almost magical effect on a person's life, the time has come to move beyond our rather arrogant clockwork model of the brain, within which a clinician has only to isolate some faulty cognitive gear and repair it. We have to begin to think of the brain as a self-organizing ecosystem, one of such staggering complexity and delicate balance that almost any aspect of a patient's life may be relevant to a diagnosis or essential to treatment, (Ratey, 2001, p. 354).

10.1 Looking Back at Keys to the ABI Cage

We now turn full circle and reintroduce Keys to the ABI Cage that readers will first have encountered in the Foreword. We do so now to ask what lessons can be learned by people with ABI, professionals, family and other carers given the study findings. We concur with Sherry that 'there is a need for important, practical revisions in the way we understand and respond to the experience of brain injury' (2006, p. 212). At appropriate points, we offset to the right principles and findings to make them easier to identify and to seek to respond to Sherry's appeal.

10.1.1 Principles Induced from the Genesis of the Cage

The birth of *Keys to the ABI Cage* emanated from the combination of Durham's own experience of brain injury (the cage being one symbol of that experience),

C. Durham and P. Ramcharan, *Insight into Acquired Brain Injury*,
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a recapturing of her professional background in education and from filtering the views of the many hundreds of people with ABI responding to her first book ‘Doing Up Buttons’. Further, though, it offered a mechanism to systematically collect data analysed in three areas reflecting a history of responses from people with ABI—‘differences and difficulties that can PUT us in the cage’; ‘how we feel about these differences and difficulties can LOCK us in the ABI Cage’ and ‘Keys that RELEASE us from the ABI Cage’. Perhaps most importantly, and yet often missed, the intention of the Cage to DO NO HARM was the most critical and fundamental contextual factor. It provided a non-judgemental context which treated people as humans and introduced artistry to engage people in a human way, with dignity and respect for what they bring to the world.

Even prior to generating the study findings then, the Cage had already built on personal history and experience and the public voices of people with ABI. Along with the study findings in this book, the importance of the Cage to Durham and to others with ABI is that it represents a ‘confirmed and consistent’ voice and view of people with ABI. Dismissing this voice would represent a dominant professional approach which uses ‘dividing practices’ (see Chap. 9) to maintain professional power and authority to act.

> Hearing the voices of people with ABI must be central to all endeavour which aims to support people to feel and fare better.
>
> Means are as important as ends. All services, supports and studies should aim to do no harm. This is not just doing no physical and biological harm; it is about doing no emotional and psychological harm also.

10.1.2 The Learning Dimension

This study shows that people with ABI struggle with learning, but that this learning is as central to a better life as is the mending of their bodies. This learning is continuous—it takes place at a time when the personal resources are least available but when the changes in life, relationships, settings and contexts are at a demand that is anomalously and enormously high, given their changed circumstances.

> (Re)learning for people with ABI is continuous. It often occurs at a time when personal resources are at their lowest and learning demands relating to ‘new bodies’, new contexts, settings and relationships are at their highest.

It has been shown that all learners need to be motivated in order to engage in learning. The use of objects (e.g., the crushed soft drink can, the flying pig, the rubber band on the ‘stretch outside my comfort zone’ ‘talk-about’ card) created interest and the small objects on the Keys ‘talk-about’ cards (e.g., miniature watering can, dog, sun, moon, mushroom, flower) created amusement.

> Learning should not be arcane and tedious. There are always ways to inspire and excite so that people remain motivated to continue.

This all helped to maintain the focus and keep the session relaxed. Holding the cards in their hands participants remarked that they now realised that they had found ways to cope with many difficulties. This reflective activity appeared to be a powerful way for them to understand and acknowledge the things they had learnt to cope with. They felt empowered not only to speak about the words on the card, but to talk about things the words reminded them of—they decided what was important to discuss, not the interviewer's interests. Moreover, placing the cards in 'Do' or 'Don't' box focused their attention and gave them a physical way—an action—to express their thinking.

> I'm still walking round dragging my cage but I can see I'm getting somewhere (Participant with ABI)
>
> '…The 'talk-about' cards led to discussions and realisations' (Participant, professional).

Keys to the ABI Cage therefore admirably supported constructive circumnambulation through which people could explore ideas in a circular roundabout way through self-reflection. Offering 'talk-about' cards helped people reflect and build connections between things, as well as discovering new ideas which they could engage in their own time, drawing upon what was important to them.

In the interview situation, *Keys to the ABI Cage* allowed people with ABI to tell stories and share their experience.

> If I'd had the CD (Keys to the Brain Injury Cage) earlier on it would have helped me to understand that I wasn't going mad. And it certainly would have given me another way of approaching things too. Perhaps then I could have asked more questions. Because if I knew that was the situation, then I could relate that to other areas. It would have helped me tracking my progress/achievements (Participant with ABI)
>
> It sets things out, it's very interesting once you start realising it's a tool for reflection (Participant family carer).

The Cage therefore supported Anderson and Krathwohl's (2001) initial stages of learning—remembering, understanding and formulating new actions on the basis of their reflection.

> Once motivated, directing and controlling engagement in areas defined by the learner as important allowed reflection and linking of concepts and ideas (understanding). This 'constructive circumnambulation' led to hypotheses about how to organise new social actions in order to flourish in their everyday lives.

Some participants expressed relief when they held cards and remarked how comforting it was to learn that others have had these difficulties too—they had not been imagining things—they were not alone, they were not mad. This was a shocking revelation that people have gone through the 'health system' for several years and not understood that their difficulties were 'normal' for people with ABI. This burden should NEVER be placed on the shoulders of damaged people with ABI struggling with their own multiple burdens. The 'Reflection kit' (used on its own for country participants and used prior to the interview by over half the interview participants) and 'Some Further Thoughts' sheets (for all participants) proved to be of great benefit. Participants who had the kit prior to the interview were pleased to have had time to think about concepts so that they could re-engage and expand on the concepts at the interview. Although some people had forgotten what they'd written on the 'Reflection kit' sheets prior to the interview with the Cage they all said they valued the combination of kit, Interview and Further Thoughts sheets. Once again some participants greatly valued the 'Some Further Thoughts' sheets they took home after the interview and took time and effort to consider issues and ideas at greater depth.

The Reflection Kit and 'Some Further Thoughts' sheets were also useful with many who had written them being able to re-engage with the concepts many had forgotten between their writing and their participation with the Cage.

In approach and content, the Cage demonstrated respect and offered a way to establish mutual respect and empathy. It allowed metaphysical concepts, for example around love, courage, support and hope to populate the narratives—for participants to exemplify their sentience and their humanity.

> A vital characteristic of any learning environment is that it is imbued with humanity, respect for each person as a sentient being and one capable of empathy. No learning can usefully prevail under disrespect, duress or rejection.

Keys to the ABI Cage has several potential uses in its physical form or as a data storage disk. A learning resource, *Keys to the ABI Cage* could include a discussion starter for ABI groups, a learning tool for people with ABI and carers, a tool with sheets for personal reflection. *Keys to the ABI Cage* could be trialled as a useful tool to make sure the people with ABI/family carers/professionals were 'on the same page'—were aware of the major problems the person was dealing with. The Cage could be a useful to introduce health science students to ABI as well as professionals.

Durham was curious as to whether participants who were vision impaired would react to the tool but they carefully touched the cage and objects while they were described. One legally blind participant joked that the pig would have difficulty flying as she had felt the wings and said they were made from fly wire. This participant said that having a mental picture in her head of *Keys to the ABI Cage* helped her imagine her ABI. Additionally when she held all the 'Differences and Difficulties' cards she said, with obvious pride, that she had not realised how many issues she had coped with.

Keys to the ABI Cage was also trialled at three different ABI Support Group sessions. Each session had up to 15 people with ABI. The tool worked well in the group situation and encouraged group discussion. One support group wanted to use the digital storage disk with a group of people using computers at the centre, with the aim of viewing the digital storage disk again in a year's time to review the individual's progress. It is interesting to realise that there could be many different uses of the ABI Cage and the digital storage disk.

> … your cage is a wonderful example of feeling they are locked in and trapped in that cage and there is actually no way forward or out. I think you're right, I think human beings generally do have the ability to um to find a way forward um against all odds, that's what people with ABI tell you it was against all odds (Participant professional).

The Cage had some weaknesses. The logistics of packing up, moving and setting up the *Keys to the ABI Cage* was not easy, but the reaction by participants made the effort most worthwhile. Because of the bulk and large size of the cage (66 cm wide by 100 cm tall, the pole was 150 cm tall) it was not possible to take it into cafes or libraries for interview purposes. Moreover it represents just one of many potentially innovative ways to build the right resources to support learning.

Although introduced to groups since the study, the use of the Cage as a research study methodology has not yet been sufficiently tested over time as a means of scaffolding learning and as a support tool in the context of everyday service delivery. However, after work done subsequent to the study with professionals and ABI groups, the portents of success remain high. The Cage is just one of potentially many devices that may engage people with ABI in learning. What is important is that those who provide services and supports, understand the importance of learning as an essential part of their professional practice. Researchers, designers and innovators need to test further the potential of new forms of learning across media and across time.

> Teaching and learning should be a major element in the training of service professionals. New learning design and media, along with the Cage and any offshoots, should involve understanding about how people learn and teaching strategies to employ to make learning engaging and meaningful. Need to be implemented and tested further over time with people with ABI and the people who support them in their local environments.

Finally, the participants in this study were all able to speak for themselves and met other inclusion criteria around not presently being stressed or engaged in legal proceedings. While acknowledging this as a partial sample given the spread of ABI, we would assert that the common threads of learning, empathy and humanity that tie this study together are applicable to the many rather than the few. It is not the extent of the brain injury that has greatest import but, rather, the damage to life and humanity—if this is the case perhaps ‘acquired brain injury’ might be better cast as ‘acquired damage to life and humanity’.

10.2 Implications of the Study Findings

This study has exposed the staggering complexity and delicate balance of the brain and also of that of the lifeworld of the person with ABI trying to cope with damage to their brain, body and beliefs; their hope, honour and trust, their security and safety.

Weighing up the plethora of complicated and complex difficulties participants with ABI experienced in their day-to-day lives, it appeared impossible that anything could balance the scales so that life could be tolerable. However, it was demonstrated that it was possible for some participants with ABI to achieve a balance and that the negative factors of physical, cognitive, emotional differences, difficulties and deficits of ABI could be balanced by the positive influences of hope, love, understanding, learning to work things out for themselves and even small everyday things. The latter were those crucial things that conferred a meaning and purpose to life that is essential in maintaining a positive stance.

Importantly, people with ABI and their families need to have some information about positive things they can do, so they can learn what other people with ABI have done to help themselves. A catalogue of coping strategies could be a valuable resource for people with ABI who have forgotten coping strategies they employed prior to their ABI. Further research is needed to find factors that help people with ABI, and help people with ABI learn about different coping strategies that could help them deal with their difficulties. We have, too, shown that learning needs to take place in context and with those who provide support over time. Learning is therefore not simply for the person with ABI but around finding new habits that support them as a group to survive and make the best of brain injury together.

Positive information from studies about ways people cope with ABI, ways to improve memory, manners and faulty thinking, factors that improve quality of life need to be 'translated' into everyday language and made available to the person who sustains a brain injury, their family and support organizations.

> All support for people with ABI should operate from a positive philosophy in which every engagement builds on strengths, in which every success no matter how small is celebrated and in which the contribution of the person within their network of social relations is recognised as a contribution to the group. People would benefit from a catalogue of coping ideas used by others translated into everyday language and made available in ways that support learning.

Since the completion of this study in 2012, many writers are making a case for such strengths-based approaches, such as in the Social Identity Model of Social Change (SIMIC) (Jetten, Haslam and Haslam, 2012), positive approaches (Evans, 2011; Martin, Levack and Sinott, 2015; Gan & Ballantyne, 2016), client centred practice (D'Cruz, Howie and Lentin, 2015; Barker et al., 2016), along with participatory and co-design approaches which transfer choice and control more firmly into the hands of the person with ABI him or herself (Knox, Douglas and Bigby, 2016; Hawley, Gerber and Morey, 2017) or which do so through self-help groups (Cutler et al., 2016; Gelech, Bayley and Desjardins, 2017).

It is worth noting that other discipline areas, such as mental health, have adopted such positive models—the recovery model in mental health.

However, the experiences of participants in our sample indicated that bio-pscyho-social approaches did not work on strengths and did not employ such positive approaches despite Hojat's (2016) argument that the model reflects the World Health Organisation's holistic definition of health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity', (WHO, 1948).

The majority focus on pathology and abnormality and in service delivery therefore further damaged the person's self-esteem and confidence. The pathological focus also made its way into hard copy information and Websites, reinforcing difference and 'abnormality'. Furthermore, all participants with ABI, mothers and wives of people with ABI, and professionals stated that people with ABI, their families and the general public and some health professionals do not understand the ramifications of ABI, and that there is a need for information in non-medical language. Lack of understanding about ABI had a negative effect on the lifeworld of most of the participants with ABI. It was disappointing that so many participants had felt that they had gone mad or insane and did not realise the consequences of ABI, in spite of being involved in the medical system. Professionals need to provide the person with ABI and their family information presented in a way that they can *understand* ABI.

> From the earliest time after injury, whilst bodies mend to the extent possible, it is vital to build through a learning approach, empathy and dignity the grounds for a positive life. Information about ABI should emphasise these positive messages and the centrality of learning to accomplish lives and relationships through which the person can feel and fare better.

This study demonstrated the need of information in everyday language that is discussed with the person and their family, about the range of things that can improve the well-being, satisfaction and quality of life for person with ABI, and the importance of learning new things. Family members need to work with professionals in supporting and helping the person understand things they can do to help themselves live with ABI and to do so in the context within which they are being asked to live and flourish. Constructive information from other people with ABI about attitudes, understandings and emotions that have helped them learn to feel and fare better needs to be provided to the person and their family.

The person with ABI and their family need information about practical everyday things that can help them learn to feel and fare better. This includes the importance of finding an activity that the person loves doing (from knitting and sewing to gardening and playing computer games), the company and companionship of pets, and being able to contribute by helping at home and helping other people with ABI, i.e. to build a new culture habituated to all within their operating social and support network.

Love, hope, understanding and everyday things *can* help the person with ABI to make progress from a life that is unsatisfactory, when they feel imprisoned in the ABI Cage, to a more satisfactory life, when they have discovered Keys to unlock the ABI Cage. Yet, as this study has shown, people with ABI can continue learning even if it takes more time. That learning takes place in context and so implicates family members and others so that they too can learn, adjust, cope and thrive.

> All learning takes place in context. The aim should be to habituate learning within everyday social and support networks so everyone accepts their roles, their strengths and limitations. Supporting learning with information delivered in ways and formats that are understandable and which support the person to maximise their use of collective resources (capitals) in pursuit of individual and collective goals is vital to accomplish a life in which habituated actions support the person to 'know their world' and, in doing so, to fare and feel better in that world. There is a need for an "ABI educator" supporting the person and their family with this information and with skills in building stronger and more robust social and support networks.

There has been very little focus on the need to place such education at the forefront of service delivery for people with ABI in the community. One exception is Silvestro et al (2017) who, in a statement which very much reflects the argument of this volume, state that collaboration between medical and educational sciences provides

> …a "functional synergy" permits the development of the person, and establishes an indissoluble link between functions and attitudes, thus allowing the achievement of the greater possible autonomy. In this way classical and pedagogical rehabilitation may be combined in a single concept of educational action. To realize this integrated educational process it is important to evaluate and promote awareness development, based on the possibilities of brain plasticity and on the presence of multiple intelligences skilfully in-tertwined each other. Therefore, self-awareness plays a prime role in educational actions for the rehabilitation of persons with severe ABI' (p. 82)

We suggest this as a major area for both research and practice in the future.

Looking at the themes already outlined above, there are many similarities between this and the 'recovery model' which has been widely adopted in mental health services. For example, Jacobson and Greenley (2001) identify internal conditions such as hope, healing, empowerment, connection and external conditions such as human rights, a positive culture of healing and recovery-oriented services as central to producing better outcomes. There may be much to be learned from such models and their recent development (Slade, Oades and Jarden, 2017).

In the present study, many participants with ABI stated that much of the information provided to them, especially while in rehabilitation, destroyed their hope. It is also false to see the rehab period as a 'golden period'. This may be so for mending bodies but it was seen by many participants as a 'deep dark hole'.

It should not be forgotten that people have to spend much longer outside rehabilitation and in their communities after discharge. This study provides evidence that people with ABI learn ways to adapt and cope with living with brain injury, year in and year out, so their life improves to some degree as the years pass. It is never 'as good as it gets' since things are always changing; a small gain is made here or there, circumstances change, people come and go and so forth.

If there was just one change that could happen from this exhausting and exhaustive study it would be that no one is ever told they will only improve for two or even five years as was the experience of many participants. The words 'vegetative state' and 'plateau' should not be used, other terms should be employed. The term 'mild ABI' does not adequately describe the difficulties a person may encounter, nor that an easy recovery will not necessarily follow, as is the case in most 'mild' illnesses. These three terms can have a negative effect on the lifeworld of the person with ABI.

> It is vital for professionals to provide feedback which sustains hope and motivates the person to continue learning. Too many professional especially in rehabilitation give the impression through their words that nothing can change once their work is through. This is simply untrue and has a huge impact on ongoing recovery. Words should always be chosen to support hope but to emphasise the need for continued effort over time.

The experience in rehabilitation, and thereafter especially given comments from participants about the negative impact of being required to complete a battery of tests, needs to be considered by professionals. If the person is given a test they should be given the opportunity to have their test result explained to them, along with positive action that will be taken by professionals to address the issue and things they could do to try to overcome the difficulty. This needs to be in clear written and verbal form. Further research into the value to the client of doing tests needs to be undertaken.

Studies need to be undertaken to ascertain the value to the *client* of IQ tests and whether there is a replacement for them. A hypothesis has been formed after interviewing people with ABI that if some of the time taken completing tests was spent *learning* about ABI, having difficulties explained, being given strategies to address issues, this could positively affect the lifeworld of people with ABI.

> In light of the findings of this study the relevance of recurrent testing of people with ABI needs to be reconsidered. Such tests should not defeat the person or act as a threat. When used, their use to the benefit of the person should be clearly articulated. More research is needed on the negative impact of these tests.

The renewed focus on biographical and narrative approaches (Greenfield, 2011; Lennon et al., 2014 and Fraas, 2015) can be equally as powerful and, if seen as part of the development of trust can deepen the relationships and understanding between professionals and people with ABI and the use of compassion as a form of therapy, (Ashworth et al., 2014). These are, it should be noted central elements of empathy as a fundamental principle underlying the therapeutic relationship.

Some participants believed that ABI was a really powerful experience that had let them experience unique and valuable things, so that they now had a fresh appreciation of life, they were aware of their strengths and weaknesses and were now a wiser, better person. The implications of these findings can provide a lifeline for people with ABI who are feeling swamped by things that negatively affect their lifeworld.

> The gap between what their lives were and what they become with ABI is more vast than the majority of people will experience. It is easy for people to fall into this chasm unless supported not to do so. Bridging this gap is ‘fantastical’ and doing so represents for many who do so a deepening for them and something from which we can all learn. This deepening also represents a painstaking reframing of life and its certainties, a huge feat of learning. Any successes in this struggle are grounds for celebration.

This study showed that there are many Keys to open the ABI Cage. Hope, love, learning to understand ABI, working things out for themselves and learning to face the facts were identified by participants as factors that helped them learn to feel and fare better. The crucial role of the empathetic professional was identified by all participants in this study. Hojat (2016) has emphasised that humans ‘are evolved to connect together for survival. Among the factors that fulfil the human need for affiliation and connectedness are social institutions such as marriage, family, and social support network, including clinician-patient empathic relationships’ (p. 17).

Drawing on a number of studies he shows how patient outcomes improve with empathy (though not necessarily with sympathy) and argues that this empathy binds the patient and professional in a bond of 'trust'. Such trust is best supported through empathic clinician engagement, 'listening with a "third ear" and "seeing with the mind's eye"' (p. 129) and where, 'the patient perceives the clinician as a helping member of a social support system…' (p. 189). For Hojath, then the science of medicine must work with '…the art of medicine (the psychological, social and interpersonal aspects of illness) merge into one unified holistic approach to patient care. Empathy is a key element in the holistic care system' (p. 72).

Professionals, service providers, rehabilitation hospitals and brain injury support organisations can all play a powerful, empathic, active role in assisting clients to understand their ABI and identify the things *the person finds helpful.* This study identified an abundance of issues around ABI and education as well as Keys that will support professional staff to play their role in the wider networks of support through which people with ABI will live the rest of their lives.

> Empathy plays a crucial role since it establishes the grounds for trusting relationships. Such trust is a prerequisite for people learning new roles and tasks within any naturally occurring support network. Strengthening the competence of this long term network of support is essential.
>
> Faring and feeling better takes place within everyday environments and relationships. Professionals need to demonstrate empathy and it should be a requirement of their practice expertise and monitored as a quality measure.

The tool, *Keys to the ABI Cage,* supported the participants with ABI to share their insight into ABI as they told stories about their experience and identified factors that negatively and positively affected their lifeworld. A conclusion that can be drawn from this study is that although people with ABI may be considered to lack self-awareness, participants demonstrated that by using *Keys to the ABI Cage,* they could reflect on their difficulties, differences and feelings and identify Keys—factors that could help them learn to feel and fare better in a constructive, positive way. The professional has an important role in assisting people with ABI to articulate their challenges to recognize ways to help themselves. The term ABI itself refers to the brain sustaining injury, but it been shown that the brain is but part of the 'person' that requires attention. In many ways, it is itself a misnomer. When we think of a person who is identified as having an ABI, we need to be thinking of the broad spectrum of their life and not just about 'mending' their brain and the physical losses of ABI. Mending lives is infinitely as complex and equally as important as mending brains and bodies.

> People with ABI have insight. Their struggle is equally about mending lives as it is about mending bodies.

This study has established that many people with ABI believe they are mad and bad and that they are afraid and ashamed. There is a stigma and humiliation associated with being a person with ABI. The emotional welfare of the person with

ABI should be of primary consideration for all contact by professionals, whether in the research, rehabilitation or medical setting.

To address this issue, the curriculum of the health professionals should concentrate on this issue, and professional journals and conference presentations should focus on the importance of ‘humanity’ as a basic value held by the brain injury professional. All professionals involved in this study could identify the physical and cognitive consequences of ABI, but they were not as focused on how the person with ABI felt as a whole person, not just a focus on the deficits of ABI.

> For ethical and humane reasons all professionals working with people with ABI should have a ‘reminder checklist’ to refocus their attention on how the client may feel. The ABI professional needs to show humanity and understanding to their clients. This could enrich and strengthen the rehabilitation experience for clients. Professionals need to have a broader understanding of the consequences of ABI, not just their specific area of expertise. This also requires further investigation.

10.3 Study Limitations

With any study there are limitations, and this study is no exception. The study was completed in 2012 but data was collected in 2008–9. Further, the selection of participants at least two years post-injury meant that much data on the experience of services would have been prior to 2008 and, in many cases as far back as the year 2000. In this sense, the study findings may be somewhat dated. However, even as an historical record, the findings are important in locating key systemic and treatment issues which should form strong grounds for the development of future services. We have in Chaps. 9 and 10 sought to update the literature to point to new approaches and new ideas aimed at addressing some of the more challenging experiences of study participants.

The sample might be considered to be relatively small, though by being so, there were advantages. It was, for example, possible to collect far more data about the meaningful experiences of participants than would have been collected in larger samples using statistical data. So what we lost in sample size, we gained in the depth of data collected. The analysis was rigorous and in being so threw up recurrent themes which indicated that data saturation was reached. However, we recognise people responding to adverts on brain injury support groups and Websites may represent a sample skewed by such involvement. For example, it may have favoured those who were seeking information, knowledge or those finding it more difficult to cope.

We would say that if the study’s aim was to seek generalization that this sampling strategy may not have been appropriate. However, since our aim to explore a collection of diverse experiences as far as was possible, we think we have accomplished this to a significant degree. There remain issues about those with ABI who are more isolated and who do not maintain contact with either services or with ABI groups and who would not have known about nor elected to participate in this study. For this hard to reach group, more research is required.

As will have been noted in Chap. 6, we resisted listing the ‘characteristics’ of the sample—their age, occupational, marital status or the impairments or struggles with activities of daily life they experienced. In looking back at the analysis of data and delivery of key findings, we can say that even were if we had done so it would not have produced gains to study findings. We have made some points along the way in which data comes from people of a certain age, gender and who have particular problems with daily life. These are made contextually, and we recognize the importance of these contexts. However, the main focus was to explore the repeated experiences of participants rather than focusing on how the plethora of demographic data might be relevant. Indeed, for a sample, this small that may have proved very difficult. Our proposition is that there was sufficient in the recurrence of themes to make the reporting of demographics details redundant. While against convention, we suggest it avoids gratuitous use of data that is given no further meaning in the analysis.

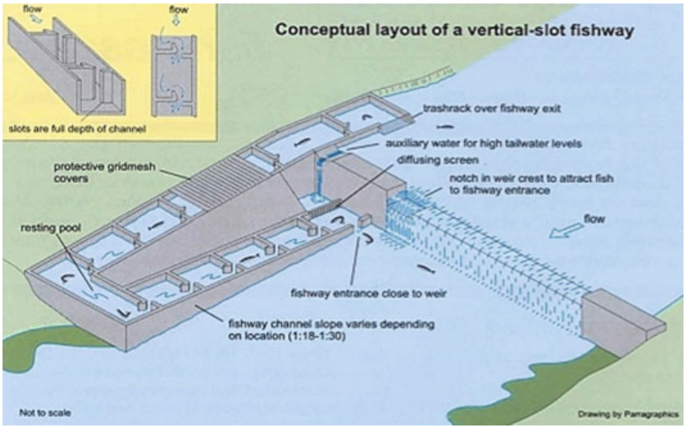
As with any interpretive method, it is easy to say that the data may be attended to with differing interpretive approaches. This is always a bone of contention. We do believe that the structure of the Keys to the ABI Cage and the opportunity for people themselves to guide the discussion were a notable benefit of this study. By the same token, the approach may not suit those who would rather have data collected in systematic categories in which the same areas of discussion were covered with each participant. Doing no harm was an important defining feature of this research, and we argue that by leaving the choice of ‘talk-about’ cards to the participants that they chose what was important to them. In doing so, they chose from a consistent series of themes. That makes their responses all the more meaningful.

10.4 A Final Few Words

This volume has used a plethora of analogies in order to provide new ways to consider ABI. It has proposed mindset changes to specifically allow the healthcare professional to revisit their concepts/mindsets/models when working with people with ABI.

The reader will be aware that a number of species of fish undertake migrations upstream, against the flow of the river to spawn and feed and to maintain genetic fitness within fish communities.

Bundles of branches were first used in France in the seventeenth century to create steps in steep channels or to allow fish to swim up waterfalls. Fish ladders or fishways are constructed today for this purpose. Fish negotiate a regulated upward flow, then have a calm pool to gather strength for the next upward push. In such a way the person with ABI can be empowered and assisted to take on the many challenges of a new lifeworld in steps with a calm period to gather strength for a further thrust. Having the opportunity to discuss their experience, tell stories and learn to understand about ABI can be the branches or fish ladders to assist their swim upstream and become ‘adept in being brain damaged’ (Skloot, 2004, p. 196).



This book has shown that participants with ABI had insight into their difficulties, differences and feelings and the many Keys that opened their ABI Cage. As they reflected, they realised that their hope, acceptance and attitude (their mindset) had helped them to learn new ways to help themselves feel and fare better.

We believe that this study adds further to the growing calls for positive models not just in relation to people with ABI, but also for those with mental health (Slade et al., 2017), disability (Martz & Livneh, 2016) and across social work (Connolly & Harms, 2015). Furthermore, this study clearly shows how, by reflecting on how people with ABI perceive their lifeworld, we open up limitless possibilities for learning. In implementing these possibilities, much still remains to be done.

The study has shown that educational principles can be applied to empower people with ABI to learn to acquire better insight into ABI.

> The power of recovery lies within the injured person…Education is the key. (Freeman, 1998, p. 14).

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Glossary

Attribution theory Students attribute success or failure according to their perceptions of why they might have succeeded or failed in the past (Weiner, 1985).

Biopsychosocial model the inconsistent interaction between biological, psychological and social factors. This model counters the biomedical model, which attributes disease to biological factors, such as viruses, genes, damage or abnormalities.

Blank spots is a term to identify an issue where enough is known about the issue to pose questions, to gather data to fill in the blank spot, as is used by quantitative research (Wagner 1993).

Blind spots is a term to name issues in which existing theories, methods and perception have not identified the issue. Enough is not known about the issue to even ask about, or care about the issue (Wagner 1993).

Circumambulation from the Latin *circum* around plus *ambulātus* to walk, literally means 'walking around'. In this volume, this term, which has been used by Jung and many religions, denotes a reflective, open approach to learning leading to construction for personal growth. This contrasts to being directed, or thinking that someone has an exact answer and course of action that will apply to your circumstances. The person looks at an issue by reflecting on it from different points of view—moving round the problem and actions they have taken, then reflecting on the action to redefine issue and further action. Circumambulation is taken in a circular, not linear way.

Constructive circumambulation We found that learning takes place as people 'circle' ideas *repeatedly to make sense of their world in order* to *test* action*s that work and allow them to gain* control over their lives. This we term 'constructive circumambulation'.

C. Durham and P. Ramcharan, *Insight into Acquired Brain Injury*,
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Fieldwork to be immersed in, live with and like the people who are studied (van Maanen, 2011).

Flow when the person becomes so absorbed in an engaging and interesting task that action and awareness merge (Csikszentmihalyi, 1990, 1997).

'Grey' literature the term used for information that is not in the mainstream published journal articles. These monographical narratives may be published by commercial publisher or self-published.

Headwork thinking about an issue making connections of how knowledge gained from the literature was analysed, evaluated and applied (van Maanen 2011).

Insiders 'emec' perspective this term is used in anthropology, social and behavioural sciences to research from the perspective of the insider—from within a certain group. In this study from the perspective of the person with brain injury (Pike 1954).

Intentionality meaningful behaviour based on the person's perception.

Interpretative phenomenological analysis a detailed exploration of how participants are making sense of their personal and social world. This is an experiential qualitative approach to research.

Lifeworld (*Lebenswelt*) the world of the person's lived experience (Husserl, 1952, 1962).

Outsiders 'etic' perspective this term is used for research from the outside, from the perspective of the observer, the researcher (Pike 1954).

Phenomenology philosophical reflective study of experience and consciousness from the first-person point of view (Husserl, 1913).

Qualitative body-object model the body as a subject—research explores intentionality—meaningful behaviour based on perception. Research exploring meaning in context. The approach is therefore more process-orientated, offering 'thick' description. Body-subject research around ABI is emergent with a focus upon identity, coping, adaptation, recovery and resilience. Much less research has been undertaken around the range of experiences and social lives of people with ABI.

Quantitative body-object model the medical model that primarily focuses on the body as an object to 'mend'.

Textwork writing after listening to and observing people to produce stories and narratives (van Maanen, 2011).

The 'golden period' We have employed this term to identify the time frame of two years directly after the person acquires their brain injury. From the perspective of the professional (the outsider), the greatest recovery is presumed to happen within this time. We have adapted this term from **the 'golden hour'**, the time directly after a traumatic injury when there is greatest likelihood that prompt treatment will prevent death. Note this term is used with the specific aim of drawing attention to the different convictions of the professional (the outsider) and the person with brain injury (the insider). For them, this is the **'dark hole period'**; this period is far from golden—it is the 'dark hole period'.

'Thick' description description that explains not just the behaviour, but its context, so that the behaviour can become meaningful to an outsider.

'Zone of proximal development' a learner achieves learning with the assistance of scaffolding from the teacher or a peer. The scaffold is slowly removed (as scaffolding is removed from a building when construction is complete) leading to more independent and autonomous change based on reflection and learning (Vygotsky, 1978).