Managed Identities: How do Australian university students who stutter negotiate their studies?

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Abstract

Previous social research focused on people who stutter has problematised and largely ignored the experiences of university students who stutter, relying heavily upon surveys of teachers and peers while almost ignoring the authentic voices of students who stutter. Using a novel bricolage approach incorporating autoethnography, this project posed the question: "*How do students who stutter negotiate their university experiences in Australia?*" In 2008, a unique, web-based audit of 39 Australian public universities concluded that little publicly accessible information about stuttering support services was available for prospective university students. In many ways, stuttering is absent from disability classifications and service systems in higher education. An online survey of 102 Australian university students who stutter, and follow-up individual interviews with 15 students, revealed how these students manage their social identities from enrolment through to graduation. Only a minority of students reported ever formally disclosing their functional impairment to university support services or academic staff. This meant they rejected and/or avoided the disability label and associated stigma. The students were found to exercise a high degree of individual agency and creativity throughout their university journey. Many employed 'concessional bargaining' techniques to effectively navigate the oral assessment requirements during their degrees. Analysis of the interview and survey data is interspersed with critical self-reflection by the author – as a university lecturer who himself stutters. This thesis makes a significant contribution to shaping our understanding of the social identities and trajectories of university students who stutter. These students have been recast as positive, purposeful, resourceful and creative agents whose actions can be largely understood from a social model of disability. A series of recommendations for supporting and teaching these students are made to key stakeholders in higher education.

Statement of Authorship

Except where explicit reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma. No other person's work has been relied upon or used without due acknowledgement within the main text and list of references of the thesis.

Signed:
Dated: 09/08/2019
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Statement of Ethical Approval

Ethics approval from the University of Ballarat's Human Research Ethics Committee was granted (no: A08-182) for this research approach. The approval notification is in *Appendix C: HREC ethics approval* and the final report in *Appendix H: HREC final report*.

Publications, presentations & press associated with this research

Peer reviewed journal article

Meredith, G., Packman, A., & Marks, G. (2012). Stuttering, Disability and the Higher Education Sector in Australia. *International Journal of Speech-Language Pathology, 14* (4), 370-376.

Invited International Conference Presentations

Meredith, G. (2018, 1st September). *Working at a University as a person who stammers*. British Stammering Association Conference. Cardiff, Wales, UK.

Meredith, G. (2016, 4th September). *Community, goals, research & self-fulfilment: Engaging the four senses,* Keynote presentation at the British Stammering Association conference. Manchester, UK.

Packman, A., & Meredith, G. (2012, 9th June). *Is stuttering a disability?* Paper presented at the First International Conference on Stuttering, Italy: Omega Edizioni.

Invited national presentations

Meredith, G. (2010, 19th February). *Stuttering: The University Experience.* Paper presented at the 13th Bi-Annual Speak Easy Convention, Sydney, Australia.

Meredith, G. (2008, 12th April). *Are Universities Stammering Over Stuttering?* Paper presented at the 12th Bi-Annual Speak Easy Convention, Adelaide, Australia.

International conference presentations

Meredith, G. (2019). *The importance of being a pro-active student who stutters.* Silence on Campus: Making a Noise about Stammering, London, UK.

Meredith, G. (2016). Fostering a culture of pride. Paper presented at the 18th International Stuttering Awareness Day Conference, Online. http://isad.isastutter.org/isad-2016/papers-presented-by-2016/stories-and-experiences-with-stuttering-by-pws/fostering-a-culture-of-pride-grant-meredith/

Meredith, G., & Packman, A. (2014, 19th July). *The experiences of university students who stutter: a quantitative and qualitative study*. Paper to be presented at the 10th Oxford Dysfluency Conference.

Meredith, G. (2010). *The Debilitating "D" Word*. Paper presented at the 13th International Stuttering Awareness Day Conference. From http://www.mnsu.edu/comdis/isad13/papers/meredith13.html

Meredith, G. (2009). *Stuttering: Falling through a hole in the academic web?* Paper presented at the 12th International Stuttering Awareness Day Conference. From http://www.mnsu.edu/comdis/isad12/papers/meredith12.html

National conference presentations

Meredith, G. (2009). *The Stuttered Minefield of Higher Education*. 9th Ballarat Annual University Research Conference: Innovation, Creativity and Engagement.

Meredith, G. (2008). *There is a Stutterer on campus?* 8th Ballarat Annual University Research Conference: Crossing Boundaries, Ballarat, Australia.

Poster presentation

Meredith, G. (2008). *Oh What a Stammered Web We Weave.* Poster presented at the Pathways 9 Conference, Melbourne, Australia.

Media article

Meredith, G. (2009). *University Education and Speech Impairment – Slipping Through the Web?* AGOSCI Infocus, 1, 26-27.

Invited public appearance

The Cost of Stuttering, Public Forum for International Stuttering Awareness Day, 22nd October 2009, Faculty of Health Sciences, The University of Sydney.

Media/Social media appearances

Critchley, C. (2009, 17/10/2009). *Understanding Stuttering*. Herald Sun

Skilton, N. (2011, 10/10/2011). *Stutterers find consults confrontational*. Australian Doctor. , from http://www.australiandoctor.com.au/news/62/0c073162.asp

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A passage to ponder

When the great eternal Father had created the world and fishes and animals and birds, he still felt a great dissatisfaction. He was lonesome. So he declared, "I shall make a creature like myself, that I may talk with him and he may talk with me." So he created man. But man did not talk, and the great Father was still lonesome. He inquired the reason. "Aha," said he, "I have it: I shall give him a tongue and then he will talk." So he fashioned him a tongue agile and supple and put it in the man's mouth. But still he spoke not. The great One pondered. "No wonder," he thought, "he cannot talk without knowledge." So he endowed him with knowledge. Still man was as silent as the winter night. But at last in a flash there came to the great Father the ultimate solution. "Give him pride." So man received pride, and immediately he began to speak, using his facile tongue to tell all that his knowledge brought to him.

(West, 1925, p.167)

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A thesis to remember

Perhaps somewhat unconventional to some readers, throughout the body of this thesis I have openly and without shame interwoven my own stuttering-based thoughts, anecdotes and assumptions. Within this narrative journey I have decided to write in the first person as to give the story which unfolds with a more personal touch and identity truly of its own. I have also decided not to frame this study as strictly formatted as some researchers may have expected, yet I believe strongly that it still retains the true seriousness of its nature. To hold back my own stuttering experiences from you would amount to academic fraud in my mind denying you the chance to read a truly significant and impactful thesis. As would have the adoption of a conventional writing style which may have prevented me from naturally expressing the voices of the research participants and the significant findings of this study. This is a thesis that undeniably, in some form, has been influenced by the fact that I am a person who stutters, a university student who stutters and an academic who stutters. You deserve the right to know that you are reading a uniquely framed, honest and informed thesis. You also deserve the right to learn more about me the author and how I fit into the grand scheme of enquiry. This thesis has sought to understand some of the experiences associated with what it means to be an Australian university student who stutters and ultimately an academic who stutters, both identities that I continue to traverse daily. This journey is thoroughly elaborated upon and laid bare throughout this thesis. Please enjoy the path which unfolds and I hope it enlightens you.

An important preface

Here I sit in yet another committee meeting. ‘Another?’ you may ask. Yes, one of countless academic committees and working groups of which I am currently a sitting member of. Yet after sitting in over thirteen years of various academic meetings of all levels and purposes, I still feel a slight sense of apprehension. I think it is because this is the first time that this meeting has been held for the year and that there may be some new members who I have never met before, or new points of business to focus on. You may wonder whether I have some form of social anxiety or related stress levels. I do not, as far as I am aware, have any such issues to manage and in fact I am known for my cool headedness amongst my colleagues. I am an experienced level B academic, an award-winning lecturer and was once the Associate Dean (Student Retention & Success) for my Faculty. How can I have such fears, thoughts and apprehensions, if but fleeting? I can only assume that I have these feelings because I am a person who stutters and despite all my confidence, I still at times feel a little apprehensive in new professional settings. Perhaps more subconsciously that consciously. I am always unsure about how a person may react when first identifying that I have a very overt stutter. An overt stutter which at times can show long forced speech blocks and pained facial grimaces. I recognise that at times those understandable reactions from peers do have a negative effect on my immediate demeanour. Subconsciously I probably simply fear negative appraisal from my fellow colleagues. Universities can be at times very judgemental to work within and assumptions may be made about talent, worth and ability to work with colleagues very swiftly. In fact, the academics who are reading this will be able to quickly sympathise with how cutthroat and elitist academia can be. Despite these challenges, these apprehensive thoughts for myself are but fleeting and I doubt that anyone would acknowledge that these little concerns even exist within me. On the surface I am calm and collected, measured and sometimes proudly controversial. But I ask you the reader. Is this identity just a mask that I conveniently wear at times to hide my true nature?

Chapter 1. Introduction to the study

Introducing the study

Before embarking upon this journey it is important to know who I, the researcher, am and how I came to be motivated to undertake this research. I want to add truth to any immediate assumptions that you may have about my motives for this research. This may be seen as an unconventional start to a thesis, but I believe that it is the best way to contextualise this research project and to engage you as the reader into investing the time required to thoroughly read it. So, I begin writing this thesis sitting alone in my home office perplexed within my own thoughts and beliefs with two questions in my mind. Broadly speaking, what is it like to be a university student who stutters? And in turn, who am I as a person who stutters? I hope to help answer both of these questions for you throughout this study and present enough insight for you to form your own opinions around them. Both of these identities are tightly intertwined within the narratives to come and as the notion of "identity" itself forms the crux of discussions pivotal to the heart of this overall study.

It may be of interest to the reader that this research project began its initial life as a very different proposal from what it eventually evolved into. The original broad early aim for my PhD was to form a framework of universal design rules to assist e-learning developers to create online teaching platforms and materials, and in turn, make them more accessible with disabled users in mind. Essentially, this was about designing software applications with the Visual, Auditory and Kinaesthetic (VAK) learning model and in turn, making digital learning platforms more accessible in nature. I am an information technology lecturer after all and have a passion for lecturing. I also have a heartfelt desire for making education accessible to as many people as possible and this passion resonates throughout this study. A passion which my own university is known for and markets from. The proposed research would have then looked at human-computer interaction design, issues of usability and the broadening of accessibility for global online learning. But this proposed research took a rather sudden change of focus due to a series of fortunate events .While in the early stages of the associated literature review, I reviewed a large range of disability action plans across various Australian universities in terms of general disability service provision and including any mention of universal application design. Along the way, I observed that there was little mention at all in terms of disability or educational provision for students who stutter or who have other commonly known verbal communication disorders. I read about quite a range of provisions for students who were mobility, hearing or sight challenged, but other conditions seemed to be less focused on or overtly mentioned. This perceived absence of support became a serious refocus for my study and it genuinely interested me. I felt a serious passion rise inside me and for weeks I pondered this mentally. After continued serious contemplation and discussion with my initial supervisorial team, I decided to change topics and to focus on researching the experiences of Australian university students who stutter. But why the sudden interest and passion in the plight of students who stutter, you may ask?

Perhaps being a person who stutters (PWS) myself may have influenced me to subconsciously focus on “stuttering” during the initial literature review, but the decision to change topic was ultimately more of an academic decision. I certainly did not walk into candidature with noble motives in mind to become the educational saviour of people who stutter and to be prominently known for such a research focus. I have to be honest with you that the plight of my fellow students who stutter was not an original idea or motive at all. My initial literature search had identified a group of individuals for whom little research and directed guidance had been conducted and formed within the frameworks of university life. Further to that, little precise university support provision was overtly mentioned for these students on the Australian university websites that I examined. Based on these findings, and my own experiences as a student who stutters, I understood that this is a cohort of students for whom, in general, the university experience has probably not been an overly satisfying journey of graduated success. But having said this, being a PWS myself and studying fellow PWS has advantages. Advantages in fact that would and have assisted my quest for knowledge. These advantages included the willingness of the studied group of PWS to be more open to truly emphasise with, understand the worth of and support my proposed study. More often than not, I have seen the PWS community cry out for people within its own ranks to conduct research deemed as “beneficial” and to be “authentically” lead. Although I believe that people who do not stutter can and do research that does benefit people who stutter. I can understand some of the frustrations vented by my fellow PWS. Many of whom believe that if you have not lived the experience of stuttering then you cannot truly understand its impact upon the individual. I take a different view because I believe that simply having a stutter does not make you an expert in the condition. Yes, you have the lived experiences of stuttering, but you may not have the respective discipline knowledge to understand a scientific view of the condition or may not have the resources to do so. A view for which I face ridicule and opposition myself from within my own stuttering communities. For myself this study has become a deeply personal social justice study which has made, and continues to make, true tangible positive changes in terms of disability support provision for university students, including, but not only limited to, students who stutter. Yes, the findings of this study will resonate well beyond university students who stutter and will help to shape educational pathways of a diversity of students in need of provision. This I truly believe.

I will reiterate that this thesis will lead the reader on a unique journey into the trials and tribulations of university students who stutter within the Australian university context, which in turn has meaning for the educational journeys of students who stutter globally. This thesis also presents findings and lessons that may be applied to students who have a form of disability and students from other minority groups who need university support provisions. Initially in this thesis, the contextualisation, justification and needs for such a study are outlined. These main threads of thought and concern will be of consistent focus throughout this thesis. I will also include and interweave throughout this journey an expanded and deeply personal account of my stuttering life in an ethnographic way, my associated educational experiences, my at times challenged assumptions concerning the findings and the overall research question of this study. The literature review sets out the framework of stuttering being framed in Australia legally as a disability, which is a major thread that winds itself throughout the thesis. This thesis also includes a unique look at the academic and educational studies and promoted provisions for students who stutter from primary education through to higher education level, giving the reader a more holistic grounding into how schools of all levels have strategised to support such students. This thesis is powerful insight into the forming of contextualised forming and the strong agency of Australian university students who stutter.

Additionally thesis will outline and employ the novel “bricolage” approach to data gathering and resulting interpretation (outlined in Chapter 4. Research design). Bricolage is a methodology that proposes the possibility of an evolving and multi-faceted approach to research design (Denzin & Lincoln, 2000; Kincheloe, 2004). Within the Bricolage research design to gather and analyse data for this research, I designed three uniquely complimentary and sequentially based studies. The bricolage approach has given me a framework to research within which is flexible and adaptable to suit the answering of the research questions at hand. These complimentary studies included an audit of Australian university online disability information related to stuttering, an online survey of 102 Australian university students who stutter and semi-structured interviews with 15 Australian university students who stutter. The open-minded methodology of the bricolage approach has enabled the research to give an overt, fluent voice to those who are at times known to be hesitant about speaking up about issues affecting their lives. In fact is has enabled a voice to those who themselves acknowledge that they often hide from social interactions and avoid confrontations requiring challenging verbal interactions. The findings of this study have the potential to push true educational provision change and with each reviewing of this thesis, I find myself pushing more towards advocacy. Throughout this thesis you will see consistent themes twist themselves through the emergent narrative. These themes include a disconnection with the term “disability”, policy-rigid provision of disability assistance and university success via the self-concessional bargaining strategies. However, overarching these operational themes is a strong emergent theme of identity, which is explored in detail throughout later discussions.

Clarifying some terms

It must be noted early in this study, to avoid any confusion for the reader, that the terms “stutter(er)” and “stammer(er)” are often used interchangeably by researchers depending on their cultural standing, but are generally accepted globally to mean the same condition (Allen, 2011; British Stammering Association, 2011). For example in the USA and Australia “stutter” is used, yet within the UK “stammer” is promoted. Actually, some PWS themselves are confused between the meaning of the two terms and I have found them at times trying to differentiate meanings. I have decided to use the more widely used term “stutter(er)” to encompass both terms and this is in fact reflecting the Australian use of the term. Personally, other than being raised in Australia with the use of “stutter” I prefer this term over “stammer” as it seems to resonate with personal tones of confidence and power. To me, “stammer” feels apologetic in nature possibly aligned to a stereotypical view of English culture.

The term “lecturer” may also be confusing to some readers. In the Australian context a person who lectures at a university is commonly employed in an academic role in which undergraduate and/or post-graduate teaching is a component of their overall academic duties. Their duties often include fractioned workloads incorporating lecturing, administration and research. However, some other settings and cultures may associate this academic lecturing role as being, for example a “professor”, “teacher”, “instructor” or an “academic”. I have chosen to use the generic term of “lecturer” due to its relevance to the Australian university students surveyed and interviewed.

The aims of this research

I think it is time to refocus you on the overall point of this research and why it is important at all. The aim of this study was to understand deeply the nature of the experiences of being a student who stutters who has been engaged within the Australian Higher education system. To reiterate this study was conducted via an exploratory bricolage methodology and evolved into three distinct, but sequentially complimentary, stages to gather data. The first stage involved a content survey of disability services websites of 39 Australian public universities looking at publicly available guidelines on how to teach and assess a student who stutters. The second stage of this study included an Australian-wide survey of past and present students who stutter as a way of, trying to gain a generalised mass snapshot of lived experience and opinion. This thesis concluded with the third stage employing a series of in-depth semi-structured interviews of a self-selected group of students who stutter identified through the surveys, in order to flesh out the personal narratives of the experiences of the individuals their university careers. The rationale for bricolage methodology and chosen methods have been explained in detail later in this thesis (Chapter 4. Research design).

The overall aim of this study was to attempt to understand and gain valuable and previously unknown insights into the experiences of students who stutter who have engaged with the Australian higher education system and to give an outlet to respondent's voices who may have remained silent for too long. This study has spanned evaluating the nature of information provided by Australian universities regarding teaching and assessment strategies for students who stutter, through to analysing the interactions of students who stutter with university-based Disability Service professionals, to investigating the general class-based experiences and the perceived attitudes of staff and students towards the stuttering students involved.

In turn the over-arching research question of this study is:

"How do students who stutter negotiate their university experiences in Australia?"

To assist to answer this question the following three sub-questions have been designed:

1. *"How do Australian universities publicly represent their disability resources to a prospective student who stutters?"*

   This question will help us to understand from a public view level found university strategies for supporting and teaching university students who stutter. This question will also help us to understand the feelings of support that these students may feel coming into university studies and will assist us to further understand their actions once enrolled.

2. *"How do Australian university students who stutter describe their experience of the student lifecycle?"*

   This question is designed for us to broadly understand the lifecycle of a student who stutters from pre-enrolment through to graduation and the sense of general agency affecting their decision-making. This question also involves looking at what identity (ies) these students form and adopt during their enrolment. It is the largest sub-question to be answered and most complex.

3. *"How has the doctoral candidate himself, as someone who stutters, framed his identity within a university setting?"*

   This final sub-question will weaves itself throughout all the chapters and discussions to come leading the reader to more intimately understand the author, their journey and how they identify themselves as a person who stutters.

Now that you understand the motivations and aims of this research, I will set the ground-work to justify this study in assisting you to understand the structure of the conversations to come.

Disability & educational equity

In an ideal world, equity of access to education and resulting experience of educational achievement along with associated self-pride would be high social priorities. But the world faces many challenges in terms of equity, and education is but one of those challenges. The challenge of addressing the equity of access to education for people globally and specifically for those who are termed “disabled” is a constant battle of priorities (Steffen & Stafford Smith, 2013). As a nation, Australia has a vested interest in breaking down these barriers of inequity to education due to the rising number of aging citizens who can be classed as being “disabled”, and who may be at times dependent (or semi-dependent) on the provision of government benefits, in need of a tertiary education to gain an employment advantage and are quite capable of successfully engaging with higher education. (Burkhauser, Daly, & Lucking, 2013; McVicar & Wilkins, 2013). A 2009 study conducted throughout Australia by the Australian Bureau of Statistics (ABS) called the Survey of Disability, Ageing and Carers (SDAC) indicated that at that point in time, close to four million Australian citizens (18.5%) had reported having a disability and 87% of those self-reported as being “disabled” had restrictions to daily life which included impaired communication abilities and access to education (Australian Bureau of Statistics, 2011). This number of disabled and impaired people will only rise in future years due to the rapidly ageing population in Australia forcing the hand of government to further ensure and plan for equity of education and planning for a more enabled future for all citizens (Deloitte Access Economics, 2011). The ABS uses the World Health Organisation’s (WHO) International Classification of Functioning, Disability and Health (ICF). The ICF is a well-established and globally accepted framework for defining and organising different defined types of disability and their associated health components (World Health Organisation, 2001). This study aims to provide in depth understanding of the university stuttering experience in order to better prepare both universities and students who stutter to bridge the barriers of educational inclusion and enable students who stutter to access support to have more empowered and satisfied educational journeys.

Justification, significance & contributions of this study

To properly understand the significance and contribution of this study to the body of knowledge and to the practical lives of students who stutter, it is important to solidly understand what stuttering is and its associated impacts to the person who stutters. It is also important to understand that it has been argued that how a person who stutters may form their identity as a person who stutters is not a strong factor in terms of providing professional intervention (Kathard, 2003). Stuttering is a condition which directly involuntarily interferes with verbal communication and many people who stutter face a world of negative perceptions and stereotyping because of their stuttering behaviours (Betz, Blood, & Blood, 2008; Dorsey & Guenther, 2000; Hughes, Gabel, Irani, & Schlagheck, 2010; MacKinnon, Hall, & MacIntyre, 2007). The cause of stuttering is still relatively unknown, continuing to produce a range of theories and models in the attempt to explain its origin and development, and in turn to validate professionally accepted treatments (Packman, 2012; Packman & Attanasio, 2017). Of late there has been a large and continuing focus on the neurological mechanics of stuttering which have generally indicated structural anomalies within the speech language areas of the brain (Ingham, Ingham, Euler, & Neumann, 2018; Packman, Code, & Onslow, 2007; Sommer & Primaßin, 2018). But still there is no definitive cause of stuttering that has been identified with more neurological research, investigations into genetic causes and longitudinal studies of stuttering development being undertaken (Frigerio-Domingues & Drayna, 2017; Misaghi, Zhang, Gracco, Luc, & Beal, 2018; Watkins, Chesters, & Connally, 2016).

Research into the human and social sides of stuttering has been viewed as being extremely limited from as early as the late 80s (Quesal, 1989). It has been only since the early 2000s that qualitative approaches to stuttering research, including the voices of those being studied, have been argued and adopted as a way of helping academics to research more deeply lived experiences of people who stutter and also as clinical alternatives to traditional quantitative style measures (Hayhow & Stewart, 2006; St Louis & Tellis, 2015; Tetnowski & Damico, 2001; Tetnowski & Franklin, 2003).

Conversation alone is framed as an essential fundamental human activity, yet many adults who stutter intentionally avoid verbal communications in social environments and in turn many social interactions themselves are purposely avoided, not to mention verbal interactions in other settings (Acton & Hird 2004; Iverach & Rapee, 2014; Mahr & Torosiana, 1999). Studies have shown that many people who stutter believe that their stuttering had a negative impact on their employability and job performance (Klein & Hood, 2004; Palasik, Gabel, Hughes, & Rusnak, 2012; Yaruss, 1998). Some adults who stutter have also reported seeking out careers that do not involve or rely heavily on verbal interactions (Adriaensens, Beyers, & Struyf, 2015; Hohulin & Sawyer, 2010). But contrary to some beliefs, in some cases once employed people who stuttered appear to seek leadership positions and did not always experience negative peer feedback at work towards their speech (Palasik et al., 2012). As a result, it follows that some people who stutter fail to pursue their preferred career choice (Manning & DiLollo, 2017) and instead choose one that they think they may be able to manage their speech more easily within. It may surprise some readers how impactful stuttering can be upon the soul of the person afflicted and how the impairment of oral communications can impede achievement and quality of life.

The following chapter (Chapter 2. Literature review), shows that there are pockets of research that have been done investigating how stuttering affects people in social and vocational settings, and in their school careers; kindergarten through to year 12 (K-12). The research in that chapter has also identified that there are far more resources in the form of teaching and assessment guides related to people who stutter available to educators teaching K-12 than are available for educators in the higher education sector. Little is known about how stuttering impacts upon the learning experiences of university and college students, and general research into the school experiences of people who stutter across all education levels appears to lacking (Ribbler, 2006). It has been debated that stuttering-related academics and speech therapists need to be included more with the devising of effective educational strategies in this regard (Davidow, Zaroogian, & Garcia-Barrera, 2016). This study proudly positions itself to be the first known academic study to focus in-depth and breadth on such impacts and experiences in a purely higher education setting. It is presumed that university students who stutter will be impaired to varying degrees by their stuttering in ways that they may have already experienced during their primary and secondary school years. One might predict, therefore, that they are likely to avoid tutorial discussions, giving oral presentations, and/or being active contributors to class debates at university. These are predictions that need to be empirically studied and presented widely to the world. As a result, you could hypothesise that it is likely that students who stutter may not be achieving their full potential in terms of academic results or performance satisfaction.

A national audit of Australian university websites outlined in “Chapter 3. The web-based audit” indicated that, despite stuttering being legally framed as a disability in Australian national legislation, very few of the public university websites surveyed provide any form of targeted information for prospective and/or current students who stutter on how the university can assist them to overcome the impairment of their stuttering on their academic performance. Also, the investigation showed that very few universities in Australia had any form of publicly viewable resources for lecturers or other relevant university staff that could inform them about the nature of stuttering or about how to directly assist a student who stutters. The reasons for which these lack of resources exist I will discuss in chapters to come.

This overall thesis, and the web-based audit in particular, has contributed knowledge that is critical to understanding the experiences of university students who stutter and has provided a basis for the development of resources for use by university disability services and other similar organisations. The purpose of this study was not to definitively prove anything either from a pure quantitative or a statistical viewpoint about students who stutter. This study, with its heavy qualitative focus, has enabled the researcher to open the doors of further exploration about how students who stutter manage their stuttering within a tertiary environment and how universities could assist to enable them to perform closer to the best of their ability. This study identifies a gap in the current knowledge about students who stutter, enables it with a pool of authentically provided knowledge and elaborates pathways for future studies to continue a focus in this key area.

This study will outline a narrative of a range of experiences of students who stutter and provide valuable insight into the nature of being a stuttering student enrolled in an Australian university. This exploratory study, and its associated rich understanding of those experiences, has enabled the researcher to make recommendations about how the university life of people who stutter can be more informed, supported and improved from a range of different lenses. The Australian-wide survey of students who stutter has enabled the researcher to gain a broad understanding of this research-neglected group of higher education students. As mentioned earlier, no such study has yet to be conducted in such a methodological manner nor in such depth in the literature. The results of the survey of 102 participants helped to shape and inform the third stage of this research, which were a series of follow-up in-depth interviews of 15 Australian university students who stutter. These interviews enabled the myself to further explore student experiences and feelings in a truly rich narrative manner. It was truly liberating as a researcher to be able to give voice and encouragement to those in need and to those who wanted so strongly to be empathised with and heard.

The results of this study will help universities in Australia and across the world to form strategies to encourage people who stutter to enroll, be more open about accessing disability accommodation procedures and be more supported within their chosen degree paths. As a result, students who stutter will hopefully increasingly make career choices that they desire and that they are suited towards, as opposed to settling for less satisfying career and job options. Positive educational and life experiences could possibly cause a ripple effect beyond their professional lives and into their personal lives and, in turn, help to foster happier and more productive citizens. The overall aim throughout all my research endeavours is to provide opportunities to improve the quality of lives of people and in turn lead to increased contributions to societies. Perhaps a pipe-dream, yet I know that even if this study can assist one person who stutters to be happier and successful within their life choices then the project has paid for itself many times over.

This research has already contributed to current literature through academic publications and presentations (see Publications, presentations & press associated with this research) globally. This research has also helped to open up further discussion about the experiences of students who stutter at all levels of tertiary education, and to further encourage debate, awareness and further research. In fact parts of this research have already lead to robust discussions at academic conferences and conferences focused on people who stutter. I have demonstrated that this research has the appeal and rigour that has been accepted by academic audiences and also to those who will benefit the most from it, people who stutter. Stuttering communities and support organisations have been highly supportive of myself and this study (see *Appendix A: Letters of support*) while eagerly awaiting the final results.

The author – the person who stutters

As expressed earlier in this chapter, I am a proud person who stutters. Not in a sense of being proud that I have a stutter, but in being proud of who I have become while co-existing with my stutter. I view my stuttering simply as one of my personal characteristics. I have experienced the good and bad nature of societies in terms of acceptance and ignorance of stuttering. I have experienced firsthand the nature of being a student who stutters engaged in both the tertiary and higher education sectors from a Certificate Two at the vocational educational level through to being a PhD candidate. I was fortunate enough to have been educated through a dual-sector university pathway in which my vocational qualifications were credited to a pathway into a higher education degree. I see myself proudly as being a child of my university and am very active in promoting it as being inclusive. In fact I was named as an Alumnus of the Year in 2015 for Federation University Australia. Having knowledge of both different adult educational sectors has also aided my career and overall university operational knowledge. I am very passionate about promoting the trials and tribulations of people who stutter and the need for self-advocacy. I helped to lead and manage Federation University Australia’s (previously known as the University of Ballarat) first, and to date, most successful crowdfunding campaign in 2013,which assisted in funding the development of an online social simulation tool for people who stutter called Scenari-Aid (www.scenariaid.com). Scenari-Aid currently has over 3600 registered clinical and individual users and is being used for conditions well beyond stuttering alone. A project of which I have recently expanded thanks to philanthropic funding to include a similar platform for children who stutter. I am also the leader of the Technologies for Empowering People for Participation in Society (TEPPS) program which sits within The Centre for Informatics and Applied Optimization (CIAO) within my School. TEPPS aims to enable the lives of people the world over through radical design of software and hardware solutions. You can see that my research passion is focused on improving the lives of others and enabling positive life change.

I am also very active within stuttering communities worldwide via participation within online support groups, publishing in stuttering-related newsletters, magazines and journals, and working closely with academics that are focused within various realms of stuttering-related research. Having access to these large and varied support networks has proven to be invaluable to the success of the present study. I have been an invited speaker at both the Irish Stuttering Association and British Stammering Association conferences. As such, this research for me is an example of empathetic research and has promoted and shown the strengths of such research focus. I am highly passionate about improving educational access for not only students who stutter, but for all people choosing to educationally advance themselves. I feel that this is a deeply personal and explicitly political project linked to issues of social justice and the basic human rights of all people, inclusive of, but not exclusive to, those who stutter. I am happy to continue to do my part in my own ways to assist in the education and enlightenment of others.

To understand my stance within this thesis, my history of being a student who stutters is important to you the reader. I recall the conscious recognition of beginning to stutter at around the age of eight. I remember well the first time that I became self-aware of my own stuttering, and in turn I noticed a point of difference between myself and other students. I was honestly unconscious of my stuttering existing before this initial awakening and have no pre-memories of problems mechanically producing speech. At the age of eight to nine I was at Somers School Camp which was a popular annual event drawing a selection of primary school students from many different and diverse primary schools across the state of Victoria, Australia. On the first night, we were individually split into student-house teams made up of students all from different schools. We then formed a seated ring to introduce ourselves to each other. When it came to my turn, I could not say my name and I blocked heavily with a contorted face. A "block" is when I am trying to speak but the words will not come out, in turn producing signs of physical struggle and tension. I was in an internal panic trying to force out my name and I cannot remember a time before that point in which I could not say my own name, or in fact that I could not say any word. I was a very talkative child who had a reputation for talking to anyone anywhere. I was fully confused and upset about what happened. I was upset by the sudden lack of ability to say some simple words and taken aback by the shocked and amused reactions of all of the other students sitting around the circle. These were young peers who themselves probably did not have the maturity or life experience to be able to react in a mature fashion to people with overt differences.

Again, I will reinstate that I had always been a socially outgoing and very confident child who could communicate freely and jovially. Not that much changed as a result of that confrontation from a speaking confidence view, but from that point onwards I was fully conscious of my developing stutter, which slowly evolved over time with varying different behaviours and styles. To be honest, even at this young age I was not sure what was actually happening, why it was happening or even what it was called. Around the time of that event I remember seeing an episode of the popular American television series called "*Little House on the Prairie*" and seeing a girl who stuttered on an episode called “The Music Box”. But I did not make the connection at that point that I also stuttered. During my growing maturity I simply did not identify with the portrayals of people who stuttered. Nor did I recognise any other children at my school who stuttered or know of any stuttering heritage within my family. It is only of late that I realised that an uncle stuttered. I just thought of his speech as being “not the same” as others. Yet I knew that something was developing within me that made me “different” to the other kids.

I grew up on the outskirts of Beaufort, which is a small rural farming town in Western Victoria, Australia with at that time a rough population of approximately 3000. The town had all levels of schooling from kindergarten to high school year 12 and attracted students from a wide country catchment area. Throughout primary school my speech was, surprisingly, not much of an issue to myself or peers. I think due to the fact that I was raised in such a small county town with associated community values and because my stuttering during that period was not severely overt all the time that I was never really picked on because of my stuttering. It was a tightknit community in which everybody knew everybody else with a strong sense of country comradery and resilience between us all. To be honest I was picked on for other things, including my woeful, mother-influenced, fashion sense and home-styled haircuts from my father. In general, my fellow students and town was fully accepting of who I was and/or were while ignoring my “different” way of speaking. The class of students who I grew up with were also a tight unit with most of us being together through our entire primary and secondary education years.

Reflecting back to those times, I remember in upper primary school some of my friends and I were picking on a new kid who had an obvious lisp. Which I now recognise as a clear state of bullying, yet then in my youth I never really identified it as such. So there I was, a kid with a stutter, picking on a new classmate with a lisp and a slight English accent! I was a community “insider” and had the acceptance that this new “outsider” lacked. I regret the introduction to my school that this kid received and although quickly accepted he was given nicknames always which reflected his speech impairment. Yet I never carried such a burden on my shoulders. I do not recall meeting or recognising anyone else who had a stutter during my childhood. As mentioned earlier, only of late have I realised that one of my uncles did have a form of stutter. But I never recognised this when I was young and would travel to Melbourne for family functions. I just thought the "umms" and "aahs" were simply how he spoke. I only actually recently recognised his speech as even being different to the norm. Reflecting back, I never saw anyone speak of his stuttering or have known of him being treated differently because of it. Nor did he ever approach me about my evolving stuttering.

My high school years, which were in the same small country town, were also filled with similar ongoing support and acceptance by teachers and fellow students alike as I had experienced throughout primary school. I remember doing some well received and personally satisfying presentations and debates during my early high school years. As my stuttering behaviours developed and changed, from requiring tapping a tempo out on the desk in order to answer a question in class through to very severe and long facially contorted blocks, I continued to be a productive student. I persevered through having to read Shakespeare out aloud in English class. In fact, I was often called upon to read out aloud in class with a constant stutter due to the teacher's appreciation of my ability to read dramatic writing and pronunciation. I was so speech-active that I even acted in my Year 11 drama play and often volunteered for debates, at one stage just missing out on selection for a high school radio quiz competition. I was completely self-aware that I spoke differently to everyone else and I was aware that everyone else knew. I was just accepted for who I was in a plain and simple country fashion. I never received any speech therapy or school-based assistance for my speech. To my surprise, I was asked during the final weeks of my final semester of my final year of high school if I required any assistance to complete my completion certificate. Of course I turned down the chance of being put onto a government funded waiting list for speech therapy at the age of 18, a month from completing high school and was slightly offended by the suggestion. Even with my limited knowledge of speech therapy and stuttering, I assumed that there not much could be done for my speech within such short time frame that may lend me an advantage in studying and completing my final examinations.

After completing high school, I worked in various careers, mainly those requiring strong communication skills. Most of these jobs were sales orientated and required constant and at times in-depth customer communication. I worked in male fashion sales for close to six months and within weeks of starting, I was competing for sales targets successfully with longstanding staff. I was not initially drawn to a career requiring a higher education degree or a large amount of further education purely because of my lack of interest at the time. I had finished high school and was unsure in which direction my life would head. So I worked through fashion sales, to different other retail positions and through to a range of wholesaling jobs. For almost one year I worked in retail for a florist shop and learnt so much about effective communication by having to interact with so many different customer types and differing situations requiring gifts. These situations ranged from Valentine's Day and anniversaries though to funerals. The wholesaling jobs I moved into required me to visit various shops and factory sites which really improved my overall communication skills and ability to have conversations with many different types of people. Please keep in mind that my stuttering had been professionally rated by a speech therapist when I was in my early 20s as being quite severe as I stuttered on 33% of spoken syllables when I was rated. I was interested at that time if there were any "easy" ways to address my stuttering as I was lightly contemplating travelling overseas to work and was unsure how it would be viewed within other cultures.

I decided to enrol at university as a mature-aged student while in my early 30s to instigate a career change towards information technology. Some friends of mine had just recently graduated from a Bachelor of Computing and I thought that I may as well follow their lead and improve my future career options as a result. I entered this new adult-filled educational environment with my usual high social and speaking confidence. I remember noting on the enrolment form that I could tick a box indicating that I was "disabled" and struggled to think exactly what they meant by that. Only one thing came to mind in my case and I thought for a moment guessing that stuttering was not a disability and also assumed, based upon my previous school experiences, that no help was available. Also, without any knowledge of what advantage in schooling I may gain from such a tick box, I did not see any real value in flagging my “disability”. I thought to myself what would they do with such information, why do they want to know and would it have an effect on my enrolment selection? Assuming that stuttering is not a disability and that there was no help available are themes that resonate strongly throughout this study, as does the fear of discrimination based upon flagging your differences. I guess I was also a little confused about why I would check the box at all in my circumstance and the advantages of doing so.

Throughout my three years of undergraduate study I faired very well from a vocal point of view and I did not have to rely on help or provision to achieve strong results. I asked questions aloud, answered questions out loud and gave verbal presentations. To achieve these results, I had to focus on my classes, study hard and submit my assessment items on time, some clear strategies that I reflect to students even now in my academic roles. In this adult-orientated educational world, I felt similarly treated to the way I had been treated during my primary to secondary years by my peers. No one seemed to care about how I spoke, but occasionally there was the odd social grin or chuckle at my speech. I was, however, accustomed to such responses similar to those I had encountered most of my life by people who did not know me or were simply not used to seeing a person stuttering. These were in my opinion completely natural and understandable responses to me stuttering. Nor did I feel discriminated against by lecturers or marking rubrics for oral assessments. It may surprise readers that during my Honours year I gave a mid-year presentation concerning my minor thesis and received a 100% grade. This shocked me as during this presentation by chance I was having a particularly heavy stuttering day and blocked on almost every second word. Yet the academics marking in the audience said that they could not fault my overall presentation ability and materials.

Once, out of curiosity, I did enquire about service provision from disability services. I am a strategist and I wished to know what assistance there was for my speech if and when I needed it. To my surprise, there were little at hand and the support that was offered was largely based on avoiding speaking. These strategies ranged from asking to do alternative assessment items through to being the person n my speaking team who clicks the “next slide” button during the presentation. But perhaps I was not the right person to make such judgement calls due to my confidence levels? This lack of informed and client-steered service provision for students who stutter has become a common thread throughout this thesis.

After completing my undergraduate qualifications, I began to work as vocational education teacher teaching information technology and eventually became a university academic, experiencing life on the “other side” from being a student. My initial foray into teaching was nervous for me not because of my speech but because I did not have training or qualifications to teach. So this period was one of immense learning and confidence building. Luckily, I had a very good mentor who had taught me himself and initially I followed his style. I soon developed my own practical pedagogy and within my first year of teaching I was assisting to develop a new Diploma-level course. This lead to tutoring at a higher education level and an academic appointment. I remember well my first real lecture where I taught web-design to second year students. This class was also being peer-reviewed by a senior lecturer. I stuttered and blocked all through it and I have to admit that I was a little down about it due to the pressure involved. The feedback I received was so encouraging and the reviewer noted that I would not be as effective a lecturer as I am without my stutter. This shocked me and I wrote about the feedback for the British Stammering Association (https://www.stammering.org/speaking-out/articles/case-stuttering-lecturer). This journey led me to start to understand the challenges that face both students and educators alike in creating a full inclusive educational environment for all. An understanding that has led to past current appointment as an Associate Dean (Student Retention and Success) for my Faculty. Thus began my foray into planning and beginning a PhD degree as outlined at the start of this chapter. As a result of my experiences as a student who stutters and as an educator, I found the focus on an educational-based PhD project to be a natural one. Thus began a journey to aid the educational inclusion of students at need and with special needs. A pathway to give students who stutter a strong global voice to instigate change and in turn to make them aware that true change will only occur if they speak up and inform the systems at play.

Understanding the person who stutters

While my life story as a person/student who stutters seems to be a tale of open success and confidence, I can assure you that I am not the average example to learn from. Life for any student embarking on their way through the winding and turbulent path of a higher education degree will be full of new experiences, stresses and life shaping events. For a person with a complex communication disorder such as stuttering, the higher education path may be even more stressful and life shaping at times. Stuttering is a complex and highly variable communication problem which “can vary significantly from day to day, from situation to situation, and even from moment to moment depending on many different factors” (Bloodstein & Ratner, 2008; Packman & Kuhn, 2009; Yaruss & Quesal, 2001). Due to the influence of this turbulent speech-centred condition, the educational journey of a student who stutters is likely to be much more anxiety ridden and far more challenging than that of the general non-stuttering student, especially taking into account that not only must the academic curriculum be navigated, but so too must the cultural curriculum (Kasbi et al., 2015; McAllister, Collier, & Shepstone, 2012; O’Brian, Jones, Packman , Menzies, & Onslow, 2011). Presumably it would be hard to navigate a higher educational pathway, let alone life in general, ruled by a condition that can cause an uncontrolled, erratic and temporary inability to move forward with the fluent production of speech due to involuntary high frequencies of repetitions of syllables and cessation of speech movements (Guitar, 2013; Teesson, Packman, & Onslow, 2003).

Recent research has highlighted the psychological risks that are more likely to afflict a person who stutters from childhood to adulthood in comparison to a person who does not stutter. Iverach and colleagues (2009) found that adults who stutter have up to a 34-fold increased risk of meeting the criteria for being diagnosed with a social phobia in comparison to an adult who does not stutter. This in turn can lead to long-lasting effects on overall quality of life, careers and levels of educational achievement (Blumgart, Tran, & Craig, 2010; Iverach et al., 2009; Iverach & Rapee, 2014). Social phobia is primarily displayed in the individual as a heightened fear of being negatively evaluated in and during social situations and occasions. Social phobia for an individual can easily lead to high levels of avoiding social situations, social interactions and speaking in public (Craig & Tran, 2006; Helgadóttir, Menzies, Onslow, Packman, & O'Brian, 2014). The stresses that students who stutter could face when trying to fit into the largely independent, self-directed, socially complex world of university life, whilst also facing the challenges involved with actively participating in classroom activities, could be very high. University students who stutter are likely to be alarmed by most forms of oral-based assessments and also less likely to be active class participants, especially in terms of verbal interactions (Daniels, Gabel, & Hughes, 2012). Even a simple action that many people who do not stutter take for granted, for example a phone call, can cause some adults who stutter higher levels of anxiety and in turn increased levels of stuttering behaviours (Breathnach, 2000; James, Brumfitt, & Cudd, 1999; Petrunik, 1982). Despite these obvious concerns and the fact that raised anxiety levels are already present in many adolescents who stutter (Blood, Blood, Maloney, Meyer, & Qualls, 2007), there seems to be little known about, and only a sparse amount of research being conducted about the higher education experiences of students who stutter. In fact, there is little in-depth research about people who stutter across all levels of education and a distinct need to focus on the higher education experience (Azios, 2017; Butler, 2013; Meredith, Packman, & Marks, 2012).

The question of why there seems to be a lack of research interested in this area is an interesting one. Perhaps this lack of research focus is partially influenced by the commonly advertised and argumentatively accepted figure popularly quoted for over 50 years that stuttering only directly afflicts around 1% of the population (Andrews & Harris 1964; Ginsberg, 2000; Ginsberg & Wexler, 2000; Metten et al., 2011; Yairi & Ambros, 2013), which may imply to some that stuttering is only a "small problem" (Yairi, 2006). This "small problem" is more graphically depicted if put into real numbers. As of the 7th March, 2019, the estimated Australian population was approximately 25,440,529 (Australian Bureau of Statistics, 2019). If the 1% is accurate, it follows that on that date, there would be an estimated 250,000 Australians who stutter. Certainly not a "small problem" once put into a numerical value. It also does not help the cause of stutterers that the public in general seem to harbour many misconceptions about stuttering, including that it is simply a problem of speech production and underestimate impact that it can have on a person's overall quality of life (National Stuttering Association, 2009). Of that 1% of the population, an even smaller, unknown percentage would at some stage in their lives wish to undertake a higher education degree. Unknown due to the lack of data about these students and exacerbated by the fact that some students who stutter may not openly identify as such. For it could be hypothesised that once enrolled in a university degree, an even smaller number of students who stutter would disclose to university staff that they do indeed have a stutter and require assistance.

Perhaps the reason there is so little research in this area is simply is that it is not a current research priority in this competitive age of research funding. The plight of students who stutter may not be seen to be priority over more advertised and heart-felt causes such as depression, cancers or mental illness. Stuttering in general does not seem to attract constant media attention enough to continually push the need to raise awareness and associated research. Even within stuttering focused research, the priority and focus of such research currently looks to investigate the neurological origins of stuttering and the ongoing effectiveness of therapy programs, as opposed to the educational experiences of people who stutter. But then again, researching the cause of stuttering for most affected people would be a priority focus leading to more informed speech therapy programs and possibly an eventual cure. I often observe in stuttering social media groups that people who stutter are often wanting research to cure their stuttering as opposed to supporting them in their lives and daily activities. Or perhaps academia, governments and university-related disability services are unaware and oblivious to the experiences and hardships that students who stutter may encounter throughout any educational experience including the university level. To assist the need of more research to be done in the education space for people who stutter I believe that stuttering support organisations need to more prominently push their cause. This study has given Australian university students who stutter a voice to air their experiences and grievances, and to push awareness of their plight firmly into the global faces of educational researchers, decision makers and policy designers.

Thesis structure

The structure of this thesis will lead you on a directed and novel approach to understanding the experiences of Australian university students who stutter. A journey which has not been written in a pure scientific sense for which most readers would be accustomed to:

- Chapter 1 will lead you through the introduction of this PhD study and through to the significance and associated research question. This chapter will also situate myself in detail as a true participant within this study and give you a general view about the challenges that stuttering may cause for an individual;

- Chapter 2 is framed as a literature review, although I have woven literature throughout all the early chapters. This chapter shows the reader the links between stuttering, disability and stigmatism. It also relates stuttering to how it fits into Australian national and state-based legislation in terms of anti-discrimination laws and the right to education. I conclude the chapter with a novel approach of comparing teaching guides which address stuttering students from a primary through to tertiary levels and also look at the state of associated research aligned to these levels;

- Chapter 3 describes and outlines the findings of a web-based audit of 39 public Australian universities and there publicly assessable disability provision information. This study has a particular focus on stuttering and the results reflected a general lack of publicly assessable information about how Australian universities can support students who stutter. This chapter will answer the first of the research –sub-questions posed by the author;

- Chapter 4 outlines in detail the bricolage approach to research design and how it has been adapted and applied to this thesis This chapter also outlines unique mixture of methods which followed the web-based audit outlined in Chapter 3 and the uses of applied thematic analysis and autoethnography to assist with the discussion of the findings;

- Chapter 5 outlines the high level findings of the survey and interview methods setting the scene for the discussions to come. This chapter also describes the basic demographics of the studied cohort and assists the reader to frame the discussions which follow with an informed particular lens;

- Chapter 6 leads the reader through the start of the student who stutter's journey from pre-enrolment through to the enrolment process;

- Chapter 7 outlines in detail the pathway that students who stutter undertook if they chose to access their university's disability services units;

- Chapter 8 studies the in-class experiences of students who stutter and the strategies that they employ to adequately perform. This chapter also studies a unique range of questions asked of survey participants to help the reader to understand more about the impact that stuttering may have upon the studies and broader lives of university students who stutter;

- Chapter 9 is a uniquely structured chapter that leads the reader through the metaphor of a traditional Masquerade ball in order to portray the main themes that were found to be interwoven throughout the findings and discussions. Each major theme is portrayed as a mask-wearing dancer to promenade and explore the findings with;

- Chapter 10 discusses the main findings of this thesis in relation to the theory and constructs that underpin it. This chapter emphasises the contribution of knowledge that this study brings to body of knowledge and gives a range of advice to all invested parties identifies within the study. The chapter ends with recommendations for future studies and the overall results and repercussion of this study to the body of knowledge.

Now that you have a solid understanding of the motivations leading to this research, its contextualised importance and the structure of this thesis as a whole, it is important to learn more about the literature review that has driven the research's design, discussions and ultimate conclusions.

Chapter 2. Literature review

This chapter is set out to discuss the relationship between disability, stuttering and associated stigmatisms and identity shaping, then relate in turn how Australian legislation is shaped to set the framework of the equity of education provision. This will aid you, the reader, to further understand the discussions to come around stuttering as a disability and its connections to the perceptions and actions of studied university students who stutter. It also firmly establishes how Australia has both moral and legal obligations to help ensure equity of access to higher education opportunities for all. The relationship between the notion of disability and being a student who stutters has vast repercussions throughout the findings and discussions of this thesis. One of the effects of this relationship appears to be their strategic concessional bargaining techniques in terms of course participation which are formed during throughout their student lifecycles. A point of which will be discussed later in detail. The first part of this chapter discusses disability in relation to stuttering, related stigma and how in turn it could shape a student's identity. This second half of this chapter examines both academic studies and established educational guides from a primary to a university level regarding accommodating and teaching students who stutter. This will enable you to understand the current educational focus of stuttering research and commonly proposed institutional strategies to accommodate such a student in class~~es~~. An approach which is very unique in its design to help you to understand the general lines of support that are available to students who stutter of all levels and how in turn the disability liaison units may be influenced in their provided support strategies for students who stutter.

Stuttering: Disability, stigmatism & self-identity

This section considers whether or not stuttering is a disability and if so, how and why, with a particular focus within an Australian setting. It will also explore the stigma attached to being viewed as a person who stutters and how it can shape an individual's resulting self-identity. Because so much of this study has set out framing stuttering as a disability and then has focused on the interactions of students who stutter with their onsite university disability services unit/officer, it must be firmly established early whether or not stuttering is seen as a disability from at least an Australian legislative sense and then if more widely. For perceptually at an individual level, the association with the term will be different for all. I can assure you that I have seen and been involved in countless arguments within stuttering social media sites concerning this very topic, often resulting in highly passionate comments and opinions from all perceptions of the topic.

The notion of disability is the cause of heated and continual debate worldwide because, as French (1994) states "There is no simple way of defining disability, it can be viewed from many perspectives" (p.3). Being labelled as 'disabled' could have profound consequences for how a stuttering individual views themselves (Van Riper, 1982). The notion of disability, and the consequences of being regarded as disabled, creates much argument within stuttering communities, including whether or not they are disabled by their stutter or whether or not a stutter should be classed as a disability. Any online stuttering related blog (for example http:thestutteringbrain.blogspot.com), forum (for example http://stutteringcommunity.com), Facebook group (for example the Stuttering Community - https://www.facebook.com/groups/98233252577/) or physical face-to-face support group for people who stutter will provide evidence of the great divides over the notion of disability and stuttering amongst those directly affected and including those involved with delivering professional therapy and treatment. Indeed, it is often a question asked by new members of these groups and the same repeated arguments for and against the ideal quickly occur. These debates I have observed often revolve around uneducated views of exactly how disability is defined through to the notion that stuttering is “not that bad” through to distinct distancing from well promoted disabilities like deafness and blindness. Arguments I have myself often been part of as I advocate loudly that stuttering is a disability and that is not a negative at all. I have also published myself and with colleagues around the ideals of stuttering being a disability and identity (Meredith, 2010, 2015, 2016b; Meredith & Harrison, 2014; Packman & Meredith, 2012). I cannot fathom that any person who stutters would indicate that their stutter is not a disability, when in fact they then complain that it limits their life choices and has influenced their ability to generally achieve more in their life. This is a stance of which I have discussed at various stuttering conferences worldwide to mixed reactions. Reactions ranging from agreement to stark and often heated opposing exchanges sometimes bordering on expressing personal hatred towards myself. Yet I continue to hold strong my own viewpoint that stuttering is without doubt a disability and that we all have the responsibility to promote disability broadly as a positive. Similar in fashion to what Boyle and collegues (2016) propose I also lecture that disability cultures, meanings and related movements are required to be promoted in order to educate about stuttering but to also facilitate more empathy-driven interactions within society.

Canadian speech and language pathologist (SLP) Ann Meltzer (2005) commented in the Canadian Association for People who Stutter (CAPS) magazine that in “…over 40 years of observation … many people who I have seen in therapy would not want to consider themselves as disabled or to have other people label them as disabled” (p.1). She also wrote of the results of her open discussion with a group of stutterers attending a speech technique maintenance group, ranging in age from 15-70 and ranging in stuttering severity from mild to severe, about the notion of stuttering being a disability. She found that few people in the group wanted to use the term disability to describe themselves or to have others consider them as disabled. She concludes that “not everyone who stutters wants stuttering to be viewed as a disability and by implication be considered as a disabled person (Meltzer, 2005)”. As mentioned earlier, this is a general opinion that I have encountered very often myself and this thesis explores it in depth. The implications of such labelling I will discuss later in this chapter.

The International Stuttering Association (ISA), which acts as a non-profit umbrella association dedicated to close cooperation among independent national and international self-help organizations of people who stutter, recently confirmed its recognition of stuttering as a disability. A recognition that you can imagine was one which met heated criticism from many people who stutter. One of the main reasons given for this decision is that if stuttering can be associated with the enormous worldwide disability movement which is as a whole striving for attitudinal and legislative actions for all disabled people, then stutterers will be able to claim the welfare benefits of being declared disabled, regardless of whether they consider themselves truly disabled or not (Irwin, 2005). This is an opinion that I discuss often publicly and have told various stuttering groups that for stuttering to be seen as a serious condition then it needs to align itself with the global disability movement. In my opinion, if stuttering is not openly framed as a disability by those who it affects, then it almost puts stuttering into a limbo state in which people who stutter say it is not too bad, yet they admit that it restricts their life choices, but not impactful enough to be known as a “disability”. There is little consensus amongst people who stutter over this issue. As mentioned, I have debated the topic via the 2014 International Stuttering Awareness Day online conference (Meredith & Harrison, 2014) and have openly aligned stuttering with being a disability a number of times at stuttering-focused conferences (Meredith, 2016a). For I proudly present the term “disability” as a positive. I believe that you should be a person who stutters who has a sense of pride in being who you are and how you speak (Meredith & Harrison, 2014). I have often challenged people who stutter to go to a disability conference and tell the attendees there with other disabilities that stuttering is “not as bad as what they have”. So far no one has taken up my challenge to firmly argue against stuttering being a disability. My reasoning behind my views are shackled within the Australian legal definition and aligned to stuttering being a disability as outlined on the next page. For me, it all just makes simple common sense.

To add insight into this dilemma of opinion based around stuttering as a disability~~,~~ are the applications of the two widely used models of disability being the medical and social models (Shakespeare, 2013). Understanding these models will also help you to contextualise the opinions of stuttering being a disability presented by the respondents of the data gathered and presented by this thesis. These two models are very divisive in the way in which they model and present disability (Manago, Davis, & Goar, 2016). The medical model is a framework that has historically dominated disability treatment portraying it clearly as a deficit which needs to be fixed in order for the individual to be considered "normal" (Oliver, 1996, 2013). In the case of stuttering, the individual afflicted must seek treatment for their stuttering and learn how to manage it. Stuttering in this case is medically identified and is a personal problem for the individual to take action upon. This is a model which seems to have dominated stuttering research literature and treatments up to recent times (Pierre, 2012). Simply put that if "you" cannot do things as a "normal" person can do, then "you" are clearly disabled (Bailey, Harris, & Simpson, 2015), a point that I reinforce myself to argue how stuttering can be defined as being a disability. In actuality, the speech pathology profession itself is primarily concerned with correcting the dysfunction of stuttering and aligns strongly with the medical model of disability (Pillay, 2003).

Stuttering identified in children are met strongly with interventions designed to prioritise eradicating the condition firstly and if need to, attempt to lessen its severity (Watermeyer & Kathard, 2016). The medical model also frames treatment as a results-based system in the sense that the client is expecting tangible outcomes for the investment that they put into the intervention (MacDonald & Mikes-Liu, 2009). The consequences of such an approach result in less all-round life orientated opportunities and often impacts upon the individual's quality of life. In contrast, the social model of disability argues that impairments, such as stuttering, are made to be "disabling" by the process of society failing to accommodate the afflicted individual's needs (Bailey et al., 2015; Landsman, 2008). The social model places a strong line between impairment and disability. In the case of stuttering, the resulting dysfluencies are the impairment and the resulting life limitations are the disability. The social model through growing embracement and aiding to influence global disability policies, seeks to construct positive identities for people with disabilities and does not lay the blame of their problems onto themselves (Anastasiou & Kauffman, 2013; Shakespeare, 2004). This is opposed to the earlier described medical model which is growingly argued to be facilitating the marginalisation of disabled people in general (Bricher, 2000; Shakespeare, Iezzoni, & Groce, 2009). I have seen this social model myself at play within the current push to promote a stuttering pride movement globally. This fragmented promotion of pride sheers completely away from defining stuttering as a disability under the medical model and pushes forward the social model ideal that society must change to enable stuttering to be more widely accommodated for and accepted.

A disability model which has been gaining ground over recent years is the “affirmation model” which involves the reshaping of the identity of someone disabled into believing that their differences are valuable to themselves and society (Swain & French, 2000, 2008). This model does seem to align somewhat with the evolving stuttering pride and acceptance movements but I have seen little evidence of this myself within the relevant literature and growing discussions around these topics. But it does align to musings of pioneering stuttering researchers and theorists Wendell Johnson and Charles Van Riper. Wendell Johnson (1930) believed that a person who stutters could develop a positive self-identity by reframing what they thought of their speech differences. Van Riper (1973) followed on from this approach by proposing that speech professionals need to enable people who stutter to live with their condition regardless of what of it has been eliminated or not. These movements from what I have observed still seem to favour the distinct medical vs social model of disability frameworks and accompanying debates.

Alongside the argued alignment between stuttering and disability~~,~~ runs deep undertones of associated stigma. The notion of stigma is, in my opinion, highlighted by being defined as a universal understanding of a spoiled identity (Goffman, 1963). Over time and interaction with people who stutter, negative attitudes towards people who stutter have become globally indentured and this notion has been researched even from a point of early childhood social development (Ezrati-Vinacour, Platzky, & Yairi, 2001; Flynn & Louis, 2011; Griffin & Leahy, 2007). These findings of overt and at times quite socially piercing views have influenced studies attempting to mitigate such stereotyping by studying proposed root causes of stuttering stigmatism (Boyle, Blood, & Blood, 2009; Guntupalli, Everhart, Kalinowski, Nanjundeswaran, & Saltuklaroglu, 2007). It has also been found by a range of researchers that teasing and bullying starts at a very young age for children who stutter (Blood & Blood, 2004; Erickson & Block, 2013), as does the self-perception of having low social communication competence (Blood, Blood, Tellis, & Gabel, 2001). To understand more about the general seeding of such stigmatism, may enable more positive embracement of differences into the future. In fact, it has been suggested that generalised public negative perceptions of people who stutter propagate simply by not having direct contact with such people (Craig, Tran, & Craig, 2003). Over the past 15 years there has been a wealth of research investigating the negative attributes associated with stuttering social stigma which include: the witnessing of adverse reactions to overt stuttering behaviours (Guntupalli et al., 2007; Panico, Healey, Brouwer, & Susca, 2005); socially and culturally set stuttering stereotypes (Boyle et al., 2009; MacKinnon et al., 2007); and associated feelings of social exclusion (Boyle et al., 2009).

Social stigma towards stuttering can have truly devastating effects on those who stutter as they are developing from early childhood through to adulthood. It has been quite broadly argued that simply by modern social standards it is “not OK” to be overtly and visibly disabled and in turn the individual may as a result be viewed quite negatively by society (Watermeyer & Swartz, 2008). It is quite often that I read and hear of stories of pivotal moments in an early life of a person who stutters which have led to continuing situational and social avoidances. At times single interactions which have been framed as being “defining” moments for the social development and inclusion behaviours for affected people. It is sad for me to think that such moments can seed early isolation and limit such a large part of someone’s future life choices. You may recall my reflection upon my first socially recognised point of stuttering in front of a group of peers who were strangers to me. How lucky I was thinking back about that event that I was not impacted heavily by their reactions and that I avoided what could have been a life changing event in terms of how people perceived me and how I then perceived myself. But again, I have heard many stories of such like events in the lives of people who stutter. And, more often than not, they were pivotal life changing moments with negative repercussions. Even within the schoolyard it has been shown that stuttering can influence the choices of friends that children make between each other (Ezrati-Vinacour et al., 2001). The proceeding issues of noted difference and social selections often result in other impactful issues such as teasing, bullying and even physical outbursts towards children who stutter (Langevin, Packman, & Onslow, 2009; O’Brian, Jones, Packman , et al., 2011; Packman, Onslow, Attanasio, & Harrison, 2003). For younger students at least, these negative acknowledgements of speech differences and related bullying have been found coupled with increased stuttering severity levels to lead to impacts on educational achievements and increased negative peer feedback (Cook & Howell, 2014; O’Brian, Jones, Packman , et al., 2011). Socially this stigma logically follows through to adulthood with people who stutter often being viewed as inappropriate for job roles revolving around strong verbal communication skills (Gabel, Blood, Tellis, & Althouse, 2004) which in turn can lead to career options being reduced self-perceived or in actuality (Davis, Howell, & Cooke, 2002; Palasik et al., 2012). It would be no surprise now to the reader that apart from the mechanical problems of stuttering, that for some people who stutter the raised levels of social anxiety and compounded stigma associated with negative outlooks of stuttering often lead to restricted social lives and contribution to society.

It is no wonder that negative media portrayals may contribute to negative stuttering-focused stigma. When you have the time reflect in your mind how many people who stutter you have seen in popular culture and whether or not they have been strong, confident characters. From my observations, people who stutter are portrayed as weak, unconfident, sometimes evil or even to the extent of linking stuttering to characters who indulge in criminal actions. Of late this is evident from the fake stuttering facade of the criminal mastermind Roger Kint in “The Usual Suspects” through to the terrorist Simon Gruber in “Die Hard with a Vengeance” and to South Park’s popular disabled stuttering character Jimmy. Arguably, it has only been recently that a strong stuttering popular-media character has been portrayed in the guise of William Denbrough in the 2017 version of Stephen King’s “IT”. A character who himself just happens to stutter and his speech is not a focal point of the plot. But visual media historically is rife with such examples with stuttering characters being shown to be of weak character and often showing signs of being socially excluded (Evans & Williams, 2015; Johnson, 2008). It has been discussed across research that the portrayal of disabilities through the media are shaped to illuminate afflicted behaviours and traits while creating strong, identifiable stereotypes (Johnson, 2008; Quintero Johnson & Riles, 2016). Think back yourself to the stuttering characters you have generally seen or read of and how their speech difficulties have often been there simply to add more negative depth to their already flawed characters and bodies. Take some time not to make a list of how many strong characters, role models and heroes that you can think of, either fictitious or in real, who have obvious stuttering behaviours. I can guess that most of your lists will be very short.

Another cause of stuttering stigma has been framed as being linked to propagated misunderstandings and beliefs about the condition. This has been found in studies which have shown that incorrect beliefs around the cause(s) of stuttering ranging from the psychological through to medical have led to negative views about people who stutter (Boyle et al., 2009; Przepiorka, Blachnio, St. Louis, & Wozniak, 2013). People who stutter themselves via the failure to communicate verbally to others with a portrayal of speaking normality experience negative self-reactions towards their self-identities (Cooper & Cooper, 1996; Van Riper, 1982). Feelings such as shame, anger and guilt exclusively and inclusively have been related to the forming of a negative self-identity for a person regardless of stuttering or not (Daniels & Gabel, 2004). Daniels and Gabel (2004) outline three distinct strategies around how people who stutter socially manage communication to reduce the resulting impacts on their identities. These strategies are: by concealment of their stuttering and the use of speaking strategies linked to word avoidance; openness by the use of disclosure of their stuttering; and disavowal by ignoring that fact that they stutter.

Misunderstandings and stigmatisms around stuttering have been attributed to the medicalisation of the condition (Boyle, 2013; Pierre, 2012) which is a model that implies that stuttering is a form of disease to be treated within the individual. A more poignant view for this thesis is the theory that Boyle (2013) presents that internalised by people who stutter themselves to produce a "self-stigma". Boyle outlines a three stage process that people who stutter become aware of negative stereotypes, then agree to them and end up applying those beliefs to oneself. In fact, Boyle (2015) further found that adults who stutter who hold such stigma beliefs also expressed lower levels of quality of life and higher levels of depression. I have personally witnessed this evidence and growth of self-stigma through conversations with other people who stutter who have contacted me for support and guidance. There has also been studied evidence that has indicated that there is little difference in how a listener perceives a person who stutters who discloses pre-conversation their stuttering or chooses not to. There is however evidence that how well a person manages their stuttering does have an effect on the listener's perceptions of them (Healey, Gabel, Daniels, & Kawai, 2007; Hughes, Gabel, & Palasik, 2017)

Now that you have some understanding of the debates surrounding stuttering, disability and stigmatism it is important for you to have an understanding of perhaps how a person/student who stutters may frame their self-identities. Self-identity becomes indentured within an individual via self-narratives once they begin to question internally who they are and their place in their world (Castells, 1997;

Mishler, 1999; Sarbin, 2000; Somers, 1994). It should be noted however that identities themselves are not fixed and may change over time due to different events and experience that an individual has been actively part of (Pfeifer & Berkman, 2018; Somers, 1994; Valsiner, 2002). In fact, identities are formed through multifaceted social interactions and the appreciation within being able to study and understand differing viewpoints of how an individual believes that they are perceived by others around them (Hagstrom & Daniels, 2004; Howard, 2000). Kathard (2006) explored the process of shaping self-identity for people who stutter when attempting to class themselves as "Able" using a life history methodology to analyse the interviews of seven participants and their recorded narrative life stories. The research outlined the importance of having self-belief and positive self-development philosophies to enable the on-going development of a positive self-identity. This helped to assist some of the participants to be more accepting of their stuttering into adulthood and formed positive self-identities of being "Able". One pertinent model of self-identity that is relevant to this study is that of "DisOther". As opposed to "Able" being viewed as a positive self-identity, Kathard (2006) describes "DisOther" as being the polar opposite in which the individual views themselves as disabled and different to others. Kathard however did continue to explore the ideal that an individual throughout their life may in fact meander to and from both being "Able" and fitting "DisOther" from time to time. The notion of DisOther was constructed by Pillay (2003) who welded the prefix of "Dis" onto "Other". "Dis" refers to instances of individual disempowerment that Pillay (2003) likens to difference and destabilisation. The suffix of "Other" relates to the individual's ability to frame themselves as being problematically different within a given context (Boehmer, 2005). The use of the "Other" used by people with disabilities to construct a distinction between the normal and their disabled selves has been widely debated. Resulting in the viewpoint that the "Other" identity is not solely based upon impairment alone, but also a raft of other social factors (Fine, 1994). Goffman (1963) himself now famously describes the notion of spoiled identity to understand disability and his theory of "Otherness". Regardless of which theory or line of framing you approach to describe disability and its impact on the individual, no one cleanly boxed method exists (Kathard, Pillay, Samuel, & Reddy, 2004).

The framing of identity with the use of “DisOther” resonates within the findings of my study as I feel empowered by being able to empathise with its foundations. I believe this situational framing of one’s identity it is a very appropriate way to help to interpret the experiences of university students who stutter within this study due to the simple starting notion that these students have expressed general feelings of situational disempowerment during their engagement with university life. In fact Azio (2017) found that students who stutter within a university setting view themselves in a subordinate fashion in comparison to their peers and expressed a range of worrying negative self-beliefs as a result. Kathard et al. (2004) interviewed seven people who stutter in order to understand the processes shaping their self-identities. The research team found that the participants felt that both teachers and peers drew attention to their stuttering at school in a negative way via a series of critical incidents which in turn impacted the continual formation of their self-identities. These findings were important points in the journey of the participants in discovering their “DisOtherness”. It was also found that the age of the participants noticing their difference to others ranged from as young as three and up to thirteen. Pertinent to this study was also the idea that people who stutter negotiated their identities by often trying to conceal their stuttering and as a result silently blending in. But this concealment of difference has been described in the literature as trying to “Pass as Normal” (Goffman, 1963; Petrunik & Shearing, 1983) and to avoid what Garland-Thomson (2009) bluntly describes as being a “misfit”. It is important to note also that complex psychological factors including the likes of stigma and self-identity have been shown to have a profound effect on an individual’s decision to disclose their disability or not within social and including a university setting (De Cesarei, 2015).

Now that you understand somewhat the discussions around stuttering being a disability, associated stigma and the forming of self-identity, it is important for you to be orientated towards how stuttering is legally framed within Australian legislation.

Stuttering & Australian legislation

In addition to considering the general arguments amongst people who stutter about whether stuttering should be seen as a disability, there is a purely legislative view to consider in the Australian context. The World Health Organisation (WHO) has declared that stuttering can be legitimately recognised under its umbrella term of ‘disability’ as an impairment within the framework of its own International Classification of Functioning, Disability & Health (ICF). The following classifications under the WHO relate directly to stuttering: b330 Fluency and rhythm of speech functions and b3300 Fluency of Speech (World Health Organisation, 2001, p. 65).

In detail the b330 and b3300 classifications are defined as:

> *“b330 Fluency and rhythm of speech functions.*
>
> *Functions of the production of flow and tempo of speech.*
>
> *Inclusions: functions of fluency, rhythm, speed and melody of speech; prosody and intonation, impairments such as stuttering, stammering, cluttering, bradylalia and tachylalia.*
>
> *Exclusions: mental functions of language (b167); voice functions (b310); articulation functions (b320).*
>
> *b3300 Fluency of Speech.*
>
> *Functions of the production of smooth, uninterrupted flow of speech.*
>
> *Inclusions: functions of smooth connection of speech; impairments such as stuttering, stammering, cluttering, disfluency, repetition of sounds, words or parts of words and irregular breaks in speech.”* (World Health Organization, 2001, p.65).

The World Health Organization recently put a different spin on stuttering and disability. Its published World Report on Disability (World Health Organisation, 2011) places forward a view of disability that may be more attractive to people who stutter. According to the report, a "difficulties in functioning approach" instead of an "impairment approach" (p. 45) better reflects the notion of disability. Within this framework, people who stutter may be comfortable seeing themselves as having a functional difficulty in communicating, rather than as being seen as having an impairment. Although this approach still aligns itself more with the medical model of disability than it does the social one, I do appreciate the WHO's attempt at trying to broaden the appeal of its definitions.

The WHO classification, however, is not a legislative one and is sometimes argued as being too focused on observable behaviours and is medically inclined. However, it can be adapted to suit the multi-faceted problems associated with stuttering (Yaruss & Quesal, 2004). A perfect starting point for the Australian context is to study the Australian Commonwealth Disability Discrimination Act (DDA) of 1992, which states that it is clearly illegal to discriminate against people due to a disability. The DDA promotes the rights of Australians with disabilities in specified areas such as housing, education and provision of goods and services.

The main objectives of the DDA are:

> *(a) to eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of:*
> *i. work, accommodation,* ***education****, access to premises, clubs and sport; and*
> *ii. the provision of goods, facilities, services and land; and*
> *iii. existing laws; and*
> *iv. the administration of Commonwealth laws and programs; and*
> *(b) to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community; and*
> *(c) to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community* ("Disability Discrimination Act, 1992, pg.1, emphasis added).

Notice how access to "education" is clearly specified within the DDA's objectives. The question remains whether stuttering does fall under the DDA's definition of "disability" and its specifications of. Under the DDA, disability in relation to a person means:

> (a) *total or partial loss of the person's bodily or mental functions; or*
> (b) *total or partial loss of a part of the body; or*
> (c) *the presence in the body of organisms causing disease or illness; or*
> (d) *the presence in the body of organisms capable of causing disease or illness; or*
> (e) *the malfunction, malformation or disfigurement of a part of the person's body; or*
> (f) *a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or*
> (g) *a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;*
> *and includes a disability that:*
> (h) *presently exists; or*
> (i) *previously existed but no longer exists; or*
> (j) *may exist in the future; or*
> (k) *is imputed to a person* ("Disability Discrimination Act", 1992, pg.4).

The question then has to be asked: Does a person afflicted with stuttering fall under the purely legal concept of the DDA definition of disability? The Australian Human Rights Commission (AHRC) on its website formally says "YES" and elaborates why:

> *The definition of disability in the DDA includes "total or partial loss of the person's bodily or mental functions". Whatever the origins of a particular person's stuttering (neurological, psychological, or more direct physical causes), it is clear that speech is one of the things we do with our bodies and so partial loss of control of speech is covered* (Australian Human Rights Commission, 2009).

It has now been established that stuttering, although not uniquely named, can fall under the definition of the DDA and legally, therefore, universities must conform with the DDA when catering for and making reasonable adjustments for all disabled students, including people who stutter. To add strength to this position, furthermore to the DDA, are the Australian national Disability Standards for Education, 2005 (DSE).

The purpose of the DSE is to provide subordinate legislation to the DDA and act to clarify the legal obligations of education providers. The DSE is very explicit in explaining the obligations of Australian educational institutions in terms of:

enrolment; student participation; curriculum development, accreditation and delivery; the duties of student support services; and the elimination of harassment and victimisation. Each of these major sections of the DSE has clearly stated sets of associated rights and obligations directed towards the education of a disabled student.

The aims of the Disability Standards for Education, 2005 are:

> *(a) to eliminate, as far as possible, discrimination against persons on the ground of disability in the area of education and training; and*
> *(b) to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law in the area of education and training as the rest of the community; and*
> *(c) to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community.* (Commonwealth of Australia, 2005, p.g.6)

Clearly, within Australian legislature, frameworks exist to ease the facilitation of a disabled student into university-level education. Even if a student who stutters does not feel disabled at all by his/her stutter, they still have the right to be able to participate on equal grounds, to access university disability services and receive associated support while studying. In the words of Summan (2007) though, “There is a big difference between having a disability as defined by law, and being or feeling disabled by it” (p.10). A point of view that I promote actively as I try to educate people who stutter about the true meaning of disability.

Now that some understanding of how disability is framed and referred to in stuttering terms in Australian anti-discrimination legislation, it is important to review educational studies involving students who stutter from a primary to university level in order to understand the focus of academic effort in these areas. This will also help to establish the body of knowledge for you the reader and, in turn, how this study fills an essential gap. Key educational guides from a primary to a university level are also examined and critiqued in order to understand from a provision-level how teachers and lecturers are commonly instructed to teach and apply provision for students who stutter.

Primary to Year 12 stuttering-based studies

Although this research was conducted with a focus on the higher education environment, it is important to look at studies concerning students who stutter in their primary and secondary years of schooling because there is substantial literature on such student cohorts. It was deemed important to look at the focus of these studies early on in the life of a student who stutters and how later on in this chapter it appears that academic focus on these students seems to dwindle as they progress from primary education through to university. Many studies have focused on the interactions between stuttering children with non-stuttering children, teacher knowledge of stuttering, and peer perceptions of stuttering students. It should be noted that, at least as far back as 1925, it was suggested by Robert West (1925) that throughout public schools “speech, the most important element in the make-up of personality, should not be neglected” (pg.168). In 1939, Thelma Knudson conducted a survey of stuttering high school students and their teachers. The results indicated that the most common reactions teachers had towards stuttering students were pity and sympathy. Teachers also felt that the treatment of stuttering in the classroom was well beyond their abilities (Knudson, 1939). You may recall that these findings concerning a negative stuttering stereotype were discussed in later studies focused on social stigma suggesting that such opinions are not new in society. It is of no shock that teachers from any era may in general feel inadequate and in most cases not at all responsible for treating stuttering in the classroom. Simply they should be open to assisting to support such students through their studies.

Recovery from stuttering has been studied at junior and senior high school level in the USA at least as far back as 1972. Eugene Cooper (1972) found through his study of 119 stuttering students that the recovery process and success of school interactions hinged on parental identification of stuttering. Cooper found that the recovery process was aided if a parent accepted the fact that their child had a stutter and continued to aid their child throughout a treatment process. But again, up to this point in time the actual lived experience of being a student who stutters was not a focal point of study, but the opinions of those who acted within the student’s support groups were.

In 1981, studies were being reported that looked at teacher-based knowledge and perceptions of stuttering. One of the first of these studies was conducted by Crowe and Walton (1981), who asked 100 elementary school teachers to complete a Teacher Attitudes Towards Stuttering (TATS) inventory and the Alabama Stuttering Knowledge Test. The results showed a close correlation between attitudes towards stuttering and gained knowledge of stuttering. The more educated the teacher was about stuttering, the more likely their perceptions of the stuttering student would be positive. In 1992, researchers began to look at peer perceptions of young stuttering students. This is a time in a life of a child who stutters that earlier readings indicate have a profound effect on the future identify of a person who stutters (Erickson & Block, 2013; Guntupalli et al., 2007). The aim of several studies was to find out how elementary and secondary school teachers perceived a stutterer based on the age and gender of the child. Lass et al. (1992) asked teachers to list as many adjectives as they could to describe the four hypothetical people who stutter that were presented to them. These hypothetical people who stuttered included both a male and a female eight year old, and an adult male and female. The results showed a very strong negative bias towards stuttering students (Lass et al., 1992). Silverman and Marik (1993) replicated this study in 1993 and their results also revealed negative stereotyping of teachers to stuttering students. However, they argued that~~,~~ although the traits ascribed to the stutterers were negative in nature, it could not be assumed that the stereotypes that the teachers projected upon the student were projected beyond the classroom environment. Lass et al. (1994) continued their educational focus and went on to look at the perceptions of school administrators towards people who stutter (a female child, male child, female adult, and male adult). A total of 42 individuals ranging from school principals to elementary education supervisors were surveyed and asked to list adjectives describing four hypothetical people who stuttered. The participants listed a majority of negative adjectives to describe these people which appeared to mirror the negative stereotypes that had been found in earlier studies of attitudes towards children. However, the lived experiences of students who stutter was still not overtly evident in the literature.

Yeakle and Cooper (1986) surveyed 521 school teachers in a school district in Alabama, in part to explore their perceptions of stuttering. Results of this study revealed that the very few teachers who were more knowledgeable about stuttering, took courses on stuttering, or who had taught students who stutter, expressed more favorable attitudes towards stuttering students and more demanding expectations of them in the classroom than did the less educated teachers. Close to twenty years later, Turnball (2006) found that a way to reduce the establishment and propagation of such negative stereotypes, and perhaps reduce associated bullying amongst primary aged children, was through educating all students about stuttering from an early age.

It is not surprising that teachers have negative perceptions of stuttering students, because these teachers have little knowledge about such students. The Stuttering Foundation of America is very vocal in reporting that teachers have expressed difficulty in knowing what to do about a child who stammers in the classroom (Stuttering Foundation of America, 2007). A study of 268 trainee teachers in Manchester sought to measure their attitudes towards, and experiences with, children with speech and language difficulties including stuttering. This study found that student teachers needed more education, resources and inclusion methods in order to successfully teach such students (Marshall, Ralph, & Palmer, 2002). A survey in Buenos Aires to investigate what kind of information teachers had about stuttering found that they had many misconceptions about stuttering and expressed real concern about their lack of training to help stutterers (Franchini, Ramirez, & Reppetti, 2002).

Davis, Howell, and Cooke (2002) published the results of their study of 403 English children aged between 8 and 14 who shared classes with stuttering students. They found that children who stutter were rejected in social interactions more often than were their peers and were significantly less likely to be popular. These young students who stutter were very aware of their dysfluencies and the negative reactions it could prompt from fluent peers. This study also found that children who stutter tend not to be willing to speak in class lest they expose themselves to the risk of negative peer reaction. All studies clearly support the ideal that social anxieties and stuttering stereotyping begin at young ages and propagate through to adulthood.

The perceptions of primary aged students towards stuttering peers have been explored in various studies. A study published by Franck, Jackson, Pimentel, and Greenwood (2003) explored the perceptions of fourth and fifth grade students who were split into groups and asked to view a videotape of a speaker either stuttering or not stuttering while reading a poem. The children were asked to rate the speaker's intelligence and personality traits. The participants were asked to scale their views on an adjective scale. Their actions while watching the video tapes were observed by the researchers. The results revealed that the children held more negative views of the person who stuttered compared to the more fluent speaker. Such negative perceptions have been discussed in studies of the bullying experiences that students who stutter have experienced from classmates (Davis et al., 2002a; Hugh-Jones & Smith, 1999). Such negative and uneducated views from primary peers and even pre-school students are still evident even in recent research projects and are not appearing to have changed over recent times (Panico, Healey, & Knopik, 2015; Weidner, St. Louis, Burgess, & LeMasters, 2015). But I will reiterate, that up to the mid-2000s, the focus of academic studies were appearing to avoid the focus on researching young students who stutter and their important voices and narratives.

To try to understand the K-12 school experiences of students who stutter, Derek Daniels (2007) conducted a phenomenological reflective study of adults who stutter using semi-structured interviews and focus groups. The results showed that "the experience of stuttering in school is influenced by many factors, and that attention should be given to not only one's speech characteristics, but also to emotional and psychological needs and the socio-cultural environment of the individual" (p.3). Earlier, Hugh-Jones and Smith (1999) used a qualitative reflective study of stutterers to inform the creation of a survey covering the areas of stuttering, bullying and parent/teacher awareness of such issues. Results indicated that stuttering students perceived that they found it hard to make friends because of their stutter, were subjected to bullying because of their stutter, and almost half of those surveyed stated that their parents and teachers were not aware of any bullying occurring at all (Hugh-Jones & Smith, 1999). There are also studies which have not focused on educational issues from the outset, such as a qualitative, interview-based study conducted by Crichton-Smith (2002) into the communicative and coping experiences of stutterers, including their educational experiences. This study highlighted the effects of stuttering on the individual, the complexities of day-to-day communication for a stutterer and related anxieties in regards to having to participate in oral-based assessment tasks. Another interesting study is by Klompas and Ross (2004) who studied the quality of life of a group of South African stutterers through the use of interviews to explore multiple stuttering experiences including: education; social life; employment; speech therapy; family and marital life; identity, and emotional issues. Among the findings was the need for teaching strategies to be developed to help educators at all levels to facilitate a stuttering student in the classroom.

Of late, Clare Butler conducted a qualitative study peering experiences of people who stutter throughout their academic endeavours, from a primary level through to university, via a series of qualitative rich focus groups and semi-structured interviews. In brief, Butler (2013) concluded that students who stutter faced high levels of different forms of educational barriers which in turn had repercussions on their social and educational development. There have also been various studies with strong relationships between classroom participation and resulting academic achievements for students in general but with mixed results when focused purely on students who stutter. (Buhs & Ladd, 2001; Valiente, Lemery-Chalfant, Swanson, & Reiser, 2008). Important to this thesis, Erickson and Block (2013) studied 36 adolescents who stutter, 75% of which reported low self-perceived communication competence in class and also similar rates of communication apprehension within similar situations. This Australian finding relates to research reported in prior American educational studies (Blood et al., 2001; Blood, Blood, Tellis, & Gabel, 2003). Erickson and Block (2013) also found that close to half of the interviewees had experienced bullying which in turn had affected their motivations to attend school and study. Only recently, Davidow et al. (2016) conducted a large scale electronic literature search to find commonly used strategies suggested to support teachers in assisting children who stutter in the classroom. The result after reviewing 2,130 found items was a commonly taught set of strategies promoted widely. These strategies focused on children who stutter, revolved around instructing teachers how to: speak to them in class; accommodate their speech; integrate them more constructively into activities; and educate the whole class about stuttering. The research team concluded that for effective strategies to exist within P-12 levels then speech pathologists and researchers must study the effectiveness and outcomes of such strategies.

While there has been quite a lot of research featuring stuttering students studying in primary and secondary based settings, the studies in general seem to lack a vital focus. This focus is the experiences of the stuttering students themselves. A lot of headway has been made into identifying peer perceptions, stereotyping and the essential need of parental support, but little effort has gone into exploration of the firsthand experiences of stuttering students. This thesis attempts to fill this essential knowledge gap and adds to a solidly identified knowledge gap at least at a higher education level. Clearly, further studies into the primary and secondary school lived experiences of children who stutter are required in the future.

Primary to Year 12 stuttering focused teaching guides

Now that common research themes in the study of primary to secondary school children who stutter have been established, it is also important to understand the contents and motives of some established teaching and assessment guides for teachers of these stuttering students. You will observe that there is actually quite a lot of information for parents and teachers in regards to teaching and educationally accommodating children and teenagers who stutter. This is important to understand within the context of this research in order to be able to establish what sort of provisions are commonly available to students who stutter at all educational levels and if there is a progression of guided assistance as education level change and the adult student world appears. Looking at some of these guides will also help you to understand the state of provision for students who stutter and, in turn, inform the assistance provided by universities to the participants of this research.

Some of the most established and supported stuttering-based associations in the world have freely available K-12 based student guides available on their websites. The Stuttering Foundation of America (SFA), which is the largest non-profit charitable organization in the world working towards the prevention and improved treatment of stuttering, maintains a large Internet site providing free online resources, services and support to those who stutter and their families. This site also provides a free online video entitled "Stuttering: Straight Talk for Teachers", which provides useful information to increase the stuttering knowledge of teachers and the special educators who support them (Stuttering Foundation of America, 2012). The site also provides a dedicated page concerning the teaching of stuttering students from pre-school to an elementary level entitled "Notes to the Teacher: The Child who Stutters at School" (Stuttering Foundation of America, 2007). This guide gives an educator some hints at providing support for a stuttering student, how to encourage the student to be an active participant in reading and answering questions out aloud in class, and also offers advice to tackle stuttering-based teasing and bullying in class.

Another United States organisation, the National Stuttering Association (NSA), also has an online educator-based research section. This source also provides general treatment information and some common classroom techniques for dealing with teasing and bullying. They also have a free downloadable brochure called "The school-age child who stutters-Information for Educators". This brochure offers some common information found in the SFA and other sources but focuses more specifically on explaining the importance of the role of the teacher. The NSA suggests that a teacher should act as a source of support and understanding for the stuttering student regarding speech issues, and that the teacher should always portray a positive attitude towards stuttering (National Stuttering Association, 2006). Situated in the United Kingdom, the British Stammering Association (BSA) has a wide ranging website with a large section concerning K-12 teachers. Some sections include first hand tips and guidance from stuttering children and teenagers themselves. Impressively, there is a long guide presented concerning the whole span of childhood and especially how to tackle answering questions out aloud in class and reading aloud. It also covers bullying and teasing. There is only a small separate section concerning the training of secondary school staff and dealing with stuttering teens (British Stammering Association, 2011). This seems to be a common trend amongst guides in which the older the stutterer gets the less guidance and advice there seems to be. It seems to me that the same strategies formed for primary school students who stutter seems to be generically applied to high school students who stutter without account of different levels of age and maturities.

In the Australian context, the Australian Speak Easy Association runs a website called YouthSpeak (YouthSpeak, 2008) which acts as a resource for children and youth who stutter and also their parents, friends and teachers. This site has some information for teachers including useful indicators to help gauge if a stuttering student needs help for their stutter. This site also lists of number of ways to support a stuttering student, and some useful class strategies concerning how to approach teasing and bullying. In comparison, the Speak Easy Association of Canada’s website only presents a short list of points concerning how a teacher can assist a stuttering child, but the list is very generic and lacks the detail and compassion in comparison to the other large organisational sites. Again it seems that generic lists of tips exist across different countries’ stuttering organisations and that little specialised guidance seems to exist.

So far, the guides viewed have been very generic in nature and all offer the same types of information. In comparison to the other online sites previously mentioned, the large online website, the “Stuttering Homepage”, created by Judith Kuster and maintained at Minnesota State University, Mankato, is dedicated to providing information about stuttering for both stutterers and professionals who work with people who stutter. It contains a wealth of stuttering resources including a large section for teachers fed from various contributors with different views and opinions. For example, Poulos and Eckardt (2004) present a clear and condensed version of teaching tips called “Some Suggestions For Teachers For Managing Students Who Stutters”. Also housed is the article “Educating the Educators about stuttering” (Cooper, Chmela, Bennett, & Williams, 1998). This article provides a brief rundown of a presentation given at the American Speech-Language-Hearing Association (ASHA) convention in 1998 and gives a 10 point list of highly helpful tips to guide teaching and some advice to help give a general understanding of the nature of stuttering students. Rind and Rind (1988) have a very descriptive guide that focuses on how to cater for a child in class whose speech seems less fluent than that of their general peers. This begins with a detailed explanation of how to recognise a stutterer in class and some general information about stuttering. The focus then turns to the importance of the teacher being a positive role model.

One of the most informative sites found with P-12 stuttering information is the “iStutter” site, created by Latrobe University’s School of Human Communication Sciences (Latrobe University, 2005). This is a wonderfully rich site focusing on issues of stuttering concerning teenagers and young children. General information about stuttering is provided along with some attention to teasing and bullying and, impressively, a range of treatment options is explained along with examples of evidence-based practise. This site, unlike the others previously mentioned, offers direct information for teachers that is split into two clear and distinct sections for children under 12 and teenagers 13-18. Both guides focus on what stuttering is, how it can be identified, how to assist the student in class and the importance of encouraging class participation. Apart from guiding the reader through information commonly seen throughout the Internet, the under 12 section focuses particularly on the early identification of stutterers, in order to address this condition with therapy. The teenager’s 12-18 section is more concerned with available treatment options, because the stutter is probably more established at this point. It also provides tips on how to encourage social engagement, which is very important in a teenager’s life. This is the first guide found that presents a more holistic view to educating about stuttering and supporting a student through early school years while keeping in mind some demographic differences.

From this review of popular P-12 based stuttering resources it is plain to see that there is a wealth of varied information available to both the teachers and parents of young students who stutter. This general information is rich in nature and covers some very important topics such as class inclusion and bullying. Although arguably rather generic and broad in nature it does at least provide starting points. But it is also important to note that it has been acknowledged that for effective strategies to exist in the classroom for students who stutter that researchers and speech pathologists need to study the outcomes of such strategies (Davidow et al., 2016). In this regards there seems to be a lack of cooperation between educational, academic and speech professionals. From all the websites surveyed in this section, an amalgamated list of popular tips was formed and is shown in *Appendix J: Common K-12 based tips*. This list indicates the rich and varied resources available for a teacher wishing to help a stuttering student in a P-12 class.

University/College based stuttering-related studies

Because this research focused on the attitudes and experiences of university students who stutter, it is important to look at studies that have been conducted at universities concerning students who stutter. After a lengthy investigation, very little research could be found concerning the university student who stutters including their lived experiences and associated challenges. In 1986, Gerald Culton reported on a 13 year survey of college freshmen who had speech disorders. Culton focused on the types of disorders which were evident in college freshman and any recovery techniques that they may have employed to overcome their problems (Culton, 1986). The study, however, was not completely focused on stuttering and covered a wide range of indicated speech impairments.

Some studies of interest for myself have investigated perceptions of stuttering students from the perspective of college professors and fellow students. Woods and Williams (1976) researched the possible existence of a perceived stuttering stereotype amongst the general public. People were asked to rate four hypothetical people who stuttered across 25 personality traits. Results indicated that participants who were classroom teachers rated the hypothetical boy who stuttered much lower than the boy who did not stutter. This was an early indication that perhaps a stuttering stereotype of a student who stuttered existed and was perceived in a more negative light compared to their non-stuttering classmates beyond primary and secondary years. An early indication within this study of the impact of stuttering stigma which seems to consistently weave itself through both the literature and society.

Dorsey and Guenther (2000) focused their study examining whether college professors and college students have negative personality stereotypes of college students who stutter. As part of their study, Dorsey and Guenther asked a selection of professors and college students to fill out a questionnaire containing 20 personality items, on a scale from 1 to 7, the degree to which either a hypothetical college student who stutters, or a hypothetical average college student, possesses the trait in question. In general, participants rated the hypothetical student who stutters more negatively on the personality traits than the hypothetical average college student. But more shockingly, the professor participants rated the hypothetical student who stutters even more negatively than did the student participants (Dorsey and Guenther, 2000). This study also backed up Silverman’s (1990) earlier claim that student motivation, participation in classroom activities, and willingness to seek out mentoring relationships, hinges on healthy perceptions of students from their professors. Dorsey and Guenther (2000) further found that apart from students rating students who stuttered more negatively than normal “fluent” students, that academic staff rated the students who stutter even more negatively. Building even more strongly upon these negative perceptions of students who stutter was the Canadian vignette study by MacKinnon et al. (2007), in which 183 university psychology students rated a hypothetical male who stuttered as “more nervous, shy, self-conscious, tense, anxious, withdrawn, quiet, reticent, avoiding, fearful, passive, afraid, hesitant, insecure, and self-derogatory" (p. 303). After reflection on these studies, it became no shock to me that such negative stuttering stereotypes continue to exist. This further raises the importance to me of helping to reframe these perceptions of people who stutter into the future to be more realistic and positive.

Of recent, a very interesting study conducted by Daniels, Panico & Sudholt (2011) employed a three section mixed quantitative and qualitative survey. This survey was an adapted version of the Teacher's Perceptions of Stuttering (Yeakle & Cooper, 1986) and the Teacher Attitudes Towards Stuttering (TATS) Inventory (Crowe & Walton, 1981) from pervious perception studies. The aim of this study was to explore the perceptions of university professors/instructors towards stuttering and students who stutter. Daniels et al. (2011) found that many of the professors studied had little to no knowledge about stuttering, how to react or respond to it when it occurs, and whether or not accommodations should be granted to students who stutter. Many professors (as a group) felt that students who stutter should be treated like every other student. However, individual comments showed that some professors would approach situations and accommodations on a case-by-case basis. The study surmised that professors need more information and literature about stuttering, as basic as it may be, since they rarely, if at all, get this information in their educational training. But in my opinion, I do like the fact that a majority of professors acknowledge the need for a personalised approach to supporting students who stutter rather than a generic approach.

When searching for focused studies purely on university/college students who stutter I found very few. I found three recent and separate studies which were of interest and importance to this this thesis. Those studies being Mark Pertijs (2009), Clare Butler and Michael Azios (2017). Clare Butler (2013) studied the educational experiences from primary through to higher education of 38 students who stutter via semi-structured interviews. This study was not solely focused on the higher educational experiences of students who stutter, but it did show well the continual challenges that face students who stutter throughout their educational journeys and it has provided a platform of university experiences for this study to both support and counter. This published study gave me more faith and desire to complete my PhD and to make sure that my findings contributed more to the body of knowledge around this important area.

In further respect to studies focusing directly on university level students who stutter, Mark Pertijs (2009), a lecturer in Speech Disorders with the University of Applied Sciences, Utrecht, conducted an unpublished and informal study of students who stuttered at his university. The purpose of his study was to help push forward the movement to include stuttering as a disability under the “Law on equal treatment on the grounds of disability or chronic illness” in the Netherlands. Pertijs conducted a survey based online and advertised via all of the major Dutch stuttering associations. The study was limited by being only available for a short space of time (two weeks) and only had a small sample group of respondents of 29 (19 graduates and 10 current students). However, despite these limitations, the findings indicated that a student’s stuttering had impacted somewhat their relationships with their fellow students and hampered their communicative abilities with their lecturers. This small study has helped Pertijs to inform the training of some European lecturers in how to teach students who stutter.

The most focused study that I found of late was that of Michael Azios (2017) who focused his PhD thesis around the question of “How do people who stutter navigate the overall college experience?” This study had a distinct focus on how students who stutter engage within classrooms, with their peers and university-based social settings. Azios via an ethnographic study and in depth interviews of four American college students who stutter found that stuttering had a negative impact on their studies, identity and locus of control within a university setting. These students focused their in-class coping strategies on attempting to induce fluency and provide a supporting structure for their studies. My study has built upon the findings of Azios and has given a larger sample of students who stutter a voice to express their university experiences beyond the classroom alone.

Apart from the aforementioned studies, very little in terms of informed and narrative-driven exploration exists on the experiences of university students who stutter. The focus of these past studies and some since are more on peer or lecturer perceptions of and negative stereotyping of stuttering within different focused contexts using university student responses for data collection (Abdalla, Irani, & Hughes, 2014; St.Louisa et al., 2014). The focus on the experiences of students who stutter themselves have seemed to be almost totally neglected, or at least overlooked by academia. Little knowledge exists on these experiences for students except for personal accounts that stutterers have published in disability and stuttering related magazines. Social media-base support groups for people who stutter are also continually seeded with such experiences and narratives which indicates the passion within the stuttering community to express their feelings. Such authentic stories help to piece together the personal trials and tribulations facing the stuttering university student (Meredith & King, 2008; Stutt-L, 1999) and also the stuttering lecturer (Grieve, 2007; Meredith, 2009). The research described in this thesis has taken a large and bold step into looking at the overlooked and rich experiences of the higher education student who stutters with empirically evaluated data in order to instigate and inform positive changes into the future.

University/College stuttering-focused teaching guides

Due to the fact that this research focuses heavily on stuttering students' interactions with disability services on campus, it is appropriate to look at what guides Australian universities have produced for teaching and assessing such students. When studying these guides, it is possible to look for any disparity between found school guides and university guides. A handful of highly regarded overseas university guides will first be studied and the Australian higher education guides will then be analysed and compared. This analysis will assist you the reader to understand the consistency of teaching strategies around the world which informs Australian practice in regards to teaching and assisting Australian university students who stutter. In turn it will help you to understand the assistance given to these students by their associated university support units and lecturing staff. It may point out to the reader perhaps how generic and at times shallowly stated support strategies may be for university students who stutter around the world and also for the participants of this research.

Of all the overseas guides, only two stood out and were referenced from many other sources. The first is the U.K. website, “http://www.stammeringlaw.org.uk/”, which is dedicated mainly at looking at how the United Kingdom's Disability Discrimination Act (UKDDA) 1995 applies to people who stutter and what social security benefits a stuttering person can access. But this site also has a dedicated section outlining how the UKDDA is applicable to stuttering higher education students and their available government benefits. This site is supported by the large and influential British Stammering Association which is a strong advocate for the rights of people who stutter within the United Kingdom. This is the only site at the time of the initial literature review to find which directly explains how legislation applies to a higher education student. Stammeringlaw.org also presents the user with comprehensive advice on how to reasonably adjust assessments to suit a stutterer. The list includes some tips rarely discussed in school guidelines, including allowing extra time for oral presentations, encouraging the use of presentation aids and removing the terms “fluency” and “clarity of speech” from assessment criteria (Tyrer, 2007).

The Stammeringlaw website and other online information portals point to a guide produced by Richard Howley of De Montfort University entitled “Working with students who stammer” (Howley, 2007). This guide is seen by many to be very concise and thorough in its approach to the teaching and assessing of higher education students. This guide first explains how a stutter could affect a student’s learning, including that they may avoid some class situations, the mixture of emotions that may be felt, the possibility of suffering social anxieties and the fact that these students may withdraw themselves from class activities. Like the Stammeringlaw guide, this guide also delves into strategies to support a student during assessed presentations and it also adds advice for supporting stuttering students in general. Both the Stammeringlaw and De Montfort guides present a unique and informed account for anybody involved in higher education to help support stuttering students. Combining the information found within these two guides alone will present a lecturer with a solid grounding concerning how to approach and teach students who stutter. These guides have been richly informed by people who stutter themselves and this is reflected within the detailed information and strategies provided.

The focus of this thesis is on the experiences of Australian stuttering students so Australian university guides explaining how to teach and assess stuttering students, found in the first stage of my bricolage influenced research outlined in Chapter 3 of this document, will be examined from an Australian higher education perspective. From all of the 39 universities surveyed (see Chapter 3 of this document) only five guides were found which mention supporting speech impaired or stuttering students. The five guides were identified on the websites of the Australian National University (ANU), Bond University, Royal Melbourne Institute of Technology (RMIT), Queensland University of Technology (QUT) and The University of Sydney. These five guides are not exclusive for students who stutter alone and focus assistance within the umbrella term of speech impairment in which stuttering is mentioned. These five guides each mention the fact that reasonable adjustments can be made to cater for the assessment needs of stuttering students and that alternate assessments are possible. These notions are generic in comparison to what is seen with school guides. A full list of general tips can be seen in *Appendix J: Common K-12 based tips*.

Of all the Australian guides found, the University of Sydney goes a little deeper in its approach than the other guides and breaks its strategies up into three broad categories: Assignments, Tutorials and Examinations (The University of Sydney, 2008). This is not surprising as the University of Sydney when surveyed annexed the renowned Australian Stuttering Research Centre (ASRC) who would have been influential in informing the content of the guide. Surprisingly, Bond University displays on its website the *Supporting Students with a Disability Guide for Staff* (Queensland University of Technology, 2007) but this guide is hyperlinked from the Queensland

University of Technology (QUT) website and not its own. This meant that only four distinct publicly available guides were found from 39 universities. The QUT guide was the most comprehensive one found from any Australian university in terms of how many disabilities it had directly mentioned strategies for. Having said that, it is broad in nature and, again, fairly similar to what was seen in other school guides generically around the world. Interestingly, a focused list of strategies like those seen in school guides is presented in the QUT guide when outlining communication tips for people with hearing impairments, but not speech impairments alone.

This is all the publicly available information that was found through the survey of 39 Australian universities concerning teaching and assessment strategies for a stuttering student at the time of that small pilot study. In comparison to other guides in the world covering the schools through to higher education spectrum, there appears to be very little focused information present and little thought or attention given to students who stutter. Some reasons for which I will discuss in future chapters along with the findings from this research.

This chapter has outlined how stuttering is classed legislatively as a disability in Australia and the fact that it needs to be accommodated for to help facilitate inclusive educational opportunities. This chapter has also reviewed the academic focus of studies in regards to students who stutter and it has been found that little research has been done on university students who stutter. Another aim of this chapter was to explore prominent educational guides which show some focus on strategies for students who stutter. Again, it was found that there was scant coverage of strategic approaches to teaching university students who stutter. When you contextualise these findings within the conversations concerning stuttering, its connection to disability, and its relationship to social stigmata, then you can start to understand how challenging it could be for a person who stutters to attempt a university education and access relevant support services.

The next chapter will outline the web-based survey conducted on the websites of Australian public universities. The survey investigated the publicly available disability support information from a legislative view and also through the lens of a person who stutters who is seeking to find out how a particular university could support and accommodate their stuttering. This will help you to establish an understanding of the precise publicly available knowledge base of Australian universities in regards to supporting students who stutter. This upcoming chapter will also help you to understand how informed a person who stutters may be when attempting to investigate how an Australian university in general could support their studies and help alleviate their worries about having a successful journey into higher education.

Chapter 3. The web-based audit

Purpose of the audit

The following research question is pertinent for this information seeking stage of the research:

> *Could a prospective university student who is seeking assistance to accommodate their stutter in class and assessment situations make an informed choice about the level of support available, based upon information about disability services available on Australian public university websites?*

The review of the literature in Chapter 2 has outlined that research and understanding in the area of university students who stutter is lacking depth and needs to be further informed to be more effective. In order to understand further the experience of being an Australian higher education student who stutters and to build on the literature, I endeavoured to establish what online materials around general support, assessments and participation requirements in Australian universities were publicly available to accommodate a student's stuttering. By understanding what information was available for possible support pre-enrolment, I was then able to have an understanding about the starting position of a potential Australian university student who stutters who is searching online for support information and, in turn, shape the design of the evolving bricolage methodology and data gathering methods of this thesis. This initial study also assisted me to understand some of the motives expressed in discussions to come concerning the pre-enrolment motives of university students who stutter and at times their surprising actions.

As described earlier, many people who stutter may have had a problematic journey through the secondary education system and many have a high chance of being diagnosed as having a social phobia of some form (Blumgart et al., 2010; Craig, Blumgart, & Tran, 2009). It could be hypothesised that a person who stutters may wish to access university-based disability services to assure their confidence about having their stuttering reasonably accommodated through their studies. This assurance might then act to encourage the potential student to make the jump into and progress through higher education more easily, informed and, hopefully, successful. This hypothesis was a motivator that drove the decision to conduct this web-based audit. An additional motivational factor was due to my personal observations of online behaviours from some people who stutter. I have observed that the Internet appears to be to be a likely source of quick information without the stress and anxieties associated with talking to a person face-to-face or on the speech-focused telephone.

Audit methodology

In order to understand the question of online accessible disability service information for students who stutter, I conducted a web-based audit of 39 Australian public universities (see *Appendix I: Web-based audit university List*) between July 11, 2008 and August 1, 2008

I endeavoured to look through the eyes of a prospective higher education student who stutters, at each university's internal disability services site and to investigate the content contained there. I put myself into the mindset of being a person who stutters who wants to become a university student and wishes to ensure that, if they enrolled, they would have access to some form of help from disability services if required. I experienced this mindset as a student who stutters throughout the multi-sectored education journey I undertook at Federation University Australia (formerly the University of Ballarat) from a vocational Certificate 2 through to a PhD. To be honest, I did not make such enquiries myself when I chose my mature-aged university education journey so this study itself was truly enlightening for me on different levels. This was an attempt to see if I could gain a solid understanding of whether a particular university could address the concerns and needs of a person who stutters throughout their academic life, and whether the person who stutters could make an informed decision to enroll on the basis of the information found. Although this study focused on stuttering-based support information it does outline a framework in which students with any disability can apply to help ascertain how a particular university publicly advertises is support systems.

All 39 Australian public universities had strong web-based presences via their websites to advertise their courses and degrees to potential students and also to act as a portal for the public, staff and students to services. Prior to undertaking this web audit, I assumed that information related to compliance with Australian disability legislation, and information about alternative assessments, possible strategies, disclosure procedures and other essential disability services information would be overtly present across all university sites.

To aid with the analysis of university-based disability information, I first compiled a comprehensive list focused on the information about disability services that would potentially be of interest and assistance to people who stutter and who are considering enrolling at university. This list is logically set out with 12 criteria used to judge the publicly available disability information provided by Australian universities. This list of desired items, features and services is shown below in Table 1: *The 12 Criteria of Enquiry*.

Table 1: ***The 12 Criteria of Enquiry***

Item	Desirable features
1. Disability Discrimination Act (DDA).	Acknowledgment of DDA, 1992. Summary of its importance to education and link to its online location.
2. Disability Action Plan	An Action Plan should: eliminate discrimination in an active way; improve services to existing consumers or customers; enhance organisational image; reduce the likelihood of complaints being made; increase the likelihood of being able to successfully defend complaints; increase the likelihood of avoiding costly legal action; allow for a planned and managed change in business or services; open up new markets and attract new consumers (Australian Human Rights Commission 1998) .
3. Disability Policy.	Formal, university-sanctioned policy.
4. Disability Access Strategy.	Strategy in place and advertised about procedures for students with disability to access their services.
5. Disability Liaison Officers (DSO).	Details of how to directly contact a disability liaison officer (DSO).
6. Registering for Disability Services.	Details on how to register for help beyond simply asking a visitor to make contact for assistance should be available.

7. Disclosure.	Details of the process and an assurance of confidentiality when a student discloses their disability.
8. Guidelines for Staff.	Information about teaching and assessment of disabled students, more specifically, stuttering or speech impaired students.
9. Alternative assessment.	Information about procedures for alternative assessments and reasonable adjustments for students with disabilities.
10. Scholarships.	Scholarships for students with disability.
11. Social activities	Links to campus-based disability social activities.
12. Responsiveness to enquiries.	Details of DSO responsiveness to enquiries about services for students who stutter.

These 12 criteria were then grouped into five broad categories:

(a) Policy and Legislation (Items 1-4);
(b) User Access (Items 5-7);
(c) Teaching and Learning (Items 8-10);
(d) Social (Item 11); and
(e) Responsiveness to Enquiries (Item 12).

The categories were ranked in order of importance to the searcher and the ethical responsibilities of a university. Category (a) was considered to be the most critical, given that in Australia stuttering is legally regarded as a disability and universities should be making disabled people strongly aware of their legislative compliance expectations. Category (b) was considered important, as easy access to information about disability services is critical for a prospective student, especially one with a disorder of communication. Category (c) refers to the information available on policies and procedures to facilitate the teaching and assessment of disabled students. Of interest within this category was additionally to see if universities openly provided scholarships (financial support). While category (d) is relatively less important, for students with a disability and whether there were facilitated social interaction for such students within the university context. Category (e) was adopted to determine the extent to which web-based university disability services respond to student enquiries. After discussion with my initial supervisorial team of three senior university academics, there was consensus that these five categories covered the relevant and appropriate information for the purposes of this study.

Table 2: ***The Five Categories of Enquiry***

Information sought	
a. Policy and Legislation	1. Disability Discrimination Act (DDA).
	2. Disability Action Plan (DAP).
	3. Disability policy
	4. Disability Access Strategy.
b. User Access	5. Disability Liaison Officers (DSO).
	6. Registering for Disability Services
	7. Disclosure
c. Teaching and Learning	8. Guidelines for Staff
	9. Alternative assessment
	10. Scholarships
d. Social	11. Social activities
e. Responsiveness	12. Responsiveness to enquiries

Audit procedure

This preliminary study did not look beyond the internal audited university website or its associated external links to find information. I assumed the role of a "web browser", as defined by Dacor (2009), who is a user who usually browses the contents of a website using only the obvious links available, as opposed to a "web searcher" who is more inclined to use onsite search facilities. By using the "web browser" mentality I assumed the role of a common World Wide Web (WWW) user and not a power-user. In fact, I simply trawled through each of the 39 public university websites looking for information concerning the 12 criteria outlined in Table 1. To add further validity to the search method employed, I used two of the world's most widely used web-browsers at the time of this study to aid with the website search. These two browsers were Internet Explorer 7.0 and Firefox 3.0. At the time of this audit, both browsers combined were used by over of 90% of Internet users with Internet Explorer holding a 52.4% and Firefox a 42.6% of the global browser market share (W3schools, 2011). Meaning that the functionality of the trawled websites should be fully functional within the two browsers that I chose to use. Any found documentation or webpage using the “web browser” method of searching was reviewed for the use of keywords, including: stuttering; stutter; stutterer; stammering; stammer; stammerer; speech; speech impediment; communication and disorder. This list of words was designed to trap and identify sections of the found documents and webpages that may fit the specific stuttering related criteria.

For the purposes of gathering information for category (e), during the study’s time span, I also contacted a representative disability liaison officer (DSO) from advertised liaison services webpages hosted within the website of each university audited by email and asked the following:

> *“…I was wondering if your university had a Disability Action Plan or Strategy in place that I could access. Also do you have any specific strategies in place for handling/teaching/assessing a stuttering or vocally impaired student? Any help would be great. At the moment I am trying to understand all the different universities' approaches to these students.”*

This method was used to measure a general feeling of responsiveness to a like enquiry and also start to gain an understanding of what strategies exist for helping a student who stutters. This method also helped with finding some of the requirements searched for outlined in Table 1.

Web-based audit results

The results of the web-audit are summarised in Table 3 below, showing percentages of found criteria within their relevant categories.

Table 3: ***Number and Percentage results of the Web Audit***

Information sought		Websites providing this information (n=39)
a. Policy and Legislation	1. Disability Discrimination Act (DDA).	35 (90%)
	2. Disability Action Plan (DAP).	24 (61.5%)
	3. Disability policy	10 (26%)
	4. Disability Access Strategy.	1 (3.6%)
b. User Access	5. Disability Liaison Officers (DSO).	21 (54%)
	6. Registering for Disability Services	29 (74%)
	7. Disclosure	18 (46%)
c. Teaching and Learning	8. Guidelines for Staff	17 (44%)
	9. Alternative assessment	5 (13%)
	10. Scholarships	11 (28%)
d. Social	11. Social activities	12 (31%)
e. Responsiveness	12. Responsiveness to enquiries	20 (52%)

The web audit provided clear information about what a person who stutters may find on the Internet regarding Australian university-based disability services pre-enrolment. The results will be discussed and outlined in detail by category in the following sections.

Category A: Policy and Legislation

References to the Disability Discrimination Act (Australian Government Attorney General's Department, 2010) (Item 1) were the legislative information most widely available on Australian university disability services web pages (90%). Of the 24 university websites that linked to a Disability Action Plan (DAP) (Item 2), two had broken links, meaning that a visitor would be unable to view them. Further, of the 24 websites that did have a DAP, only nine of the linked pages were current. Some of those that were out of date did in fact have a creation date noted, but also did not advertise an expiry date. No specified time spans for the life of many documents were given, which meant effectively and openly that only 23% of universities had a current dated DAP available on their website.

Of the 11 universities that advertised a Disability Policy (Item 3), one had a broken link. This meant that in reality only 10 (26%) of the audited universities had a web-accessible policy. In the defence of the universities involved, their disability policies may have in fact been part of some type of overall equity policy and not specifically mentioned as a standalone policy. If this is the case, this should be clearly stated and clarified by the institution. Only three universities outlined in plain language that they had a disability policy and what it meant, but they did not show links to their policies. Hence, only 36% of universities either had an accessible disability policy statement or an accessible disability policy. Only one university had an advertised and accessible Disability Access Strategy (Item 4). A strategy is an agreed upon method of putting a policy into place. This single university out of all 39 performed very well overall and had a disability policy, a disability strategy and DAP online for a potential student to access.

Category B: User Access

While all universities offered a range of alternative methods to contact a DSO (Item 5), including postal, email and telephone options, only 21 named a point of contact. For some people who stutter, meeting new people and asking for directions is fraught with anxiety and fear. I know from my own experience of working within a university that this is not always possible due to staffing changes at times, but not having a direct line of contact with a named DSO could cause some people who stutters not to bother enquiring at all, considering the effort and, at times, anxiety involved with verbally negotiating a meeting.

Of the 29 universities that presented the web visitor with a detailed description of how to register for Disability Services (Item 6), three advertised the use of a registration card. With this card, a student with a disability could more readily access onsite disability services and alert staff to their need for assistance, if required. Due to not having to constantly verbally identify, the use of this card may indeed encourage more people who stutter to access services at times of need. The card would act as their identification for assistance and may ease the anxieties at times with having to introduce one’s self. However, the card may indeed act as a deterrent for some students with disability who do not wish to carry around such an overt identifier of being a person with special needs. I personally have never encountered such an approach and would be very interested in enquiring if such a strategy is still in play ten years after this initial audit was conducted.

Of the 18 universities that outlined the process of disclosure of disability (Item 7), 17 gave information about both the registration process and the process of disclosure. Having a clear understanding of the registration and disclosure process may give a person who stutters a more informed and confident approach to seeking assistance if required.

Category C: Teaching and Learning

Almost half of the universities had links to disability-related teaching information (Item 8) that were visible to the general public; however, upon clicking the provided link, public access to the webpage containing the information was blocked for some of these websites. By re-assuming my role as a lecturer of information technology could I assume that perhaps that some universities had either incorrectly referenced the linked files or were in the process of updating those materials at the time. The blocked content on some sites required you to enter a username and password. This a strategy that could be considered flawed because requiring authentication to access this material meant that you had to be formally within the university system and therefore, this material would not be available to prospective students. I would think that having such information would have been a transparent strategy for all universities to publicly show how accommodating and legislatively compliant they are to all.

Further, the found information guides covered commonly known broad disability groupings such as hearing impairment, vision impairment, mobility impairment, mental health conditions and even heart conditions. But it was unclear quickly where and how stuttering or general speech impairments fitted within these categories. One university highlighted its “Inclusive Practice Awards”, which are presented annually to staff members who have demonstrated exceptional commitment to assisting students with disabilities. Three universities advertised a form of “Disability Advisory Committee” or “Inclusive Practices Committee” which are university-wide committees designed to give advice on and promote full and equal participation of students with disabilities. This sort of information may give some visitors to the sites a sense that the university is taking disability and educational inclusion seriously, and is open to ideas from students with disabilities.

Only five (13%) of university sites advertised any form of alternative teaching and assessment guide (Item 9) with sections specifically focused on speech-impaired students. The information that was presented was very general in nature and was not given as much text space as that of other disability types. At times, speech impairment was mentioned within the context of other disabilities, more notably hearing impairment, almost as if speech impairments were a result of other disabilities or acquired conditions of some form. For example it is not uncommon for a person with an acquired brain injury to have their speech motor skills affected as a result. But any speech therapist can tell you that a wide range of speech impairments exist within isolation from other medical problems. For speech impairment, in general two assessments strategies for oral assessment were given; presentations being audio recorded prior to the assessment and one-on-one interviews with the lecturer. There were limited strategies for speech impaired students advertised and they all seemed to hinge on the student either shying away from speaking or avoiding speaking in front of a crowd. The general teaching and assessment information across all found guides ranged from some very basic information to well-developed policies. Twenty-seven (69%) universities advertised relevant assessment strategic information in some form.

For some students, including those who stutter, scholarships can be a great incentive to enrol into a higher degree. However, only 11 universities provided some form of information and links to either university scholarships or scholarships designated for a specific disability (Item 10). Although I like the idea of having scholarships designated specifically for disabled students, I can understand how such an approach may itself be discriminatory and act as barrier for some students to access. Some students may not want their financial support clearly badged and advertised in terms of their disability.

Category D: Social

Social activities (Item 11) for students with disabilities were scarce amongst universities and included the likes of blogs, discussion groups, newsletters and news reports. However, a newsletter from one university had not been issued for a period of two years and one from another university was almost a year out of date. This lack of updated materials could be seen as a worrying sign in terms of a focus on disability. One university offered a very informative *news and current events* section on their site, with success stories of current and past students with disabilities. On the whole, online and publicly assessable information about social activities for people who class themselves as disabled was lacking. It could possibly be assumed that students with disabilities at the time were either not strongly interested in such targeted activities. Or if such activities were advertised, then perhaps they were marketed in a targeted, discreet fashion and not to the university student cohort as a whole.

Category E: Responsiveness

Of the 39 DSOs contacted by the email (Item 12) outlined in section “Audit procedure”, only 20 (51%) responded and they offered very little information or guidance about stuttering. These informal responses from the DSOs fell into three distinct categories:

1. There were no formal structures in place for the teaching and assessment of stuttering students, and in some cases speech impaired students;
2. Such students were usually looked at on a case-by-case basis;
3. DSOs rarely, if at all, had professionally encountered a stuttering student requiring their assistance.

All findings of which make more sense when included within the discussions to come of the further findings of this thesis. For it seems that this study itself has found that very few Australian university students who stutter access DSO support and if so then they are not overly satisfied with the support offered. But you will read these findings in detail in chapters to come.

Overall criteria results

Each of the above 12 criteria met by individual Australian university disability services is shown in *Figure 1*. Not a single university met all 12 criteria outlined, with the best performance being one university, which met 10.

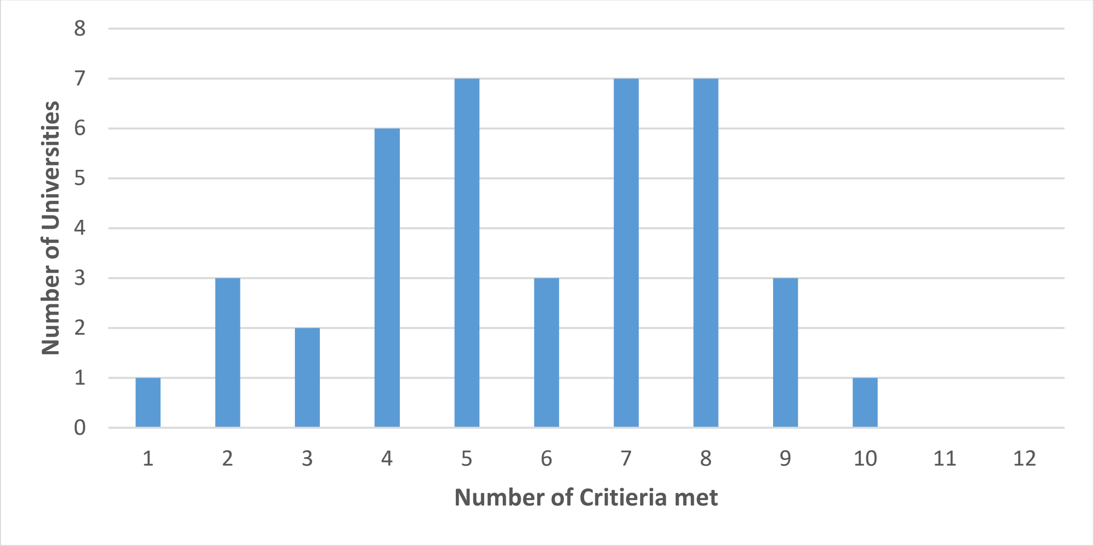


***Figure 1*: Web-Audit Met Criteria**

Discussion of audit results

To my knowledge, this was the first study of the availability of university disability services for people who stutter and the findings are concerning. From the results it is apparent that between the periods of 11th July, 2008 and 1st August, 2008, there was a dearth of information on Australian public university websites about disability in general and particularly about stuttering. Only 13% of universities had any available guide to indicate how communication-impaired students might be assisted and only four of those mentioned stuttering directly in that context. While the content of these guides provided very little information, there were many more guidelines for catering for other disabilities. Some of the disabilities that were mentioned in the guides are more commonly promoted throughout society and some are not. For example, five guides had sections relating to Asperger Syndrome. This is surprising, because it is thought that only around 1 in 1000 people have this condition continuing through to adulthood (Saracino, Noseworthy, Steiman, Reisinger & Fombonne, 2010), which is low compared to the generally accepted figure of 1 in 100 for stuttering in adolescence and adulthood (Andrews & Harris 1964; Ginsberg, 2000; Ginsberg & Wexler, 2000). Although at least in a United Kingdom setting there was growing concern around the rising numbers of university students disclosing and presenting with Asperger Syndrome (MacLeod & Green, 2009). Concerns of which may have been also experienced within the Australian setting and causing more disability unit focus.

Particularly disappointing in the context of this overall study was the lack of guidelines regarding teaching and assessment strategies to assist students who stutter. Furthermore, the assessment guides were generic in nature, referring to speech impairment as a whole and offering poorly defined options. Alternative assessment options and guides should be prominent for students who stutter, because having this information could give a prospective student some confidence that the university has flexible assessment procedures and can meet their individual needs. Not all speech result in the same impairment characteristics and associated general needs. A student who stutters and who is fearful of public speaking and hence worried about oral assessments would benefit greatly from this information. It is likely that the student would look more positively on a university that advertised that is was open to arranging suitable assessment procedures for students with a communication disorder. If a university is open to flexible assessment arrangements and provisions for people with disabilities then they can surely only benefit by advertising them.

Finally, the lack of scholarships and information about social activities for disabled students is also of concern. For some disabilities, the costs associated with attending university could be prohibitive. If scholarships act to encourage disabled students to enrol in a university course, then it could be argued that more scholarships should be available. This would be very helpful in general if the student in need did clearly identify as being disabled and wished to access specified financial assistance.

Organising and/or advertising social events with other disabled students might also encourage a prospective student to enrol and might also discourage a socially anxious student from dropping out. I would like to think that at least a list of various disability focused advocacy groups could be linked from a university website indicating that the organisation is somewhat knowledgeable about how to direct students to relevant external support.

On a more positive note, a large percentage of universities acknowledged the DDA. This at least indicates that they acknowledge the Australian government requirements by which they are legally obliged to abide. Also, a large majority of universities did outline the registration process, which would help ease a student’s anxiety about seeking support because of their stuttering. On the other hand, a lack of current disability action plans could deter disabled students. The fact that fewer than half of universities gave a potential student a direct contact point for disability-based assistance would be disheartening for the student. Of more concern is the fact that only around half of the email enquiries made to university disability services were responded to. If this response rate was reflective of wider practise then it may have been dissuading factor upon a wide range of prospective students waiting for a response before choosing to enrol at a given university.

It is worth stressing that university disability services for students who stutter would only be used if those students actively sought them out and perhaps mostly only by those who identify stuttering as being a disability. Perhaps the reframing of stuttering being a participation problem rather than a disability, as proposed by the recent World Report on Disability (World Health Organisation, 2011), could encourage such students to seek out these services more, if needed.

Audit conclusion

Based on the web audit, it is clear that a prospective student needing support because of a stutter could not easily make a solidly informed choice to enrol in an Australian public university based on the support information provided by disability services via the web. There are a few outliers that came close to meeting all 12 criteria, but they are the exception rather than the rule, and even then, did not specifically cater to people who stutter. Universities need to provide more information for potential about services and strategies for accommodating stuttering, and indeed for all other communication disorders. Australian universities must also let it be known that stuttering can be annexed by the term "disability" and that there are services available to help with related issues. These suggestions will benefit not only students who stutter but a range of potential and current students with special needs. But in the case of stuttering, it is also up to Australian stuttering organisations to strongly promote stuttering to universities and in fact all levels of educations in order for it to be more recognised as an area of concern to be addressed and accommodated for. It is also worrying for me that the DSOs that I contacted have said that they rarely encounter a student who stutters in terms of accessing support. This is worrying because it makes me think about how many of these students are for various reasons avoiding, or are simply not aware of, such support services. As a result, I could assume that for some, their educational journeys would not be as successful or self-satisfying as they should have been. These are concerns in which I find validity for in the chapters to come when I research university students who stutter themselves. It also makes me think about their ability then to inform disability support services in how better to facilitate their studies. In a sense, a true vicious circle may exist in which university support services seem to lack specific strategies to assist students who stutter, yet few of these students seem to present themselves for assistance and thus perhaps such needs are not seen as priority.

At that point in my PhD journey, it was still unclear why there was such a gap in this information. It may be that university disability services were simply not aware of the experiences and hardship that students who stutter may encounter at university. This may be due in part to the generally low profile that stuttering and its associated problems has in the general community. Nonetheless, stuttering is legally regarded as a disability in Australia and universities need to demonstrate their understanding that it is against the law to discriminate against anyone with a disability. But I have to admit that support officers cannot specialise in all conditions and that students who stutter need to understand the need to drive and inform further education of such services.

It is of course of interest that this audit was conducted in Australia. Australia provided a suitable country to study because stuttering is legally regarded as a disability, and it is against the law to discriminate against people with a disability. Research into this topic in other countries would be of great interest. While other countries will have different legislation regarding disability, it is certainly clear from previous studies (Dorsey & Guenther, 2000; MacKinnon et al., 2007) that stereotyping of students who stutter by other students and by academics occurs in other countries. I think that it will also be of benefit to replicate this study within an Australian setting to see anything has changed within a 10 year period (2019 onwards). I would like to think that over a decade period that Australian university websites and contained disability support information has become more searchable and assessable over time.

Overall I concluded that little online information existed at the study’s point in time in regards to the accommodation of a student who stutter through the websites of Australian university support services and indeed there was little mention at all of stuttering within this context. It could be proposed that the lack of information could act to deter some people who stutter from enrolling within a given university. It could also be hypothesised at this stage in my overall thesis that the lack of mentioning stuttering as a disability through these services could also serve as a deterring factor for students who stutter who are looking for assistance. If stuttering is promoted within that context then perhaps many students who stutter simply do not ask disability services for assistance, or possibly think that there is simply no support out there for them. Considering the debate within stuttering circles themselves about whether stuttering is a disability or not, universities need to be loud and clear about what impairments and conditions fall under the realm of disability support services. Some students who stutter may clearly not identify with the term “disability” but possibly may ask disability services for assistance if it was advertised as being under their umbrella of support. Chapter 2 established that there is an evident gap in the literature concerning students that stutter and in this chapter that Australian universities had little publicly assessable information about how they could provide support services and provisions for such students. It became apparent that a richly informed and in depth study of students who stutter was in order, to gain a window into their lived experiences that could inform and instigate educational provision and assistance.

The next chapter will articulate the research design that underpinned the gathering and interpretation of the conversations to come. The research employed a unique bricolage methodology and a unique methodology structure to uncover the required narrative stories which have informed a wealth of valuable new knowledge about Australian university students who stutter.

Chapter 4. Research design

The choosing of an appropriate methodology and associated method(s) to facilitate the answering of a research question in itself can be an arduous journey of justification, appropriateness and decision-making. To allow me to answer my overarching research question *"How do students who stutter negotiate their university experiences in Australia?"* I researched a range of research design approaches to come up with the uniquely structured and rigorous approach outlined in this chapter. Guiding my overall research design was the use of the fluid bricolage methodology that allowed me to adapt my enquiry to the directions in which the data was taking, leading me to be enlightened even more. In order to gather the data the stories of Australian university students who stutter, I deployed a nation-wide online survey and followed that up by conducting 15 interviews. I have interwoven a unique autoethnographic approach of narrating my own story throughout this thesis to assist you to understand my own journey as a university student who stutters and my experiential alignments with the studied cohort. I believe without doubt that I have used methodology and associated methods that have lead me to understand the value of a flexible and thorough approach to qualitative research design. The rationale and journey associated with this decision-making and justification I will outline during your reading of this chapter.

Absorb what is useful

Before leading you down the path of the methodological framework that has led to the design of this study, I want you to keep in mind the following quote from world renowned martial artist and movie star Bruce Lee concerning his philosophy of becoming a rounded martial artist of mind and spirit.

> "*..absorb what is useful, discard what is useless and add what is essentially your own.*" (Lee, 2009, p. Quote 58).

Some would call it a cheesy quote which has no justification to be within serious academic writing, yet I would say it is a simple way of framing self-empowerment and your own unique research journey. The philosophy behind this quote resonates with an unshackled, yet informed drive forth into a powerfully informed research design reaping the rewards that it envisaged upon its conception. In fact this is a quote that has resonated personally within me ever since I first read it close to 40 years ago. I found that Lee often peppered his writing with selected Chinese philosophical musings from Confucianism and Taoism to drive his life actions and decisions. I have applied it to all areas of my life including my academic and leadership endeavours. In fact when discussing stuttering treatment and options within stuttering online groups and conferences, this is the one quote I use the most often to frame the personalisation of treatment and the individual's private journey. In my opinion, a researcher must keep an open mind while understanding established paradigms and yet create their own ways to achieve their goals. This seems especially true to me when approaching social research for which I have found that being open to different research approaches achieves different viewpoints, opinions and answers to surface. This philosophical stance led to the development of my methodological positioning that I will now explain to you and how it came to light.

Evolution of a methodology

Every journey has a beginning and an end, yet as you read in chapter 1 of this thesis concerning my original research topic that not all planned journeys go to where they originally envisaged. When I originally conceived this study I had a larger idea in mind for its design. I was going to study three different groups of people all associated with the research question and then triangulate responses to attempt to have a holistic understanding of the experiences of Australian university students who stutter. These three groups being university students who stutter, university lecturers and university disability liaison staff. This approach was initially presented at the Australian Speak Easy Association convention in 2008 to an audience of esteemed academics within the speech pathology discipline. They thought the premise of the overall study was worthy and that perhaps the scope was too large as presented for a PhD. Initially, I also envisaged a more statistical approach to gathering data which in itself would have distanced me more from the studied cohorts by the use of a series of online surveys. This initial approach to gathering data had a strong focus on descriptive measures to describe the analytical story as it unfolded. For an academic grounded within the quantitative world of information technology, science and mathematics, with world-class statisticians at my doorstep to call upon any time for analytical guidance and advice, a way to construct the most meaning from a quantitative analysis seemed like the logical approach. However, this numerical approach was soon to change because of the eagerness of the participants to speak up and express their feelings and experiences. The Bricolage methodological approach outlined further on in this chapter appealed to me for its openness and adaptive nature allowing me to give true justice to the words expressed by the participants of this study. I will outline the Bricolage mindset to you in more detail in the next section of this chapter concerning its appeal and ability to give this study both rigour and depth.

My research design turned into a series of complementary methods that evolved to find as rich data of experience as I could. Each of which I will describe for you in detail throughout this chapter. As part of my investigations I had initially planned to audit all Australian university websites for their online stuttering provision information (see previous chapter) and then survey Australian students who stutter about their university experiences (outlined further in this chapter). This led to the need to find out more precise and rich information about the actual student experience. After the approval of my University’s Human Ethics Research Committee (HREC), I sent out survey invitations to Australian university students who stuttered via the assistance of Australian stuttering organisations and social media, and awaited the responses from a cohort that I had assumed would be difficult to extract detailed responses from. For I had heard from some fellow researchers in the stuttering world that people who stutter are sometimes hard to get interested into research studies that were not of a clinical nature. The first question of my survey was placed purposively at the beginning of the survey to elicit expanded responses and to stimulate the participant’s interest to respond to the further 50 plus questions that followed. That question was simply put “*Do you consider stuttering to be a disability?*”

To my surprise that one question alone in a matter of days elicited close to 40 expanded responses and a plethora of powerful and, at times, very heated opinions. One participant was strongly offended at being asked this question and wrote to me to express their discomfort and disgust around the notion of it. The true voice of this study was soon becoming the combined chorus of Australian university students who stutter, who were beginning to express passionately and explicitly about their university-based experiences. Based on prior assumptions, participation levels in the open question was very encouraging and I believe that the participants may have perceived my study topic as one to which they could easily relate to and that might instigate foreseeable changes. It is not uncommon to encounter robust conversations in social media stuttering support groups related to the irrelevance of the different focuses of stuttering research. But these debates are amongst people who stutter themselves and not often on openly public arenas. In such cases only those who are members of these communities actively see the different lines of friction and interest that are spoken about.

To be blunt, I have found people who stutter do not generally understand how research works and the time it takes to clinically define and validate findings. In terms of stuttering research, anecdotally many are hoping for a definitive cause to be found and associated cure. The fact that I identified myself to the participants as ‘one of them’, a person who stutters, may have aided with the response numbers and wealth of passion expressed throughout the survey responses. ~~For~~ over time I had gained a trusted reputation within different stuttering communities in Australia and globally online. This trust within a community certainly would have aided with gathering the number of participant responses and ongoing offers of help. I also had the professional backing of prominent Australian and global stuttering support organisations as cited via the letters of support shown in *Appendix A: Letters of support*, all of whom saw worth in the study and looked forward to the findings. As the survey was unfolding it was also becoming apparent that I would not gather enough responses to show any strong statistical analysis due to the statistically insignificant response count. The numerical data alone would not be able to portray statistical significance or power to elicit enough academic impact required for a PhD. Nor did I believe that numerically analysed data alone would be able to give true justice in describing the meaning of the findings to come. University students who stutter wanted to talk and I firmly believed that they deserved the respect and method to be able to do so.

As a result of the loud shouts of emergent voices, a shift in the focus of this study occurred, towards giving true voice to those who at times choose to remain silent. I did not have any ethical right or moral confidence in deciding not to allow the strong and fluent outwardly projected voices of people who stutter. I certainly did not lack the academic integrity to decide not to follow the path of rich narratives and not to investigate the strong emergent streams of opinions and experiences. As a result of the passionate voices evident in survey responses, I began to feel the empowerment associated with focused qualitative research and the gift of being given the voices of others and having the opportunity to tell their passionate stories to the world. Their voices were feeding my hunger to find new knowledge and to inform processes to empower them. I was being very driven to a robust fashion in which narrative methodologies could give voice to expression and researching personal experiences (Plummer, 2001). The participants were embracing the opportunity to speak and as a result some were keenly volunteering to be further interviewed. They truly wanted an outlet for their personal and combined voices to be valued and heard. So, as a result, an emphasis was placed on the emerging qualitative narratives and the descriptive numerical-based data for this study was de-emphasised. I also changed the way in which this thesis was written as I found the more conventional scientifically inclined write-up style did not suit the unfolding stories nor did it narratively flow well. I found that using a first person voice to narrate this thesis was empowering for both myself and the readers. I also discovered that intertwining my own opinions and relevant anecdotes made this whole journey of discovery self-empowering and personally touching to convey to the reader. These approaches were not understood nor favoured within the discipline area of the Faculty where I worked at that point in time, but had been argued as being an appropriate alternative methodological approach to quantitative measures to enabling sociological research on people who stutter (Hayhow & Stewart, 2006; Tetnowski & Damico, 2001; Tetnowski & Franklin, 2003). My approach was met with some negative comments from colleagues after they had read some of my initial draft chapters for such colleagues were well versed in stricter academic writing conventions and established schemas to ensure publication outputs.

Some comments for example:

“*Is this a joke PhD*? *Seriously, you must be joking?*” an early career researcher.
Or
“*If you cannot quantify the research then it is useless*” a senior lecturer.

There were also expressions of praise and support from those who were more akin to mixed methods frameworks, cross-discipline research and from some who had delved themselves into qualitative research.

For example:

> “*I like that!!! Strong statement [thumbs up] - if you can't do it your way, what’s the point of a PhD?”* a senior lecturer.

As a result of this adapted shift in the methodological thinking of my study I decided to shift to a different overarching research methodology that appealed to me and that was of “Bricolage”. An approach which I had not heard of before it was recommended to me by one of my supervisors. At first I was full of apprehension because I had not heard of this research framework in any research skills class I had taken or post-graduate seminar I had attended. It seemed a very fresh approach generally throughout my university. Upon further investigation into this framework, it immediately became an ally of mine to establish a powerful research structure open to adaptability. An approach that I will now outline to you in detail.

Enter the Bricoleur

The term “bricolage” is French in origin and is simply defined by the Oxford Dictionaries (Oxford University Press, 2019) in mass noun form as being “construction or creation from a diverse range of available things”. A “bricoleur” has been nicely described and contextualised by who some people view as its forefather, Joe Kincheloe (2001) as being a “handyman or handywomen who makes use of tools to complete a task” (p.1). The question ‘How does bricolage contextualise itself within a research framework?’ may arise. There may be some confusion around the term, at times, because the term is used within many different disciplines including the arts, business, information technology, education, architecture and others. Not being a term unique to academic research only lends itself to having a broad definition and resulting application. No matter though which discipline uses the term within its specified context, the undercurrent of its root definition remains the same.

Bricolage frames a methodology around a multifaceted approach to conducting research and the notion that there is no one single way to frame, gather or analyse data both of a qualitative or a quantitative nature (Denzin & Lincoln, 2000; Kincheloe, 2004). An approach which at first was alien to my computer science upbringing. It goes as far as stating that a position of truth in research in unattainable by using one single perspective only and deviant cases can be used to assist with balanced reporting (Guest, MacQueen, & Namey, 2011; Kincheloe, McLaren, & Steinberg, 2011). Even in a rigidly quantitatively-based project, the researcher should acknowledge that their personal experiences and preferences will have added a subjective nature to the outcomes (Kincheloe et al., 2011). Bricolage is often framed as being a rigorous and yet adaptable methodology, making use of the resources that are at hand, while enabling innovation for research structure and in turn driving the elicitations of powerful and fruitful outcomes for the researcher (Cunha, Cunha, & Clegg, 2009; Duymedjian & Ruling, 2010; Innes & Booher, 1999; Whitsed & Wright, 2015). A bricolage approach is not only concerned with the research project at hand, but also the wider prospect of what overall effect a research project is capable of expressing for human empowerment (Earl, 2013; Kincheloe et al., 2011). After reading so much about bricolage, I sensed a growing feeling of confidence and empowerment within myself. I felt an academic freedom to express myself and to write the thesis that I indeed wanted to stylise. It was the chance to frame my research and to express the findings closer to my own style of lecturing. A lecturing style that is always evolving, open to change and focused on expressing the narrative voices of the subject matter.

On the surface, bricolage may appear to be lacking the rigour and complexity of using a single research approach, but my own view is that it actually appears to be a complex and multilayered methodological approach to research which perfectly fitted my research project. In fact, to have a strong command over bricolage methodological design, you need to have wide and strong knowledge of, and ability to apply, multiple research frameworks and methodologies (Kincheloe, 2004; Kincheloe et al., 2011). I have personally found the bricolage approach to offer a flexible and dynamic approach to research design, enabling me to adapt my methodology to maximise participant input and further inform stronger outcomes. I liken a “bricoloeur” to being a Special Forces research operative, one who is professionally trained, who is constantly adapting to the mission at hand and who completes the mission to the best of their ability to the satisfaction of their generals. To quote in context the popular United States Marine Corp motto (United States Marine Corps, 2015), the bricoloeur researcher knows how to “improvise, adapt and overcome” to give their study a rigorous research grounding and their participants empowering voices.

With bricolage in mind, this study and its emergent voices evolved into a mixed method approach (Creswell, 2003; Tashakkori & Teddlie, 1998) to form what

Greene, Caracelli, and Graham (1989) describe as a *complementarity* study in which different methods examine overlapping and different traits of experience and phenomena. The whole journey of which is explored later in this chapter. Mixed methods research is a firmly established third research paradigm for use for behavioural science research and was deemed as appropriate within the design of this overall study (Lopez-Fernandez & Molina-Azorin, 2011).

Empathy & autoethnography

As narrated earlier in this thesis, I stutter and I continue to engage with the Australian higher education student experience. In fact I proudly can say that I stutter rather well and during a speech block my facial grimaces can win a gurning competition. Any joking aside, my stuttering is impressive at its finest and I am often described as a “triple threat” in the stuttering world because I overtly show all the common characteristics of a person who stutters. When stuttering I can block, repeat and prolong sounds. Being a person who stutters, in turn, has led to me being able to identify broadly with the targeted study group. But this was not always the case to be honest, due to my supportive upbringing. Before embarking on this study I had little contact with other people who stutter. Simply this was because I did not know any socially and had little exposure to the support group scene. or Although I am a person who stutters, each of us has our own unique life experiences couched within our respective demographical settings. Additionally, I do understand the lived stuttering experience very well and this study has led me to more broadly understanding this experience. Being able to truly empathise with the participants of this study has enabled me to have a greater insider understanding of their experiences. Of course, we are all unique and I did not live all the same university experiences as the participants, nor did I expect some of the found results to emerge which I will outline in the chapters to come. There is power in the combined voices of the many, but one of the beautiful aspects of social research that I have found are the unique individual cases which cause moments of personal enlightenment. I sometimes find a single outlier comment to be so more thought provoking than the mass of consistent data and this often leads me to different angles of enquiry. The research of people who stutter by one that self-identifies in that group is seen as a unique lens shared by some notable experts within the area of stuttering. For as Shames (2006) explains:

"It is interesting to note that many of these pioneers for dealing professionally with stuttering, were themselves stutterers. Their personal experiences as a stutterer gave a voice of validity as well as empathy and understanding to their diverse work and achievements" (p.1).

I aimed myself to add a true voice of validity to this study and all the associated research I do around supporting people who stutter. Patton (2002) makes a similar point: "The only way for us to really know what another person experiences is to experience the phenomenon as directly as possible for ourselves" (p.106). In the case of this study, I have clearly experienced the phenomenon of the aims of this study firsthand and continue to do so during my course as a higher degree student researcher. My unique grounding within this study has led to interesting reflections on the findings which you will read in later chapters of this thesis, which are often counter intuitive to my own expectations and experiences.

To help you the reader understand my own stuttering story and my analysis of the data to come, I have employed an autoethnographic approach to intertwine my own persona onto and throughout this thesis. Autoethnography is a method of writing used in sociological research in which the author can write themselves into the narrative of the research in either a fictitious and/or non-fictitious form and focus on the stories of lived experiences (Bochner, 2012; Denshire, 2014; Nevill-Jan, 2004).

Autoethnography has been argued to assist researchers to "achieve an understanding of their lives and their circumstances" (Bochner & Ellis, 2006, p. 1). In fact, autoethnography does not have to rely on the narrated word alone and has been seen to employ a range of other mediums to make its research more appealing to non-academic audiences (Adams & Manning, 2015). These means have included but not limited to artistic performance (Metta, 2015), blog posts (Boylorn, 2013) and music (Bartleet & Ellis, 2009). Autoethnography was coined as a term by anthropologist Carl Heider when he wrote his doctoral thesis on cultural accounts of growing sweet potatoes in Irian Jaya (Chang, 2016). However David Hayano (1979) used the term arguable more approachably in 1979 when described the autoethnographic researcher as being an insider within their "own people". The common practice of "silent authorship" in which the author avoids overly intertwining their own experiences into the narrative of their research was from inception and continues to be challenged within in academia (Bochner & Ellis, 2016; Holt, 2003).

Despite the values of such an approach being thrown into doubt in terms of validity and legitimisation, autoethnography is finding itself widely accepted and published amongst a range of different disciplines some of which are not traditionally open to such approaches such as education, business and information systems (Bødker & Chamberlain, 2016; Boyle & Parry, 2007; Trahar, 2009). In fact even within the mostly quantitative world and close to my lecturing discipline, Riordan (2014) argues strongly that the quantitative rich information systems discipline has made a serious research error in the past by ignoring the voices of themselves and of the users of their many systems. Autoethnography gives the researcher a unique insider voice and personalised writing style to their research which arguably other research methods cannot allow (Dyson, 2007; Griffin, 2012; Wall, 2006). Autoethnography has successfully been implemented into academic studies where it has been used in conjunction with other methods in order to give deeper meaning to the data. For example Bosanquet (2017) described her own experiences as a female early career academic mothering a sick child and coping with secondary infertility using autoethnography. She then went on to describe her analysis of her survey of other Australian female early career academics who had caring responsibility for children. Both methods seamlessly complemented each other and created a deep connection to the data and resulting analysis.

Kravia and Pagliano (2016), in a form closer to this thesis, employed a more complex mixture of methods to study the scope and effectiveness of school guidance and counselling services in Papua New Guinea. The research team used autoethnography of the lead author's own experiences working in Papua New Guinean school counselling services, a survey of caregivers and key stakeholder interviews to qualitatively portray a holistic understanding of ways to assist the transformation of Papua New Guinean school support services. Of late, one study that further inspired my justification of the use of autoethnography within Bricolage and combined with other methods was the doctoral thesis of Thoo (2015) who studied the contextual impacts that affected learning behaviours for medical students enrolled in medical schools in both Switzerland and Ireland. Thoo combined a survey of students along with an autoethnography study of an exchange student, and a review of official documents allowed characterisation of both academic contexts. This approach allowed him to explain how small changes in the learning behaviours of medical students within this context were powerful influencers of positive changes within a range of educational factors. I have found using autoethnography to intertwine my own story into this thesis to be such an empowering form of expression which flowed so well for me when writing. Although I am usually very private about my stuttering in person, I have found this whole study to be such a liberating exercise for my self-expression. I hope you, the reader, are enjoying the journey that I am taking you on and that you are learning about my motivations and experiences along the way. Autoethnography also lends itself so neatly to assist me to discuss the later findings of this study allowing me to sympathise and at times counter my own experiences with those of the research participants. Now I will continue to discuss how I believe that my personal connection with the research participants have aided my study.

I believe that empathy and respect from the target audience has at times resulted from my well known contributions to stuttering-based magazines, conferences and online discussions. This shared empathetic and respectful relationship may well have helped with the gathering of data and also for the richness of its content. I am often faced with both strong support and, even at times, loud objections for my academic work and opinions to empower people who stutter from people who stutter themselves. I am not shy at all from putting myself “out there” amongst these communities to discuss and debate my own views on a range of stuttering-related topics. But more often I am backed with strong praise for my efforts to work on ways to further empower people who stutter, from people who stutter. The interviewees, who you will learn more about later in this chapter, may well have opened up more and shared more personal stories to an interviewer who can sympathise truly with their circumstances. I could sense in their voices as we spoke that they felt very comfortable and empowered by sharing their experiences with me. In my opinion the interviews, therefore, were perhaps more likely to become authentic conversations involving genuine sharing and exchange of information and opinions rather than question and answer exchanges which can be rather artificial and shallow at times. At times, I found it hard to contain the interviews within the bounds of subject matter and timeframes with some interviewees wanting to explore their whole life stories. Their willingness to express and share their stories appeared to be confidence-building for the participants. I honestly believe that they were all waiting for their stories and opinions to be heard. The interviewees expressed full confidence in my ability to relate their stories and express them respectfully to the intended audiences.

It should be noted that empathetic research may lead no doubt to bias from the researcher, as arguable all research projects are (Davies & Dodd, 2002). But as a bricoleur, I know that research generally has a subjective nature to its design and analysis (Kincheloe et al., 2011). It has been convincingly argued that having a personal distance from the subject matter in no way guarantees objectivity anyway, so a closer approach is very appropriate (Patton, 2002), particularly if it leads to greater levels of rapport and trust between the researcher and interviewees. This has clearly been the case within this study. It is possible that a researcher who did not stutter may not have gained such a rate of responses and such deep and detailed narratives from participants. I know that having such a deep connection to the participant audience has only strengthened the ability to have their voices heard and to instigate educational change. Scientific measures and methods alone cannot understand the human experience, but having empathy with the sample group can aid this understanding (Martin, 2003).

As the researcher, I will outline in the thesis my own experiences and perceptions of the nature of the experience at hand autoenthographically, in turn supporting a technique supported by Merriam (1998) called “Clarifying Research Bias”. This will alert the reader to the identity of myself as the author, my outlook on the study and any unintentional biases that may occur. I will also intentionally seek out contradictory data that may disconfirm my own assumptions constructed through my lived stuttering experiences. These are patterns and trends that I have followed and led throughout my entire thesis write-up.

The online survey

After the web-based audit, the next stage of this bricolage research design involved a survey of people who stutter who were 18 years of age or older, currently enrolled in any Australian public university, or had been enrolled within an Australian university within the past 10 years. These demographic inclusion criteria were decided upon so as to allow the gathering of as much informative data as possible from this small subset of the general population. The web-based audit had expressed the lack of public online support content for Australian university students who stutter, and next I needed to start to truly understand their actual lived university experiences.

The survey was open for a period of four months after focused promotion through prominent Australian stuttering organisations. The survey involved a mixture of question types and was designed to generate a broad view of the issues being researched from a qualitative descriptive viewpoint. The design of this survey can be viewed at *Appendix E: Survey design* and the survey flowchart can be viewed at *Appendix F: Survey flowchart*. As far as my supervisorial team and I were aware at the time, this survey was the first of its kind and scale to be focused solely on students who stutter engaging within higher education. This was verified by the extensive literature review that was conducted and ongoing conversations with national and internationally-based stuttering support group leaders and leading academics within the discipline.

A web-based forum for people who stutter (http://www.stutteringforum.com/forums) was used as a test bed to trial the survey questions, test question response values and patterns to gain feedback in order to help to shape the survey design during the early months of 2009. Prototyping of the survey required only a small amount of participants and sped up the process of the informed survey design which in turn led to the formation of possible hypotheses about likely answer trends for Australian-based students. These test responses also assisted with the early design of the semi-structured interviews used for the second stage of this study. The survey was able to be completed by participants by using either a paper survey or a web-based online survey. Because of the dispersed nature of the support groups and targeted participants, the online survey became the preferred method used to submit data with only one paper-based response being submitted. The online survey was constructed using the LimeSurvey environment which is a professional, open source package used by many academics and governmental institutions around the world (LimeSurvey, 2009). The LimeSurvey environment was securely hosted on the University of Ballarat's (now known as Federation University Australia) internal servers which gave myself total control and ownership of the data. I found LimeSurvey to be an intuitive tool which enabled myself to quickly view and analyse both individual and accumulated results with descriptive statistics. The ability to view emerging answer trends as data was being entered "live" by the dispersed participants, enabled the ongoing design of the semi-structured interview stage of this study. "Live" meaning that I was alerted to each individual survey submission as it occurred and I did not have to wait for the total accumulation of the data before starting to interact and analyse it.

The resulting survey design contained 55 questions in six themed sections (see *Appendix E: Survey design*) and was estimated to take a participant between 25 minutes to 45 minutes to complete depending on their level of interest in responding to the presented questions. A participant who wanted to simply answer the bare minimum of the closed answered question types would have taken the estimated 25 minutes to complete the survey, on the other hand if the participant wished to expand upon their answers to the questions presented, then it would have taken them up to 45 minutes to complete. Most of the questions were Likert scale in nature and allowed agreement levels to the posed question to be gauged. The Likert scale design used in the survey was a five-point scale ranging from: Strongly Agree; Agree; Neither Agree nor Disagree; Disagree; and Strongly Disagree. It was not deemed necessary to cut the scaling options to these questions down to even finer amount of options because the five point design was adequate enough to show descriptive results with clear opinion trends. Participants were able to expand upon all of the questions posed in an open and freeform nature if desired. In turn allowing the respondents to expand beyond the closed response and Likert style questions allowed me to gather a large amount of descriptive and narrative data from the survey alone (see *Appendix L: Frequency of survey expanded responses*). Upon completion of the survey, the respondent was invited to volunteer to participate in a one on one interview with the researcher which is outlined in section of this chapter entitled "*The interviews*".

The survey contained the following six themed sections set out in an order to reflect the average university lifecycle:

1. *Demographics:* Designed to gather general demographic information about the participants such as gender, opinion concerning stuttering being a disability or not and self-rated stuttering characteristics. This section enabled a general respondent profiles to be formed and for future demographic differences to be established.
2. *Upon enrolment:* Designed to establish whether or not people who stutter investigated pre to enrolment what services a university could offer them to support their stuttering whilst studying. This section was also focused on if they did seek help then how influential was what information they had found in terms of their resulting enrolment decision;

3. *University Disability Services:* Designed to provide a comprehensive look at the reasons why some students who stutter had asked disability services for help and what were the results and feelings springing from this journey of assistance seeking. It was important that this section of the survey deeply studied the university provided facilitations of disability assistance;
4. *In class:* Designed to look at the effectiveness of the strategies offered by the disability service officer(s) to students who stutter who went through the provision services covered in section three of the survey. This section also enquired about the general impact that a student's stuttering has upon their class-based interaction, endeavours and assessments.
5. *Overall:* Designed to enquire about the impact that a student's stuttering has had upon their academic abilities, results and student life. This section also looked at a student who stutter's perceptions of what they thought their lecturers and students thought of their academic abilities;
6. *Stuttering impact:* Designed as a series of agree/disagree questions that looked at notions of stuttering related health neglect, anxiety and cure desperation. This section also looked at the impact that stuttering had on the post-university employment and career choices of graduate students who stuttered.

A sample size of at least 100 participants was optimistically hoped for to enable and to more accurately portray the frequency of emerging trends to give strength to the applied thematic analysis to come. With 102 gathered replies though, any statistical significance that could be assumed from most answers was nominal giving more justification for the decided qualitative analysis approach. The survey was also issued in paper form to individual stuttering support groups when required, but this method did not seem overly appealing to the potential participant with the online option being preferred. The stuttering-based support groups promoting the survey were Australia's largest non-for profit self-help association for people who stutter called the Australian Speak Easy Association (twenty groups at the time spread across five Australian states and one territory - http://www.speakeasy.org.au/) and secondly, the Australian McGuire Program (at the time eight groups across five Australian states -

https://www.mcguireprogramme.com/en/au), a non-professional program for adults who stutter. The Australian Speak Easy Association advertised the survey through their frequent *Speaking Free* magazine to their membership. The Australian McGuire Programme sent out email invitations to all members in their graduate database over the age of 18 and via their Internet-based Yahoo group for people who stutter called *Freedoms Road*. Members of both support groups were also invited to pass information about the survey on to other adults who stutter to create a snowball recruitment affect. A snowball effect (Tashakkori & Teddlie, 1998) was predicted throughout the associated stuttering groups to capture responses of non-active members and the friends of a member who may stutter.

It must be noted early in this study that most of the members from the Australian Speak Easy Association were assumed to have gone through a form of professional fluency shaping programme/speech therapy before joining the organisation. This programme would commonly have been smooth speech-based technique which is an evidence-based technique commonly supported and used throughout the Australian speech pathology community (Australian Speak Easy Association, 2011). All members of the McGuire Programme have been through at least one intensive McGuire program-based stuttering management course which is designed to assist them to manage their fluency. This means that a majority of the study's participants are assumed to have all gone through a fluency shaping/management program of some form. The survey and interview phases of this study did not enquire though if they were using their learnt fluency technique while at university. But the survey did enquire if a student who sought help from their relevant University's disability liaison unit thought that the disability officer who assisted them sought the guidance of a speech professional when designing support strategies. The goal of this study was to investigate the experiences of university life for these students and not to promote or give value to any given fluency technique.

The survey was active from the 22nd of July, 2009, until the 31st of December, 2009. The five month deployment schedule was enough time to receive a sample size of

102 fully completed responses. Participants were 102 adults who stutter and who were currently (n=21) or previously (n=81) enrolled at an Australian university. A strong response rate from both organisations combined was indicated via the influx of activity during the periods for which each organisation promoted the study. This strong response rate was gauged because according to records officially provided by the two targeted associations, there were 27 Speak Easy and 70 McGuire members who met the criterion. With 102 responses in total and a predicted 97 eligible members combined plus some snowballing effect has led to a very strong representation of the targeted population.

The interviews

As the responses from the survey steadily came in, it became apparent further qualitative enquiry was required to tease out the detail motivating and helping to explain the emerging answer trends. With my bricolage-fuelled mindset, I was able to adapt quickly to the data and the need for deeper inquiry by instigating a round of interviews. Keep in mind firmly~~,~~ that the research question and study aims outlined in Chapter 1 lend themselves to qualitative inquiry as they are mainly concerned with both “What” and “Why”. An intention of this study was to make the results available to multiple and varied audiences for which qualitative results may be more appealing. As mentioned earlier, pure statistical and number-based enquiries were deemed not adequate enough to be able to give this study justice alone, and a rich qualitative approach was required to explore and reflect the human experience and to give voice to people who stutter. The next stage of this study involved a succession of interviews over a 3 month period from the 7th of September, 2009, until the 20th of December, 2009 (see *Appendix G: Interview schedule*), as the survey was still gathering data. Interviews were conducted with a purposeful sample of 15 survey respondents who volunteered via the survey stage to participate. Purposeful samples are used to highlight information rich narratives about the phenomena being research (Patton, 2002). By the 15th interview response, a saturation point was reached in which little new information, views or opinions of value were building or emerging. No more participants were required as qualitative studies may only require a small number of participants and, as Silverman (2005) describes that they often are designed to "...sacrifice scope for detail". This sample size was seen as quite adequate for a qualitative study as it focused more on depth of experience rather than breadth (Patton, 2002). The participants who volunteered for the interviews were purposively selected and this selection method (described below) helped to give a deep qualitative understanding of stuttering issues that were specific to the research aims and needs (Cohen, Manion, & Morrison, 2000). The participants' ages were not recorded as they were deemed not relevant to the study, nor was it asked for within the initial survey design, but their Australian state location was recorded, and participation spanned across six Australian states. This purposive sample included key cases based on the amount of time spent at university; those who did/did not ask disability services for help; different degree choices and gender. Volunteers were selected in order to maximise the diversity of types of respondents rather than in any attempt to obtain representativeness or randomness. Even extreme or deviant cases were viewed as being information-rich and quite a lot what learnt from these due to the variation of personal experiences. At times I have to admit that I found the more deviant case stories quite fascinating and they often lead to a new paradigm of thought.

As described previously in the previous section, *Online survey*, at the end of the survey, all respondents were invited to contact the researcher to discuss the option of an interview at a future time. This method ensures that there was no direct link between an individual survey response and the interview volunteer. Survey forms and transcripts of interviews were stored separately making it impossible for a returned survey to be associated with an expression of interest to be interviewed. Pseudonyms were allocated to the interview transcripts in order to assure anonymity but to still reflect gender. The interviews were semi-structured and focused on an evolving set of themes and areas of interest that were developing from the survey responses. Importantly, the interviewer and interviewee were allowed some broad freedom of questioning and response. Exploratory interviews complemented the bricoloeur way of thinking because they are conducted to be dynamic and without a rigid design

(Schensul, Schensul, & LeCompte, 1999). This use of broad freedom of interviewing helped to capture the opinions and feelings of people beyond a fully structured and closed approach by encouraging open expression of experiences and further investigations to previously unknown lines (Patton, 2002). This kind of interview outcome was decided upon also because of the shared bond or experience and understandings between the researcher and the interviewees. The discussions were deemed therefore, to be more likely of a conversational nature than a direct question and answer session. The open nature of the interviews helped the interviewees to decide for themselves what should be stated without being pigeon holed into a restricted line of answering or within a set of categorical answers alone. I felt the non-rigid design of the interviews complemented the desire for the interviewees to openly answer my questions and offer their opinions.

The interviews were audio recorded in different ways according to the interview method. Face-to-face interviews were recorded using a small non-intrusive iPod device. Telephone and Skype-based interviews were recorded using a software recording package called PrettyMay (http://www.prettymay.net/). Skype is a highly established and commonly used online software package (http://www.skype.com/intl/en-us/home) used for instant messaging and video calls. The use of Skype enabled stable and reliable interview calls to be made and the option of video conferencing when appropriate and able. Skype also enabled the two people involved to be able to see each other via webcam and in turn conduct a more personally facilitated interview. All of the interviews were conducted for close to one hour each and were held in a location and at a time suitable and comfortable for all parties involved, which made the interview process very flexible and accessible to all involved. Once completed, the interview audio files were thoroughly transcribed by the author and the contents and validity checked by the principle supervisor. Each transcribed interview was sent back to the interviewee for verification and edits/amendments. Only once the interviewee gave the approval to the transcript~~,~~ was their data securely set aside for the analysis phase. It is also important to note that the interview quotes that I have used throughout this thesis have not been modified in any fashion including the fixing of spelling or grammatical errors. They are raw and authentic expressions of experience.

Applied Thematic Analysis

As outlined throughout this thesis, this research as a whole was not directed at uncovering objective or absolute proof about factors that affect people who stutter within higher education settings. This study was not intended to be that form of definitive research. Rather, the purpose of this study was to better understand the nature of the negotiated experiences of being a student who stutters studying within a higher education environment. Drawing upon that understanding, to identify ways in which the university experience can be improved for students who stutter in the interest of social justice and educational equality. Further research will no doubt be required to pursue the agenda of removing barriers that put people at a disadvantage – in this case, students who stutter and this study aimed to present the ground work to encourage further research. It is commonly proposed that qualitative studies "…do not have endings, only questions (Wolcott, 1994)". However, the style of conclusion of this study will be an account of the negotiated experiences of students who stutter from which, it is anticipated that an agenda for more specific further research will be identified. I have described a range of further research directions in the conclusion chapter of this thesis (see Chapter 10: Discussions, recommendations & conclusion).

Both the survey and the interview stages conducted throughout this study produced a wealth of qualitative response far beyond what I had initially estimated, for even I, a person who stutters, assumed that perhaps this cohort may be difficult to elicit expanded answers from. But these expectations were mostly born from my past interactions with people who stutter at related conferences. Often I have found my fellow "stutterers", yes I know the term is not politically correct, but often that is how we refer to ourselves, to be introverted in nature and hard to extract a lot of conversation from. This is quite a difference to my own character because I love a good conversation and are quite open about many topics. The qualitative narratives provided by the participants in both the surveys and interviews were transcribed into a Microsoft Word document and then analysed using the Nvivo7 qualitative analysis software tool to help identify key words, themes and relationships between responses. The information-rich narratives that were gathered were so integral to understanding the human experience of the phenomenon of being a student who stutters engaged in higher education. Narratives can be seen as the best way to understand the human experience because it is the very way that humans understand their own lives (Richardson, 1990). Audiences in general have been found to be very receptive to descriptive and rich qualitative research (Creswell, 1995). The narrative writing style of this thesis overall was chosen to assist with merging my own narrative experiences in with the voices of the participants.

To aid with the interpretation of the rich narratives that this study has produced, it was decided to apply Applied Thematic Analysis. Applied Thematic Analysis (ATA) is a form of inductive qualitative data analysis which can be lent to analysing the results of different methods within a single study. ATA can combine multiple approaches into one methodological framework. Unlike “pure” research, applied research looks towards practical problem solving instead of expanding existing knowledge for the sake of knowledge itself (Guest, K. MacQueen, & Namey, 2011). One of the overall aims of this thesis is to provide a very practical and applicable understanding of the experiences of students who stutter in order to influence relevant changes. ATA focuses on the study of emergent themes which are given codes sharing many characteristics and features with grounded theory and phenomenology. It is a methodology that combines with bricolage in philosophy as it also uses whatever approaches that are appropriate to enable the analysis to be efficient, ethical and reliable. It does not waste findings because all data, even unreported or required for the study at hand, will have been catalogued as part of its natural analytical process. The scrutiny, rigour and transparency applied to ATA via the forming and sorting of themes enables what Ulin, Robinson, and Tolley (2005) describe as displaying the “credibility” of the qualitative data. Data reduction techniques follow once themes have been strongly established and give the researcher freedom to follow the trends that they find personally important to their study. The use of thematic codes assists with the identification of emergent themes and helps to add to the quality control mechanisms by assisting to eliminate analytical bias, but frequencies are not the drivers to force themes (Guest et al., 2011).

The use of thematic coding and grouping of data was crucial to the formation of themes both at a survey/interview question level and broader in terms of over-annexing study-wide themes. Some examples of thematic grouping below are drawn from the analysis of the first question on the survey method “Do you consider stuttering to be a disability?” The simple encoding of TQ as “Theme Question” (theme within given question area) and followed by the theme and question numbers allowed quick thematic groupings to occur.

TQ01_04: Stuttering is not a disability, more a hurdle or recoverable

> **16 (no):** Stuttering is not a disability, but rather a challenge to overcome.
>
> **32 (no):** no, I think of disabilities as being non-recoverable. People can recover and learn to manage stuttering (and in some cases completely rid themselves of it), even though there is not a one size fits all cure. It should also be said that by labelling stammering as a disability in the eyes of the public would probably only make stutterers feel more insecure about their condition, thereby making it worse.
>
> **43 (no):** It is an impediment to day to day speaking situations, which can cause anxiety and related psychological effects. However it is not a disability which cannot be overcome. More of a psychological condition caused by anxiety, which can be managed using certain tools.

The thematic grouping of all the survey questions combined with the interview questions gave some solid understandings of the opinions and debates that students who stutter had around key areas of their academic lives which lead to the formation of broader study-wide themes.

As a result of the ATA methodology, I formed five key thematic areas for discussion outlined later in this thesis. I have framed these findings creatively in the form of a

Venetian style Masquerade ball so you, the reader, can meander through emergent themes in a way which is not dry and purely scientific in design. This novel Masquerade ball approach I believed contextualised the shape-shifting and yet truly hidden identities of the research participants who were averse to revealing their inner selves.

The five key themes that I have formed which govern the entire study are:

1. The assumed absence of institutional support to accommodate stuttering concerns while studying at university;
2. The unwillingness in general to align stuttering with the term “disability” in broadly and in order to access the provision of assistance;
3. The rigidity of supplied provision for a student who stutters once they have accessed university support;
4. Frustration involved with a journey through higher education which is not as fulfilled as the student who stutters would have liked; and
5. Concessional bargaining in terms of underperformance and all aspects of university life in order for a student who stutters to manage their own stuttering lives.

In the next chapter the overall results will be described to you and set the scene for the discussions to become. To begin with, I will discuss a broad overview for the results as a whole and outline to you why in my opinion this view does not portray the truth of the studied phenomena.

Chapter 5: Setting the scene of success

To introduce the important outcomes of this study, this chapter is designed to introduce to you, the reader, the basis of the in-depth findings and discussions to come further within this thesis. For, from a very high level view of the survey data alone, there appears to be a series of great stories of success during the university student lifecycle and beyond for Australian university students who stutter. But is this an umbrella view of a successful student journey just acting like a harlequin’s mask and is in fact hiding a differently expressed face of emotions below? I will outline my opinion and then let you be the judge in this regard. Having said that, in more than twelve years working as an academic and often incorporating student-facing support roles ranging from being a lecture to a program coordinator and through to an Associate Dean (Student Retention & Success) I have never encountered a student who stutters asking me for any advice or guidance, nor have I heard of my colleagues having to accommodate such a student within their classes. Even when it has been overtly noted that I myself am a person who stutters, I have never been called upon by any section of my university to provide guidance to a student who stutters.

As you have learnt, I lecture with an overt fluctuating stutter and yet I rarely have heard of anyone describing me as that “lecturer who stutters”. I truly believe that for colleagues at work it is not how they generally identify me as. Yet I have noticed in my classes students who stutter but have never felt the need to “out them” or even align myself to them simply because they stutter also. But then again, some of my University’s key intervention and support processes do not require direct student face-to-face communications or interactions with their lecturers and nor do lecturers need to know all the associated details of such allowed provisions. Often such processes rely on the student themselves taking up the invitation to make contact with an academic coordinator or taking the proactive step to contact relevant support services. In some cases the student may have some form of support/learning access plan in play that has been negotiated outside of their enrolled school by another university department and there may generally be no need for stuttering to be mentioned at all in that context. In fact many students may have asked disability services for assistance and as their lecturer I would never have known unless I had intervened myself in regards to their academic progress. But then again, perhaps many students who stutter have avoided the need to follow up intervention or to ask for assistance themselves knowingly at the risk of under-performance. As a former Associate Dean (Student Retention and Success), this ideal worries me that there could be so many students out there who may not be accessing support services aa there should be. It was my job in that role to plan about how to support a diverse range of students across a range of potential problem areas.

Yet I have identified students who stutter via my “stutter-radar” which is fine-tuned and I have an ear to be able to quickly recognise a genuine stuttered speech pattern. I have identified many covert stutterers in the past who try very hard to hide their stuttering using behaviours such as words substitution, quiet voices and speaking avoidance. One such person I have identified works at my university and speaks in a deliberately slow and quiet fashion. Please believe me that it is very easy for me to identify an unusual pattern of speech and to notice social avoidance techniques. I am not the Inquisition, though, and I have never “outed” any of these stuttering brethren to the general public. But I have never myself identified to any of these students or staff as being a fellow person who stutters. Nor have I done so when encountering a fellow person who stutters in social settings. The thought never occurs in my mind as I do not automatically assume that they would want to know me as that identity or care. Actually only one year ago at my university’s new student orientation day I stood next to a student and we both heckled a contortionist who we thought was doing an average act. We were both overtly stuttering and then after the show we both just went back to our respective activities. There was no instant bonding, hugging or venting. The beauty about this study as it unfolds is that it not only educates you about students who stutter, but it also has educated me so deeply. All because I stutter myself does not mean in any shape of form that I am an expert on all things stuttering related.

This chapter will now outline broadly the key demographics of the survey data, respondent debates concerning stuttering as a disability and then lead you into the largely positive story annexing this study which had been told by 102 survey respondents and the 15 interviewees. Survey respondents are identified by the term “Respondent” followed by their automatic survey generated identification number (e.g. Respondent 76). Supporting comments from the interviewees are identified by a given pseudonym (e.g. Craig)

To be or not to be, that is the question

The first question of the online survey was designed to gauge if the respondents thought of stuttering as being a disability or not. I have to admit that the question was also intentionally designed to confront the respondent to try to ensure a passionate view of opinions without following sets of questions impacting the initial question answer response. Basically an intentional “shock and awe” approach to data gathering as opposed to a standard bank of general demographic questions to start off the survey. In fact this question resulted in the only complaint I have ever received in my academic life as a result of any research endeavour I have undertaken. The complaint was from a respondent who was very taken aback from the mere posing of the question. The respondent was very angry that I had aligned stuttering to being a disability in any regard and felt personally insulted by the alignment. This question was deemed essential to know, understand and to see if the mindset of acknowledging stuttering as a disability affected the choice of a student who stutters to disclose upon enrolment and perhaps it was to act as a barrier for seeking assistance from disability services units. Discussions in Chapter 2. Literature review clearly outlined that the notion of disability amongst the stuttering community being a hotly debated topic with arguably strong cases for and against a clear identification with the term.

The results of this initial survey question were intriguing with only 24 of 102 respondents viewing stuttering as a disability and that a large number, 78, did not. A strong weighted divide of opinion which will clearly help you to understand the strong stances shown in future questions by the general surveyed cohort. Not unlike the spread of opinions about disability that French (1994) mused could be due to its complex nature of differently perspective meanings. This is a defining finding that will show to have repercussions throughout this entire study in terms of influencing disability disclosure, support access and provision. It sets forward a clear path of identity aligned with the majority of participants within this study and their need to as Petrunik and Shearing (1983) debate to project themselves socially as being "normal". But the numbers alone simply tell us frequencies and what was required were expressed personal views and opinions. It is a testament to the adaptive bricolage influenced design of this study that the respondents were allowed to narrate passionately when expressing about this subject and offered a tangled web of replies both for and against the proposition. In fact this was one of the survey questions that elicited a very large amount of qualitatively offered answers (see *Appendix L: Frequency of survey expanded responses*) further emphasising its passionate nature.

Answers broadly ranged from total and simple disbelief through to some more articulated groups of opinions. Opinions often reflecting very uneducated views about who actually is commonly classed as disabled or not, and how disability is commonly defined. Such opinions often expressed with common social ignorance in mind towards how disability is legally viewed in Australia, if not globally. An example of this ignorance is how some respondents viewed stuttering not as major of a problem compared to other problems some people may have. A clear case of the distancing of oneself from those you see as less fortunate and to avoid the identity of the "misfit" as posed by Garland-Thomson (2009). An uneducated view because disability is not generally seen as having a competitive nature around if you were wishing to be classified as. It is the overall effect of stuttering upon the individual that counts and not as simple as defining some form of self-created severity criterion. Or perhaps the following respondents are simply so functional in life with their stuttering that they honestly see it as not a big problem for themselves?

> *“No I am quite capable of most actions and there are people far worse off than me.”* (Respondent 01)

> *“There are so many people far worse off than myself is so many ways.”* (Respondent 11)

A more understandable and interesting response pattern was grounded in rejecting being labelled as “disabled” either by themselves or further throughout society because of the stigma and connotations that it may bring. An ideal that Van Riper (1982) warned of as a large reason why people who stutter would avoid the term and resulting changes to their self-perceived identities. These students did not want to let themselves be lead into culture of tokenistic actions to satisfy bureaucratic university needs. But as this study will show further on, there was also some fear of such stigma having more impactful effects on the ability to gain entry into a university and be treated fairly within. A~~n~~ line of opinion that you will find further on this study as questions related to disability services at universities are explored.

> *“I do not want to be labelled for the sake of fitting a nice little box somewhere in the government system. If I want help I will ask for it!”* (Respondent 01)

> *“There is a stigma with the word disability that I have always wanted to avoid. My stuttering, while affecting me at times, does not control what I do.”* (Respondent 22)

One interesting theme of response alluded to the notion that stuttering was seen as more of just a hurdle which could be perhaps managed or controlled. As opposed to disabilities for which perhaps the respondents thought that there was no way to recover from. In a sense stuttering is just an “inconvenience” that can be worked around if need be. In turn such opinions were giving more voice to the general ignorance shown concerning a legislative definition of disability and pointed more towards a stereotypical social view.

> *“Stuttering is not a disability, but rather a challenge to overcome.”* (Respondent 16)

> *“…no, I think of disabilities as being non-recoverable. People can recover and learn to manage stuttering (and in some cases completely rid themselves*

> *of it), even though there is not a one size fits all cure. It should also be said that by labelling stammering as a disability in the eyes of the public would probably only make stutterers feel more insecure about their condition, thereby making it worse."* (Respondent 32)

> ***"****Stuttering is more of a hurdle than a disability. A deaf person cannot work on their hearing, they can buy more powerful hearing aids or learn sign. A blind person cannot do eye exercises to improve their sight. An amputee cannot will himself to grow a new limb and thus relies on prosthetics. Yet I can work on my speech and whatever recovery technique that I wish to practise. The ball is in my court and absence of hurdle is achievable naturally. That makes me different to the commonly disabled."* (Respondent71)

> ***"****It's a hindrance but with the correct knowledge and tools it can be effectively managed."* (Respondent 76)

Although viewing stuttering as an inconvenience, I still have a sense that the participants were trying to distance themselves from those more socially and commonly seen as "disabled" because of the connotations they may personal endure from such an alignment (Van Riper, 1982). Continuing this interesting path of discovery, other respondents admitted that they felt that even though their stuttering restricted activities in their daily lives, the general impact was not great enough to fit the disability label. Again in a sense a way of down-playing the stuttering condition and the negative effects that it can have on the individual and to reiterate Bailey et al. (2015) the fact that "you" cannot do things as a "normal" person can do, then "you" are clearly disabled at least situationally.

> ***"****It sometimes creates obstacles for me during day to day living but I am in no way disabled."* (Respondent 56)

> ***"****I don't associate it with a disability. To me a disability is something that hinders me from functioning effectively on my own. I do stutter in some situations, but I do not require aid or the aid of others to help me through it."* (Respondent 64)

A point of difference that I have myself discussed at several stuttering-related conferences as being a paradox. In similar fashion to Bailey et al. (2015) I find it hard to fathom that if you openly admit that your speech difficulties are impeding your day-to-day decision-making then how can your stuttering not be “disabling” you? But harking back to the fears of stigma reflected earlier in this discussion, perhaps some respondents would convince themselves to avoid the term and alignment by any opinion possible in order to avoid the notion of having a spoilt identity as described by Goffman (1963) The theme that disability had to be a permanent non-recoverable condition continued when some respondents indicating that because they still had the ability to speak then how could stuttering be classed as a disability?

> ***“****No. Speech is not impossible in any situation.”* (Respondent 87)
>
> ***“****Speech is still possible with difficulty at times.”* (Respondent 95)

Quite an interesting opinion set which again simplifies the notion that having the ability to do something, even with management, means that the impairment is not seen to them as being a disability. You could in turn contextualise the opinion within terms of other physical disabilities and it still does not logically stand firm. For example if you had badly damaged your legs and yet they still functioned to some degree then going by such expressed views then you would not be disabled. And yet more respondents did not see stuttering as a disability in general by associating the definition alignment to the level of stuttering severity. Such levels themselves may or may have not been self-rated and not be of generally consistent measures.

> ***“****Not for me personally - but for people who have a severe stutter, I think it could be a disability.”* (Respondent 34)
>
> ***“****Well if it is very severe then it probably would be yes. But I do not consider mild or even moderate to be a disability as such because it can be improved upon and most disabilities I see as permanent.”* (Cameron).
>
> ***“****I would say that stuttering is not a disability as such. I would say however that it is an inconvenience and that that inconvenience ranges from a mild inconvenience for mild stutters to a much more severe inconvenience for severe stutterers.”* (James).

A truly intriguing view of the term disability being applied to stuttering which adds somewhat of a competitive nature to the classification. A phenomena that I have not seen quite easily applied in real life. In fact I have seen many people who stutter myself who appear to have rather mild stutters mechanically on the surface and yet their lives seem so much more impacted by it compared to others who I have met with extreme overt stuttering conditions. My own opinion about why these observations are so wavers from time to time and there is little current research in this area to draw from directly. I theorise that the more character-strong people with severe stutters often succeed so well because they accept the fact that they cannot hide their condition and assertively drive their lives. As for people with mild mechanical stutters I often view them as being not able to align themselves with the more overt people who stutter as a matter of self-pride. They do not want to be personal viewed as a person who could be socially viewed as obviously having a disability and then accept how that label would affect their character. Again I see this as an attempt of some respondents to separate themselves from the disability label and to focus that label upon those whom they feel are more impacted and clearly identifiable.

But interestingly one participant expressed the need to label themselves as being disabled within the university support system in order to receive some form of assistance for their stuttering when required.

> **“***No, but I had to say so to get assistance.”* (Respondent 100)

Almost a begrudging response and admission to gain assistance. But again an interesting response showing true avoidance of the term “disability”. For sure I would think that if you needed assistance for your stuttering at university then surely it is a disability. But then again as some respondents have expressed for this respondent is stuttering simply an inconvenience in their mind? The reasons expressed by the minority who believed that stuttering is a disability were polar in their opinions to those who did not believe that stuttering is a disability. Restrictions to daily life activities was a loud and vocal reason for some respondents who did view stuttering as being a disability. This opinion aligns well with the legislative view of how to define a disability.

> ***“**It has most certainly been a disability for me. There have been countless occasions in my life when I have not said or done something because of the fear of stuttering. In that sense it is disabling because I have not been able to reach my full potential.”* (Respondent 15)
>
> ***“**Yes I do. Not being able to speak or not speaking out of real fear of stuttering or not even trying to make an attempt to speak as not to attract any attention to oneself, is a real disability.”* (Respondent 20)
>
> *“…even though it is not a 'physical' disability, I am still left with minimal options when it comes to living my life. Having to rely on others to make telephone calls for me, enquire about things on my behalf etc.”* (Respondent 66)
>
> ***“**Yes it has limited my life and my speech. I am unable to be the person I strive to be."* (Respondent 116)
>
> *“I definitely classify it as a disability because I know for a fact that there are some things I cannot do. I see it as a disability personally. I know it is a subjective thing but I also know it is an objective thing also.”* (Nigel)

It makes a lot of sense to align an impairment/disorder with a disability not only due to the physical mechanical problems and but also account for impacts upon the quality of life of an afflicted individual. This is a more holistic view beginning to be used more within policy and an opinion which can be easily applied amongst people who stutter. At times I have seen people who stutter who have almost been belittled themselves by other people who stutter because they seem quite comfortable with not seeking any therapy or program to manage it. Even though they stutter, they show a level of acceptance of it and are not socially impeded by it. The ideal of stuttering “acceptance” is one itself now heatedly debated globally and deserves the future focus of academic attention. I also hypothesise here that generally stuttering is not viewed as a disability because of the covert nature of people who stutter trying to hide it. In a sense the covert nature of hiding stuttering makes the true impact that stuttering can have upon an individual largely unknown and underrated to society as a whole. Basically, the less society sees of a problem, the less of a problem it appears to be. Malcolm below outlines strongly the ideal of the impact of stuttering on an individual's quality life factoring into how it should be individualised in terms of levels of severity.

> *"I think it is a disability. It is not a visual or fixed type like someone on a wheelchair can never walk. It depends on their problem but a stutterer sometimes might be able to speak fluently but in the long term like for job interviews or a relationship he can't always be fluent and stuttering always reduces his ability to communicate and progress in life. So according to me it is a disability."* (Malcolm)

Although accepting to be disabled one participant did raise the concern of ambiguity around the definition of disability as being a possible deterrent for seeking assistance.

> ***"****Yes, but it is precisely the ambiguity surrounding this issue that acts as a disincentive for stutterers to register as "disabled" students. Put plainly, when I see students with spina bifida or wheelchair-bound students, you feel you do not have the right to place yourself in that category. Perhaps the word "disabled" itself acts as a disincentive, and should be changed."* (Respondent 92)

The ambiguity around the definition of "disability" is one aim that this thesis is trying to clarify for people who stutter in general and a topic that I have explored openly (Meredith, 2010). Respondent 92's suggestion around disincentives being attributed to the use of the word "disability" will come into play later in this thesis when we explore the experiences of students who stutter and have enrolled at an Australia university. Some respondents simply answered "No" with a clear, yet shallow distinction being drawn between those termed as "disabled" and themselves. Again showing more of a societal shallow view of clearly visible and promoted views of those who would be disabled and those who would not be.

> ***"****No, not at all. I think I could disable myself by it if given enough thought. I may have some anxiety attached to it but I have all my limbs and brain matter!"* (Respondent 02)
>
> ***"****Do you see me in a Yooralla advert?"* (Respondent 09)
>
> ***"****I have a speech problem. I wear glasses due to poor eyesight, but that does not constitute a disability. The same as my speech*." (Respondent 75)

> *"When I do get nervous though I do become an overt stutterer and that does infringe on my life at times but is not as bad in comparison to other disabilities I guess."* (Dave)
>
> *"It is a very difficult question because if you are going to claim that you have a disability you are lumping yourself into the same group as people who are in wheelchairs or aren't able to see."* (James)

Clearly these respondents have a very generic view of those who are disabled and those who are not. Stuttering for them does not fit these generic views of disability and what is socially promoted as. For those readers not from Australia Respondent 09 referred to "Yooralla" and that is an Australian support organisation for people with disabilities. (http://www.yooralla.com.au/). It is clear to see now how divided the respondents were to aligning stuttering with the term "disability" and how ignorant at times those opinions can be regarding how it is usually defined at least from a legal standpoint. I find it so interesting how it appears that many respondents are trying so hard to distance themselves from the aligned and resulting labelling associated with stuttering being a disability. Perhaps this talks loudly about how society in general understands and promotes the meaning of "disability". But nevertheless, a majority of students who stutter within this study have clearly rejected the labelling and are trying to distance themselves from it. Later in this thesis you will see how the rejection of this label can lead to problematic journeys for these students once they enrol at university and in turn leads also to the rejection of accessing support services which more often than not themselves use "disability" within their department titles.

A demographic snapshot

An important start to this study of the major experiences of Australian university students who stutter, is to outline in brief the demographics of the 102 survey participants. This will give you, the reader, an informative demographic snapshot of the survey respondents in order to help you to better identify with and understand the experiences of these under-researched students in the discussions to come. I want you to have a broad understanding initially of this whole cohort in turn for yourself to more clearly understand the base on which they chose to enrol into university from.

Not wanting to focus too heavily on the survey-based demographical data I have decided to break it down in brief and to highlight the more relevant findings to the discussions to come. It is intended that publications resulting from this thesis will at times give greater weights to the more surprising demographic results. In brief the major demographic findings of interest are:

- The gender breakdown of the survey respondents indicated that 74 identified as male and 28 female. This is almost a 3:1 male to female ratio and is not representative of the academically published and generally accepted social 4:1 male to female ratio (Yairi & Ambros, 2013) attributed to the general stuttering population. This surveyed ratio was much lower than the general Australian university student gender demographics for the year that it was advertised. In fact in 2008 it was reported that 55% of Australian university students were female (Department of Education and Training, 2008b). Keep in mind though that not all survey respondents were current students at that point in time though;

- The 102 survey participants ranged in age from 17 to 54 upon enrolment. However the mean average age was close to 25 years old which indicates that very few of the participants were enrolling into university directly from a secondary school level education and would have been generally classed as “mature aged” students by the Australian government. This figure was just slightly above the average entry age bracket (20-24 years of age) as reported by the Department of Education and Training for the year of 2008 (Department of Education and Training, 2008a). Quite an interesting finding though and it would be interesting in the future to find more about the motivations of such students to enrol into University at that point in their lives;

- A large percentage of respondents (62%) self-rated their stuttering severity levels whilst studying at university as being “moderate”. Only relatively small percentages of people rated themselves as being “mild” (22%) or “severe” (16%). I would have self-rated my own stuttering as mild while I was an undergrad student because even though physically evident it had little effect on my studies or wider life. I believe that some respondents may have chosen to take the middle ground of a “moderate” response as opposed to going to either side of the extreme. A self-rating system was used for this question because it was highly unlikely that all participants had been clinically rated for stuttering severity in the past and if they had been it would have been unknown by which clinical measure if any would have assessed the outcome;

- There was almost an even split between whether a respondent thought that their general stuttering behaviour would be classed as “overt” (45%) or “covert” (55%). This is a very split decision with no real favour either way and to aid with the answer I supplied my own simple definitions of the two terms “*To help you answer this consider a "covert" stutterer as one who employs complex strategies to try to hide or mask their stutter. An "overt" does not*” as there appears to be no strongly used professional standard for such terms.

In fact there appears to be no set definition for these two terms (covert/overt) amongst online stuttering communities. Often I observe members within these groups mixing the covert/overt between general personality traits and speaking avoidance techniques without any clear framing of them. Actually I class myself as a covert overt in a sense that I openly stutter, yet I rarely hear work colleagues and friends identifying me as a person who stutters. My own definitions for this thesis were formed in consultation with a leading Australian stuttering focused academic and speech pathologist. But this is a very interesting finding in itself due to such an even split. Anecdotally more people who stutter usually define themselves as being “covert” in nature, as opposed to being “overt”. But perhaps this even split of identification reflects the general speaking confidence levels of the divided survey cohort or their own personal confusions around how to fit within the defined terms.

To summarise the demographics the survey of 102 Australian students who stutter this study showed that female students who stutter were strongly unrepresented during the time period of data gathering. Another finding of note is that it appears that the average student who stutters enrols into university after they have had life experiences and some time away from formal education, instead of transitioning straight from secondary school. Students who stutter were also mainly self-rating their stuttering as being “moderate” in behaviour and were evenly divided between stuttering behaviour characteristics. Next we will begin to understand the umbrella view of the greater story to be told resulting from this study. A view which will set the overall tone of the discussions to come, a tone that may not be as honest as you first believe.

A story of great success or of great challenge?

After the survey data gathering was complete a quick analysis of the broad data told a story perhaps too positive to be initially true. Or was it too good to be true? For on the surface it looked like the general university educational journey of an Australian student who stutters was in fact that of academic success and personal fulfilment. A story fit for a generic motivational speaker to base a career around or to base a vanilla feel-good Hollywood movie script on. What was initially found was an inspiring story rather broadly unexpected to myself who is a student who stutters, but at a surface level mirroring my own past tertiary education journey. For I had pessimistically hypothesised to see a general journey perhaps less successful as was shown. Maybe I was subconsciously expecting journeys less successful and as smooth as my own. For at my university I do believe that I am very distinct and original. I know not of any other academics who stutter working there and if so, we have never crossed paths. After reflecting upon the survey data I seemed to be a genuine mirrored representation of the general cohort of survey participants. After this initial data analysis I felt like a “walking and dysfluently talking” broad stereotype of my own survey participants. In fact the survey found that most respondents had successfully graduated (84, 82%) and that only three had dropped out of university study all together. As an academic who was once an Associate Dean (Student Retention & Success) I can vouch that this is a student retention rate to be admired and is certainly not representative of the general university retention rate at my university at the time or at the point of thesis submission. An additional 14 respondents were still studying at the time of the survey and only one single respondent had indicated that they had dropped out of university study due to their stuttering. The fact that only one single student openly admitted that their disrupted fluency had influenced their decision to leave university is an indication perhaps of the driven nature of the cohort being studied. These overall success numbers appear to be an incredibly positive result from this cohort. A set of results that from my own teaching experience I would say were much more successful in detail if compared to a random sample of 102 students of all types and varieties that I may have taught myself and who in general did not stutter. Certainly data that I would proudly present to my own University's Learning and Teaching Committee as an exemplar case of success.

The survey then asked for respondents to list the degree discipline area that they were currently enrolled within or had completed. The answers of which were sorted and consolidated into the following common discipline areas defined by the Australian Standard Classification of Education (ASCED). These broad discipline areas are defined by ASCED (Australian Bureau of Statistics, 2001) as:

- 01 NATURAL AND PHYSICAL SCIENCES: the study of all living organisms and inanimate natural objects, through experiment, observation and deduction;
- 02 INFORMATION TECHNOLOGY: is the study of the processing, transmitting and storage of information by computers;
- 03 ENGINEERING AND RELATED TECHNOLOGIES: the study of the design, manufacture, installation, maintenance and functioning of machines, systems and structures; and the composition and processing of metals,

ceramics, foodstuffs and other materials. It includes the measurement and mapping of the earth’s surface and its natural and constructed features;

- 04 ARCHITECTURE AND BUILDING: the study of the art, science and techniques involved in designing, constructing, adapting and maintaining public, commercial, industrial and residential structures and landscapes. It includes the study of the art and science of designing and planning urban and regional environments;
- 05 AGRICULTURE, ENVIRONMENTAL AND RELATED STUDIES: the study of the theory and practice of breeding, growing, gathering, reproducing and caring for plants and animals. It includes the study of the interaction between people and the environment and the application of scientific principles to the environment to protect it from deterioration;
- 06 HEALTH: the study of maintaining and restoring the physical and mental wellbeing of humans and animals;
- 07 EDUCATION: the study of the process of learning. It includes the theories, methods and techniques of imparting knowledge and skills to others;
- 08 MANAGEMENT AND COMMERCE: the study of the theory and practice of planning, directing, organising, motivating and co-ordinating the human and material resources of private and public organisations and institutions. It includes the merchandising and provision of goods and services and personal development;
- 09 SOCIETY AND CULTURE: the study of the physical, social and cultural organisation of human society and their influence on the individual and groups;
- 10 CREATIVE ARTS: the study of creating and performing works of art, music, dance and drama. It includes the study of clothing design and creation, and communicating through a variety of media;
- 11 FOOD, HOSPITALITY AND PERSONAL SERVICES: the study of preparing, displaying and serving food and beverages, providing hospitality services, caring for the hair and body for grooming and beautification, and other personal services;
- 12 MIXED FIELD PROGRAMMES: programmes providing general and personal development education.

A truly encouraging result from the survey was that the respondents did not strongly favour any single discipline area and were in fact quite spread across a range of disciplines. The largest discipline intake was in the area of society & culture (22%) but this was only marginally above the four other popular areas of study being: natural & physical sciences (14%); information technology (13%); health (15%) and; management & commerce (17%). These results were a shock to myself because at least anecdotally many people who stutter often discuss with me and others how they would overtly avoid careers involving strong, required verbal communication interactions. A conversation itself that will instantly be hotly debated in stuttering-based social media support groups. However if you study the career paths within the favoured discipline area and it is clear that strong communication skills, including verbal skills, are essential to that career then you have with a high level of confidence chosen that path. For example there are students here who would be going into medical, business and educational careers all of which rely heavily on verbal communication skills. In actuality the students wishing to become nurses or teachers need to pass placements within hospitals and schools which increase in demands as they progress through their degrees. This indicates that the studies cohort of students appear to be very driven in terms of their career choices which is the opposite to the literature in which it has been reported that people who stutter often avoid such career paths (Davis et al., 2002a; Palasik et al., 2012).

Self-reflecting again, these are findings close to my own journey because my undergraduate degrees were in information technology and computing. Both disciplines, despite popular stereotypes, were communication heavy career paths and the grounding in these areas eventually led to the start of my post-graduate and academic career. Often I have found that these anecdotal reflections of educational avoidance were in fact from university educated people who stutter and prior to enrolling in the degree of their choice they seemed to believe in a delusion ideal that a modern professional could somehow work comfortably and fruitfully without having to talk direct and verbally with another human being. Often citing careers like programming, accounting and engineering. Careers which I know professionally require high levels of communication skills across different modes of communications. Careers with modern communication standards well beyond socially and pop-culture influenced stereotypical portrayals. This survey showed that those surveyed students who stutter did generally choose degrees involving future careers which do, and at times heavily, revolve around verbal communication and will continue to do also into the foreseeable future. The education, health and management sectors for example are industries that we know require professional and at times rigid lines of communication. Professions which at least for the foreseeable future will continue to revolve around personal human-to-human contact to be effective and empathetic.

Once it had been indicated that the respondents were enrolling in a wide variety of degrees it was important to understand in fact how influential they perceived their stuttering to be on them choosing their degree path. Encouragingly a large number of respondents, 88 (86%), stated that their stutter was not an influencing factor when pursuing their chosen degree. Only 14 (14%) out of the 102 respondents indicated that their speech was an influencing factor. This was a highly encouraging finding and perhaps again contrary to my own initial instinct for the findings. For again anecdotally I had often heard so many stories of people who stutter discussing degree choice based upon their perceived speech abilities. It was becoming so apparent to me how influential social media could become in the lives of people who stutter and the reading of the same waves of negative journeys into higher education. It was truly becoming my responsibility to make sure that the findings of this study are promoted loudly to present some facts about the university lives of students who stutter. It was inspiring to me in general that the surveyed cohort seemed to be very successful and confident overall when approaching their educational pathways.

When respondents were asked to explain the feelings behind their choices of degrees, some more encouraging trends developed. One of the largest response trends was that of interest and passion in their chosen discipline area as being a major enrolment decision, a selection criteria that you would hope would be at the forefront of most student’s minds, let alone just of those students who stutter. I would go even further to say that this is a reason that all academics truly want to hear from a commencing student.

> *“I have always been interested in computers.”* (Respondent 04)
>
> *“Have always had an interest in humanities: been and continues to be a life-long journey.”* (Respondent 75)
>
> *“My desire to help heal people was factor.”* (Respondent 93)

With at least one respondent clearly using their degree choice as a way to push the normal boundaries associated with their speech difficulties and to overtly confront their stuttering. Which again is a motivation that I personally love to read. For I personally try to make it my goal to educate a student and also encourage them to push out their personal comfort zones. As an example when I teach in China I sometimes have students from my university travelling with me as part of an Australian Federal Government funded cultural experience initiative called the New Colombo Plan. When on residence at a Chinese university we will be asked to engage in a number of events outside of class times, which include English Corners and various culture sharing nights. At these events I invite selected Australian students to do speeches and presentations to the Chinese audiences. I never do this to embarrass the Australian students, but to actually give them a character building experience. I see them all truly grow from having to present outside of their comfort zones. A notion alluded to within the survey by Respondent 34.

> *“I deliberately chose law to challenge myself to enter speaking situations.”* (Respondent 34)

Interestingly one respondent confidently saw their stuttering as an advantage for their degree choice and in turn for their future professional path. In fact I have noted myself that it is not uncommon to encounter a speech pathologist or student studying to become one who themselves stutter. All of whom seem to be full of the passion to help others who stutter and certainly have not chosen the profession for the money alone. But this is certainly not used as an entry criteria into the degree.

> *"I figured I would be a great Speech Pathologist."* (Respondent 31)

It was personally confronting and disappointing that some of the respondents who did choose an area of study because of their stuttering based their decision on perhaps a misguided understanding that their career choice was not verbally communication heavy. A common reflection that I had heard of many times and have always shook my head at due to their unworldly views of their chosen career paths and related skills. In reality such views further strengthen misleading stereotypes concerning people who stutter and career paths. An opinion I often only hear from those who decided not to study those degree paths totally or who were very early on their academic careers.

> *"I wanted a job where I did not have to talk much. My understanding back then was that as an accountant, I'd be dealing with numbers and computers. It sounded good!"* (Respondent 20)
>
> *"I thought that I didn't have to talk much by being in engineering, little did I know there is a lot of talking now that I am working in the field."* (Respondent 38)

Encouragingly, of the 84 respondents who had graduated, only 11 believed that their stuttering was a major influence on the type of work that they have undertaken since graduating. This is a very positive finding and perhaps against what some people believe would be the case. Some respondents sounded very confident, happy and seem to be challenging themselves within their chosen career paths beyond university.

> *"I'm now a lecturer - so no!"* (Respondent 16)
>
> *"I chose law to challenge me to speak"*. (Respondent 43)

> *“As mentioned previously. I have always had an interest in humanities and I am now employed in a human services organisation. I think that even if I didn't stutter, I'd still be employed doing similar work.”* (Respondent 75)

You would have to hope that a person who stutters who has chosen a degree path out of passion for the area and had successfully graduated from that degree would as a result work in the career path that they have studied for.

As a result of all of these broad findings overall we can see such a fruitful and gratifying journey unfold for an Australian university student who stutters. In summary the surveyed Australian university students who stutter appear to be enrolling within the degrees of their choices without the discipline decision being influenced negatively by their stuttering behaviours. In turn most of these students graduated successfully and moved into career paths of their choice, again indicated to not be overtly influenced by the impact of their stuttering. But this is a story though, which in my opinion, is one that most students who stutter would want you to read. It could form such a great headline of success in any news item or motivational speech. A resounding confident story of success and satisfaction despite facing socially believed adversity. It has been portrayed though as a perfectly acceptable journey through the higher education system with positive results reverberating beyond university and out to a successful career beyond. A journey that seems on average to be even more successful than perhaps that of average university students who do not stutter.

But, I think it is time to get real about this premise, time to smash the rose coloured glasses and to break the shackles of relying on the numerical data alone as means of understanding the experiences of Australian university students who stutter. For although on the surface all appears to be fine and courageous, in fact this is not an unfolding story of unmitigated success, when in reality I will further argue that it is a story of pure strategic survival for many such students. To put it bluntly to you, the reader, it is time to cut through this surface level success-ridden propaganda story and to start to explore the truth about the experiences of university students who stutter.

These truths are linked heavily to themes of identity and concessional bargain making. The discussions which follow will outline these stories by exploring more the words expressed by students who stutter through a bricolage journey interpreting the survey and interview responses. At times the quantitative numbers will be lightly used to express key moments of direction for these students, but they will be the focus of analysis. So please begin reading the next chapter with a refreshed open mind and enjoy the voyage of discovery which follows.

Chapter 6: The journey begins

To begin this informed journey of enquiry into the experiences of the lives of Australian university students who stutters and how they negotiate their studies, it is important to first frame some of the general challenging situations faced by some of the study participants. With these experiences in mind the findings and discussions which follow will be set into a more honest and confronting context as hinted at in the proceeding chapter. Instead of the superficial positive broad umbrella view of success posed to you in the last chapter, a more informed, gritty and at times brutally honest set of experiences will be outlined and discussed. But it is still so important to reflect upon these broad success stories as you will now learn the underlying factors influencing those journeys. So let's begin trying to understand the answer the initial research question.

"How do students who stutter negotiate their university experiences in Australia?"

When directly asked "What were your worst university-based stuttering experiences that come to mind?" a range of quite understandable negative responses quickly came to the minds of respondents. For some students who stutter the initial introduction to university class-life elicited negative experiences which would overshadow their student life to come and shape behaviours throughout their ongoing student careers. These experiences you will note in further discussions lead to strategic decisions being made throughout their student career. Imagine in yourself the possible large amounts of initial shame involved with stuttering out loud in front of a whole class of students, many of whom probably had never seen you stutter before and most of whom you were hoping to make a positive initial impression upon. Keeping in mind that most people are aware that first impressions count when forging relationships in this society and that people who stutter are susceptible to social anxiety. Stuttering in front of a new panel of peers with a fear in your mind that you will be judged negatively by them from that point onwards could be so debilitating to some people who stutter. Job interviews alone are a cause of anxiety for many people regardless of stuttering or not. These are fears which anecdotally for many people who stutter influence pivotal life decisions often negatively. Key negative student-lived experiences are exemplified by comments from the following interviewees all of whom felt an adverse start to their student careers.

> *"Also once in class I said my name and stuttered very hard. I prolonged the first syllable for 5 seconds and then the next syllable. This caused my eyes to roll back from the stress of holding in the stutter and a student said "Woah, what was that?" That really hurt and just not my eyes."* (Eleni)
>
> *"There are lots of small ones where I have not been able to say my name and I have not been able to introduce people to others."* (Lauren)
>
> *"I would have to say that one time in the tutorial that time when the tutor asked me my name. That was one of the worst ones I had. That would have been my worst experience."* (Nigel)

For some students who stutter this would be a truly discouraging start to a degree path with impacts well beyond the classroom. In fact introduction-based scenarios are those often feared and commonly avoided by many people who stutter. Due to the stress involved with the high perceived probability that you will stutter on your name based upon previous similar experiences. In a sense a stressful determined setting behaviour built upon the results of previous similar interactions. Adding stress to the introduction situation is the fact that your name is an identity that you cannot easily substitute for a different alias in such circumstances which may be easier to say. Word substitution is a common coping strategy, certainly not speech-professionally endorsed, used be people who stutter to manage their stuttering socially (Petrunik & Shearing, 1983). In basic terms using an alias that you know that you can commonly and fluently say instead of your actual real name. This is the creation of a short-term identity to deflect the possible impact of negative peer views from your true identity. Introducing yourself to peers and lecturers within a university environment is unlikely going to give you an opportunity to swap your name. It would be quite easy to adopt a pseudonym in a casual social setting when talking to people who you have no real connection to and for whom you may never meet again. It would be highly confusing for all involved if your stated name in a class setting did not match student records. Although for example my University's student enrolment system does allow for "preferred" names to be recorded usually because of our high enrolments of international students whose real names may be hard to generally pronounce. A student who stutters uncontrollably may spend their whole degree journey with many of these peers who they meet during their first weeks through to semesters of classes and you would hope that initial negative perceptions would be replaced by more positive ones over time through more intimate person interactions. But as the old saying goes "*first impressions count*".

It is of no shock to myself that experiencing negative feedback from peers, either real or perceived, featured prominently in many responses. An experience as highlighted by Cameron that could impact an individual who stutters for life. Whether we stutter or not we all may have a degree of anxiety about negative peer feedback in such prominent talking circumstances. I teach public speaking confidence-building skills to university students across a range of different disciplines and levels. Yet with years of experience in public speaking and lecturing I still have nervous thoughts and unconscious fears at times in such circumstances. But to me these apprehensions are completely normal and what I would expect for most public speakers. Cameron highlights his negative life-changing experience at the end of his degree journey by explaining:

> **"***My Honours research proposal and final talk. Also my practises for those. I remember that after my Honours proposal one of the markers was visibly acting awkward and did not know what to say. My final talk improved although my first slide and first few minutes were bad. I progressively got better but it was still quite humiliating. Because it was a very important part of my academic life. I did get pretty good marks but that was despite my stuttering and not because of it. I had stuff to say and it was frustrating as well because I could not get it across."* (Cameron)

Cameron really portrays the conflicting pressures of balancing fluency anxiety, peer feedback concerns and the stress of wanting to academically perform well. These feelings of introduction-based fears and the escalation of stresses are further emphasised strongly by Tim.

> *"There was a fear of presenting, fear of stuttering, fear of being rejected and a fear of being looked down upon. All these things pile up and become massive."* (Tim)

Tim's comment emphasises the multi-faceted nature of how an individual could be impacted by stuttering beyond the pure mechanics of interrupted speech. Of all the negative experiences described it was class-based presentations that featured prominently as having a negative impact to a student's overall university experience. The fear of this scenario, like the previous experienced outlined, is tied strongly to the fear of rejection by peers and the feelings of shame associated with public perception of stuttering. But to add even further anxiety to these presentations is the fact that they would usually be assessed and in turn tied directly to the results outcome of the associated course. So perhaps in the minds of some students who stutter, there could be an internal conflict revolving around whether or not to do the presentation and in turn what would be the resulting final grade implications? I frame this way of thinking as "concessional bargaining" of which you will learn more about in chapter discussions to come. More feelings and fears revolving around in-class oral presentations are emphasised in the following quotes.

> *"Just presentations where just the words would not come out."* (Conrad)

> *"Doing an oral exam I stuttered so badly on some questions that in order to keep to his timetable the lecturer actually skipped some questions. It was one of those situations where he was so intensely embarrassed that he did not know what to do. It was just a complete disaster and I got a 50% pass just to get me through. I knew that I had not answered anything anywhere near well enough to for him to give me that mark but I knew that he could just not face doing it again."* (Stuart)

> *"One class presentation. I just stood up. I froze and I was shaking. I was sweating like a mad dog. I actually got sick the next day. That is how stressed I was. Not even my name would come out of my mouth."* (Tim)

Those three comments alone emphasise the anxiety, fears and shame associated with unsupported stuttering in class-based situations and are strongly aligned with factors affecting the uptake of support assistance (De Cesarei, 2015). Imagine the shame that Stuart must have experienced from the actual speaking situation itself, but more strikingly in the way that the lecturer had tried to accommodate the dysfluency. Stuart did not know for sure if he had earnt the passing grade or not and had just assumed that his lecturer did not want to face the situation again. Tim portrays a more severe outcome of facing a feared speaking situation which led to direct impact on his health. Harrowingly neither Stuart nor Tim during their interviews indicated that they have asked their respective universities for support or speaking accommodation. Another strong, common trend resounding from this initial question were the negative feelings arising from not being able to fully participate to a satisfying level in class-based activities. This for some interviewees lead to feelings of inadequacy and deep regret. The following quotes clearly communicate these feelings of inadequacy and the negative self-thoughts involved with not being able to present as fluently as they wished in front of peers and teaching staff.

> *"I have had some. Probably just blocking in tutorials and wanting to say something and the words just not coming out. Having that five seconds of complete silence is pretty bad. So I would say blocking in public while presenting something or reading out aloud is pretty bad. While on placement it wasn't just the blocking. It was more than that."* (Hasaan)
>
> *"I think asking a question in class. If you stand up and volunteer then people expect you to ask that question. A few times I stood up and stuttered badly. This makes you yourself feel bad. One bad experience was that presentation when the girl was laughing at me. I had no idea of what to do. I had prepared for the presentation very well. I had a few stutters and then my confidence went down. I saw her laughing and then I continued to stutter a fair bit. Another one was during a group presentation I was with four other students and I was stuttering badly with them. I had a lot of problems communicating with what I wanted in that particular presentation."* (Malcolm)

Clearly there are many frustrations involved with wanting to participate in class but having to consciously hold yourself back in fear of giving negative impressions to your university peers. Frustrations also tied to the lack of academic achievements and socialisation as a result of impaired participation. After an understanding of some of the general negative experiences that students who stutter have faced at university and firmly establishing in *Chapter 3. The web-based audit* that there was little guidance online in terms of how an Australian university could accommodate a student who stutter, it was time to explore the complete journey for such a student from pre-enrolment through to graduation. This is the first known time that such a comprehensive study of the university journey of students who stutter has been undertaken and I hope it enlightens you as much as it did for myself. The initial part of this journey embarks from the pre-enrolment strategies used by students who stutter through to the notion of disability disclosure by exploring the combined, rich narratives of both the survey and interview responses. Emergent narrative themes of varying identification and strategic sacrifices strongly start to unfold and resound throughout this entire study.

Pre-enrolment through to enrolment

Every journey has to have a beginning and the perfect start for this journey is to look at the pre-enrolment actions and the associated feelings of university students who stutter. This is a very eye-opening start to the journey due to the insignificant amount of participants who sought to find out how any given university could accommodate their stuttering pre to the decision to enrol and begin a degree. This was initially a fascinating start to my journey of understanding due to the finding found in “Chapter 3. The web-based audit” which showed a distinct lack of online information concerning how most Australian universities could accommodate and support specifically a student who stutters. The fact that so few people who stutter looked for stuttering accommodation information pre to enrolment is somewhat surprising as you would think that people generally at higher risk of social phobias and perhaps more at risk of simply feeling anxious about a large jump into the independency and self-relying nature of the higher education environment would be more eager to strategically look at the availability of help before entering such an environment. Of the small amount of those who sought to find out how a university could offer them support, only two out of the 102 surveyed looked for information online. Both of these participants found this information understandably via a university website. Both respondents were split in their opinion whether or not the found information was influential or not towards their decision to enrol at that particular university.

Interestingly both participants indicated that they were not satisfied with what information they did find, but they did not choose to explain why this was so. These two respondents may have only used a university website as a source of pre-enrolment information because simply navigating the website did not require any interpersonal communications and would have been a relatively stress free set of actions.

Most of the other avenues of seeking university support guidance would have relied directly on speaking to another person for example a phone call or face-to-face enquiry with a support officer. These interactions may generally not be favoured at times or not preferred by a person who stutters who we already know within this study that have apprehensions around introducing themselves and presenting. This finding perhaps indicates to universities that there is a need for up to date and rich information regarding disability services and their accommodations for people who stutter. I will also argue further in this thesis that universities need to define what disability actually means within the context of how they operate and accommodate students in need, or to at least universities need to consider which disabilities are clearly promoted and identified in provided support literature. So the question is then why are a large amount of people who stutter not looking at all for pre-enrolment assistance or at least for the knowledge that a given university could assist them with their speech if and when required? Perhaps based upon previous experiences though the majority of participants simply thought that there would be little, in anything, in terms of educational assistance for them at a university and in turn simply did not bother to look online for guidance. A notion teased out somewhat by Azio (2017) which found that some students who stutter brought past educational support and cultural expectations into new educational settings. I will continue to explore this idea more throughout this study.

Of growing concern some respondents did express that that they had simply assumed that there would be no assistance available and in turn they did not bother to enquire. Assumptions that I propose would be those upon their previous school experiences.

Interviewee Tim for example expressed an expected lack of assistance to accommodate stuttering and when he did look at one university website he could not find any documented assistance.

> *“In what ways before you enrolled did you find out? I had no idea before I enrolled that there were things at university that I could get support from. I looked at a website (of a university) but they did not have anything you know”*

Tim may have been too specific in his online searches though and did not find “stuttering” specifically mentioned. A problem that I emphasised in “Chapter 3. The web-based audit” that when searching myself I found little specific mentioning of stuttering myself within the online disability support literature of Australian universities. I needed to read well into the found guides to find how stuttering could be accommodated within a more broad sense of disability. But Tim continued to express further feelings about his thoughts and motives preceding his support search that were informed by his past educational experiences:

> *“When I was originally studying for my first degree it did not even occur to me that a university would be interested in helping me.”*

This is quite a disturbing initial finding which will reverberate throughout this entire study. Why would Tim have that simple thought in his head that a public university would not be “interested” in helping him? It is so personally harrowing to myself to think of how many students who stutter and perhaps with other disabilities who have simply assumed that no support exists for them in a university setting. I lament on the thought of how many lost opportunities now lay out there due to these opinions. In turn, how many of these potential students chose not to undertake a university education at all? Having now known that very few students who stutter appear to be looking at support options it is important to understand their preconceptions about what challenges the academic journey ahead of them will present to their stuttering. When asked what concerns students who stutter had when considering enrolling in a degree feelings again answers reflected initial fears linked to class introductions. A fear which we know has resonated strongly throughout the academic journey of a majority of those studied and was a situation for some which was a noted problematic situation.

> *I would have been pretty nervous at least. On the first day would have been introductions which as you know are hard for stutterers. I was concerned about them. I saw IT as not a very speech-based course in comparison to other courses. Maybe the decision to enrol in IT for that reason was a factor but if it was it was not a decision that I was conscious about.* (Cameron)
>
> *My main concern was having to do introductions to the class. Like most stutterers I have a lot of trouble saying my name out aloud in public and introducing myself. I was always fearful of that. I was worried that perhaps people would see me not in a strong positive light as a result. Apart from that I really had no concerns or fears except for reassuring myself that I had made the right choice for my future in regards to returning to study. I was a little concerned about doing oral presentations. I have not had to do any yet but I will have to next year. I may enquire about assistance for them if I see the need.* (Mary)
>
> *I was worried about the amount of presentations and also the amount of job interviews that I would have to do. To get into the degree itself I had to do some interviews and that gave me a taste of what I was up against. I was mainly concerned about the amount of presentations that I may have had to give.* (Dave)
>
> *I was concerned about talking in front of groups and being perceived as being nervous. Even though I was nervous I think I would have been marked down because they may not have seen me in class prior and realised that that is the way that I talk and so when they hear me for the first time they may think that I might be nervous and mark me down. I also thought that people may think that I am not smart enough. They were my main concerns.* (Lauren)

Again we read so many concerns directly linked to the stressful thoughts of self-introductions and class presentations to peers. Lauren added further thought to the premise by outlining a fear not previously mentioned and that was one of being penalised. Penalised actually in her mind if she had not been very active in class and formed a class-based relationship with teaching staff in order to alert them of her stuttering. Of interest was how some participants were worried about the university experiences to come and also their likely career path beyond university graduation even before they had begun studying. Indicating at least for some elevated levels of anxiety pre to starting a pathway of study.

> *I guess I was just concerned that I would not be able to communicate that well in the future. I did not have any direct concerns with my university course. My stutter was really just something that I wanted to fix.* (Hasaan)
>
> *I think I was concerned about future studies and my future career. Future studies wise I guess I was concerned regarding marks. Especially with oral presentations I was always concerned that I would not pass those and if you do not pass an assessment at uni is does make it harder to pass overall. So I was concerned about passing, whether I was good enough and all those negative self thought concerns.* (Trevor)

Next it was important to start to investigate and understand how engaged students who stutter were with the university in terms of being open about their stuttering and in turn having the ability to register early for disability-related support for their speech challenges.

Disclose at enrolment

The topic of disability itself, let alone disability “disclosure” is very debateable as was emphasised earlier in this study from the results of the initial survey question. This study sought to see how many students who stutter were disclosing their stuttering upon enrolment and the reasons for and against their decisions. In turn how did their general opinions of stuttering being a disability and their identification with the term have a ripple effect through to their decision to seek professionally help lead to the support accommodation of their stuttering throughout university? Flagging a disability is a common option that Australian universities would normally ask as a question on their commencing student enrolment forms to let these students know that help may be available for their related disability issues. However it is unfeasible for a comprehensive list of all specifically known and accepted disabilities to be presented to a student to choose from either on paper or via a web-based enrolment portal. So usually at least on the enrolment form “disability” itself remains broadly undefined and would require further enquiry to a university disability liaison unit to be assessed in turn eligible to access related help. At least a university could link to the Disability Discrimination Act (1992) website which thoroughly defines "disability" and this is the definition which is applied federally all throughout Australia. Some participants indicated that on the enrolment forms of some universities that broad categories of disability were mentioned and at times unsureness reigned concerning in which category of disability that stuttering would fit within.

I found these broad categories evident myself when auditing Australian university websites for online disability support information. More generalised broad disability categories were focused on such as sight, hearing or mobility impaired specifically. But at a glance, where would stuttering fit into these? I know myself that for example a stroke victim may as a result of their impairment have speech-related issues such as slurred speech or acquired stuttering. But is applying this rationale to the generic guides then stuttering is a bi-product of another condition and not an exclusive condition of its own. A case which I happen to know is not common at all. Another clear strategic reason for asking this probing question upon enrolment would be for a university to maintain a log of the number of self-described disabled students that are enrolled and at perhaps at times associated broad categories of disabilities. This information would help a university to strategise and provide future provisions for affected students both in terms of allocated budget, related resources and the forming of strategies concerning both student retention and inclusive teaching pedagogy. The process of providing one-on-one support is resource heavy for a university and funding must be appropriately applied for the speculative number of students involved into the future.

When asked if students who stutter had disclosed their stuttering as a disability upon enrolment the responses to this question were strong and showed that very large majority of respondents, 95/102, did not disclose their stuttering at the point of enrolment to the university. In fact only seven out of 102 respondents in total chose to disclose at that initial point in time. It is unknown by this study if the respondents simply flagged themselves as having a disability or if they chose to elaborate further and mention it as stuttering. It was more important for me to know the reasons behind choosing to disclose or not instead of some of these more minor questions. Respondents gestured to explain their decision and the reasons for which were varied and at times very strong in opinion and language.

The reasons for not disclosing were large in number and decisively opinionated. One clear answer trend which emerged was that of not wanting to be labelled or stigmatised as being “disabled” from disclosing the option upon enrolment.

> **“***I did not feel the need to. It is my business to disclose when and if I choose too at a period in I choose. I refused to be labelled from day one!”* (Respondent 1)
>
> “*As my previous comment says, I didn't want anyone to know I had a stuttering problem, and so I never disclosed this. I felt there was a stigma attached to stuttering. I still feel this way.”* (Respondent 15)
>
> **“***I did not want to be forever more known in the system as a stutterer."* (Respondent 74)

So clear in opinions were those linked to believed stigma and the possibility of discrimination as a result of disclosing their stuttering at the point of enrolment. An interesting line of responses concerning the fact that such disclosure would never be made “public knowledge” and only those who needed to know would have access to the information. I know this myself within my academic leadership roles and I often have to emphasise the confidentiality process of disability support help to both fellow staff and students. To put it simply only those who need to know are informed, and even then they are told only what they individually need~~s~~ to know in order to provide provision. Students often are not overtly aware of such privacy requirements governed by Australian law. It is important to note that these legal requirements under The Privacy Act 1988 are so specific that I cannot even talk to the parents of a university student about their progress without the permission of the student in question. I would expect though that many respondents would not know this system and legal requirements as intricately as myself of course. But perhaps there was apprehension about anyone in fact knowing? This would especially be the case for those students who indicated that they were "covert" in the nature of how they portray and live with their stuttering. Some other respondents simply did not see the need to disclose due to lack of perceived relevance of it to attending university and the associated further tasks at hand.

> *"I did not feel the need to. It is my business to disclose when and if I choose too at a period in I choose. I refused to be labelled from day one!"* (Respondent 1)
>
> **"***I did not see it as relevant"* (Respondent 9)
>
> **"***Did not consider the disclosure as being relevant to my application"* (Respondent 90)

I can understand of course how some respondents who view stuttering not as a disability would of course not see the relevance in disclosing it as such. But the relevance of the timing of this disclosure is of great interest to me almost as if some respondents were used to accessing help only at the times when it was required. In short, perhaps having a strategy of accessing "just in time" support. At times opinions were mirroring strong earlier expressed views that stuttering is not a disability, so in turn there was directly no reason or relevance for these students to disclose at all upon enrolment. These responses portrayed a binary view of stuttering not being a disability and also expressed heated emotions.

> *"Did not see the point or an opportunity to, as I do not consider it a disability"* (Respondent 58)
>
> *"It mentioned DISABILITY. I am not"* (Respondent 86)
>
> *"What? As a disability? I do not think so!"* (Respondent 87)

This polarised view of stuttering aligning to disability was not shared by all and others chose not to disclose due to lack of clarity. Some respondents indicated that perhaps the reason they did not disclose was due to the enrolment form not specifically listing stuttering or even noting speech impediments in general as being disabilities.

> **“***There was not a place (which I recall) which asked for a speech impediment.”* (Respondent 29)
>
> *“There was a section about health problems and disabilities. But I do not fit either compartment.”* (Respondent 80)
>
> **“***No there was not one which specifically mentioned stuttering. There was one for disability but I was not sure what their reaction would have been if I told them I stuttered.”* (Malcolm)

I had discussed earlier that it is not feasible to list all know disabilities within university literature, but it would be advantageous to have links to the broad meaning of disability readily available to potential and commencing students with some worked examples included. These examples should look at different individual stories and how their conditions could be classed as disabilities and supported. But these examples need to be clear that having a disability dos not automatically mean that the student in question needs support. Only that their specific differences can be supported if and when required. At least one respondent expressed that after reflection that they would now flag their stuttering as a disability if invited to. They also expressed the need for more education about how stuttering can be classed as a disability as a way of encouraging other students to be more open to flagging their disabilities.

> **“***I cannot remember whether or not there was, but there is usually a section on whether or not you have a disability or not (I think). I always said no. But I think now I would reconsider that actually. My belief is that there is a lack of awareness, I think, concerning stutterers and I think there is a stigma that many stutterers believe exists which prevents them from identifying themselves as stutterers. So I think that if it was a disability that had a lot more exposure then I think that more stutterers would be likely to identify themselves as such.”* (Nigel)

Some other respondents gave a general opinion that disclosure was not made because they had doubts and reservations that their university in question would care about their plight. Coming into a university with the pre-conceived idea that no help would be available was becoming a sub-theme that is winding its way all throughout this study. This pre-conceived opinion set revolving around the provision of support services most likely as a result of past experiences either in previous education or the workplace. But a terrible and worrying set of thoughts also emerged indicating that perhaps stuttering was not serious enough to warrant support.

> **“***a) No place on the form to do so. b) Did not think this would be of relevance to unis. c) Did not think universities would assist me in any way.*” (Respondent 75)
>
> *“I did not feel the need and I highly doubted they cared."* (Respondent 115)
>
> *“Yes, as I mentioned earlier I do not view stuttering as a disability and so I did not tick the box. The form did not mention stuttering in it either. I do not think that the university does view stuttering as a disability. Although I do know that I have read some literature where they have classified speech problems as disabilities and that you can get assistance for them. I do not think stuttering was mentioned or highlighted though.”* (Mary)
>
> **“***I doubted that they could do much except but in practises that would dent my self esteem even more.*” (Respondent 73)

All these responses truly are worrying to me in different ways. Respondent 73 for example has the opinion that if support exists then it could be of detriment to their own self-esteem. Some of the other respondents also seemed to think that their stuttering would not be taken as seriously as other disabilities for which perhaps support services were more able to cater for. Wanting to know more about what was impacting disclosure looked at the response of other respondents who had some definite personal reasons for not. One theme of responses of which were related to the fear of possible future repercussions within their future student life. Perhaps feelings of discrimination based upon past schooling or work-based experiences are influencing their decisions? Respondents passionately expressed these views and you can tell their true concerns about telling a university about their stuttering regardless of needing support for it or not.

> “*Revealing may lead to questions and questions lead to the need to answer.”* (Respondent 12)

> “*I thought it would be a cause of discrimination.”* (Respondent 20)

> “*I did not want to be forever more known in the system as a stutterer.”* (Respondent 74)

> “*I was unsure what would happen to me if I did. Would I have been locked up or forced to wear a huge hat advertising the point. What would the uni have done with that information? I was unsure. Would it ever be held against me in some form?”* (Respondent 101)

> “*I do not think I did tick it. I guess I did not want to draw attention to myself. Because I wanted to fit in as normal and I had had some bad experiences with former workmates in the past who I thought I was confiding with in a positive way about my stuttering and they thought it was a great joke. They told other people and it all felt very nasty.”* (Arthur)

> *“I guess I did not want to draw undue attention to myself as there may have been an element of concern. Studying medicine is highly competitive and letting someone know that you have a weakness may be not a good thing.”* (Tim)

It is of interest that these feelings of discrimination exist when it comes to undertaking a university degree and being successful within. How have these thoughts and feelings been seeded within the individual? Anecdotally I have heard many stories from people who stutter in regards to perceived work place bullying and discrimination due to their speech and there are studies which add some validity to the basis of these views (Klein & Hood, 2004; McAllister et al., 2012). It is often of course not known to what extent and how true most of these stories are due to the pure anecdotal nature of them and the tainted self-perceptions enclosed within. But real or not, there are definite concerns of discrimination filtering from enrolment through to the future classroom. It also appears that the fear of discrimination is evident in some minds around success within very competitive degrees and in Tim’s example medicine. Often in these degrees in which admission requirements are much more competitive than others and the perception of any “weakness” may seem to be a threat to the selection process. Certainly some students who have studied so hard to achieve high secondary school finishing scores would not want to detriment their selection for such a prestigious degree by simply ticking a box on an enrolment form.

Carrying on the concerns around discrimination some respondents indicated a degree of shame governing the decisions and the need to not appear different to others as a reason for not initially disclosing.

> *"I did not want anyone to know that I had a stutter. And I also think that I was in denial."* (Respondent 37)
>
> *"Only to close friends which new I stuttered, otherwise no, I would always try to hide it."* (Respondent 38)
>
> ***"****Tried to hide it, thought it not relevant, shame."* (Respondent 77)

Again opinions showing the lack of understanding of the privacy around their supplied data and possible repercussions of indicating such. Respondent 77 is a worrying indicator in my mind. Worrying because they indicate a level of shame so early in their university lifecycle from the act of a simple checkbox action. This shame of stuttering disclosure at least for this individual would could have had negative repercussions all throughout their student life at times of need. I cannot see this problem as being solely isolated for only people who stutter. Yet at least one felt the need to have a strategic view of approaching university and the possibility of requiring future assistance. In my opinion a very wise move indeed and a strategy that I advocate myself within my university roles. Often students will come to see me with pre-existing circumstances that "may" impact their studies. I always advise these students to officially flag their circumstances with their Faculty just in case they may need some support into the future. This helps to build confidence and assurance that if the times comes for assistance then it can be accessed in a timely fashion.

> ***"****I thought that I better do it just in case I was pulled up on the issue at some stage in the future."* (Respondent 116)

Now that you have some understanding of the pre-enrolment feelings and disability disclosures opinions from students who stutter, it is even more important to study the continuing journeys of those who actually did access support. Support that you would hope would be both personally and practically satisfying to the student in need.

Chapter 7: University Disability Services

Once it was established that very few students who stutter were looking for assistance pre enrolment and were opting not to identify their stuttering as a disability, it was important to understand the journey of those who in fact did seek assistance from their related university disability services units. This study has opted to use “disability services” as a blanket term to encapsulate all the slightly differing terms that may change from university to university for their respective disability services units and governing departments. University disability services in general aim to support students with disabilities through their studies in terms of working with academics and other university services to better accommodate a student’s disability or special circumstances to help facilitate fair and equitable outcomes for all. For example, my own university has a process of forming a learning action plan with a student who has flagged their disability as a condition possibly needing future support. These learning action plans discuss agreed support strategies and form a basis of course-based support in negotiation with a course coordinator when required. This section of the survey was initially directed at all 102 respondents and, as you will read, the journey through this essential provision of service may not be as empowering as you would have expected.

Asking disability services for help

A pivotal question for this study revolved around how many students who stutter actually asked disability services for assistance and in turn how empowering and successful was the followed process? How did the thread of identity weave itself through the provision of assistance? How strategically satisfying were the support provisions offered to the students? Of all the 102 survey respondents only 14 in total asked disability services for help after enrolment. This could be seen as a low uptake of service provision and perhaps is an early indicator about the perceived help that disability services and alike can could offer a student who stutters. Or in turn the low uptake may be simply majorly influenced by the lack of identifying as a person with a disability. Again you have read earlier in this thesis that many students who stutter do not view stuttering as a disability for a range of reasons. In turn then why would they go to disability liaison units for support help without a very strong need to do so? To my surprise I found that pre-enrolment feelings about the lack of available support continued through the enrolment process. There were strong indications that some students doubted the ability and care for a given university to provide them with support for their speech even once enrolled. This request for assistance was done in most instances without the suggestion of a university staff member and nor were respondents seemingly interested in asking non-disability staff for assistance. Of concern not a single respondent chose to ask any other university staff member for assistance and seemingly because they did not want it widely known that they were seeking assistance and accommodation for their stuttering. This is an issue to reflect upon in this thesis because most of these students, if not all, would have been provided with further university support materials and presentation throughout the orientation phases leading into their first semester of study. So even after being more educated about the support help that was at hand and the general process of academic accommodation some students still doubted that a university would consider stuttering as requiring assistance provision. Responses continued to reflect feelings of perceived possible discrimination as reflected in the previous chapter of this thesis. A worrying trend that needs more focus on in future studies.

> *"I do not want too many people to know that my stutter bothers me."*
> (Respondent 17)
>
> *"I would not want anyone to know except those directly effected."*
> (Respondent 82)
>
> **"***No. Because when I was at work they treated me like I was disabled and here was the place to start off with a clean slate. I do not know if disability services could help me in anyway because I did not need to find out."* (Arthur)

It is also important to note that eight of those 14 students who stutter seeking disability services assistance only asked for help into the third year of their studied degree and not sooner for a range of very interesting reasons often tied to identity and independence. An interesting finding indeed concerning the timing of assistance provision and the importance of that timing to their degree path. I can understand how generally in most Australian under-graduate degree being three years in length that the final year would be more academically demanding and pressure filled. In these cases obviously the demands of the third year of study were enough to urge the students to seek direct university support and intervention. But importantly the opinions of those who did not seek assistance from university disability services gave insights into this strategic and somewhat at times resourceful cohort of students. Students who appear to be proactive in determining the direction of their degree paths within the confines of a policy-driven higher educational framework. These views are important to being able to understand how to better improve the advertisement and attraction of university support services to students who stutter, and in turn all students whose personal circumstances may warrant university support and personalised provision of services.

Some respondents opted to take matters firmly into their own hands by totally avoiding disability services and themselves directly negotiating with academic/teaching staff. For some respondents this in itself would have been a brave communication step and reflected the opinion of only telling those who directly need to know about their special needs.

> *"I have always spoken to lecturers and tutors, but nothing formal. In saying that, I may soon."* (Respondent 22)
>
> *"Sought assistance from psychology lecturer, not disability services dept."* (Respondent 22)
>
> "*I just disclosed to all my tutors in the first class that I stutter. In second year I had to see the disability services so I can fill out a form for group presentations.*" (Respondent 72)

This is strongly independent approach shown by some students which I do admire and shows true confidence. But not all students who stutter would be confident enough to approach teaching staff in such a manner. These approaches to studies do show strategic thinking beyond what you may believe. For example Respondent 72 shows a technique commonly taught to people who stutter and that is disclosure. Disclosure is often employed to let a listener know that a person who stutters, stutters and in turn is said to release tension around the speaking situation for all involved. The same technique is commonly employed by people who stutter for job interviews letting the interviewer know without surprise of the interviewee's speech condition. Interestingly some respondents did not see any need for being treated in any exclusive manner because of their stuttering in terms of support provision. A same opinion expressed by some for not wanting to disclose their stuttering at all to anyone. Often expressing a very independent and assertive approach to their own educational destinies without requiring specialised assistance, even though perhaps for some it may have positively influenced their future grade outcomes.

> **"***I didn't want an easy road through - I wanted to be treated the same as everyone else."* (Respondent 34)
>
> **"***I have asked for no special treatment outside of university so why should I have asked in this case?"* (Respondent 73)
>
> **"***If I were ask for help here then I would not have bothered going into law and having to talk so much."* (Respondent 79)
>
> **"***My stutter is obvious and severe but I still cope. I cannot be asking for help all my life."* (Respondent 87)

These comments are expressing a fierce desire for independence and ownership over their educational decisions. Some respondents did not overtly seek assistance because throughout their classes they seemed somewhat satisfied with how they were performing and did not see a need for further help. This is a worrying finding because their performances at times were not as gratifying as they could have been and their results may have suffered as a consequence in comparison to what they may have achieved if they had have asked for and been granted assistance.

> **"***Was passing my subjects to did not think I needed help."* (Respondent 29)
>
> **"***I could cope ok, not prosper, but I could cope."* (Respondent 94)

It is clear to me though through my academic roles that purely “passing” or being able to “cope” does not no mean excelling or thriving. Nor do these terms in such a setting express satisfaction or earnt achievement. I have had to council and assist many students in my time who purely “cope” the best they can without assistance until really needed. I hope that this study assists such students to confidently excel and thrive with their studies. Interestingly for Respondent 112 seeking assistance was viewed as not being of relevance to their degree discipline area.

> ***“****I am not sure how it would have helped me in my discipline*.” (Respondent 112)

This is a thread of opinion weaved lightly throughout this study because for some respondents they were obviously very aware of the communication requirements associated with their studied degrees and career paths beyond. At times they almost sound taken aback when asked about their stuttering experiences. This would be surely true of those studying such disciplines as medicine, law and education. A resounding theme continued on throughout this study was the broadening lack of identity to the term “disability” and the resulting repercussions from that lack of identity. For some respondents the disconnection with the term “disability” seemed to be a clear and presented a barrier preventing the seeking of assistance with some firmly drawing the proverbial line in the sand between those who are disabled and those who are not.

> ***“****I didn’t think it was the kind of thing that would warrant a disability service - the real disability of stuttering isn’t the stuttering itself but the social anxiety that comes with it.”* (Respondent 32)
>
> *“Did not view my stutter as a disability*.” (Respondent 75)

All responses downplaying stuttering as not generally being a disability and warranting university treatment. Respondent 32 makes an interesting point concerning a division between the mechanical speech problems associated with stuttering and resulting psychological issues. Again continuing feelings seemed to express confusion over whether or not their university actually classed stuttering as a disability. An opinion set which was expressed earlier in this study with a strong general divide from the cohort of stuttering being a disability or not.

> *"I honestly do not think that my university would acknowledge my stuttering as a disability."* (Respondent 66)
>
> *"Did not know if the Uni categorised a stutter as a disability - probably would not have either because I am not disabled."* (Respondent 76)

Yet still opinions around the categorisation of stuttering as a disability and if a university would itself recognise it as such existed loudly. Or yet again some respondents may not have associated stuttering as a disability, but they were at the least unsure if their university could offer any assistance at all.

> *"Did not believe any services would be available."* (Respondent 90)
>
> *"Again I did not at all think that the uni would have any structure in place to help me when required."* (Respondent 93)
>
> *"After 50 years plus of stuttering I doubted they could tell me anything that I already knew."* (Respondent 104)

Apart from the disbelief that a university would have any ability to assist them in their studies, Respondent 104 reflected an even stronger view that they themselves would know more about stuttering than what strategies would be offered to them. Although, some respondents indicated that for various reasons they did not initially ask for assistance but eventually saw the need due to matters of urgency and importance within their courses of study.

> *"I did not. But I did have to disclose later on. I had to attend classes and give presentations, which I could not do at that time. I'd have real fear of making oral presentation and this would lead to depression and anxiety. I was on anti-depressants for a while. I started missing my classes and tutes and this would all catch up on me as a massive pile. And result was that I failed miserably. All of my fails are "absence fails". I was in a depressed mode and there was a time when I was even contemplating suicide. Anyhow, University contacted me after all my fails. I was going to get kicked out. But I applied for special consideration and had a letter from my social worker and so forth to the Uni, explaining my situation and they allowed me to continue my studies.*

> *I did not receive any helps from Uni as far as my stuttering goes. There is a real lack of general awareness as far as this situation goes. I am still enrolled and hopefully would finish my degree next year."* (Respondent 20)
>
> *"I have only recently sent an email whilst I have been enrolled in medicine. I guess this process is really about making sure that school of medicine is informed as I have some concerns about being marked down in clinical examinations. This is after 5 years of tertiary education."* (Respondent 28)

You can see from reading the responses of Respondents 20 and 28 that asking for assistance was due to extreme circumstances within their academic careers and not always stuttering-related. For example Respondent 20 did not ask for help not for directly for their speech but due to very serious life problems including mental health issues. Respondent 28 expressed the stress previously shown in terms of the more exclusive degrees and their challenging professional requirements. In this case the need to do well in clinical-based examinations. Interestingly some respondents did not want to ask for assistance for fear of "coming out of the closet" so to speak, being identified as a person who stutters and further feeling related personal levels of associated shame.

> ***"****I did not want anyone to know that I had a stutter. And I also think that I was in denial."* (Respondent 37)
>
> ***"****I was ashamed of my stutter and embarrassed. Besides, I would never have thought that help was available."* (Respondent 61)

It worries me about exactly how many students with disabilities may have neglected their studies due to the feeling of shame associated with asking for help. During my opening speeches to commencing students I strongly encourage the seeking of support provision when required and to never feel ashamed to ask for help. I strongly emphasise that there is more shame in not asking for help regardless of whether you think you deserve it or not as opposed to simply enquiring about support options. Stuart in fact expressed these feelings of shame very overtly and strongly:

> ***"****I think because I was basically so ashamed of it there was no way I would have been prepared to publicly acknowledge it enough to seek help."* (Stuart)

When asked to expand further upon his associated feelings of shame Stuart expressed deep emotions and concerns:

> *"I felt like a complete fool. I always felt intellectually and socially inferior because of it. It was always a profound and humiliating experience. Not only because there was always a chance that you were going to be laughed at, but you always entered a social interaction from an inferior position. You were reliant on the indulgence of the other person to have a reasonable interaction. If they chose not to be indulgent about it then they could immediately come out on top of the encounter and there would be nothing I could do about it."*
> (Stuart)

It is shameful in itself for the Australian higher education system that some students in need of assistance express that there are too many negative feelings and stigmas associated with accessing related disability support services. In fact, the access to such services should in practise be an empowering process, yet at least for students who stutter, they did not want to face this provision of services for a range of reasons in general. Reasons both worrying and at times surprising to myself.

Of much interest was the fact that yet again at least one respondent feared asking for help or disclosure because of the competitiveness of their degree. In this case a degree in medicine which is highly competitive to gain entry to requiring very high entrance marks of various forms and in some cases even a process of candidate interviews.

> **"..***thought this would be a sign of weakness in competitive environment."*
> (Respondent 83)

For Trevor at least, disclosing turned into a safety net that helped to alleviate the anxiety of possible service provision into the future. Trevor is an example of the pro-active views that universities should be strategising and planning for. Disclosing does not mean that you will in fact need support for your disability, but it does mean that a university can better plan and in turn fund for the student numbers involved for possible support service provision into the future. Within the following paragraph Trevor shows a very positive and educated view around the accessing of disability services.

> *"Yes I did decide to go and talk to the disability support services officer and I am registered with them. The reason why I went to discuss that with them was because we have a student support office in medicine and he discussed that if we have any problems that we should talk to him or to them so that they know that if there are issues with exams or assessments then we can talk to them about it."* (Trevor)

Now that we understanding that few students who stutter disclose their disability at the point of enrolment has been understood it is important to understand the motives behind those who did disclose. Keeping in mind that at the enrolment point of disclosure that specific about a disclosed disability are not asked for. In actuality personal disability details and associated concerns are only ever discussed when a student actually approaches disability services for support. So exactly for what reasons are students who stutter seeking support for?

Specific reasons for disability assistance

To begin understanding the journey of service provision for students who stutter, it was imperative to know for what reasons support was being sought for and how they align to the concerns expressed by students who stutter pre to university enrolment. The fourteen respondents who sought disability services assistance were asked to list the reasons that they were seeking assistance for from a provided list. This list was formed by my own experiences of reading countless posts on social media from students who stutter expressing their university trials and tribulations. The respondents were allowed to "tick all that apply" from the list of given reasons and were also able to provide their own answers.

	Responses	
	N	Percent
In class oral presentation	13	**48.1%**
Oral participation in a lab/tutorial class	3	11.1%
Oral based examination	7	25.9%
Practical based oral examination	3	11.1%
Other	1	3.7%
Total	27	100.0%

Table 4: ***Reasons for asking disability services for help***

The table above indicates the most common reason for asking disability services for assistance indicated by the fourteen respondents was for an "In class oral presentation" by almost all respondents 13/14 and was almost half of the entire reasons given (48% of all cases). The next most evident reason was for an "oral based examination" by seven respondents. Interestingly the single "Other" reason given was bound to overall staff awareness and not a specified assessment task.

> *"Making sure my faculty knows I stutter."* (Respondent 28)

For some people this list may not be at all surprising, but it clearly sets the tone that assistance is generally being sought for tasks tied to assessment and in turn the need to achieve better results in this tasks. These reasons then aid the ability to succeed and pass the course work associated with a degree with higher levels of confidence and fairness. Earlier, this study expressed a host of fears associated with class introductions and interactions. The expressed list of situations requiring support focus purely on tasks linked to assessment only. This indicates to me that students who stutter manage in their own ways the social aspects of university classes which would involve various forms of introductions and interactions with teaching staff and peers. For these students who stutter, priorities seem focused around the stressful areas associated with oral assessments and the gaining of associated fair grades.

Proving your disability

All fourteen students who accessed disability services assistance unsurprisingly had to prove that their stuttering was in fact real and not simply a made up excuse to unfairly gain academic support services. It may be of surprise to some readers that some students, at least at my university, have tried to access support services without any form of verification of their disability. For some students their disabilities are very overt and they had felt that due to that reason no official proof was required. For other students their disabilities were not that obvious on the surface. Stuttering for example if a perfect example for what some people class as a "hidden" disability (Olney & Kim, 2001). Stuttering is only made overtly obvious to the listener when they engage in vocal communication with a person who stutters and they notice the involuntary disruptions of speech. I have personally dealt with students who have either attempted or pondered faking a disability to try to, in their view, have easier assessment requirements for a course. But as a lecturer, unless a student admits this to me, I am bound to take direction from disability services in how to accommodate a disabled student. If disability services has accepted a student for support provision then I and any other lecturer have no real right to keep questioning the authenticity of the student.

The burden of proof to access such essential and at times perhaps under-resourced disability services is rightly placed firmly upon the shoulders of the would-be student client. As mentioned earlier stuttering lends itself to requiring professional proof due to its general covert and variable nature. Stuttering is a somewhat hidden disorder only overtly prevalent when a person who stutters attempts to speak and cannot be diagnosed by simple visual observation. Stuttering behaviours are generally not consistent in nature or frequency for the individual who stutters and between individuals who stutter. Making it hard to establish a stuttering norm for a person who is not a speech professional to clearly diagnose stuttering and to understand its impact upon the individual. In fact you may have spoken to or heard many people who stutter speak socially and not even know that they stutter. This is due to the inconsistent nature of the behaviours associated with the disruption of speech patterns that stutter causes for an individual. Using myself as an example some people who have worked with me for years have been shocked when either I tell them that I stutter or if they hear about it from someone else. Walk past me in the street and you would never know that I am a person who stutters. In fact even as confident as I am in my university roles, each and every meeting is a wildcard performance for me fluency due to its inconsistent manner. More often than not, I am more fluent in stressful situations than I am in comfortable ones. This goes against that commonly held opinion that higher levels of anxiety aggravate stuttering behaviours. Well at least for myself. But I think that due to my career that my established speaking comfort zones are often those which many people who stutter would actively avoid. I have often spoken in research meetings at times with speech pathologists who had no idea that I stuttered until either I told them or in fact I did stutter in front of them. I have seen some of them quizzically look at me once I started stuttering and some have even asked me what type of therapy I am doing. They have been surprised when I state that I do not use any formal technique at all to manage my stuttering.

When asked how they had to prove their stuttering to a disability services officer (DSO) the responses from students who stutter were quite worrying indicating a resulting rigid process of confusion and shame. Considering the emotions and motives behind accessing support services it may not be an immediate thought in a student who stutters mind in terms of a burden of proof. So the question begs to be asked “How does one prove that they have a stutter to a disability services officer?”

The responses to this question were very interesting and provided much food for thought. Not all respondents answered this question though but the most common response was logically of course the responsibility of the student having to prove their stuttering in order to gain assistance. It makes sense that the DSO would not take the proposed conditions of their potential clients purely at face value without evidence being provided. Even if these conditions were clearly overt there are university procedures and policies that must rightly be followed to make the process “fair” for all. For this study what was very interesting was how stuttering was validated and proven to a DSO. In turn how did this validation process make students who stutter feel about themselves and the University? It was also important to me understand the resulting impacts of this process on their emotions. The majority of responses indicated interestingly that a simple diagnoses from a general practitioner (GP) was required as proof for what you would assume would be a condition that a speech therapist would be more professionally competent to assess. But there could be some logical reasons for this that I will outline later in this section. Initially the use of a GP to validate a stutter even confused and bemused myself, let alone the respondents below.

> *"Well yes, I was instructed to go and get a doctor's certificate to prove it. Even though I stuttered all through my initial interview. The officer felt that I did stutter but that was not proof enough."* (Respondent 01)
>
> *"A visit to the onsite GP."* (Respondent 11)
>
> *"I am currently in the process of doing this. I have been informed that I should get a letter from my GP. I have done that and need to make an appointment with the officer at my university."* (Respondent 28)
>
> *"I was asked to visit and consult with a GP. Strange as a GP is not a speech therapist."* (Respondent 100)

So it was so interesting to me that the preference from a DSO for diagnosis appeared to be a GP over a speech and language professional (SLP) who in turn is presumably professionally trained in being able to identify stuttering to a diagnosable level. As opposed to a GP who you would assume would have no diagnostic professionalism within the realm of speech therapy. I would doubt myself that much weight would be given to stuttering during the medical training of a GP. Perhaps the direction of a student who stutters to a GP for a diagnosis could be one of simple reasons. Reasons in fact to help enable a swifter pathway to support? The GP suggestion could be due to the generally faster and cheaper nature of accessing a GP over a SLP for an average university student? This decision to point a student towards a GP for diagnosis does upon reflection actually make sense to me because most likely a university has general medical provision services on campus. As a result it may be easier for a student who stutters to make an appointment with A GP due to much short waiting lists for general health care provision, as opposed to the long waiting lists to access publicly provided speech therapy in Australia. In fact you may have to wait weeks if not months to be able to visit a public speech therapist for a diagnosis and a private practitioner may be too costly for the average university student to justify visiting. I am lucky that I live in the rural city of Ballarat and are so many free GP options within a close proximity of each other. I could easily make an appointment to see a GP on my campus and maybe wait one or two days at the most for this to happen. Or I can actually go to a health clinic around the city in which I could probably see a GP on the same day and in many cases not pay a single cent. Australia as a wide public health system in which different levels of free benefits apply in comparison to what you earn. Clinics which "bulk bill" the government for public health services are usually free for all Australian citizens for general healthcare.

Yet surprisingly one respondent was given the option to provide the "vote of stuttering" confidence from an SLP, but it was not required by the DSO. It was more required for the sake of noting a fair and informed process of service provision and perhaps in this case for the DSO to justify their decision if their decision to provide support was ever challenged?

> ***"****I was asked to provide documentation from a speech therapist confirming my condition. This was NOT required by the disability services officer but they suggested it would be helpful to have on file."* (Respondent 21)

Alarmingly for one respondent they felt as if they had to try to make their stuttering more overt in nature to be taken seriously as for needing assistance. But such actions and feelings should never be invoked by the need to access a support service. The DSO of course followed the due process of a medical referral also seemed to not understand the inconsistencies involved with stuttering behaviours and in turn it provides an early hint that more education about stuttering is required.

> “*Yes the officer did not take my word for it that I had a stutter and seemed a little stunned about me wanting some assistance.”* (Respondent 02)

So now that we understand the forms of stuttering evidence that were required, it was even more important to understand the resulting feelings of how satisfied and empowered students who stutter felt about this part of the support provision process.

How did this process make you feel?

Once I had established that there was a logical, but perhaps confusing procedure of stuttering proof, it was important to explore the feelings involved with this stepped process of disability support. Perhaps the ordeal of accessing support provision could be a negative situation fraught with damaging emotions for a student who stutters? A student who may be obviously afflicted by stuttering and yet has to prove the fact to more than one official party, in most cases to a GP. Yes more than one professional for at this point in time the student who stutters has taken the brave step to seek assistance, met with a DSO to discuss how to access support and then be directed in most instances a GP to whom they have to explain the whole situation to again.

Initial feelings around this burden of proof to access support services and disclosure to a medical professional revolved around personal feelings of embarrassment.

> **“***It felt very strange having to justify myself. I hate arranging interviews and appointments as it is. I felt a little embarrassed firstly asking for assistance and then being somewhat doubted that I stuttered.”* (Respondent 01)
>
> *“I was embarrassed to have to show evidence and more stressed. I was worried about then proving it to lecturers.”* (Respondent 110)

For some students who stutter there was genuine confusion about why they had to justify their stuttering at all to be eligible to access services. The confusion at times would appear to revolve around why a DSO would require proof even though the student’s stuttering behaviours may be overt and at times severe in nature. But could be solved by the promotion of the provision process in turn helping the student who stutters to understand that all who seek assistance for no matter what issue are treated the same. You would assume that students with more overtly identified disabilities would also have to go through the same process of providing evidence and not be taken on face value. In turn I hypothesise that those such students would also be facing the same types of feelings and emotions as those expressed within this study.

> *"It felt very strange having to justify myself. I hate arranging interviews and appointments as it is. I felt a little embarrassed firstly asking for assistance and then being somewhat doubted that I stuttered."* (Respondent 01)

> *"Not the best. I felt a little confused about why I had to prove it."* (Respondent 12)

But this support process had led at least one respondent to being upfront about feeling as if they needed to perhaps try to make their stuttering behaviour more overt to please the assessor. An action perhaps of desperation which may not be overly empowering for some students who stutter to consider. I even questioned myself to how could I make my stuttering worse, if I was placed in the same situation? I have tutored an actor for a project about how to stutter for his role, but even then it sounded fake to my ears. But if I had not told anyone that his stutter was fake then most people saw the video would never have known. I guess desperate times lead to desperate measures.

> ***"**It made me initially feel like a fraud. I felt under pressure to stutter badly to prove the fact."* (Respondent 118)

For another respondent there were feelings of confrontation when contemplating having to disclose to more parties than perhaps initially expected. There is a logical understanding that one would have to disclose their stuttering to at least one support officer, but some disbelief at having to continue to disclose and then prove. But in the case of these students the process it at possibly at least a three step procedure of disclosure. Starting with: 1) disclosure of having a disability at the point of enrolment to; 2) having to disclose their stuttering to a DSO to start the provision of assistance to; 3) having to provide professional evidence from a separate health professional.

This could be a pressure filled process for some students who stutter which seemed to get more stressful step-by-step emphasised by following quote by Respondent 11.

> *"To open up to one professional is fine but to open up to many different ones was daunting."* (Respondent 11)

Frustrations manifested themselves for other respondents around the proof process which featured within their responses for a number of different reasons. These reasons revolving around the overt nature of their stuttering and the reason for being directed to a GP to provide a stuttering diagnosis.

> *"Well I was a little miffed by it all. It was very obvious that I stuttered!"* (Respondent 02)
>
> *"Luckily, my GP is very approachable. But I was angry when I had to do this after I explained that I have never had medical treatment for stuttering from my GP. I was more or less relying on my GP's willingness to write the letter for me."* (Respondent 28)

This clear burden of proof also seemed to heighten the stress levels of some respondents and in turn it could be presumed that at least in the short term that their stuttering severity levels may have heightened as a result. Perhaps inadvertently lending validation to a GP to validate their stuttering without having to ham it up themselves.

> *"More anxious and worried because more people had to be involved."* (Respondent 100)
>
> *"I was embarrassed to have to show evidence and more stressed. I was worried about then proving it to lecturers."* (Respondent 110)

Disturbingly at times this burden of proof process made some respondents feel heightened levels of alienation or strangeness. The process itself seems to "other" some respondents within a situation which should always feel supported and empowering.

> ***“****Odd, different, not normal.”* (Respondent 17)
>
> ***“****It felt strange.”* (Respondent 60)

These are certainly not the feelings that you want associated with seeking the provision of disability support and are all within the psychological barriers for intervention seeking as described by De Cesarei (2015). I will emphasise again that a university DSO should be aiming to install confident and empowering feelings associated with the assurance that the given university can professionally assist you with your studies and accommodate discreetly your differences. Now let’s explore more the continued burden of proof associated with accessing DSO support.

The continued burden of proof

It is an accepted process that one should have to prove their disability in order to gain assistance. But the question is how and who should a student who stutters verify their stuttering to? In fact “how does one prove that they do indeed stutter?” is an interesting question for you the reader to reflect upon. Stuttering is a condition that I have explained throughout this thesis that can vary in severity for an individual throughout any given moment in time without warning. For example, I often find myself stuttering sometimes more in perceivably stress-free conditions such as talking to friends than I do in front of a large public audience. At times there are people who I meet professionally who have no idea that I stutter at all after talking to me. Yet at other times my stuttering can be an out of control train wreck of an experience for all involved except myself who just brushes it off. As we just read the requirement of a student who stutters proving that they indeed did actually stutter was on the surface a confusing requirement due to respondents in general being directed to a general practitioner (GP) who was themselves is not an expert in speech or language disorders. This study now wishes to delve deeper into the feelings around the process of disclosing and then proving one’s stuttering. The survey showed that unsurprisingly all but one of the 14 students who had sought disability services help had to prove their stuttering beyond disability services staff members. So it is important to now understand the feelings of these 13 students who stutter who indeed had to prove their stuttering.

Previous questions had clearly indicated that students who stutter were being prompted more often than not towards a GP to provide proof of their stuttering to provide to a disability services officer (DSO). This was further exemplified within the responses to this question with an overall feelings of pure convenience and haste in order to fulfil the requirements of the process.

> *"I had to make an appointment with my local doctor in order to clarify the fact that I did indeed stutter."* (Respondent 12)
>
> *"The nearest and quickest doctor."* (Respondent 17)
>
> *"The on-campus GP."* (Respondent 74)

As I alluded to earlier, a GP may be suggested by the DSO because they know that it would be relatively easy in an Australian university for student to either see an on-campus doctor or local area GP quickly and cheaply as opposed to seeing an actual speech pathologist. Options I would think that students who stutter would opt for themselves due to the ease of the process and the speeding up of support acquisition. Alarmingly one respondent discussed how evidence from their speech therapist, who is a speech professional and not a GP, was called into question by a tutor. There seemed to be resounding objection throughout the tone of this response that a tutor would have any rights at all to call into question a decision made by a DSO. An opinion that I can support personally knowing how the provision of support services work.

> ***"****The difficult tutor (previously mentioned) did not believe that I had a speech impairment and demanded to see documentation. I refused but referred him to the disabilities office who confirmed that I did have a speech impairment. He then demanded to see the documentation and argued that the analysis performed by the speech therapist was performed six months previously and may not still have been accurate."* (Respondent 21)

This comment really is alarming due to the one indicated time that a true speech professional was involved then this expert opinion was questioned indicating that the tutor involved needed more education about disability services and the burden of proof. In fact an academic does not have the general right to question the decision made by their official disability services unit and certainly does not have the right to question the diagnosis of an accepted professional medical opinion. A medical opinion that was made by a true professional in the diagnosed field. In this case the tutor clearly needs to be more educated about the university's provision of disability assistance, that of stuttering behaviours themselves and the fact that stuttering will not magically leave an individual one day into the future. Without sounding arrogant to you the reader my opinion would be that a tutor has no right at all to question such decisions made by a section of the university responsible for support provision, and if questioning the evidence, the tutor should simply have a discreet discussion either with the related lecturer or DSO.

But beyond this requirement of having a medical practitioner provide written evidence that a student who says that they stutter does indeed actually stutter, this study sought to explore and give voice to the feelings involved throughout this process. The fact that a student who stutters had to prove to someone other than the DSO was a point of continued contention was of interest to find out more about their feelings and experiences during this essential provision step. Again, keep clearly in mind that for most students who stutter this step involved a GP and not a speech therapist as the provider of proof.

Some respondents were obviously puzzled about why they had to discuss the matter with a party outside to the evident university staffing structure, more likely a GP.

> *"It felt very odd having to make a doctor's appointment for this process and then open up to him and ask for proof."* (Respondent 12)
>
> *"A doctor is not a speech therapist! It was a quick and nasty decision made on the spot that I stuttered without any real enquiry."* (Respondent 17)

If you think about it more deeply the 13 students who were asked to provide professional evidence of heir stuttering had to actually disclose to a party external to the university and in turn yet another party who they had to have faith in the privacy of their disclosure. I would think that this process itself would be even less attractive to those students who had earlier indicated fear of their disclosure information potentially being used to their disadvantage at some point in their academic future. But I must emphasise that some respondents were genuinely puzzled about how does one legitimately prove a stutter or even perhaps ensure that they are stuttering enough to be clearly diagnosable to a non-speech professional. Do you simply walk in the door and explain your predicament hoping to stutter quite overtly, or will a GP give you some form of test? This confusion may have been exemplified by that fact that most students were proving their stutter to a GP and not a speech professional. It certainly would be confusing for myself and maybe hard to achieve because I am a very confident speaker in social situations. This overall process could perhaps lead to higher levels of associated anxiety simply due to the overt burden of proof to a party not usually involved with the speech therapy process. Anxiety which could have much broader effects on the student who stutters apart from their speech at that unique point in time. A student who stutters would need to have the process and reasons for each step carefully explained to them in order to start managing their possible social anxieties. But confusion reigned supreme throughout this process as outlined below.

> **“***It felt very odd having to make a doctor's appointment for this process and then open up to him and ask for proof.”* (Respondent 12)
>
> *“Again how does on prove? How many extra steps do I have to take to get help?”* (Respondent 74)
>
> *“I was asked to see an on-campus doctor. Again how does one prove it. It was a little embarrassing having to ask so many people for help and then prove it to all of them!”* (Respondent 82)

These responses continue to reflect strongly the concern around the number of disclosure steps involved for a student who stutters when seeking support provision.

In turn perhaps universities need to be more clear advertising and articulating their information revolving around support provision and what evidence may be required to gain support. If this process and burden of proof was more clearly advertised pre to support enquiry, then perhaps some students may more professionally seek a diagnosis of their stuttering pre to meeting with a DSO and in turn avoiding the commonly suggested GP option of disability validation. This process may in turn also lead to the inclusion of a speech therapist within the forming of class-based strategies for such students.

One respondent seemed bothered by the extra cost and effort that they had to go to in order to prove their stuttering outside of the usual DSO structure. Again lending support to my idea that more information needs to be clearly visible pre to seeking disability support in terms of the process and any required supporting information.

> *"Well it was a lot of effort to go and make an appointment (at cost). The campus doctor was booked out and I needed to act on this quickly"*
> (Respondent 02)

Now that we know that the process of proving a stutter seemed to be a confusing and stressful step within the support provision process I wanted to tease out even more what emotions were being invoked by what should be an empowering process.

A required process: A tempest of emotions

Once within this required process of validating their stuttering respondents reported an alarming range of associated negative emotions and feelings. Let me instantly reiterate again "respondents reported an alarming range of associated negative emotions and feelings". Some respondents indicated that the response from the appointed GPs seemed rushed and perhaps even uncaring in nature, almost like the GP seemed somewhat annoyed or fussed by the request. In reality the scenario reads that usually the student who stutters had been sent to the public health system to gain validation from a medical professional not trained in the area of stuttering and working within a system which in itself is stretched for time and resources. It is no wonder then at times the diagnosis and provision of proof was perceived to be rushed while lacking empathy and professional knowledge. It would always have been better to seek out a professionally trained speech therapist who would certainly not wish to rush a diagnosis or seem uncaring. In fact some of these students may have a past or current speech therapist who may have been able to validate their claims also swiftly. At this stage in the study it seems the DSOs did not offer the speech therapist option. You can now truly understand the view of a student who stutters that a GP could be no better suited to diagnose a stutter than what a DSO themselves could do. But obviously it is a required step within the policy-governed process of university support. In the way this step has been managed is causing frustration and confusion around the value of such stuttering validation step and faith in the overall support process.

> *"The doctor wrote the certificate out while I was still trying to finish the sentence and did not elaborate. I could have been faking it!"* (Respondent 01)
>
> *"A doctor is not a speech therapist! It was a quick and nasty decision made on the spot that I stuttered without any real enquiry."* (Respondent 17)
>
> *"I felt low and shameful having to do this. The GP looked at me funny and I am not sure if they knew how to diagnose a stutter. I was shunted out of the office with little enquiry."* (Respondent 100)

It is so alarming to read the negative emotions emerging from the respondents associated with the support process. More shockingly to read was that beyond the confusion and relevance of seeking professional validation of their stuttering from a GP, some respondents expressed strong negative feelings associated with the process overall. This resounding range of negative feelings cast a disturbing and looming shadow over a process that in fact should empower and fill the student with emotions linked to confidence. It also starts to cast a darker shadow over the sun-filled broad story of success that I began framing these findings as. Because suddenly this apparent journey of strong success is at least for some students impacted by a support process wracked with confusion and personal shame. Negative attitudes towards the proof process continued with harrowing feelings of embarrassment and violation often linked to the relevance of the GP.

> **“***Embarrassed, violated.”* (Respondent 21)
>
> *“It was like I had to announce it to the whole world.”* (Respondent 60)
>
> *“Again embarrassing to have to fess up to a doctor and be judged. Really he did not seem at all interested.”* (Respondent 110)
>
> *“Not really that crash hot. I avoid medical practitioners as is but having to be forced to make an appointment and then plead for help was not a soul satisfying ordeal.”* (Respondent 113)

In fact most respondents agreed that simply disclosing their stuttering to a disability services officer alone made them feel varying levels of uncomfortableness and embarrassment. Respondents also indicated that they did not feel empowered by this formal disclosure and assistance seeking. Imaging then the continued impact of negative feelings tied to having to prove their stuttering in the first instance, more commonly to a GP and not an SLP. Tying these feelings then back to the generally found disconnection to the term “disability” most of these respondents who sought help also felt levels of discomfort in regards to formally being labelled within the university system as being “disabled”. As explored early in this thesis “disability” is a label and term that many students who stutter strongly disassociated themselves from. Even though due to privacy policies their disability status interactions with DSOs would only have ever been promoted to staff who directly needed to know for support purposes and would not have been on public record for all university staff to see. Disturbingly most respondents who sought DSO assistance expressed that they felt discomfort with this labelling within their university identity and most did not consider themselves to be disabled before this official disclosure. Some respondents though did not feel any sense of heightened disability identity, but did seem a little burdened by the overall ongoing process.

> *“No not disabled.” Maybe hindered.”* (Respondent 11)

> *“I don't feel disabled. Maybe just disadvantaged.”* (Respondent 28)

> *“No not really. I have always felt different, but different is not the same as disabled.”* (Respondent 118)

Again an opinion set deliberately distancing the respondents from the term “disability” and attempting to distance themselves from those who they would consider to be disabled. These respondents continued to mirror an earlier stated opinion set downplaying the affect that stuttering can have on an individual’s life and ignorance, purposeful or not, around the the legislative definition of disability. Although interestingly one respondent reported a heightened consciousness of being “disabled” more in terms of policy and legislation, but was seemed to be not overly impacted by the labelling except for some sudden personal reflection.

> *“Only in a legal sense. I was still the person I was before that. It did feel a little odd though suddenly being disabled.”* (Respondent 01)

Alarmingly most of the 14 respondents agreed that they felt ashamed when disclosing their stuttering to disability services. Which is not surprising due to the heated debates around stuttering being a disability as expressed earlier in this thesis. It is also not surprising due to the strong resistance found by students who stutter to distance themselves from disability. Very little narrative was expressed concerning this worrisome finding with only two respondents being very split in their opinions.

> *“My only real concern is having to go to the officer's office. I also feel some guilt about whether it is necessary.”* (Respondent 28)

But what arises from these findings and comments is the fact that most of the respondents felt more disabled after disclosing their stuttering to a disability services officer than they did previously to seeking support services assistance. But more disturbingly are the levels of shame and embarrassment being loudly described associated with this essential support provision. “Shame” and ‘embarrassment’ are two words that you would never want to see associated commonly with the provision of support services and are findings of true concern.

Encouragingly there was at least one respondent who reflected a truly positive story of DSO support above and beyond what all other respondents had expressed.

> *“The disabilities office was fantastic and very accommodating. They made the entire process very easy and they were extremely supportive (even coming to watch my end of year presentations etc).”* (Respondent 21)

What a truly supportive experience Respondent 21 has reflected to the point of a follow through of guidance into the classroom itself by the DSO. It is important to be able to express some positive experiences from the acquiring of support to give you the reader of this thesis a feeling that that the access of support provision has not been totally negative. But this chapter is not over yet and there is more of the DSO experience for students who stutter to be explored.

You have your foot in the door

Once a student’s stuttering had been proven and disability support services had begun to have been more fruitfully accessed, more was required to be known about the process of the facilitation of assistance. The logical next step for a student in need would be to meet with a disability service officer (DSO) to form a personalised plan of support and to discuss associated strategies. My university calls this a learning access plan (LAP). When asked if respondents felt that the involved disability liaison officer seemed genuinely concerned about their stuttering the majority of respondents agreed that they in fact did. A positive finding indeed that diverts the journey of support provision back onto a more positive path forward. Once in the consultation phase with a DSO most respondents felt no time pressure to answer the posed questions or to express their needs. This is an encouraging sign of good training on behalf of the DSOs because a common strategy when talking to a person who stutters is to allow them as much time as feasibly possible to respond and not to place them under extra stress. Certainly this could be a challenging situation itself for a perhaps time-poor and resource stretched DSO. But having said that, most respondents felt throughout the process that the consulted DSOs were not very knowledgeable about stuttering and its effects on a person who stutters. Perhaps in turn not giving some students who stutter an initial feeling of confidence that the provision of support would be well informed. Earlier in this study you may recall that many students opted not to seek support for their stuttering because they assumed that a university would not be knowledgeable or care. At least these findings have found that DSOs do express a high empathy of support towards students with special needs, but in the case of stuttering they do give an impression of not being knowledgeable about the condition.

One respondent however did expand upon their consultation experience and offered a negative perception of the stuttering knowledge of the DSO they had encountered.

> *"Seemed to be slightly confused about what all my fuss was about and noted that they had never seen a stutterer in their office before!"* (Respondent 82)

Certainly not the ideal situation for a students who stutters to be comfortable within and feel assured. I am taken aback by the fact that the DSO did not use person-first language and obviously has little knowledge about stuttering. Almost an ignorance about stuttering being classed as a disability reflecting that of some of the participants of this study. Once provision had been granted it was the role within the overall service provision process to discuss amongst all involved parties various strategies to facilitate the respondents stuttering through their academic activities. When asked whether or not a disability liaison officer was not open to their own suggestions about possible strategies to help support their stuttering during class times the opinions of the students who stutter were completely mixed with no strong weighting of opinion for or against this question. I tend to think this is probably due to the students themselves perhaps not offering or thinking of strategies pre or during the consultation and probably mostly going along with what was on offer.

With the findings in mind that there was a general perception that most respondents felt that the DSO was not very knowledgeable about stuttering it was essential to establish what general strategies the DSOs offered for class-based activities. For it could be presumed that if a DSO lacked knowledge about stuttering then offered strategies to manage class-based activities could be very generic in nature and not as constructive to the needs of the students to fulfil them. Keep in mind that almost all requests for assistance were based around in-class assessment tasks. But I have a question for the reader to keep in their mind as they read these offered provisions. Do you think that the provisions and strategies were exactly what the students who stutter was hoping to achieve and would have been fully satisfied with? As you read also try to form in your own mind what alternative strategies that you may have offered to a student who stutters. Perhaps you may find that you cannot think of a large range of strategies simply due to natures of the class-based scenarios and settings.

When asked what strategies were offered by a DSO the options did indeed seem very generic in nature and at times not overly inspirational. One popular strategy for accommodating stuttering was to attempt and submit an alternative assessment item to replace for what was most likely to have been an oral presentation.

> **“***To hand in a written report and sit an written test instead of oral.”* (Respondent 02)
>
> **“***Non-participation in oral based activities. Videoing myself in privacy making a presentation.”* (Respondent 11)
>
> **“***For lab based I was told to hand in a report instead of reading results out in class. The same was offered for presentations.”* (Respondent 118)

Alternative assessment are a very common strategy used within learning action plans that I have dealt with and accommodated myself. I have found them to work very well with students who are satisfied with their implementation. I have found though that care has to be taken making sure that implementing alternative assessments do not overtly single out the students in the eyes of all their fellow students. It is not uncommon for fellow students to note other students being treated differently. As a lecturer I work very closely with the student to find a solution that satisfies all parties and builds their confidence. Another popular strategy was for the student who stutters to work within a group, negotiate their responsibilities and effectively avoid the perceived burden of a solo-based oral presentation. At times this is of course mandated by the course requirements by having assessed team-orientated skills. A strategy which may have helped to the student who stutter to avoid speaking tasks at times, but in hand would have let more of their fellow students become aware of their assessment accommodation. A situation which I explained earlier needs to be supported and thought-out well to be both satisfying and effective for all involved.

> *“Mostly alternative group based assessments which shielded my stutter.”*
> (Respondent 01)

But proposed strategies in general tended to revolve more so around non-oral participation, perhaps a times contrary to what the students who stutter felt confident or satisfied with. It should never be assumed that a person with a verbal communication disorder simply wants to avoid verbal communication in parts or altogether.

> *“Most options offered to myself hinged really on non-participation.”*
> (Respondent12)
>
> *“How to hide the fact that I stuttered. e.g. not talking out aloud in class.”*
> (Respondent 60)
>
> *“Basically offering as many options as possible not to have to talk face to face with any lecturer or class mate. Removing my speech from the equation.”*
> (Respondent 82)

The previous comments emphasised the strategy of speaking avoidance. This would have been quite contrary to a majority of the respondents that would have had previous speech therapy or speech management. Speaking avoidance is seen as strategy which encourages a person who stutter to talk less, not challenge their speech-based comfort zones and in turn could negatively impact their social skills. Indeed as a result of seeking assistance one respondent felt very frustrated and angered at being pointed down a path that they were not satisfied with and with being lead down the path of not being required to speak at all. Knowing themselves that this was preparing them for an unrealistic future in terms of career requirements.

> *"An alternative assessment if possible. The problem was that I had to do the task as an assessment and also in real life for my career. I wanted to do it as it stood just not under the same circumstance. I was steered into not doing the assessment as it was. I did not like that approach."* (Respondent 100)

It may be interesting to the reader that I was once offered such an approach by a lecturer who took it upon themselves to offer me assistance after seeing me outwardly struggle speech-wise during their tutorial class. It was the first time they had taught me and they of course quickly noticed how my speech patterns were very different to the other students in the class. I can understand how they have been alarmed when first seeing me speak openly with long speech blocks, a loud voice and with involuntary body movements. At first I was caught off guard by such a sudden offer of assistance, but I understood the motives behind their move and knew that they were sincerely trying their best to make me feel comfortable and succeed stronger. I however did politely decline while thanking them for their understanding. In fact at least one of my fellow students themselves was a little confused about why the lecturer had offered assistance when throughout the last two years not a single other lecturer had. My fellow student expressing even that the lecturer should mind their own business and if I wanted help then I would ask for it. It was nice however to see some empathy and accommodation at play. In fact that I felt a larger amount of respect for that lecturer due to their intervention and student care.

It was obvious to this study that DSOs were providing students who stutter with a range of strategies on offer for which all revolved around the notion of speech avoidance. In reality a set of strategies focusing around participating in the assessment, but reducing the physical speaking load. But in fact what strategies did these students really want to be put into place that would satisfy their personal needs and also the required course-based outcomes? To attempt to answer this question I was not so interested in what was offered, because I could already list those myself quite generally due to my experiences both as a lecturer and by having past experiences accommodating the studies of many students with special needs. I wanted some answers from respondents concerning how they would make the provision of services by DSOs more beneficial and helpful for students who stutter.

One loudly proposed strategy from respondents revolved around the starting point of education for DSOs about stuttering in general and its effects on the individual.

> *"Be more knowledgeable. Try to take into account that perhaps the stutterer does not want to be noticeable different to the rest of the class during oral assessments."* (Respondent 01)
>
> *"Think more holistically beyond the stutter and focus more on the needs and feelings of the person."* (Respondent 12)
>
> *"Learn more about the how stuttering affects the person. Knowing simply what the condition is not enough."* (Respondent 110)

Each previous respondent outlines that more knowledge is need by DSOs in order for them to more successfully understand and accommodate stuttering at university. In fact there's quite a lot of general guides about stuttering and how to interact with people who stutter freely and easily found on the worldwide web, as I reviewed earlier in this thesis. It would not be very difficult or time-consuming for a stuttering organisation to promote a fact-fuelled website to the small amount of Australian universities. Whether it be their own website or one that they see promotes high standards of related guidance. Another proposed strategy tied into general service level training that would enable a DSO to be more approachable with future students who stutter. In turn to further ensure that the DSO has an approachable manner with all clients regardless of their reason for support and accommodation.

> **"***I guess my only suggestion is to ensure that the officer is approachable. Regardless of things that are put into place, there is always going to be problems with stutterers disclosing their stutter to people."* (Respondent 28)
>
> *"Be nicer and more friendly. Less scientific and more human."* (Respondent 118)

Personally, I would have expected all DSOs to have been trained to a high level in terms of client interactions and liaisons. All DSOs must be seen as highly approachable and logical in their decision-making. For some respondents and I think one of the major findings of this study so far has been to prompt an attempt to simplify the provision of service. Or to at least make all the steps leading to the provision of service as stress free as possible, logical to the client and relevant to the personal case at hand, while working within associated governing procedures and policies.

> *"Not to have too many steps in the process of getting help*." (Respondent 17)

> *"Eliminate extra steps. Perhaps contact where I have had therapy to prove. This would be more of a guarantee."* (Respondent 74)

Respondents expressed the need when formulating strategies to focus more at an individual level and not a standard blanket approach, or at least not feeling so generically dealt with by DSOs. This ties directly into the approach of offering fairly vanilla strategic options to those students who may be at risk of commonly avoiding speaking.

> *"Listen more carefully to the wants and needs. Consider the person above the problem."* (Respondent 60)

> *"Be more open to client suggestions and needs. Look beyond a generic textbook approach to care."* (Respondent 100)

Leading to the fact that a DSO should not generically assume that a student who stutters does not want to speak. In fact it could be more empowering for a student who stutters to speak within the challenging situation in a manner that they feel satisfied and proud with, as opposed to simply avoiding speaking yet again. Avoiding speaking situations is a characteristic that is often employed by people who stutter throughout their lives and is focused on heavily addressing during speech therapy. Certainly avoidance is not a promoted strategy within the stuttering support communities regardless of learnt speaking techniques. Avoidance from speaking situations is professionally seen as counter-productive to any reputable form of treatment and/or managing stuttering.

> *"Have in mind that some stutterers wish to speak but perhaps need help with setting it up in a comfortable fashion. Do not assume that speech all together is a no no. Consider the person beyond the simple act of speaking."* (Respondent 82)

Respondent 82 expresses firmly the need for a DSO to know more about stuttering in general and to not automatically shield a student who stutters from speaking situations. In fact at least one respondent expressed that they would have liked the DSO to contact their speech therapist for two main reasons. One in order to prove their stuttering and secondly to perhaps gain more education around it to assist with informed service provision.

> *"Eliminate extra steps. Perhaps contact where I have had therapy to prove. This would be more of a guarantee."* (Respondent 74)

I would also suggest to students who stutter that they should be more pro-active and aware of the evidence required to gain support services and at times pre-prepare for the situation before seeing a DSO. Finally it may also be evident that DSOs need to advertise their services more widely and prominently to all students in order for them to consider those strategic options.

> *"More advertising about the services they provide. I only found them in final year because of a particularly troublesome tutor - I would have seen them earlier if I knew they could help me so much."* (Respondent 21)

Now that a solid understanding of the journey of disability support provision has been understood for student who stutters it is important to continue this journey of understanding into the classroom itself. The next chapter will lead you through the class-based experiences of both the students who stutter who asked DSOs for assistance and also those who did not. The upcoming chapter will also importantly explore how effective and satisfying the offered support strategies by DSOs actually were for the students who stutters who asked for their help.

Chapter 8: Class life & stuttering impact

Following on from the findings outlined in the previous chapter the first lines of enquiry around class-based interactions and impacts were directed only at the 14 respondents who ask disability services officers (DSOs) for assistance. Out of the 14 respondents who did ask for DSO assistance only one chose not to implement during classes the suggested and agreed upon strategies. Although this respondent did not answer why they chose not to implement the strategies the answers of some of the other respondents give a solid clue perhaps why the offer was not taken up and this reasoning seemed due to feelings of being restricted in terms of class-based strategic options.

> ***“****It felt like there were no other options available.”* (Respondent 11)
>
> ***“****Little alternative!”* (Respondent 60)
>
> ***“****I felt that I had little choice at all. I was being told and not able to shape it myself.”* (Respondent 100)

These feelings are further backed by the findings that most of these students did not express a strong feeling earlier for or against the satisfaction felt towards the offered strategies. It almost felt like there was a nonchalant sense of feelings around the proposed strategies when apparently no other options were suggested or put into action.

Once some feelings about the negotiated strategies were established it was important to know if the respondents felt if academic staff were open to implementing the agreed strategies. It is shocking to note that 10 out of the 14 students felt that academic staff were not open to implementing the agreed to strategies. A truly negative finding indeed if true. For academic staff should feel confident with the decisions being made to support students in need and be open to supportive strategies offered by their own disability liaison units. An academic should also be an active contributor to the strategies being offered. In a perfect support world the student, DSO and academic should all be actively involved in the negotiation of a disability support plan. Especially in terms of stuttering in which it has been found in the past that lecturers may have little knowledge about its characteristics and impact on inter-class relationships (Daniels et al., 2011; Pertijs, 2009). Furthermore, alarmingly over half of the respondents indicated that they did not feel personally empowered by the suggested strategies in terms of their studies. This suggests to me that there is a hint of a power imbalance existing for these students within the university system and not in their overall favour. Empowerment should be a key emotion that you would wish to evoke in all students seeking support. Feelings of empowerment should be felt from the initial point of DSO contact through to the actual implementation of class-based strategies. On the other hand, most students who stutter felt that the strategies, although not overly satisfying or empowering, did indeed at least lessen their anxieties about stuttering in class-bases situations. This was also despite the finding that all respondents agreed that the suggested strategies did make them standout from the other students in class.

Standing out from other students in their classes was perhaps not a result that students who stutter wanted from support provision for their speech. In fact it may be have been counterproductive in terms of students who stutter seeking even further support into the future. But from personal knowledge of implementing support for students with special needs I have to admit that it is at times difficult to always strategise well so that for some assessments like oral presentations that other students do not notice how a particular student is being treated. I have had to deal with one such case myself only recently where a student with high public speaking anxieties wanted to present in front of smaller audience. Their idea was to present with their team last on the presentation day and then give the other presenting teams the option of leaving first. I told them that in my opinion that would be an odd strategy as some we try to insist that all students in a class stay for all the presentations as a sign of respect. In this case we negotiated presenting to a smaller audience of academics in a separate room with the aim for a more traditional setting for the second required presentation of the course later that semester.

However one respondent did continue a reflection of lack of satisfaction with agreed strategies, yet they were effective.

> **“***Agree but that does not mean I was overly happy with the suggestions”* (Respondent 82)

As this study panned out it was important to understand if the offered strategies complemented what the respondents have been taught in speech therapy/support that they had undertaken in the past. No respondent refrained from answering indicating that they had most likely all undergone some form of speech therapy/support before coming into the university environment. The responses suggested that most felt that the strategies did not complement their learnt speech management techniques. Only one respondent was very vocal about what strategies were suggested to them and how they complemented their speech management techniques. .

> **“***Strategies were counter-productive to what the McGuire Program had taught me.”* (Respondent 01)

But this is not surprising because only one respondent was asked by a disability liaison officer about their stuttering therapy history. This is a very poor result from DSOs hoping to make informed decisions about strategies and assistance. You would think that even a little case history about how perhaps the student had managed their stuttering socially in the past may have been able to influence strategic decisions for university interactions

> **“***They simply asked about the treatments - not so much on techniques for using them in class.”* (Respondent 21)

Nor did most respondents believe that a disability services officer had contacted a stuttering professional for advice. This is also alarming as this type of guidance would have proved invaluable for a DSO. But not overly surprising because it could be assumed that a DSO would usually be under the pressure of large case-loads and would only think of contacting a medical professional for guidance if there was a very pressing and unique need. Unless they were proposed with an individual with very unique and challenging circumstances then a DSO would apply their past experiences an generic support services to a student in need. But it would be interesting for me to have known how many students who stutter who sought assistance offered the DSO a direct contact point of a stuttering professional to seek guidance from.

So here lies a question. What strategies would these students have preferred to have had at their disposal that were not suggested by DSOs? For as the survey found, many students who asked for assistance were not overly satisfied, empowered or happy with what provisions and strategies that they were offered. Question 39 of the survey "What strategies would you liked to have had at your disposal that were not suggested to you?" sought to fill in this knowledge gap.

Some respondents expressed that they did not wish and nor was it their intention to avoid speech all together in class when asking for strategies. They wanted to be active contributors to the vocal task and at times simply present within a context more comfortable to them.

> ***"**To present in front of some trusted friends instead of simply hiding from it and doing something completely different."* (Respondent 02)
>
> ***"**There seemed to be an automatic assumption that I did not want to talk in class. I am not mute. I just want more of a command of how and when I speak."* (Respondent 17)
>
> ***"**To somehow work with my stutter and still be an active participant in classes."* (Respondent 117)

It is becoming very clear that students who stutter seeking support want to challenge their speech and still be an active class member during oral assessment tasks. It was of no surprise to me that some respondents did want more direct input into the strategic process.

> ***"**More say in the process. I did not want to hide away. I just wanted perhaps some more time and consideration."* (Respondent 100)

Interestingly some respondents bought up the notion of stuttering disclosure to the class in order to relieve anxiety. Stuttering disclosure if a technique promoted as making the listeners aware of the speech problem and in turn relieving the stress associated with being both the listener and the speaker. This is a strategy that seems to have been avoided by DSOs who seem to prefer more direct assessment orientated strategies as opposed to strategies designed to relieve stuttering anxiety in all class-based situations. But respondents kept expressing the desire to want to disclose to their classes.

> *"A strategy of disclosure to the class and some class-based education about stuttering would have lessened my thoughts about it and made me feel more comfortable?"* (Respondent 12)
>
> *"Disclosure. The chance to talk in front of a crowd."* (Respondent 74)

One respondent encapsulated in one statement the struggle at hand well when working with a support service that at times seems to not be overly informed with the way that students who stutter may wish to be accommodated.

> *"This is a hard one to answer because all the offered strategies sounded fair and easy to implement. They just made me feel a little worthless."* (Respondent 11)

It has been clear to read that the offered DSO strategies have been effective for students who stutter, but the process and narrow-banded range of strategies is not satisfying or empowering. A lot more education needs to be presented to DSOs in terms of working with students who stutter and the need to look beyond assessment needs only as a point of assistance. A student who stutters needs to feel comfortable, their opinion valued and empowered by their brave decision to ask for support and then incorporate negotiated strategies in front of their peers.

Once in class

Beyond the provision and embracement of DSO strategies into class-based environments, this study aimed to explore the overall feelings and actions of all 102 students who stutter and the 15 interviewees who participated in this study. The story of a collective voice expressing the trials and tribulations involved with managing a stutter within a higher education pedagogical environment. When asked if their general academic performance had been impacted upon by their stuttering close to 80% of students who stutter agreed to some extent that this was true. This is a concerning thought-provoking result considering that very few students who stutter accessed any form of provision of their speech difficulties and assessments. This is also a very upfront result with this cohort of students who stutter being very clear that despite assistance being freely available at universities, very few of them opt for assistance even when aware that their speech is impacting their academic performances. This finding represents a very strong admission that although on a surface level many students who stutter are having successful journeys and outcomes through their university careers, that many factually are sacrificing grade achievement and personal fulfilment by not seeking assistance or provision. As I have described earlier the overall broad journey of academic success of these students truly masks a plethora of negative trials and tribulations. In order for you to understand these problem areas this study will now investigate the class-based experiences of students who stutter.

Preparing for the first classes

With upcoming classes of a given semester and at times pivotal points in their degree approaching the respondents expressed a range of different mixed emotions and feelings concerning their stuttering and studying. These feelings often indicated a range of apprehensions for the upcoming classed based around the challenging speech-based experiences that they had faced in the past and at times commonly still encounter day-to-day. Self-introductions and being able to adequately communicate within and outside of class with peers and academic staff were resounding apprehensions when approaching upcoming classes.

> *"I was just worried about having to do introductions and making friends. I was not worried at all about the course work. It was the first year of uni and you go there to get pissed. I was worried more about the social side than the work side. All your mates in high school know that you stutter so that is fine but new people who you meet do not know that you have a stutter. That was my main concern."* (Conrad)

> *"I was scared about not being able to say my own name and what degree I take. I have a very hard time saying "Biomedical Science". Also I was fearing that I would be mocked and treated differently. I knew beforehand the activities in my first lab involved verbal introductions and interactions with one another. So I did not turn up. The stress was too much for me to handle. I still act like this."* (Eleni)

> *"I guess the same feelings and fears that I experience in day to day life. I was not specifically worried about it. It is just hard generally. You know how hard it is. There is always an underlying sense of slight worry in some situations. I guess I just hoped that I could not reveal myself as a stutterer which I think is a thing that we all struggle with. I think I was careful to try not to reveal myself as a stutterer out of the fear that people may think less of me."* (Hasaan)

In reality, self-introductions are a commonly feared and often avoided situation for people who stutter in different settings (Crichton-Smith, 2002; Woolf, 1967) The difference is that you can sometimes strategise to avoid socially set introductions or have various speech professionally-frowned upon social strategies to deal with them. These strategies may include simply choosing not to introduce oneself in public, to having a friend to do your introduction for you and even resorting to the extent of using an alias name that you have less issues possibly stuttering upon. The first class of a given course may present some students who stutter with a very confronting challenge of worrying about embarrassing oneself in front of new peers and perhaps in turn perceiving that stuttering will make a bad impression to peers.

First class: First contact

With apprehensions and anxieties at hand the respondents delved head strong into the experiences with their first classes with mixed voices. It is not surprising at all that there was a lot of anxiety revolving around oral-based requirements and in particular fears of not being able to make friends within class. This is because commonly these are probably experiences that the students who stutter have faced in the past through other educational situations and they would have concerns about them being perpetuated through to the university setting.

> *"For me it was about making friends and we had a lot of group assignments. My fears were about working well with strangers. I looked through the assignments early to see which ones had presentation requirements. I was also worried of course about introductions to the class and individuals."* (Dave)
>
> *"There was orientation when you were meant to get around and meet people. You were also encouraged to join campus clubs and organisations. I was very fortunate that through a group at uni I ran into a person that I vaguely knew in year 12 and I just sort of latched onto him. That enabled me to get around the social part of it."* (Stuart)

Impacting further upon the need to both function well as a student and make good social impressions with fellow students, there were the common strong fears associated with class-based introductions. Fears often brought in from wider past social interactions. Even for myself as a very confident speaker who is a shameless overt stutterer, I still do notice the apprehensive and shocked reactions at times from people at the meeting table who see me stutter and block through an introduction session. For even for myself the situation is consistently a challenging one without any obvious anxieties or worries revolving around speaking socially. Challenging in the sense that it is always unpredictable how fluent I will be. It continues to puzzle me to which factors conscious and unconscious influence the severity levels of my stuttering. In fact the unpredictable nature of my stuttering I think at times confuses people I work with when they see me at times talk fluently and at other times with obvious struggling.

> *"I had an increased heart rate. I was sweaty. I was very anxious because I knew that I had to say my name and introduce myself to people. People are always nervous for their first class but I think it is exacerbated because I do have troubles saying my name."* (Lauren)

> *"Again my main problem was introducing myself. I felt a lot of anxiety because I knew that a lot of tutors made you introduce yourself during the first class and give a little talk about yourself. That was the hardest moment for me. I did not want to start the degree off to a bad start and worried a little about what others may think."* (Mary)

This fear of talking to others wove itself firmly into the more personal and intimate nature of tutorial classes. During a lecture a student can often refrain from asking or answering questions out loud and in front of others. But this is a more difficult situation to strategise for when confronted with the more intimate settings associated with tutorial sessions. Sessions for which in some discipline areas can very interactive and conversational in form making it very difficult in general to avoid speaking aloud with others.

> *"It would be speaking in tutorials and also when you need to give presentations to the class and that sort of thing. One of the subjects I am enrolled in for next year in fact, one of the main assessment tasks is a presentation to the class. The weighting of that assessment task is 40% of the total mark so I will need to negotiate that with the course coordinator and see what can be worked out."* (James)

It was found that there was a link between the approachable natures of a lecturer to the encouragement of more open participation by SWS. At least in my experience this is true for most students who stutter or not. If you ware an approachable, inviting and encouraging lecturer, then usually wider class participation follows.

> *"I was the one who never asked the questions that came into my mind. It depended subject wise. With some teachers I had more confidence than with others. In those classes I could participate more. Whereas in some classes I would just not speak. I was scared of the teacher. Like in my business law class I would often answer questions, but not as much as I would have liked to. I had lots of answers and lots of questions that I would have liked to share"* (Malcolm)

On a positive note there was no indication that students who stutter were regularly choosing to miss tutorial classes due to the continual interactive nature of class design.

Classroom impact

Once within class respondents commonly expressed strategies of vocal avoidance in a range of forms. These strategies ranged from intentionally missing assessment tasks involving talking through, to simply avoiding verbal participation. Strategically avoiding assessments involving oral interactions and/or team work, even though disability services assistance was available, would have had negative results upon both achieved grades and personal satisfaction. These strategic choices are not those that you wish to associate with a student in need. In fact the findings are of real concern to myself on many different levels. I do not like the thought of a fellow student who stutters making such decisions that would so clearly impact their overall degree results. Results that would have to be unsatisfying from a personal level and could have impact impeding the selection into further studies including Honours degrees through to post-graduate degrees. In the cases of these higher degrees, often a student's grade point average (GPA) from their past studies is taken into consideration when making enrolment selections and resulting offers of enrolment. In the cases of a students who stutter it appears that is some cases their strategic decisions to avoid or not ask for assistance with assessments would have had direct overall impact upon their final results and resulting GPA.

> *"In my first year I failed like 3 subjects simply because one of the major components of each was a class presentation. Giving an oral presentation and I just did not show up. The presentations were mandatory components and I just failed the whole course."* (Tim)

> *"A very large impact. I find it difficult working in team-based activities as I cannot communicate. I think the other students just think I am lazy. As for oral presentations I either skip them or have someone else help me."* (Eleni)

> *"One time last year, which was probably the lowest point in my speech, I missed a class. This was the first and only time at uni that I had intentionally*

> *missed a class because a word in the title of my topic was a very difficult one to say."* (Hasaan)

Tim's response above is so alarming in the fact that he admitted to failing three complete subjects of a degree due to the avoidances of a major assessment tasks involving an oral presentation. Again this begs the question about how to make disability services more accessible as an option for students who stutter. In Tim's case there would be direct repercussions on the amount of time it would have taken to complete his overall degree and also subsequent length it would take him in the future to pay off his probable student fees debt to the Australian government, let alone the impact upon his personal feelings of self-worth as a student. Following on in the study it was often found that respondents felt frustratingly silenced by their decisions not to be fully interactive within classes. Frustrations often reflected anecdotally by many people who stutter when wishing to interact more socially, professionally and educationally. But frustrations which at times could be managed to some degree with support.

> *"It stopped me speaking in class unless absolutely necessary. It stopped me from engaging in that aspect of tutorials."* (James)
>
> *"Well I was never going to ask a question. I was never going to volunteer information. That had improved later after I started working and I became a lot more open about asking questions and participating."* (Stuart)

Nigel though below, broke the mould of being silent in class and mustered the courage to speak up more, but only to perceivably having his self-esteem damaged as a result. In case of Nigel, more than just his self-esteem was damaged, his whole future confidence in being able to speak up and interact in class was in his own words "destroyed". Fractured confidence because he thought that the first impressions his peers would have of him interacting would have been negative ones. A fear commonly reflected throughout this study.

> *"I would never participate at all in class discussion. I would always keep my head down. Although on the one occasion that I did actually have the courage to participate I was in a tutorial and I was the only person in the*

> *class who knew the answer and I was confident that I could say it without stuttering. Unfortunately the tutor who was taking the class asked my name so I stuttered there and I have never forgotten that occasion. Thinking back at it now it is surreal. That destroyed my confidence so much because after that I was terrified that it would happen again. That is also why I avoid making phone calls at all costs because I know that with almost all phone calls you make you have to identify yourself and the first impression a person will get will be gauged on how you say your name. I am terrified of making phone calls."* (Nigel)

Adding to the general impact of not participating as fully as they had wished, which in turn impacts overall results, is the fact some students who stutter may have not even contested their grades when perhaps there were cases to do so. Again a true impact on personal satisfaction level and academically speaking their overall GPA.

> **"***At one point they gave me wrong grades and I knew from my marks that I had passes. I called up my teachers and certain staff departments so they could add those marks. I found that quite hard. I almost gave up and thought that marks do not matter. But then I thought there is a difference between 50 and 77 so I had to call and I stuttered badly."* (Malcolm)

Now that some of the experiences of students who stutter are understood from the views of class interactions it was pivotal to know more about their interactions with lecturing staff.

Communicating with lecturers

Once it has been established that students who stutter are strategically and openly avoiding class-based interactions at the detriment of their overall results and self-esteem it was important to try to understand some of their interactions with lecturers. A commonly known area of concern which can negatively impact the relationship between a student who stutters and their lecturer (Pertijs, 2009). A common strategy expressed by students who stutter when gaining assistance was that of personally approaching the lecturer for guidance, clarification and support after the class had finished and in a one-to-one fashion as opposed to out aloud in front of peers. Quite a logical tactic considering that students who stutter commonly do not want to ask questions within class for fear or peer-rejection. Quite a logical tactic that I would suggest to most students in need of stronger clarification of taught concepts, but an interesting option for students who stutter. Not a single respondent mentioned communicating with lecturers using non-verbal means such as an email or perhaps a forum posting within a learning management system which are commonly used to facilitate class-based conversations out of class-hours. Options which I would have thought would be more accessible and convenient to students who stutter.

> *"Maybe at times. I never really asked many questions during lectures. I would never call out during the lecture like other people would. I would normally save my questions until afterwards and talk to the lecturers after class or at their offices. I was not restricted that much and only really during the lecture itself."* (Cameron)
>
> *"Yes during classes and during lectures when there were a lot of people around. I found that I could talk to them one-on-one a lot easier. There were some lecturers who either I did not want to talk to privately if did not need to. The ones I did feel comfortable speaking with I would approach after class or in their offices."* (Dave)
>
> *"I guess during a lecture I wouldn't but if I had an important question I would always go down and ask them a question one-on-one. I would just go down to them after the lecture and speak to them then."* (Hasaan)

James below on the other hand expressed that he would approach his lecturers, but only if no other way was at hand. Again it is an interesting approach that has been employed by avoiding non-verbal forms such as email for example. In actuality only as a last resort would James approach his lecturer for the means of finding assistance.

> *"Yes. If it were a situation in which I felt that I had to speak to them then you do not really have a choice. Sometimes I would not approach them and I would think that I would go home and check if the information I need is on the website. My stutter has that sort of effect. If it is a situation where I need the information straight away and the only way I can get it is to verbally ask them then I will do that. However I would exhaust every other avenue before I went to ask."* (James)

Alarmingly at least one student who stutters, Malcolm, expressed the self-defeating attitude of not wanting to communicate to his lectures no matter what the reason and at the detriment of his results. In this case the rationale for not seeking assistance seems aligned to the skills that Malcolm perceived that were relevant to his future career and whether or not the lecturer would be inclined to accommodate his needs.

> *"Yes many times. Before giving presentations I thought about mentioning to lecturers that I have a stuttering problem but I didn't. That is why I think I only used to get passing marks. I would either stutter or I would look down and read from the paper. I would thought that they may say "What would you do if you had to give a presentation at work".* (Malcolm)

Now that we understand that there is a pattern in which some student who stutters in avoiding lecturer contact in terms of direct assistance unless required, it was important to gain an understanding of how they felt that stuttering impacted their grade achievements.

Impact on results

Continuing on this journey of strategic decision-making for student who stutters it has been found in this study that very few of them are seeking assistance for their stuttering in a number of ways and they openly know that it has an impact on their overall results. But how impactful actually are these decisions on their assessed grades and overall course/degree results? Whether or not their stuttering had impacted their overall academic results the respondents expressed no clear strong line of response and were very mixed in views. For some expressed that their stuttering had minimal impacts on their results. Admittedly, their responses focused on the results of courses and assessments not requiring oral inclusion.

> *"I think minimal because I guess the only area where it may have had an impact are my oral exams. But I think I have done pretty good in those. Again I would say minimal."* (Hasaan)
>
> *"Amazingly, very little impact. That's got a lot to do with some of the courses that I did where the main assessments were not oral presentations and were mainly exams and written assessments. But even in the courses that did require oral presentation I amazingly did very well."* (Nigel)

So at least for Hasaan and Nigel the impact on their course results appear minimal. But having said that both did admit impact, even though minor, when oral assessments were required. Stuart on the other hand was more impacted and very upfront about the fact that his avoidance behaviours had challenged and impacted his overall results and academic outcomes.

> **“***I reckon that because of my reluctance to engage in class and tutorials, to ask questions and to gain clarification or to even challenge a mark that I may have received on an assignment. Even in the technical courses every once in a while there would be an oral exam which was always a complete and utter disaster for me. I think that my stuttering has had a reasonable impact on the marks that I have been getting.”* (Stuart)

At this point in this study it is clear that this is an area worthy of further study in order to understand so much more about the impact of stuttering upon the grades of student who stutters. This study has only found out some light insights to this area with little expansion upon the question being given by respondents. Perhaps the lack of narrative expansion to this question tells us something about the true impact and feelings involved with this question. For experience now tells me that how a student perceives they are succeeding at university and the reality of their circumstances often do not align. I can attest to this as having chaired my school’s Academic Performance Committee for four years and I have sat through many cases of students facing possible exclusion from my university. I think at times shame and regret has prevented some respondents from being more open about their results and academic performances. For as stated earlier a large majority of students who stutter have admitted in this study that their speech had impacted there overall results. I am proud that at least in this study alone apart from many social media-based conversations that at least some students who stutter have been given the chance to formally give us all an insight into how much impact stuttering can have on university studies.

Lecturer awareness of your stuttering

With the knowledge that very few students who stutter were seeking provision and indeed also being open to lecturers knowing about their stuttering, this study sought to enquire about in what ways they thought their lecturers were made aware of, if at all, about their stuttering. Not surprisingly upfront disclosure to a lecturer about their stuttering was a very rare act.

> *"I mentioned it to one of them when we were going out to a field trip. It happened as a result of her commenting about the large amount of input that I was having giving to the class and I mentioned then that I am a stutterer who uses techniques and likes to practise."* (Arthur)

But for the most part students who stutter were happy to let their lecturers find out about their stuttering naturally through usual day-to-day class interactions and observations. But having said that the study has also indicated that students who stutter are commonly hiding from speaking situations, so we do not know how easily lecturers are indeed finding about their presence in their classes. So clever are some people who stutter in terms of covert strategies that it would not be uncommon to simply think a student is socially shy or reserved as opposed to having a speech impairment.

> *"I am pretty sure most of them would not know. I have never spoken to any of them about it. I do not think most of them would have found out because I am very covert. During my Honours project research proposal at and every lab meeting I think they would have known but during undergrad I do not think so. I was a good covert"* (Cameron)
>
> *"They found about it by hearing me stutter in class. I guess it is the normal reaction that you get when someone hears you stutter for the first time. You get to see various emotions cross their face. Probably shock and a certain amount of sympathy as you struggle on. Just what I consider the usual reactions."* (James)
>
> *"I think it was fairly obvious to them as I spoke. I think they realised without making it an issue. I have been very lucky that I have seemed to have always had very supportive and understanding lecturers."* (Mary)

Some students who stutter thought that they were forced to disclose their stuttering during their degree due to circumstances tied to requirements to passing assessment requirements within their degrees or due to worries about future implications on their studies and careers.

> *“Well in my first two years I did not really tell anyone that I had a stutter. But I guess in third year being on placement I did disclose to quite a few of the supervisors that fact that I had a stutter. They were quite supportive. One of them said not to worry and they would give me more time to answer questions.”* (Hasaan)
>
> *“I think all of them picked it up. I think it was quite obvious when I was talking to them. I never really spoke to them about it during my undergraduate degree because there were really no relationships there. During my current degree I have bought it up with a lecturer because I was worried about my future career.”* (Lauren)

You can read that Hasaan and Lauren both opened up about their stuttering to some of their lecturers and supervisors only because they were forced to due to the upcoming requirements of their degrees. So seemingly able to navigate most of their degree without disclosure at least in these cases both of these students who stutter seemed obliged to open up about their vocal challenges eventually.

Peer awareness of your stuttering

Once established how students who stutter were opening up to lecturers, I wanted to know about how their peers found out about their stuttering and the associated personal reactions involved. When asked “How did your fellow students find out about your stuttering and what were their reactions?” most people were quite open in stating that they felt that the general reactions from their fellow students reflected what were perceived to be reactions they would normally face socially day-to-day.

> *“Well if they did it was because I stuttered and that would have been obvious. I do not remember any negative reactions at all.”* (Cameron)
>
> *“The ones which were close to me did and I think that was because they spent a lot of time with me. I did tell the ones that I became friends with that I did have a stutter. Some of them seemed surprised maybe because I am a covert stutterer. Other than that I did not notice anything out of the ordinary.”* (Dave)

> *"Through hearing my speech either in class or when they met me outside class. Their reactions were like every other section of society there is a broad spectrum of reactions, some of whom are more tolerant and sympathetic. There are always people who smirk at you and try to use it to make you inferior I suppose. There will be people who are generally unwilling to engage in conversation or share views with people who stutter."* (James)

So here lies a very interesting line of enquiry of which I have never thought of before. If the peer reactions for some students who stutter were in fact mirrored to that of what they would encounter commonly socially, then it basically makes sense that they themselves would reflect the same levels of social anxieties and avoidances back to their educational situations. But then again is the students who stutter were confidentially sure of what the reactions would be to their stuttering from their classmates then surely it would make class-based interactions more comfortable for them.

Class interactions

So now that we know that stuttering was impacting the results overall for students who stutter and that they were avoiding class participating to the best of their abilities academically speaking, more was required to understand about the impact of their stuttering during class interactions. For this question surprisingly there was sparse narrative expansion concerning the answer. A result mirrored similar in nature to the early impact question revolving around stuttering impact upon grades. The results narratively were expressed only two respondents indicating impact, but in these cases not severe. But we know from an earlier question that most students who stutter agreed that their stuttering was impacting their overall results and resulting satisfaction levels.

> *"Whilst the stutter did impact at times on verbal presentations, the bulk of my study was based on written work."* (Respondent 75)
>
> *"It has had a slight negative impact at times but I am still successful and happy with my results."* (Respondent 86)

Very interestingly one respondent hinted at the impact being negative beyond the classroom and into their future career path.

> *"I believe that my career path and career choices have been adversely affected by stuttering, but not my general academic performance as such."* (Respondent 54)

To exacerbate the amount of negative impact caused by stuttering on academic results a large amount of respondents indicating that they had purposely avoided class-based tasks and oral assessments that required speaking to a peer audience. Not a surprising result though, but considering many of these respondents would have went through some form of program for fluency shaping and speech management either before enrolling a university or during, you could have presumed a lower figure. For stuttering therapies and treatments commonly teach a person who stutters not to avoid feared speaking circumstance and in fact to challenge their speech and confidence in such scenarios. One respondent continued the feelings of unsatisfied outcomes and indicated that speaking avoidance during their studies was at the cost to their resulting grades and to their future career skills.

> *"Looking back, I realize that I did not participate to the extent I would have liked. I avoided assessments which involved speaking, which in one case resulted in a zero mark for that particular assessment. Also did not use my time at Uni to make contacts, which would have helped me in my career."* (Respondent 43)

Another respondent expressed how the variable nature of the severity of their stuttering condition caused also impacted their confidence levels concerning their levels of participation. Even I at times, have some days and moments where I prefer to sit back and listen instead of being a fully active participant. But for me that decision is not tied to my stuttering, more so my underlying personality. I will also admit that I am slowly learning in committee meetings the strategy of picking the battles that are the most beneficial to fight as opposed to those in which you can be more passive within.

> *"Sometimes I do not speak up in class or in meetings (in front of bigger or unknown groups). Most of the time I am okay to talk though."* (Respondent 91)

One respondent indicated that they did not avoid speaking situations, but were limited in their capabilities to do so. In this case perhaps it was easier to read a set script of rehearsed and controlled words instead of speaking more adlib. A strategy though which I teach all students who have public speaking fears to start off with to assist with their presentation preparation and confidence levels.

> *"There were so many presentations which i could have done better with the knowledge I had rather than reading from a paper."* (Respondent 99)

Again, it was not a shock to me at all that most respondents did not verbally participate in all class-based activities. This is perhaps not surprising as you may expect people who stutter to stereotypically and naturally shy away from social verbal participation. Although at least one student reflected that they wished to participate and was frustrated by their lack of ability to do so.

> *"I always tried to participate where possible and genuinely wished I was able to give oral presentations."* (Respondent 21)

Encouragingly one student fully embraced the opportunity to talk and lead the class. Seemingly boosting their confidence by volunteering to lead the class and step outside of their regular speaking comfort zone.

> *"On one lecture I attended the lecturer asked if someone would like to take the class. I looked around thinking somebody would, so I volunteered. Best thing I ever did."* (Respondent 08)

Yet other students who stutter were fully aware and making continual conscious efforts to avoid class-based speaking situations. This seemed to strategically impact course choice decisions and be very frustrating for the student.

> *"I purposely have chosen subjects that require no speaking."* (Respondent 28)

> **“..***last year for one of my subjects, the tutorial consisted of us mainly talking about environmental issues. Now I have a lot of passion for the topic, but I just couldn't talk obviously. On the first day of the tutorial the activity was to get to know the person next to you and briefly report your findings verbally to the class. I found out about this activity earlier on and remained absent that day. Any group work that involves orally speaking, I always make sure I take on a small part."* (Respondent 66)

> *“Of course I do. It is a coping mechanism. Not to say that it is right!”* (Respondent 87)

For some the decision not to participate seemed to hinge a lot on the anxiety and fear associated the perceived negative feedback. Conditions of which I know are manageable with the right professional support and guidance.

> *“There were times I wanted to say things and I knew the answer but I didn't say anything due to the petrified fear that I felt all inside me with my heart pumping.”* (Respondent 33)

> *“I have always wanted to participate in class discussions and presentations but was always too anxious and self-conscious to do so.”* (Respondent 37)

But, it was become very apparent in this study that the ability to not participate to the extent that was satisfying was a real blight on the university experiences of students who stutter. There were frustrations continually evolving around the hampering of self-expression, wishing to interact with peers more and the desire to show more outward passion for their discipline areas. Although this is not a general set of experiences that I share with the cohort, I have dealt with students myself who have been frustrated with their introverted personalities causing them to appear shy in class and at times not interact outwardly very strong with their fellow students.

> *“There were situations in class where I had a question, idea, or answer, but the thought of stuttering delayed my vocal participation in class and especially in lecture theatres and the moment would past by. Other than those voluntary participation which I missed out on, i fully participated in verbal assessments and where i was expected to such as subjects that marks based on class participations. I find that the classroom environment easier and more conducive for verbal participation as it is.”* (Respondent 64)

> *“..last year for one of my subjects, the tutorial consisted of us mainly talking about environmental issues. Now I have a lot of passion for the topic, but I just couldn't talk obviously. On the first day of the tutorial the activity was to get to know the person next to you and briefly report your findings verbally to the class. I found out about this activity earlier on and remained absent that day. Any group work that involves orally speaking, I always make sure I take on a small part.”* (Respondent 66)

Although at least one participated but was not overly satisfied with their class efforts even though they did attempt interactions.

> *“I did engage in tutorials, projects, etc. But due to the stutter, there were times when I may not have engaged as much.”* (Respondent 75)

With hesitant confidence one student made the tutor aware of their stuttering to avoid it impacting their potential marks. But this could have been more manageable and less stressful for them if they had of asked Disability Services to assist and form an action plan to implement when the need existed.

> *“Sometimes I did tell the lecturer before a speaking assessment that I had a stutter so they knew and didn't mark me down for sounding uncertain or unaware of the subject matter. In hindsight it was probably naive of me to assume I was fooling people about my stutter!”* (Respondent 34)

One respondent felt they had been let to pass an oral assessment due to pity from the lecturer. But this is an action impossible to quantify and is only the perception of the respondent.

> *“Once got through an oral exam because the examiner was obviously embarrassed by my stutter."* (Respondent 77)

I remember once I had stuttered my way through one of my Honours presentations. The amount of stuttering I showed was very severe with hard block motions on almost every word throughout the 20 minute talk. It was to my surprise that I achieved almost perfect marks for the presentation and in fact a student peer was the one who questioned the result. My peer felt that I had received “pity marks” due to my stuttering and not due to the content of my actual presentation. The marker responded to myself that I had easily met all the criteria and that they were more focused on the message of the presentation as opposed to the method. In this case the fact that the presentations were graded by more than one marker and then the combined resulting grades were moderated gave me more confidence that I was not simply handed strong grades.

Strategic stuttering?

A focus of interest to this study was to enquire if any students who stutter had used the excuse of their stuttering to gain an unwarranted and negotiated way to avoid an assessment task. I can tell you that from my own personal experiences dealing with students with special needs that some have confessed to me that they use their conditions as crutches from time to time to try to achieve stronger grades without having to do so much work as other students to gain them. Up to this point in this study many of the responding students who stutter have portrayed stories of speaking avoidance and frustration. But perhaps I thought there may in fact be some students who stutter who may leverage their perceived disadvantage actually as an advantage. Almost half of the respondents agreed to some extent that they have never used their stuttering as a way of avoiding an assessment task. Interestingly though, one third did not commit a firm response and a small amount disagreed. This is perhaps an interesting finding in regards to strategic involvement in classes and assessment tasks. Perhaps there is a small amount of students who stutter who use their stuttering at times an avoidance excuse? Actually I do not doubt and is an attitude reflected by the following respondent.

> **“***If you have got it why not flaunt it or use it to your advantage?” (*Respondent 12)

But if there are students who stutter who are purposely using their stuttering as a way of avoiding assessment tasks in a way it is somewhat logical to myself. It makes logical sense that a students who stutter who is looking for a way to avoid speaking out aloud in class and has the ability to do so without impacting their final results, will at times do so. At times it would in fact be seen as a smart strategical move to help ensure better assessment outcomes and related grades. However you would like to think that the students who stutter would be using their associated disability liaison units to help facilitate this provision and in turn better inform the provision of assistance into the future. But this study indicates that this is not so and that students who stutter generally continue to ignore the formal disability liaison unit line of assistance and self-manage their own educational journeys.

Continuing the line of enquiry concerning the strategic use of stuttering, I sought to know if any of the respondents had purposely used their stuttering as a way of getting an easier road through an entire subject. For we do know that at least some students who stutter purposely use their stuttering as a way of avoiding speaking tasks. Encouragingly mirroring the response rate from the previous question close to half of the respondents agreed to some extent that they had never purposely used their stuttering as a way of getting an easier road through a subject. Interestingly again though nearly one third, were non-committal with their answer and a small percentage agreed that they did indeed use their stuttering as an advantage.

As expected some respondents were loudly against such a strategy though.

> *"The thought never crossed my mind to use my stutter as a way to get out of certain assessments, as that would have meant admitting I had a problem, and suffering the embarrassment (or so I imagined) that would go along with that. Even though I always received very high grades, I still believe it impacted upon my academic potential, if not my academic performance."* (Respondent 15)
>
> *"I don't recall using my stutter as an excuse to get out of any academic related activity. It didn't occur to me to try!"* (Respondent 16)

Perhaps this question is also alluding to the fact that perhaps a small minority of people who stutter are strategic in nature to use their stuttering as an advantage throughout other forms of life interactions and activities. I have to admit that at times in meetings I purposely give a meek impression of speaking confidence levels through seemingly introverted body language in order to lull people into a false impression that I will be a push-over during some negotiations. But then when it comes time to present and fight my opinions I often shock people who do not personally know me with a sudden broad chest and confident stuttered voice. Interesting to note though is the large amount of respondents who were non-committal in their answers to these two questions. Does this actually indicate that there are a set of students who stutter who are unclear themselves about how much their stuttering is truly impacting their studies and how much they may be actually using it as a light excuse at times to get an easier road through their classes. Now that we have learnt a lot about the general strategic class-based interactions and experiences of students who stutter it is important to look at some broader issues that may be influencing their behaviours.

Stuttering impact

It has now been established that for the majority of students studied that their speech problems had clearly affected their university experiences, grades and interaction levels. It was of interest to this study then to tease out even more about the overall perceived impact of stuttering on the overall university journey of students who stutter. A novel starting point was to ask all students if they thought that disability services staff at their chosen university needed more education around stuttering. It was interesting to see that 83 of the 102 survey respondents believed that disability services staff should have more knowledge about stuttering. Keep in mind though that only 14 respondents in total had had direct contact with disability services staff. The majority of these 14 students answered earlier that they did not at least find DSOs very knowledgeable about stuttering. But the other 88 students who never asked for assistance were making an assumption with their answers based upon their own perceptions of DSO knowledge. Or were their line of thoughts based upon their perception in general that society itself needs to be more knowledgeable about stuttering?

Some respondents were very clear with their opinions that disability services staff should be more knowledgeable and possess a more holistic view of stuttering beyond the mechanics of speech alone.

> *"I don't think that stuttering has ever been perceived as a true disability, when it is. Therefore, more understanding of this matter is certainly needed, especially the impacts it had upon a student's social and academic life, as well as the impacts it might have upon their future."* (Respondent 15)
>
> *"They should be aware that stuttering can be incredibly debilitating to people. However the last thing a stutterer wants to hear is that he/she is different. It has been shown that stuttering could stem from parents pointing out disfluencies in children while they are learning to speak, and that this pointing out inhibits the child from wanting to speak thus leading to stuttering in later. stuttering really is the process of 'holding back."* (Respondent 32)

It was also mentioned that perhaps disability services need to advertise more clearly and precisely that stuttering falls under their services. This is an ideal that I Have explored earlier within this study. Having stuttering clearly promoted by a university as being a disability may in turn may encourage more students who stutter to access support services. It is untenable though to think that DSOs could tailor their advertising to mention every single condition that would be classed as a disability In fact I believe it would be more constructive advertising what the definition of disability is that they are using as a criteria to enable the provision of assistance and making that definition in turn more accessible.

> *"I think staff of such services would need to be forthcoming in advertising their knowledge, understanding and acceptance of stuttering. It seems that most untreated stutterers would not be forward in asking for help due to feelings of shame, embarrassment and guilt."* (Respondent 61)

Of course those who perhaps strongly identified with stuttering not being classed as a disability would not even entertain the idea of asking DSOs for help. These findings keep pointing to the promotion of the true meaning of disability to students who stutter and the wider student population. For if students who stutter are deterred to access support services due the term "disability", then surely students with other conditions are also. But I also think that some students who stutter may have to be less stubborn and closed minded in terms of accessing support provision. Having said that, I also believe that people in stutter generally have to support stuttering openly being framed as a disability whether they are personally disabled by it or not.

> *“My issue here is that I would not have gone to disability services, they would have needed to have called themselves something else.”* (Respondent 54)
>
> *“I feel that the use of the term "disability" is a problem, and a disincentive to register as a "disabled" student. Perhaps the university's website should mention that people with speaking/listening issues should register. My current university does this.”* (Respondent 92)

An interesting strategy that was suggested throughout some responses was that of university campuses having speech pathologists at hand or at least directly contactable.

> *“It would certainly make me feel more comfortable if the university had at least a speech therapist available somewhere. They provide general counsellors for all students - but I understand that a university cannot take on 1 speech therapist when I may be one of 5 stutterers in the entire university. I am sure, and hoping, that the staff would be understanding of stutterers and not force them to take part in oral examinations.”* (Respondent 66)

This makes sense for the universities which lecture or research in the area of speech pathology, but would be very difficult to justify and service such an ideal across all other Australian universities. Perhaps a solution could be that at least DSOs could have closer contacts with speech pathologists within their local areas perhaps to see advice from or suggest student referrals to for consultations.

So let’s locate ourselves back into the general findings of this study so far. We know that students who stutter are open that they are sacrificing results and the full student experience at the expense of avoiding speaking. Now in this study I wanted to gain some general feeling of how much of an impact these choices have actually been for the student. It is alarming that a very large number of survey respondents, 94 (92%), agreed to an extent that their stutter had hindered their academic life. This though does not give us a strong understanding of what sort of hindrances they face. But based upon previously explored results we can assume quickly that their grades, self-esteem, social interactions and personal satisfaction levels had been generally hindered to various levels. Luckily, some respondents opened up about this but more needs to be known and is a direction of future studies.

One of the main problems associated with university study that arose seemed to revolve around voluntary participation and this was a set of feelings not expressed well earlier within this study. It is obvious actually that a student who stutters may not want to voluntarily participate in verbal class-based tasks, but at what cost?

> ***“****There were times when I did not contribute as much in tutorials etc, if my speech was problematic.”* (Respondent 75)
>
> ***“****I have 90+ average, so my ability was never questions. I didn’t ask many questions in class as the content was not challenging. But my stutter did interrupt my involvement in class based activities....(although my social life was very active and my stutter didn’t affect it at all)”* (Respondent 83)

The challenge now lays around how to encourage students who stutter to seek support and/or to gain the confidence in able to be more active contributors to class and in turn feel more satisfied with their academic journey. This is becoming one of the major outcomes from this study.

To understand the impact that stuttering in general may have upon this cohort of students who stutter, I plainly asked respondents if stuttering had impacted their results as opposed to their overall university experience in general. It is of no shock then that a large number, 76 (75%), agreed to some extent that their stuttering has had a negative impact on their academic results. Again not surprising in regards to the expected avoidances and strategies revolving around non-participation that I have found throughout this study as they exist within the literature (Azios, 2017). But this result further indicates that students who stutter need to be encouraged more to access support.

Interestingly, one student who appears to have been very successful, yet still felt that they could have achieved even more if it was not for their stuttering.

> *"My good university results/achievements have been in spite of my stutter. It hasn't severely held me back, but I could have achieved more and experienced more than I have."* (Respondent 36)

Yet, Respondent 36 did not seek support assistance. Another respondent felt somewhat supported at university, but not so with their experiences in the workplace.

> *"I think in general people gave me extra points for performing with a stutter rather than avoiding things - so in that respect people may think me smarter. I had a lot more trouble in the workplace with my stutter than at school and university. People generally supported me if they see me giving it a go, despite my difficulties."* (Respondent 34)

To round off trying to understand more about the overall impact of stuttering on the individual, it was important to gauge some feelings around students who stutter perceptions of what they felt their peers and lecturers perceived about their academic abilities. A large percentage of respondents, (80%, 82), believe that their lecturers under-estimate their academic ability because of their stuttering. This is a very strong and interesting perception, and a perception perhaps influenced by their general feelings around how the wider world may view them. But most likely due to interactions and feedback, verbal and non-verbal, perceived from their lecturers. Only one respondent though opened up at all about this and there was unsureness in their response.

> *"Could have been occasions. I think this could have been the case in some situations. As I have stated earlier, there were times when I could be quiet in tutorials and I would try to avoid giving verbal presentations as much as I could. There were times when I did feel that particular lecturers, and tutorial supervisors, doubted my abilities. I hope, though, that as my written work came through, they may have changed their perceptions of my academic abilities."* (Respondent 75)

Now that some understanding was evident around students who stutter, perceptions of their lecturer's opinion of the impact if their stuttering upon their academic ability it was important to understand what perceptions they have felt of their academic ability from their fellow students. Encouragingly, 69 (68%), do not believe that their fellow students have under-estimated their academic abilities because of their stuttering. This is almost the opposite finding to the previous question with academic staff in mind. Interestingly some of those who did feel underestimated were very vocal in their explanations.

> ***"****People do not understand stuttering and they think you are either shy or stupid, when stuttering doesn't have any influence on your intelligence, only your ability to communicate your thoughts and ideas."* (Respondent 33)
>
> ***"****I believe that stutterers are stereotyped as being dumb, stupid and nervous. Despite my strong marks, I believe that these negative connotations influence people's perception of me."* (Respondent 91)

But one respondent alluded to the fact that once the others got to know you as a direct contact then their opinions may have changed.

> ***"****Some students may have underestimated me, but the people with whom I was engaged in projects with, did not."* (Respondent 75)

Now that you have been led through the general findings of the survey and interview respondents in terms of the university journey of students who stutter, the next chapter will in a unique way frame the general themes that I wish to focus on from the responses.

Chapter 09: Thematic discussions

As described earlier in this thesis, through the use of applied thematic analysis I was able to formulate five sub-themes running within the participant narratives.

The five sub-themes that I have formulated are:

1. The assumed absence of institutional support to accommodate stuttering concerns while studying at university;
2. The unwillingness in general to align stuttering with the term “disability” in broadly and in order to access the provision of assistance;
3. The rigidity of supplied provision for a student who stutters once they have accessed university support;
4. Frustration involved with a journey through higher education which is not as fulfilled as the student who stutters would have liked; and
5. Concessional bargaining in terms of trade-offs between being prepared to avoid oral-based assessments and interactions against underperformance in all aspects of university life.

The sub-themes above are summarised in an easily digestible way, but in particular, they lend themselves to a much more engaging and interesting thematic portrayal. The students who stutter who participated in this study often attempted to disguise themselves, guarding their identities covertly behind their imaginary masks. Each sub-theme can be represented as a mask, such as used in the dance of the harlequins, in which the masquerade masks can change over time. But is their identity as covert as some students who stutter think they are, and are the resulting strategies as effective as they are made out to be? Sometimes you only can assume that those around you are unaware of the true identity that you may be shielding from their view. Sometimes you can only guess the effectiveness of your disguise and transparency of your actions. Keep in mind the following phrase as you read this chapter open your mind to the thematic dance that is to come: “*The irony of life is that those who wear masks often tell us more truths than those with open faces*.” (Lu, 2015, p. 5)

Introducing the Dance of the Harlequins

I will begin the thematic framing I will remind you of the main research question of this thesis which is *"How do students who stutter negotiate their university experiences in Australia?"* and then focus on two sub-question that are encapsulated within it in order to plant the seeds of further discussion and debate into your conscious thoughts.

The two sub-questions important to these discussions are:

"How do Australian university students who stutter describe their experience of the student lifecycle?"

How has the doctoral candidate himself, as someone who stutters, framed his identity within a university setting?"

While attempting to answer these two questions, I will intertwine discussions around this study's findings further personal anecdotes and reflections about my own stuttering story. So it is time to focus more heavily on the experiences of students who stutter during the entire span of their students lifecycles. You have read throughout the previous chapters that this study is heavily themed around the notion of "identity". For university students who stutter, this concerns their general alignments with being overtly framed as a person who stutters and to what that means deeply to their persona. This in turn leads to the associated impacts of being a person who stutters and wanting to study at and ultimately graduating from an Australian university. Identity, as you have read, has further repercussions throughout this study in terms of the supported journey of a university student who stutters, who is attempting to navigate the winding turbulent world of tertiary life and feel satisfied with the repercussive results. Indeed, how I identify myself as a person who stutters has been challenged throughout this study. For at first, as confident as I am as a speaker, you could say a professional speaker and an academic, I have experienced some deep revelations about myself as a person/student who stutters. I thought that aside from the fact that I stutter and have been/are continuing to be a university student that I would have little in common with the studied cohort. I am portrayed as one of the emerging influencers of the globally fractured stuttering pride and acceptance movements and have been invited to discuss such ideas globally (Meredith, 2015, 2016b; Meredith & Harrison, 2014). I have constantly argued stuttering as simply being a characteristic of oneself. Having such a view often puts me in direct conflict with other people who stutter who cannot align at all with a view that you can be proud of being a person who stutters. For some people who stutter, the challenging ideal for them to accept due to the outreach of global social media, is that not all people who stutter are now actively trying to eliminate it from their lives. So I have to admit that I have come into the analysis of this study initially with a very different mindset about stuttering that perhaps many other people who stutter align to or can understand.

Perhaps to add a touch of ignorance to my initial expectations of the gathered data is the fact that I have rarely professionally encountered another student who stutters at the universities that I have worked at, either as a peer or as a student of my own requiring support. I have never had to intervene with such a student or assist to strategically plan to accommodate their stuttering within their studies. I have noticed a few students who stutter from overhearing their conversations with other students as I have a very acute inbuilt “stutter radar”. But I have never approached them to introduce myself as a fellow who stutters. Why would I? I cannot assume that because they stutter they will want to know me or feel good in the fact that I approached them to say hello because of it. I have a large nose but you do not see me spending my day introducing myself to other people with big noses. So I came into this study with an almost arrogant view that, as confident as I am, I would have little in common with the participants in my study. I basically “othered” myself from aligning with the studied cohort and tried to imagine myself a pathfinder into the new knowledge that this study would present. However, as the findings emerged, I found myself at times being a mirror image of the other students who stutter as they were expressing their views and experiences. In fact, I began to feel that my own personal journey through university was nothing really out of the ordinary and close to the generalised mould of my studied cohort. Perhaps in general, I was actually just a touch more confident than some of the studied students who stutter as I did not shy away from oral participation in class. Aside from small variations in confidence, self-opinion and attitude, we were all quite similar.

Identity itself can have many faces and meanings to an individual who may change masks from time to time when the situation influences or if strategically required. Indeed a "harlequin" may change masks from different parties to festive halls to encountered party goers, ever shifting their outward identity while attempting to cloak who they really are. Unlike a clown whose true expression you can see under their forced-smiled crusty makeup, a harlequin's expression is completely hidden from view with ~~one~~ their eyes and mouth showing out from their intricate facial masks. However, identity in this study has brought with it some large implications, impediments and its own "handicaps" in relation to continuing further education in a truly satisfying manner. From being organisationally labelled as "disabled" in order to attain timely support for academic challenges, through to the acceptance of strategically led unfulfilled university experiences, yet ultimately gaining positive systematic academic successes. Throughout this constant battle with identity, there are under-currents related to how students who stutter work within the perceived rigidity of the bureaucratic university system itself governed by many policies, procedures and regulations. Running alongside rigid bureaucracy is another plight related to self-concessional bargaining. These academic journeys are peppered with decisional branches related knowingly to negative impacts on overall academic achievement.

At this stage in the discussions, I will remind the reader of the earlier positive umbrella view of the overall study's findings that you could headline such a positive tabloid story from. At a high-level view, Australian students who stutter were generally enrolling in degrees that were not influenced by their stuttering and were graduating successfully, followed by finding employment in career paths that they had studied for. What a story indeed! So I can say "job done" and walk off with my head held aloft as I high-five students who stutter from all corners of Australia. For looking back at the research question: *"What is the nature of the experience of being a student who stutters engaged within the Australian Higher Education system?"* I could swiftly say that the experiences are productive, satisfying and of little concern at all for future enquiry. Actually, the findings contradict from a high-level view, the thousands of stories I have read on social media. So should I then walk off into the sunset, hang up my spectacles of deduction and boldly yell "case closed"? No, I should not, because no case is ever that simple to crack and deep waters of enquiry may often show a shallow surface level of balanced tranquillity. For as I alluded to earlier, on a surface level this may be true, but underneath the uplifting highly marketable story of success, lay overt journeys of unsatisfied pride and negative self-esteem. As this grand party of dancing and merriment unfolds, there are hidden frowns and tears evident behind the masks of the players amongst the giggles, wine and finger food. But this is a party in which by its very nature, everyone is trying to mask their true identity and feelings.

So let us begin examining the harlequins of new found knowledge which adorn this party, keeping in mind that these costumed students are a group of individuals who have, in general, successfully engaged with, and in most parts, graduated from a university. In turn, I would assume that they are able to apply logic, research and rational thinking to problem solving, including their own. A group of tertiary educated individuals from a range of different academic disciplines who have managed paths through their chosen degrees, and surely would be less open to ignorance. As I gingerly enter the party, I see the partygoers cheerfully around the hall, some dancing, others chatting and yet all with a mask in hand supported by a stick shielding their faces from each other, and each with a range of notably different masks tucked within their belt straps. I take a deep breath and spy my first dance partner for the night, whose body language gives an appearance of slight hesitation in their dance steps and overall confidence.

The mask of Assumed Absence of Support

The many faces of identity emerging throughout this study start with the harlequin wearing the mask of “Assumed Absence of Support”. This is the first harlequin that I choose to dance with as they are very quick to look for a dance partner and they are even quicker to accept my hand. This was the one theme that struck me very during the thematic analysis as being important and long weaving. Most students who stutter reported that they did not attempt to investigate how a particular university could accommodate their stuttering before choosing to enrol. This was a surprising finding which at first did not make a lot of logical sense to me due to myself having a pre-conceived idea that this cohort would be very anxious about studying and would like to have assurance that support and academic accommodation would be at hand. Again, perhaps my thoughts were influenced a little due to my lack of wider knowledge around this topic.

But I actually believe as a result of this study that these students were not as confident or uncaring about accommodating their stuttering while at university as they may on the surface level appear. In fact I think that they were indeed apprehensive and anxious about the heavy leap into a higher education degree, which for many was not a journey straight from a secondary education. I believe that there have been other influencing factors that I will explore further in this chapter that may have led to this lack of strategic enquiry prior to enrolment and in many cased beyond. The decision to study at a university could have been a leap that for many participants was in their early to mid-twenties and in turn would have been a life altering decision often impacting their families and related support groups. It would not have at all been a choice without decisions considering current financial states, the time it would take to complete their degrees and future career options. At the core of this decision not to investigate what assistance would be available to them as a student who stutters, was the preconceived idea that based upon previous educational experiences that there would be no assistance for their speech at a university level. This has been a commonly expressed opinion all throughout this study at different points. It has been constantly mentioned in parts that no assistance had been found or offered to these students at primary or secondary school levels, so logically in their minds then no assistance would exist at a university. For some respondents, this opinion was also carried further on as they expressed that they had not had any assistance for their stuttering while employed in the workforce. So you can understand why suddenly now they would assume that there would not be assistance for their stuttering at university. This was an opinion set which rippled itself throughout this study and although not initially elicited at a pre-enrolment level, it did raise throughout further discussions in terms of disability and related assistances.

> *“Did not believe any services would be available.”* (Respondent 90)
>
> *“Again I did not at all think that the uni would have any structure in place to help me when required.”* (Respondent 93)

This is definitely a thematic problem that needs to be taken up by universities when it comes to advertising their support services in an attractive and encouraging manner. But more of that discussion will come up later in this chapter. This mask of “Assumed Absence of Support” worn by some respondents wove its way throughout this entire study from the initial point of university discovery through to the class environment.

This harlequin spins from circumstance to circumstance with the ever present pre-conceived thought that support for stuttering would not be available at all within the university system. This harlequin’s mask is a stubborn one to remove once placed over ones true identity and the wearer often was commonly refraining from further questions of enquiry. However, you will read later that it is an identity, like others, often worn in combinations. For when asked if a respondent had flagged their stuttering as a “disability” on their enrolment form, this mask was still evidently worn for some with the assumption again that no support would exist. Another mask shows its play at this point, the mask of “disability rejection”, but this mask will be explored in detail further on in this chapter as it is an impactful identity to wear and has results-impacting repercussions. But waltzing back to the wearer of the mask of “Assumed Absence of Support” I see a deep reflection of self in the wearer’s eyes. I can clearly identify with this harlequin for I also did not seek to find out what assistance my chosen university could offer pre to my enrolment, just for different reasons. As mentioned earlier in this study, I had never received support for my stuttering during my primary or secondary years and only once was it suggested. I was offered some assistance from my secondary college towards the final weeks of the final year of my education. I saw this as a token gesture and, to be honest, tactically too late in my education to be of any use. I did not see the need personally to work on my stuttering and I have to admit that it was also a matter of pride. I was a very confident student and at that point in my life the simple act of a teacher making such a suggestion felt in part like an insult and made me question myself. Why did the teacher suddenly offer me assistance? Was my stuttering actually an issue? It was slightly confusing why the offer was made at that point in time and I politely declined. Having said that, my situation through my primary and secondary school years was supported by the fact that for most of those years I was with the exact same students who I had been with since grade one through to year 12. In a small country town, most people know each other and throughout those school years most of us kids had grown up together forming very tight bonds and acceptance of each other.

Like some of the respondents indicated, I also had not been offered help for my stuttering while employed in any industry. This for me was an attitude that I reflected during my under-graduate university years. I simply did not see a need for assistance for my personal circumstances because my stuttered speech was not affecting my academic journey in any negative fashion. I am a little reserved at times by the very nature of who I am, not due to my stuttering. Out of interest, I did enquire once with my university’s disability liaison unit about what assistance would be at my disposal if asked for. I was thinking strategically at the time, as I often do, and I wanted to understand what processes were in place if and when required. But this is a journey that I will discuss later in dances with the other harlequins of identity to come.

The mask of “Assumed Absence of Support” boldly rejected the flagging of being “disabled” at the point of enrolment partially in part due to its presumptions, but this opinion weaved itself through to the classroom with strong negative repercussions as you will understand later. These repercussions have an effect on the student’s overall performance, grades and general satisfaction levels. In summary, for some students who stutter, the assumption that no support would be on offer for them at university meant that they did not actually access the support that was on hand, and in turn presumably did not achieve as highly or as satisfyingly as they may have had with support in place. For we have learnt that many students who stutter openly admitted that they did not achieve as highly as they could when at university, nor did they feel satisfied with their holistic journey once complete. Additionally, they did not ask their lecturers for assistance in general. This mask of “Assumed Absence of Support” I would presume has continued to be a worn option in their career paths and lives beyond university. Again perhaps leading to further lost opportunities, but that is a dance that needs to be studied more in the future. As mentioned earlier though, things are never so simply stated or examined. For there are more factors and identities at play which have interweaving influences creating often a tangled web of understanding. Now let’s swap dancing partners and look into the eyes of a very committed and steadfast harlequin. The harlequin who is wearing the mask of “Disability Rejection”. A harlequin which I can tell from its body language can be very steadfast in its opinions and beliefs. So I bid adieu to the harlequin wearing the mask of “Assumed Absence of Support”, and I get to know my new dancing partner.

The mask of Disability Rejection

Before I start this dance, I want the reader to know one finding from the survey that I have not yet shared. This finding was from a group of questions at the end of my survey that I used to enquire about some more broad impacts of stuttering upon the individual. It was of shock to me that when asked to answer their level of agreement to the question of “I often neglect my own health to save talking to a medical professional” 70% of students surveyed agreed to a certain degree that it was the case.

This finding means that there is a large group of seemingly well-educated and logically thinking people who confess that their stuttering influences their decision whether to engage with professional health care, and as a result perhaps negatively impacts their personal health to various degrees. Now keep this figure in mind as we change our dancing partners and into the waltz to come. As I leave the hands of the mask of “Assumed Absence of Support” harlequin I notice the broad strutting step of the harlequin with a face that shows a continual flow of expressions and emotions. Similar to the mask worn by Rorschach in the graphic comic “The Watchmen” it mesmerises the viewer who has troubles focusing on the actual intent of the wearer. A mask which itself resembles an ever-altering Rorschach test continually delving into the perceptions and opinions of the people looking into its gaze. This is the most decisive mask worn by respondents and reflects often deep opinions and decisions. It is the mask of “Disability Rejection” and it is firmly placed upon the face of the wearer. A true mix of wavering emotions and feelings at times expressing deep passions, through to firm opinions, through to at times blatant ignorance. This harlequin expresses a dance that has firm gaits peppered with changing dance steps sometimes at conflict with the tempo in the air.

So I begin this dance with a deep look into my own identity for I have worn this mask also. But maybe not in the same fashion or with the same motives as some of the other dancers. I have never really felt “disabled” by my stuttering throughout my life and in fact I consider myself more “able” than many other people who stutter I have met. I have not been restricted in life due to my stuttered speech patterns and nor do I feel inferior because of having it. Personally I rationally know and promote stuttering as being a disability quite loudly in social media and academic writing. I strongly promote stuttering as being a disability and that the global stuttering movement needs to align itself with the ever-growing disability movement as a whole in order to be appreciated and be taken seriously. Even though I state that stuttering is a disability that does not mean that I am, or will be, disabled by it. So while choosing not to frame myself as being disabled, I do recognise stuttering firmly fitting most accepted definitions of “disability”. I think actually my untreated, shockingly flat feet will come into play when I am much older and my knee joints are worn down more over time. This new harlequin, like all, has other masks at their disposal throughout the night and may often wear multiple masks at the one time.

When asked if these respondents had sought pre-enrolment information about how a given university could support and accommodate their stuttering, they were very loud in saying no. Saying no because, apart from some respondents simply not expecting support to exist, they firmly did not view stuttering as a disability, in turn assuming that a university would not and did not expect a university to offer specialised assistance. Also, if they did not view stuttering as a disability, why then would they seek assistance? But this is an opinion set at conflict as I analyse additional themes and their applied masks, as you will read. The discussion moves to the university enrolment form, which in most cases presumably would have had a section on it to flag yourself as being disabled, which support services use to strategically assist students and plan for the proposed numbers. Again, it seemed that the majority of respondents gave this option any attention due to the option not being relevant to them. This all makes sense because if you think stuttering is not a disability then why would you indicate it as such? But this understanding about disability and what it at least legislatively means is largely uneducated and shows a clear misunderstanding about how disability is framed (Meredith, 2010). I still believe that many people who stutter are confused around the whole issue of disability and how stuttering aligns to it preferring to other themselves from the term to avoid the associated stigma. These people need to give more thought to the notion, that clearly under different legislative and policy driven definitions of stuttering, that it can be applied as such. This does not of course mean that your own stuttering is disabling to you. But separating yourself from the definition will clearly open your eyes to the fact the stuttering can be aligned and annexed to such definitions even if not explicitly mentioned. So in this mindset at least you can accept that stuttering is a disability and can disable people who have one. I have yet to see on social media any clear and logical argument that stuttering is not a disability and the views often point to its personal affect, as opposed to its global definition.

Remembering back the Australian Human Rights Commission's statement that "*The definition of disability in the DDA includes "total or partial loss of the person's bodily or mental functions". Whatever the origins of a particular person's stuttering (neurological, psychological, or more direct physical causes), it is clear that speech is one of the things we do with our bodies and so partial loss of control of speech is covered* (Australian Human Rights Commission, 2009)." So if you apply this simple interpretation of the Australian Disability Discrimination Act then stuttering is a disability. But do these harlequins in general reflect a greater societal view of stuttering and its inconvenient nature? In turn, is this reflection a greater mirrored reflection of how society itself in general sees disability? For it seems that this harlequin has a very distinctive view that stuttering is not a disability and so there would be no support available. But this is such an ignorant perception wrapped up in an uneducated view of disability beyond those clearly visible and popularly promoted. Such are the likes of deafness, blindness and impaired mobility, all very obviously and stereotypically disabled conditions seen commonly in society and in various forms of media.

> *"It is a very difficult question because if you are going to claim that you have a disability you are lumping yourself into the same group as people who are in wheelchairs or aren't able to see."* (James)

Interviewee James clearly does not want to associate himself with what he sees as groups of people identifiably disabled, but he did not expand upon his reasoning why. How is his stuttering any less than a disability as those that he mentions? This ignorance of how disability is more holistically applied and defined is shown glaringly by the following response:

> **"***Do you see me in a Yooralla advert?"* (Respondent 09)

For the information of the reader, "Yooralla" is an Australian disability organisation which offers support services to a wide range of people while actively advocating and promoting social inclusion and empowerment. You can watch Yooralla's popular advertisement used during the 1980s at https://youtu.be/hjgWuioXQ_0 and this may give you an understanding of the framing of Respondent 9's response. Disabilities with their own powerful movements and publicity drives are commonly recognised and used in discussions. In both cases, such drive and publicity I have not seen embraced within the global stuttering movement.

I have myself experienced an interesting reflection around how disabled I feel. I have presented at a small range of disability-centred conferences in Australia and at one of the first ones I attended I had a strange out of body experience. I was there to present about assertive technologies that I was developing as part of my Technologies for Empowering People for Participation in Society (TEPPS) Programme. As I entered the conference hall, I saw a wide range of people with overt disabilities, their care assistants and other attendees. I was soon standing in an ocean of such people and for a brief moment, I stood still and tried to understand how I was to be identified amongst such people. For believe it or not but I felt a lack of identity at that point in time with these "disabled" people. I was able bodied, could see fine, hear fine and had no developmental issue that I was aware of. On the surface of things I resemble a stereotypical normal everyday person. Logically stuttering is a disability and thus I had something in common with all the people in that hall. Then I refocused and after the conference I had time to reflect and framed in my own mind what I thought disability meant to society and to myself. I think that was the point in time where I really embraced and connected stuttering with disability. A true moment of reflective awakening which has shaped me so solidly since. At the conference though, something really interesting happened which possibly lends itself to how a widespread scattering of general society may view stuttering. I was talking to some attendees about this thesis and research study. One attendee was obviously sight impaired and another mobility impaired and in a wheelchair. Once I had explained my study, both questioned me about how stuttering was a disability and how they had never thought of it as such. In fact neither had seen a person who stutters at a disability conference before. So I guess never seeing it presented as such, basically kept it out of sight and of mind. This is a problem that I have argued myself often to stuttering-based organisations concerning their plight for greater public awareness and access to funding dollars. Having said that, they clarified that they had never seen a person who stutters at a disability conference who, to their knowledge, only had stuttering as their sole disability, but rather, combined with other impairments. This furthered my thoughts about how people who stutter in general identify with the term disability and its related movements. So I stood there in a disability conference having to defend how stuttering is a disability to people with overt disabilities. Did you read this correctly? I had to somewhat defend myself at a disability conference about how stuttering is a disability. I actually felt at that moment that I was not part of the "gang" so to speak and had to somehow earn my colours. A fascinating turning point in my life both professionally and academically I must say, which caused me to re-evaluate my own identity and standing. The disturbing ignorance, intentional or not, shown at times by this encompassing harlequin in terms of how stuttering is a disability deeply impacts the life journeys of those who hold such opinion. Such opinions are tainted by the lack of a logical definition by the wearer of this mask.

For example the consistent and common reasons touted that stuttering is not a disability is because:

- It can be managed or in a sense is somewhat recoverable. Not curable, but recoverable;
- Stuttering does not stop you from doing physical things like walking, running and even talking. Even though speech patterns are involuntarily interrupted by its behaviours;
- Is not as "bad" for example being a paraplegic or deaf. Respondents often compared stuttering in terms of severity to other disabilities. Some of these disabilities actually having large pride movements did not seem to faze respondents from belittling them slightly. Perhaps another case of distancing from "disability" for the sake of pride?

These reasons raise my eyebrows and I shake my head at the sheer misunderstanding about the term "disability" and how it applies to a person who stutters. For these seemingly educated and rationally thinking students and graduates of higher education show a clear misunderstanding or perhaps pride-influenced arrogance of the meanings of disability. The term “disability” is not associated with being able to manage an annexed condition and if so, then for example, deafness would not be included because you can at least wear hearing aids to help to “manage” your hearing. Nor would paraplegia, which can be managed in some cases by the use of mobility devices. In actuality, following these respondents’ logic, then we should not refer to any known disability where “management” of it exists, as an actual disability. Unlike the perceptions of those that wear this mask, general and lifelong impedance on all life duties does not come into play with a condition as being termed a disability. Disability can be situational and fleeting depending on the condition and individual. I have felt disabled by influenza which one time left me bed-ridden for days. So it has become clear to me that the social stigmata associated with the term has come heavily into play for some respondents who clearly want to distance themselves from those who are “disabled”. Some respondents made clear statements that stuttering “is not that bad” compared to well-known disabilities and so it should not be classed as such. Again, an opinion tainted with general ignorance and misconception. In no shape or form has disability ever legitimately been framed as a competitive sport in able to be classified as such and there are no “disability” gangs in which you have to prove your severity worth in order to gain your ‘colours’.

In reality, like myself, go to a disability conference and you will see a plethora of differently affected individuals who are both covertly and overtly disabled. Most of whom are quite comfortable to wear the term and talk about their situations. But the notion of competition is interesting, because in online stuttering support groups, often there are discussions revolving around severity and how that is the measure of impact. Often, I have rebuked these claims stating that the severity of the effect of stuttering upon one’s speech patterns does not necessarily correlate with the impact upon their individual lives. For example, I have been rated at my worst as stuttering on 33% of all syllables spoken over a period of time. Yet I class my stutter as minor because of its limited impact upon my general life. We have to keep in mind that stuttering behaviours are famously not consistent through the day from situation to situation. I often tell the story of the worst person who stutters that I have ever met. This young man was a tradesman in a highly specialised area and when his speech involuntarily blocked, his face contorted for a long time and his eyes almost popped out of his skull. His stuttering behaviours were so clearly obvious, harsh and attention giving. Yet despite all this he was a small business owner, active socially and married with children. These are but a few examples of plainly misguided opinions which were explored previously in the results chapter. But they are so telling of how people who stutter often try to distance themselves from the general social view of disability.

But now I raise a question: "Does this harlequin ignorantly carry general opinions about the root meaning of disability or does it want to find any excuse not to align with the word 'disability'"? This study has also found that the stigma associated with the term "disability" has also acted as a deterrent to identify to the university system as being such. The label "disability" has obvious connotations with links to the previous discussions about the ignorance of its legislative meaning. The harlequin of "Disability Rejection" at times parries distinctly away from this term with a sense of urgency. For in its mind persecution and retribution may arise in from aligning with such a label. For a small number of respondents, it seemed that due to the competitive nature of selection criteria into their chosen degree paths that they feared that any alert to and perceived weakness, in this case a stutter, could be used against their chances of selection. This is a worrying concern to have firmly nested within the mind of a potential student that a demographic data point at least at the point of enrolment may have such strong repercussions on their academic journeys and act as an early alert system to identify them as students somewhat at risk.

It is harrowing to think that if students who stutter are refraining to flag for disability assistance, then in fact how many other students with other types of disabilities are also worried about the impact of flagging upon enrolment. The pure fact that a simple tick box on a form can act as such a point of decision and anxiety at a pivotal point in the commencing life of a student is a point of concern. If students who stutter have a concern of a system working against them at the point of enrolment, then imagine the similar concerns which may hound some of them through to graduation and beyond.

It is no surprise to this study then that the mask of “Disability Rejection” is further worn in this academic dance to the point of actually accessing the help of related disability liaison units. When it came to actually asking for help from university disability services, only 14 (of 102) students who stutter ventured forward. As described earlier those who wore the mask of “Assumed Absence of Support” avoided this decision as they doubted strongly that there would be any helpful assistance or that the university would be interested in helping them. But those who wore the mask of “Disability Rejection” continue to carry on their very clear attitudes that stuttering is not a disability so of course we will not ask disability services to help. The direct rejection of being aligned, or in better words, defined as being disabled and also requiring assistance for this harlequin is a strong indicator of their attitudes in general. Yet, is it not interesting to the reader that most of the respondents have gone through some form of speech therapy and/or speech management course? They reject stuttering as being a disability, yet they have sought help to manage it. So we enter a paradox of opinions early on in this discussion. So many students who stutter did not see themselves as being “disabled”, yet they had sought professional help to help them to manage their stuttering. Presumably because they were finding that their stuttering was impacting their lives to a point that it was not satisfying and was having an unsatisfying effect on pivotal decisions in their life. So in simple terms: Stuttering impacts their lives negatively yet they will never align to the identity of being labelled as “disabled”.

So, how in fact how do we encourage the wearers of the mask of “Disability Rejection” to identify and align to the term “disability” to be able to, with less stigma and associated shame, access university support services? A starting point is to educate people who stutter more, concerning true and accepted broad definitions of “disability” and how it applies not only to them but all people. Part of this education process should involve understanding the growing disability pride movement and how it promotes itself. This movement promotes "disability" as simply a characteristic in which one has, and has to manage, like all humans do at an individual level. Important to this discussion is the promotion of Affirmation model of disability which I explained earlier frames disability as having positive worth to self and the wider community (Boyle et al., 2016). The movement does not in any frame promote disability as a negative, nor does it say that you should not simply accept it and leave it untreated. Then this education should focus on the stuttering pride movement which is in its infancy around the world. Although a splintered movement without any strong leadership or harmony, exposure to it will show the differing growing opinions of many people who stutter. For its mindset revolves around the notion that it is ok to stutter. This movement for some people who stutter is hard to accept and often itself swathed in miscommunications due to its splintered nature of a global accepted definition amongst its communities. At its core, it revolves around centring some pride on being who you are despite having a stutter. In no way does it say that you cannot seek therapy or program assistance to help you to manage your dysfluencies. This education would be optimal to happen as early as possible in the treatment of a person who stutters to help install a senses of resilience, community and self-pride.

Universities also have to start to promote disability more openly and positively in able to attract more students to self-identify, feel confident, and that help will be at hand without the fear of prejudice. However, it is interesting to contemplate how this fear of prejudice was perhaps born in the minds of some students who stutter. Did it begin with child-to-child interactions in the schoolyard and propagate through to adult life? For we know that negative peer feedback can begin as early as in a pre-school setting. Or are these feelings tied to a more adult-orientated world and setting where there is a lot of pressure concerning professional careers paths and decision-making in such competitive environments? These are some lines of future studies to be discussed later in this thesis. Suddenly amongst my dance with the harlequin wearing the ever-changing mask of "Disability Rejection" I see a shyer harlequin on the outside of the main dance floor. This harlequin is wearing a neutral facial expression and has a blindfold covering their eyes. Yet despite the perceived blindness, this harlequin still maintains a command over its general area and is aware of its surroundings with confidence. This harlequin sees me and gestures to dance with them. But this harlequin dances differently to the others encountered so far as the dance steps are conventional and formula driven.

The mask of Rigid Procedure

The harlequin wearing this new mask resembling somewhat the visage of the morality driven and judicially used Lady Justice leads me into a set of traditional dance steps. This harlequin is wearing the mask of “Rigid Procedure” and is the only harlequin to have actually experienced the provision of service offered by university disability support units. As mentioned earlier, only 14 of the 102 surveyed students who stutter opted to enquire about how the university could actually support them through their studies and accommodate to some degree their stuttering. This decision to probe about and seek assistance was for most, during their 3rd year of study, a year which for most would be close to the end of their degree. Perhaps this is influenced by the more serious matters tied to the assessments and resulting outcomes of final year courses? It makes sense that there is more stress and anxieties involved in the final stages of a degree and more rigorously assessed tasks compared to earlier years. But considering the reason to seek assistance was tied to oral-based assessments, as would be expected, it is interesting to ponder why support was sought mainly in the later stages of a degree and not earlier. Keeping in mind that the support offered must be deemed reasonable and fair for all involved, without impacting the academic integrity of the degree. All of these respondents, like all harlequins, have worn other masks throughout the party and differing identities from time to time. Some have also so far worn the mask of “Assumed Absence of Support” and a majority had worn the mask of “Disability Rejection”. I myself had asked for assistance from support services more out of interest’s sake than of necessity, perhaps as an unconscious move on my own behalf actually leading to this thesis. I asked my university’s disability liaison unit for assistance with an upcoming oral presentation. I was truly interested in what they would offer and how they would assist. This is a story that I will weave in and out of the dance with this harlequin.

The harlequins wearing the masks of “Rigid Procedure” as a group had a very consistent story to tell during their university experiences. They all were brave or confident enough in the first place to ask for assistance and were obviously in a space of need. Once they had taken this step though, they were quickly presented with a hurdle to surpass and it was an obstacle which truly confused some. They, like myself, had to prove to the university that they truly had a stutter to be able to gain services. This is not a step which really surprises myself and I can understand why this would need to happen. It would be wrong to simply take a person’s word for it even if they did present themselves with overt dysfluencies and speech problems. I was initially taken aback with how to prove my stuttering and to whom. I asked the disability liaison officer and they said to see a doctor or commonly known as a general practitioner (GP). At first I did not think anything of the request and made an appointment to see the campus doctor. Reflecting back on the request, to be certified as a person who stutters it did indeed feel odd and not empowering at all. I felt strange and in some way vulnerable by simply asking for this to happen. The campus doctor obviously attuned to such a generalised request, simply wrote a small note on official letter headed paperwork and told me to show the liaison office. There was no actual proof that I had to provide to the doctor or any form of test. I guess the doctor had witnessed me stuttering when requesting the letter and that was enough evidence in itself. This was a very neat and slick procedure as both had offices opposite each other in the same corridor. So in the space of half an hour, two appointments later and at no out-of-pocket expenses I was a bona fide person who stutters. But I honestly did not feel like a changed man, simply I was suddenly “official”. But to the 14 respondents who did ask for help this initial step started off a chain of confusion and narrow minded support.

For most of the respondents, the initial face-to-face disclosure of their stuttering to a university employee, in this case a disability liaison officer, was indicated as being not an empowering action. But in reality this initial step of assistance discovery should indeed have been reflected upon as an empowering action as it would have led to the strategising of assistance. Which in turn would have, or should have, been a relief to these students. Beyond the uncomfortable experience of disclosing their stuttering to a disability liaison officer. Which for most was a logical step in a process, there was then the proving of their stuttering to a medical professional and in all these cases a general practitioner (GP). Like myself, most respondents were initially bemused and confused about why they had to prove their stuttering to a medical professional. A medical professional that was not specified as being one focused in speech therapy. I have to admit that I was also bewildered about how a general practitioner could accurately diagnose a stutter. This step in the process of support gathering seemed to some like a pure token gesture due to the lack of expertise and even perceived interest shown by the GP.

So, why did all of the respondents, including myself, opt to see a GP? A GP, who in some cases seemed confused, sometimes uncaring and somewhat fussed about being asked to validate such a claim. These outward feelings towards the request must at times not have been overly encouraging or confidence building for a requesting student. At least it appeared that no respondent was interrogated by a GP about their stuttering. The answer to this question was not alluded to during the survey or during the interviews in much detail so I will hypothesise. I will claim that the answer lays heavily within pure convenience. For myself, having a campus doctor close by and actually within the same office departmental area as the disability office made the process so quick and simple for me. I can understand how it may be easy and timely to have an appointment with a GP rather than an actual speech therapist. When making an appointment with a speech therapist within the Australian public health system, you could be placed within a long waiting list just to be able to have an initial consultation. It could be quicker to make an appointment with a speech therapist within a private clinic but the associated costs may be higher and they may need to be paid upfront as opposed to a public speech pathologist. So perhaps the combined conveniences of location and timely access are the main influencers behind the decision to seek a GP over a speech pathologist. But do these drivers also influence the willingness of a disability liaison officer to accept the diagnosis of a GP instead of a speech and language expert? It was so interesting to learn that no respondents who asked for assistance were directed to a speech and language therapist as a point of referral for validation. The disability liaison officers involved with the cases were quite happy with the validation given by a GP. I would presume myself that the disability liaison officers themselves were more often than not acutely aware of the timeliness and costs being associated with making an appointment with a speech pathologist and were happy enough to have validation from at least a licensed GP. In other words, any professional medical validation would have been probably fine enough to start the process of provision and would have been in line with procedure and process. So now during this dance with the harlequins and I discuss the findings of my research I noticed that there are more dancers at play than what was previously thought. Because it is not only the respondents that at times wear masks of differing identities, but so do those who at times interacted with them during their studies. For as I pirouette with the dancer wearing the mask of “Rigid Procedure” I notice a table full of other party-goers wearing the same mask and they all belong to the different disability liaison units of Australian universities. Yes, it appears that at times disability liaison officers, as would be expected, are driven by rigid processes and procedures when assessing a student for support. It would be interesting in further studies to delve into if and how restricted such support staff feel when offering assistance within such a bureaucratic and process driven university system.

But this journey of strict process driven support is far from over and the harlequin holding my arms prances to the centre of the dance floor to further express the reasons behind wearing the mask of “Rigid Procedure”. For some of these students, a shift of identity had occurred mid-dance with disability liaison staff themselves more broadly speaking. This change of identity is directly influenced to the simple procedure, and now seemingly brave act, of asking for support and as a result being “confirmed” as a person who stutters. For most respondents who asked for support had not viewed themselves as being “disabled” prior to seeing a disability officer.

This is a surprising discussion point that directly influences the identity of the student as they start to wear internally a social mask of identifying as a person with a disability. Now that is not to say that this was a negative identification shift in the least. Actually this shift in identification may have been due to understanding more how disability is defined and used by their chosen university. A definition which is supposed to be aligned with Australian Federal Government defined ones throughout disability legislation. This in turn may have led to a more informed personal understanding of what disability is and in turn helped in some small way to influence a greater cultural educational shift positively. The opposite could have also been true and more needs to be known about how this identity shift had affected the student within the university environment and beyond. For some students carrying this new identity and associated social stigma may have been quite a negatively impacting experience from a deeply personal level.

Even more distressing is the fact that all students who had asked for assistance indicated that to some degree they had all felt more "disabled" after simply disclosing their stuttering to a disability liaison officer than they had felt previously. What they meant by "more disabled" can only be hypothesised on. It is such an alarming figure to think that more likely than not, these feelings are less empowering and less satisfying than what we would like to think, especially for the students who had indicated that previous to accepting help that they never thought of themselves as being "disabled". So the decision to seek assistance for some students began a new personal identification process in their lives. The questions arise in what way did they feel more disabled by this action? Was it a self-realisation that stuttering was indeed a disability and that is was now somewhat officially applied to themselves? Or was the stigma associated with the label not an issue and that other factors were at play?

Were the students feeling "disabled" not by identity, but by process? Were they feeling powerless within the support provision process? This may be somewhat true later in the process once the right to provision had been agreed upon. But at this early stage in the support cycle I tend to believe that their attitudes were tied stigmatically to the term “disability” and their associated negative feelings towards it. At least most of the students had the impression that the disability liaison officer had shown true care about their stuttering and its impact on their studies. Care enough to encourage the application for provision and strategic reasonable adjustments for problematic assessment tasks.

Once support had been granted, a different journey of discovery was encountered by these students. I will relate my own experiences first as a benchmark. When I had enquired about assistance and strategies, a small range of options were presented to me. These options were very generic in nature, and to be honest, not generally empowering. For example, if I was in a team-based presentation then I could assist with creating the presentation and then be relegated to being the team-member who presses the “next slide” button on the laptop. A strategy which I could understand why it was suggested but it would have surely singled me out in the team as the one member who for some reason was not talking. It was also suggested that perhaps I should just ask to do all written assessments instead of talking at all. But I was never asked about speech therapy, how I would like to personally be included and if the offered strategies were empowering to my self-esteem. I was simply presented with a restricted and unenthused list of strategic options to help facilitate my stuttering and be able to achieve satisfying grades. I have to admit that I was just a little deflated by the solutions and lack of inspiration. I went home to reflect upon these and surprisingly could not really come up with any other strong solutions myself. Perhaps being such a confident speaker in general myself, blurred even my vision of what strategies may be offered? Then again, perhaps in reality there were little other options to have?

It was of little surprise that only a handful of years later the 14 students who stutter who accessed disability liaison services to the point of provision basically experienced the same journey as myself. For they expressed some dissatisfaction with the suggestions offered by the disability liaison staff, but not entirely. Actually, when posed that question, they were mainly non-committal about a strong point of view on it. Yet they also did not seem to offer a lot more advice on the subject except that they felt that the disability liaison officers in general lacked knowledge concerning the effect of stuttering upon on individual. Perhaps their past experiences about how their stuttering was accommodated for previously during school experiences had come into play and generic, yet effective strategies were expected and accepted? Or, were these students simply opting not to argue with offered support, or to offer their own solutions, and let be what was suggested? If so, they could then receive support which the university system could accommodate and in return achieve higher grades. But beyond this provision of support services were the feelings that were produced as a result, feelings of which you would never wish to invoke as a result of providing support. For beyond the simple feelings of uncomfortableness around disclosing their stuttering to both a disability liaison officer and a GP, opened a Pandora's Box of negative impacting emotions. For most of those students going through this process of seeming empowerment, reflect that the process actually made them feel ashamed and embarrassed when disclosing their stuttering. All feelings of which have been proven as barrier to disclosing a disability and accessing related help (De Cesarei, 2015). In fact reflecting that they generally felt that the process they experienced was uncomfortable and not initially empowering. But how can such a process of support provision not be empowering? Could it be that because although support and provision were given that the student did not feel in control of the situation and was just going along with the process? That they were simply a passenger going along for the ride in the hope of reaching the destination of the situation that would at least help appease their needs to be able to achieve adequate assessment results. The process when you step back from it, which mirrored my own journey of enquiry, seems to be rather rigid and not overly personalised. So after such a lingering dance with the harlequin wearing the mask of rigid procedure, I let go of their hands and paused for a short rest in this long party. I then saw most of the other harlequins wearing this same mask change into another disguise quickly. This mask bore the look of shyness and was the mask of "Frustrated Confidence".

The mask of Frustrated Confidence

Of all the students who asked for disability liaison assistance, only one of them chose not to implement the suggested strategies and they gave no reasons why not. For the others they changed identity again once they chose to implement the support provided to them. The mask of “Frustrated Confidence” holds expressions that bear despondency with a taint of happiness because the wearers experienced a journey into the classroom using agreed upon strategies which was perhaps not as smooth or as empowering as they had imagined. It was with disbelief that of the 13 out of 14 students who stutter who chose to implement the suggested strategies to support their stuttering during class, a majority of them believed that their lecturers were not open to implementing such reasonable adjustments. Now you may think to yourself that the students only “believed” this, but a belief in this case must have originated from interactions with the lecturer either directly or indirectly.

It is harrowing to think that most of these students who actually went through the process of gaining assistance felt that their lecturers were not inclined to accept the strategies offered once in class. That, in a sense, the university itself that they were enrolled in, was not inclined to have full support of its own services by all staff. I do understand how there can be some resentment at times by lecturing staff in implementing disability support strategies, as I have seen this myself. I have seen my fellow academics frustrated by the support provision system for a number of reasons. These reasons revolve around issues of growing academic workloads and information sharing. I have witnessed lecturers very busy with teaching while trying to also find time for their research, then having to think about how to incorporate accommodation for a student’s special needs. At times I have also been aware of suspicion about the legitimacy of a student’s claims. Mostly due to interactions with students in the past who have at times falsely presented themselves directly to a lecturer to ask for assistance or “conveniently” are suddenly in need of provision every time a major assessment is due. But more commonly, my fellow academics are most tainted against the disability system simply due to not having been very involved and informed about the student’s needs prior to receiving a notification that strategies have been put into place. So I can understand how lecturers from other institutions may face similar challenges and also hold such opinions. It is still disheartening to know that students who stutter, and students with other special needs, are feeling these views from lecturers who they would have assumed would be fully open to implementing agreed support.

The question which now arises is exactly how prepared and satisfied were the students who asked for support and, where given it, how satisfied they were with the strategies once initiated in the classroom? Only around half of those who chose to implement the suggested strategies were clearly undecided around whether they felt satisfied or not with the methods once implemented into the classroom. The other half of the students were evenly split between being satisfied and not. The reasons for these split opinions may hark back to the earlier findings that the majority of these students did not feel like active contributors to the strategic planning. So although strategies may have been agreed to and implemented, they in turn may not have been completely satisfying to the student and maybe even the teaching staff involved. It is often overlooked, that at times teaching staff have existing educational relationships with students and often know their needs quite professionally. This in my experience sometimes leads to differences between what a disability services officer may suggest as a strategy and what exactly happens and is agreed to between the lecturer and the student. This is the type of good-hearted, yet underhanded, support provision that we would always want to avoid. The aim is to have the university community as a whole with a cohesive cultural understanding and support of the whole provision system.

Another issue affecting the satisfaction levels of the student who implemented support strategies was that of identity. In this case all of those students had the consensus that the agreed upon strategies made them standout in class. This would be certainly not what the average student who stutters would like to achieve due to the general covert nature of associated with hiding their condition. In fact such strategies which would have made the student overtly stand out due to their stuttering may have well even attributed more shame upon the students involved and perhaps was counter-productive to their overall confidence levels. This problem of blinkered collaborative assistance is further impacted by the finding that the majority of students who asked for help also did not feel personally empowered by the offered strategies. So the journey for these students meanders through a confrontational and shame-filled endeavour to receive assistance and then when assistance was implemented, elements of shame and disempowerment continued into the classroom as themes.

Another form of blinkered offering of support arose from the fact that most of the support seeking students agreed that the strategies that they had agreed to use~~,~~ did not at all compliment the therapies or techniques that they had learnt in the past to help manage their stuttering and shape their fluency levels. In fact, most also believed that their disability liaison officers lacked general knowledge about stuttering and also had not further enquired with a stuttering professional for further advice about how to support students who stutter. It is no wonder that these students felt restricted in the amount of control and say that they had concerning the shaping of their own disability support plans. It further emphasises how such support needs to be more informed to be constructive for the students involved from both a practicality level and also a personal empowerment level. But it may also point to the fact that perhaps disability service units simply do not have the workforce and associated workloads to be able to fully individualise strategic planning for students and are in turn restricted organisationally. It adds fuel to the thought that if these problems are present for students who stutter, then other students at need are more than likely experiencing the same outcomes. But after all of these negative feelings and reflections on the provision of support, one interesting finding surfaced. This finding was that almost all of the students who employed strategies did say that the methods did help to alleviate their stuttering-based anxieties in class. So in fact although not completely satisfied or empowered with the strategic process, in the end at least having a plan was better than having no formal plan at all. For at least the strategies did help to ease the stress around both their speech issues and the ability to academically perform well in the task. It is unknown if the strategies actually assisted the students with being able to gain more self-acceptable grades than if they did not employ them. But the strategies seemingly eased their anxieties with the assessment-based requirements, in turn more than likely creating fewer negative effects on their fluency levels overall and aiding their general confidence levels. So I can understand how a student who stutters could be somewhat satisfied with the outcomes of support. But if this process of support provision is true for students beyond those who stutter, then I shudder at the overall impacts on the individuals involved and their general levels of confidence concerning how society both views and treats them. This harlequin now stops and for a moment I think I do notice a small, wry smile on its frozen face. I leave their arms and look to see if any other new dance partners are on or near the busy floor.

I soon noticed a final different harlequin wearing a face which is a combination of both relief and anguish. A face wreaked of despondence and yet confidence. They saunter over to me and through confident sign-language they introduce themselves as the mask of “Concessional Bargaining”.

The mask of Concessional Bargaining

This bold confidence that this harlequin displays seems somewhat stifled by an undercurrent of hidden anguish. I can sense an uneasy tempo in their dance step and a desire to achieve more in their moves. In fact at times their dance steps seem to be leading me into a move that is not in line with the tempo. This is a mask at times worn by the majority of my study’s respondents throughout their academic journeys. For now we come to a truly conflicting set of findings which seem contradictory in terms. Actually more than just a set of simple contradictions, but a really thought provoking set of opinions which still intrigue me. Now I will lead you back to an early discussion in this chapter and study, the finding that very few respondents felt that stuttering was a “disability”. You may remember that opinions around stuttering being a disability were divided, but the cases against was often argued strongly and with a feeling of ignorance around the applied meaning of its definition. Some of these opinions were revolving around stuttering not being seen as a disability because it was manageable or was deemed as “not that bad” in comparison to more widely identified disabilities like deafness and paraplegia. So keep firmly in mind that the majority of respondents did not view stuttering as being a disability. This is a part of the study which in fact the findings were not of a surprise to me at all and were what I predicted. Unlike some of the earlier findings and opinions which were against my pre-study thoughts and instincts. When asked if their stuttering had a negative impact on their academic performance, the majority of respondents said yes it did. This line of response is fully in line with what I have read anecdotally across many online forums for nearly a decade. On Facebook, for example, within stuttering support communities there are often threads around how to cope at school or how to prepare for upcoming oral assessments. There are actually social media groups dedicated to assisting students who stutter and rising movements in stuttering-based organisations to push for greater awareness of stuttering in schools. Responses to these social media conversational threads are often numerous with much support being shown and similar cries for assistance. Another source of these cries for help come from the parents of children who stutter, who share the plights of their children trying to fit into their classroom communities and adjust to their vocal differences.

Now I am going to present an interesting quandary in my analysis of the findings. Actually a paradox of sorts. As a reminder, the majority of respondents have the opinion that stuttering is not a disability, and in turn they opted not to access support services or ask for reasonable accommodations. Yet a majority of students also claim that stuttering has actually impeded their academic progress and has negatively impacted their journeys through university. This study has shown that the impacts of not accessing and utilising support services for some students has clearly negatively impacted their grades and resulting overall results of their degrees, in turn affecting their overall grade point average (GPA). But this is an impact purely from a grades-perspective, but still it is a perspective that is perplexing to me. So then what is a disability?

If their stuttering behaviours are influencing them not to seek support and in turn not take full advantage of a university degree, then how, logically, is stuttering not a disability? But this puzzle deepens through further investigation. This study further uncovered that over 80% of the survey respondents purposely sought out class-based activities that required little speaking. So as confident in general that this cohort appears to be in terms of angrily rejecting stuttering as being a “disability” it is clear that stuttering to them is at least disabling. Whether they choose to align stuttering with the term “disability” or not it is influencing negatively their life choices, including those at university. So apart from largely agreeing that they did not participate to their fullest, often avoided oral-orientated class activities and that their academic performance was impacted by their stuttering, there were some more interesting findings.

The interesting finding is tied to a term that I briefly introduced you to during earlier discussions called “concessional bargaining”. You may believe that “concessional bargaining” is an odd term to use within this study as it is used within industrial relations when discussing an interest-based bargaining technique between employers and employees (Coleman, 2014; Odell, 2012). Such agreements use “concessional bargaining” as a form of negotiation in which each majorly invested party attempts to negotiate a series of benefits at the expense of the other parties (Coleman, 2013; Hum, 1998; Ranjan, 2017). I believe that the use of “concessional bargaining” strongly encapsulates the inner-decision-making strategies that have been employed by many students who stutter within this study. This strategy appears to both negatively influences the grades of these students and have a negative impacts on their self-esteems~~?~~ This theme has uncovered how such students engage in inner-decision-making when negotiating their academic journeys and associated trade-offs against the chance of gaining higher grades or participating in class to a more satisfying level than what was achieved. The students who I have identified as using this theme were generally open and direct about their decisions and willing to accept the attributed consequences.

To further emphasise the bargained decision-making processes of these students some respondents totally confessed that they did use their stuttering as a strategic advantage at times to seemingly achieve higher grades. To add more fuel to this fire was the finding that some respondents also admitted to using the stuttering as an excuse to gain an easier path overall through a given subject. I find it very interesting indeed that some students who stutter are very open about strategically using their stuttering at times of need as an excuse to avoid assessment tasks. In a sense though, this is beginning to make more sense to me than I first reflected upon. I have to remind the reader that for most of my academic career I have had student support roles within my overall academic workload. I have coordinated programs, different levels of students and been responsible for issues of student retention. During those times, I have had to deal with a wide range of student issues, opinions and strategic decisions. To be honest, I have experienced it all, from students whose same uncle has died almost every semester, through to high range medical problems presenting in my office, and of course, car mechanical problems. I have become very savvy at forming an understanding of the needs and motives of a student. I can understand and have seen students who have used their differences to their advantages when required and sometimes without any overt real need. But in this case I actually think the motives behind the actions of these students who stutter are not necessarily done with sly malice, but with a sense of desperation often against their true characters. I believe that some of these students who use their stuttering as an “excuse” to perhaps get an easier road through a subject are in fact crying out for help by doing so and are not as in control of their educational journeys as they would have you believe. I would present their opinions as a matter of pride in which they wish for us to believe them as confident and unencumbered by their stuttering, when in fact they label that they often shy from is true, that their stuttering is actually “disabling” them. But having a sense of control over their actions makes their self-esteem feel higher.

Now that you have danced along with me through the themes that I have identified through the shared narrative discussions of my research’s participants, it is time for you to read on and let us refocus on the significant findings and repercussions of what this study has found.

Chapter 10: Discussions, recommendations & conclusion

This chapter has been written to be practical in nature to readers of all interests to understand and begin strategising for future changes concerning how to more successfully support, accommodate and teach a student who stutters within a university setting. It is important again to be reminded that the experiences of students who stutter in a university setting has been vastly overlooked by academia and that there are little studies to refer or compare to when discussing the following findings. This closing chapter will begin with a discussion around significant findings and then direct back to the research questions. This chapter will also present a range of action-orientated recommendations for vested parties concerning university students who stutter ranging throughout their student life-cycle from pre-enrolment through to enrolment and into the options of seeking support. I will then lead you to the concluding sections of this chapter via a list of future research directions that I believe can extend upon this thesis, and conclude by summarising the contributions to knowledge that have been found as a result of this study.

Key findings & significance

I hope you have enjoyed and found interest in the journey in which this thesis has taken you on. I also hope that you appreciate the work that has gone into the design and analysis of this bricolage enthused study. This is a completely authentic and rigorously researched account of the consolidated experiences of close to 120 Australian university students who stutter. The unique methodological combination of an Australian university disability website audit, the surveying of 102 students who stutter and the interviewing of a further 15 of these students has brought forth such rich expressions of combined experiences and personally unique narratives. To assist you to understand these emergent stories was a unique approach to frame the applied thematic analysis in the form of a masquerade ball with individual themes portrayed as mask-wearing harlequins. Interwoven into this methodology was the autoethnographic musings of my own personal story and reflections, which I hope has enabled you to understand me as a person who stutters, my own journey through university and my connection to the research participants. This empirically designed study about the experiences of Australian university students who stutter has recast completely the orthodox views around their academic journeys. I hope you have now thrown away any pre-determined stereotypical views of just how a person who stutters may act within a university environment and that your understanding of how these students navigate their academic journeys has been reshaped. This thesis makes a significant contribution to the body of knowledge about Australian university students who stutterer for what has been academically published or presented about university students who stutter as a whole has been limited in design and depth. The existing light enquiries into such experiences bring forth mostly only stereotypical views of people who stutter being disengaged in educational settings or victims of circumstance at the mercy of educational systems. This study, my study, is the most thorough and narratively deep investigation to date to look explicitly at the university experience of students who stutter and precisely within an Australian educational setting. Contrary to the evidence and anecdotal accounts, it has been discovered that these students are in general not students who are victims of circumstance within the policy and process driven world of Australian universities. Nor do these students generally see themselves burdened with a disability which they had overtly framed as a deficit. In actuality a large percentage of these students did not even recognise stuttering as a disability at all. These students are in fact showing a high level of driven agency in how they negotiate or bargain through their academic journeys from enrolment through to graduation. I will go further to say that these students have narrated to us that they use high levels of intelligence and calculated planning through a process of concessionary bargaining, or some may call it coping strategies, to help ensure academic success. This is not to say though that at times sacrifices in terms of internal personal concessional bargaining have not been made to ensure strategic plans of success. This study has brought forward views about students who stutter which has not existed within the literature up until the publication of this thesis.

The significance of this study and the new knowledge that it has brought forth to the literature should not be understated. You may recall from the literature review earlier in this study that to date the mainly focuses of research within the stuttering realm have focused on the neurological origin of stuttering, the general life experiences of people who stutter and the impact of stuttering on their overall lives. Studies themselves which have been largely quantitative in nature and did not strongly include the voices and stories of those studied. In regards to stuttering in an education setting though there has been little research at all from a pre-school to a university level. In fact most of these studies were situated in the primary and secondary levels of education and did not themselves enquire deeply into the personal experiences of these students. These studies were mostly the view and opinions of peers and teachers as opposed to the authentic voices of students who stutter themselves. Students who stutter at a university level have been thoroughly under-research and I would propose actually overlooked, if not neglected by academia. I will reiterate again that what studies that have been conducted to date again in this area only lightly investigate the experiences of university students who stutter and only give the reader a shallow glimpse into their lives. This study has also redefined the characteristics of what people believe that the identity of who a student who stutters is and how they are believed to behave within a university setting. It is anticipated that results of this study will have immediate impact within the stuttering world and beyond once communicated more directly via conferences and publications. In fact this study has already been informing academia, university support systems and the greater communities of people who stutter (see Publications, presentations & press associated with this research). The results from this study will give encouragement to those people who stutter considering enrolling into a university and will give strength to those already enrolled.

So where does one start to discuss such a large study with many complex threads? The answer is to start from the initial research question of *"How do students who stutter negotiate their university experiences in Australia?"* Without doubt loudly and proudly I can state that Australian university students who stutter negotiate their studies with a sense of agency which they are in control of. The participants of this study expressed many times over that they were not passive passengers during their university studies and in actuality are calculating drivers throughout their educational journeys. Again let us start at a high level view of this cohorts university experiences. In general, most of these students have enrolled into degrees of their choosing and which demand professional levels of verbal communications. Of those who had graduated from their studies they had leapt into careers aligned with their education. This is an incredible finding in itself regarding that fact that the general public and even the research shows that perceptions of people who stutter are generally those of lacking social confidence, being introverted and at times even lacking intelligence. This broad finding I would argue is more successful in general than what I would find if I took a similar size random sample of Australian university students who do not stutter and applied the same questions. I can tell you this because I was an Associate Dean (Student Retention and Success) for my past Faculty for almost four years. I knew the numbers of graduating students and students who dropped out of university studies across all Australian universities. But, as you have learned, the journey to success is one of shifting identities and a series of concessional bargaining trade-offs steering key points of decision-making.

To assist me to recap the whole study for you and outline the importance I will direct you back to the three sub-questions of the study:

1. *"How do Australian universities publicly represent their disability resources to a prospective student who stutters?"*
2. *"How do Australian university students who stutter describe their experience of the student lifecycle?"*
3. *"How has the doctoral candidate himself, as someone who stutters, framed his identity within a university setting?"*

Australian universities at the time of when this initial study was conducted in general poorly represented their disability resources to a prospective student who stutters. There was no consistency of how they publicly presented their disability resources and how they in turn aligned to Australian legislation. There was no stand-out university at all to promote as an exemplar that other universities should learn from.

Stuttering was rarely mentioned in any disability guide as opposed to more prominently promoted disabilities. Having said that, I could understand myself how stuttering could be accommodated due to my understanding of the meaning of the term and how it applied to universities. But I would say that some students who stutter may be deterred from seeking assistance if stuttering was not explicitly mentioned for support purposes. This is a set of alarming findings in itself and is a clear directive to Australian universities to strategise how to advertise their support services to make them more appealing and inclusive to all students. The crux of this study is not within this sub-question though and it was more important to understand the overall student lifecycle.

I will re-iterate that Australian university students who stutter appear to be generally confident and strong with their decision-making concerning their student lifecycles. These students are entering the Australian higher education system with a sense of independence and inner strength which appears to be a result of having to be self-reliant, resilient and strategic in their educational throughout their primary and secondary school years. These students already come into university life with a general perception that little support if any would exist for them. Nor do they in general see themselves as being disabled which in turn makes accessing university disability support systems less appealing. These students have a very confident agency in being able to act within university settings to a high standard. But even with this strong sense of agency these students still at times admit to underperforming in their academic studies and do not engage socially to their levels of satisfaction. They also do not generally engage with university support systems which logically could assist them to perform as students much better. However I must make you aware again that I cannot fully generalise this series of findings because of the self-selective nature of the participants of the associated studies. The participants appear to be in general extremely confident in nature and willing to narrate their experiences. This sample of respondents may have limited the overall findings of this study due to the very nature of their personalities and obvious academic journeys of success.

One major finding from this study is the general rejection of the term “disability” being applied to stuttering. The term is a highly debateable topic within this study and one of inflamed narrative outbursts to the point of the research participant being insulted by the mere question of is stuttering a disability or not being posed to them. The narrative opinions of the participants showed a general confusion around how stuttering could be a disability or not. In fact their responses did not align simply to one model of disability being spread amongst both social and medical models. The generalised opinion of stuttering being a disability or not seemed to hang within a limbo area within these models amongst the research participants. I propose that a new theory and/or model of disability needs to be created to describe stuttering as a disability and how students who stutter function within a university setting. In fact this new framing of identity should not be restricted to a university setting at all and with more research into careers of people who stutter who I think will have similar journeys of strategic and concessional decision-making and resulting successes would emerge.

“Disability” as a term for students who stutter needs to be described and promoted in a way that is applicable to their condition and also empowering. There needs to be more pride created to enable stuttering to be generally viewed as being a disability and in turn enabling. “Stuttering Pride” itself as a term needs to be clearly defined and embraced by stuttering organisations all over the world so that is can become consistent in application and understanding. Creating pride would in turn encourage more students who stutter to access university disability services. This redefining process may also help stuttering organisations and individuals to be more open to aligning themselves openly with disability and the global disability movement. It is important to remember that most of the participants refused to indicate in any form that they had a disability from the point of enrolment through to graduation. This decision added to the invisible nature of these students within a university context and strengthened their covert decision-making.

But now we get to one of the most disturbing finds of this study and that is the journey of those students who stutter who actually engage with university support services for assistance with their studies. Very few students asked for assistance and usually only in their final year of study. This is a reflection of how confident these students usually are within their general studies and how only at final points of their studies did they seek help. Only 14 students out of 102 sought help and the experiences of these students were productive but not individually empowering. Gaining access to support systems and negotiating strategies to assist you would think would be a fluid process without large amount of stress and anxiety. But in the case of Australian students who stutter this appears to not be the case. The 14 students who accessed support indicated that they felt high levels of shame, helplessness and confusion around the process of support provision. The complete process of seeking and receiving assistance appeared to be counterintuitive to students who stutter and destructive to their incoming identities. This process made these students feel more personally disabled than they felt pre to accessing support and they felt that their individual needs were not being factored into allowed strategies. Having said that, the strategies offered to them did actually meet the basic of their needs. But this is a large problem that needs to be rectified and university support services need to reflect upon how to be more inclusive and positive identity building for students who would normally be adverse to accessing an assistance at all.

When it comes to the general student lifecycle, students who stutter become master tacticians and generally in firm control of their destinies. Their generally employed concessional bargaining strategies shows the extent in which these students are aware of the repercussions and effects associated with their decision-making. This study has totally refined the identity of a university student who stutters at least within the Australian context. Once in class, these students employ a general series of strategies that enable them to hide their speaking differences and in turn make their “invisible” disability as covert as they possibly can. But these students are perfectly aware of what the repercussions of their actions are upon their academic results and social life. They are not helpless victims struggling to achieve results at all. These students are calculating and very strategic in their decision-making. Even to the point that some of these students admitted openly to purposely using their stuttering as a way of either avoiding an assessment task or finding an easier way through a course. These students have used their perceived “disadvantage” to their advantage. Although successful in their studies, these students often discussed their frustrations around not being able to fully engage with overall university life. So it seems that in their studies their concessional bargaining strategies is helping them to forge confidently through their degrees, but not so confidently through the social aspects of university life.

Another significant finding of this study was just how calculated these students were during their daily studies. Through their interactions with past educational achievements, the workforce and daily social interactions these students were very aware of the speaking situations that they would face within a university setting. Students who stutter were openly avoiding class introductions and socialisation. But they bigger finding is the extent in which they would go to avoid oral-based assessments. A majority of students admitted openly that their studies suffered due to their stuttering and in turn their grades did also. Remember back that most of these students also avoided asking university disability support services for help. The fact though that they were openly admitting to avoiding assessments requiring speaking, even though support for them existed, shows just how much ownership these students had over their educational destinies. It also shows the extent to which these students were going to avoid being openly identified as a person who stutters and how important it was for them to have a positive outward identity. An identity that was not to be any less than average and certainly not to be aligned with having a disability. It still fascinates me that such educated students who had been taught to critically think and reflect upon their actions, had no open reservations in taking a sacrifice at the expense of their grades in order to avoid the stigma associated with being seen as a person who stutters.

Now we get to how the third sub-question which asked "*How has the doctoral candidate himself, as someone who stutters, framed his identity within a university setting?"* Throughout this thesis I have been completely open to you and have told you things that I would not normally divulge about my stuttering experiences and opinions. I do not walk around the town discussing my stuttering with everyone and anyone who I pass. Within my university setting I do not identify myself as a person who stutters at all and are simply an academic. I describe myself as a covert-overt when discussing my speech with other people who stutter which often confuses them. Yes, I am a person who stutters, but I believe that most of my colleagues do not identity me as such. In a sense I hide in plain sight. I am simply Grant Meredith who lectures in IT and occasionally teaches in China. I am very confident in my ways in understanding how the university functions. In fact I am a resilient survivor of multiple university restructures and three doctoral supervisorial team changes all which have occurred during the period of my candidature. Within the game of academia, I am very much a politician and I know how to negotiate outcomes for myself, School and students. The agency in which I act is not like the stereotypical person stutters. I am actively sought out for guest lecturing, for attending career events and to visit partner school locations. No one to my knowledge has refrained from asking me to do a communication-orientated task for the university due to my stuttering. I have and continue to hold leadership roles within the University and sit on numerous committees. To put it bluntly, I am just Grant, who, by the way, just happens to have a stutter.

Now that I have re-emphasised the significant findings of this study I will lead you through a discussion around them and their importance to understanding university students who stutter.

Discussion of results

How does one begin to discuss the importance and significance of the findings of a PhD thesis? I pondered this for a long time, perhaps for too long, as I believe now I should have simply let my hand and mind instinctively narrate my thoughts. So I believe it is justified that I start with what I think is the most important crux of this whole thesis and that is the notion of identity and its overall relationship to the overarching research question that I posed to you earlier:

"How do students who stutter negotiate their university experiences in Australia?"

This study has shown that students who stutter enter into university life with a series of stigmatised moulded identities that they shapeshift to and from depending on situational circumstance and need. This resonates strongly with the shapeshifting identity of character that (Kathard, 2006) describes in their behaviour in regards to an individual having the capacity to jump from being able to what Pillay (2003) calls the disempowered "DisOther". Pillay described how an individual who is disabled or not could see experience their life with frequent meanders between empowered decision-making and individual disempowerment depending on context and setting. This process is framed by Boehmer (2005) as a shift of identity as the individual views themselves as problematically different within a given context. The notion of the "DisOthered" identity lends itself well to this study as Australian university student who stutters appears at times to be satisfyingly able in their studies and then in times of need somewhat situationally disabled by course requirements. These are the points in time within their academic journeys which appear to be import to the continual evolution of their identities and such events have been commonly stipulated within disability research (Castells, 1997; Mishler, 1999). The combination of experienced stigma towards their stuttering and contextualised disability within an educational setting appears to have begun at the primary and secondary school levels which aligns closely to past studies (Boyle et al., 2009; Flynn & Louis, 2011; Griffin & Leahy, 2007). These school experiences have been narrated by some participants to be those of little offered support and if support did exist then these students rarely accessed it

(Butler, 2013). Research has shown that negative peer behaviours can be identified very early in the life of a child who stutters and can have a direct bearing on the development of one’s identity (Blood & Blood, 2004; Erickson & Block, 2013). In the case of children who stutter their identities have been shaped through actions of their peers who have identified them as being different and in turn treated them with negative difference with acts as bullying and exclusion (Erickson & Block, 2013; Ezrati-Vinacour et al., 2001). I would go onto propose that these early peer reactions start the shaping of the self-identities of these student as what Goffman (1963) describes as identities which have been spoiled. As a result, I would hypothesis that this strategic decision-making that I have termed as “concessionary bargaining” discussed in this study at a university level actually starts to occur early in the educational journey of a child who stutters in order to avoid being seen as different. This journey and beyond is similar to the cycle alluded by Butler (2013) in her broad study of the educational students of people who stutter and lends itself to what Boyle (2015) describes as a cycle of developing a self-stigma over time where people who stutter grow through the awareness of being different and then over time adopt that role.

These resilient behaviours would in some cases become more refined and situationally applied as the child grows up and traverses the ever-demanding educational world. It is of little wonder then if those behaviours fuelled themselves on through into university life. If what I term “survival strategies”, like refraining from participating in class discussions or being absent for an oral presentation, had worked in the past throughout primary and secondary school levels then these DisOthered behaviours could be strategically applied in a similar educational context into the future. In fact, I would assume and I know from experience that such behaviours would also be applied throughout a person who stutters life in different circumstances. It is quite common for example for people who stutter to discuss how disabled they feel when dating, going for job interviews or when ordering fast food. Within given individual contexts people who stutter have reported feeling less able and empowered opting to behave differently and less satisfying what they would like including educational settings (O'Brian, Jones, Packman, Menzies, & Onslow, 2011). These behaviours inside and outside of the classroom are a result of what Boehmer (2005) has behaviourally described as happening when an individual sees themselves as being problematically different within a given context. In the case of this study, that happens within certain points of university studies and commonly tied to oral-based assessments/requirements. It is quite common to read on social media conversations revolving around strategies to study successfully at university from people who stutter as these conversations are racked with apprehension and concern. Upon reflection this finding makes solid sense to me as I have seen such resilience and success among members of many stuttering communities globally. They appear to rarely ask for professional help or access it, opting to be as independent as possible and thereby either outright rejecting or attempting to distance themselves from the disability label. Often leading to successful careers often of which rely on having strong communication skills. This study has significantly shown this journey of university behaviour within an Australian setting and is the first in the world to do so. I believe that although the situation of studying within a university setting is on the whole challenging for these students and it does present disabling factors they in turn display a strong sense of agency in terms of their strategic decision-making. These students have found a range of oral tasks stressful to consider participating within and these concerns start from the enrolment stage. Such concerns are tied directly to negative feedback from the first week of studies, where they may have to introduce themselves to the class through to course-tied oral assessments. They also relate that they are hesitant to participate within an open class group discussion, to ask their lecturers for assistance and willing to totally avoid if need be at the expense of achievement public speaking focused assessments. They do this with the ideal of "concessionary bargaining" within their decision-making and appear fully aware of the repercussions of such decisions or trade-offs upon their university life. This shows a high degree of agency within these situations in my opinion and these students are not simply victims within a larger university setting. They are calculated and at times cunning actors within a university setting who strategically choose how they wish to act within a given setting which is troubling them.

So when I begin to discuss how a student who stutters negotiates their university life it begins with a series of ingrained strategies, assumptions and shifting identities. As hinted at by Azios (2017) students who stutter enter with a pre-set understanding that no or little support will be available to help them with their studies based upon their previous educational experiences. In turn very few attempt to seek support pre to enrolment or after enrolment. Actually for most of these students the idea of seeking assistance does not even seem to be present at all. This is an indication for what I believe to be an indication of the resilience and independent nature of such students. But also this is an indication to me that they are attempting to avoid having a perceived negative shift in their self-identities and do not want their identities spoilt as Goffman (1963) aptly describes. This study has established firmly that Australian universities had very little content in terms of publicly available support advice for students who stutter. An issue that I argue could have an effect on the decision-making for such students whether to enrol at a given Australian university or not. But having said that, this study showed that less than 2% of survey participants bothered to look online for such information. Surprisingly though even once traversing through their degree and experiencing problems with classes due to their speech, they still do not want to generally engage with support. A strategy in itself that seems solidly linked to the notion of overall identity and stigma. I propose a combination of stigmas associated with being seen by others as being disabled or in fact the avoidance of a self-identity of seeing oneself as disabled.

It is very clear from the literature that people who stutter are often viewed by others as being communicatively inferior to people who do not stutter (Gabel et al., 2004). Studies have shown these negative perceptions through a range of different ages and cultures (Craig et al., 2003; Klassen, 2001). Disability is also still commonly framed as being inferior and not as able as so called “normal” people despite a rise in advocacy and positive media (Joachim & Acorn, 2000; Staniland, 2009; Werner, 2015). These perceptions be real or not would play with the covert nature of people who stutter and who have visual speaking differences to the norm and do not want to be identified as being disabled. This thesis is the first known study to have enquired in detail directly about the notion of stuttering being a disability from large range of narratives of people who stutter themselves. As you read earlier in this thesis the divide around stuttering being a disability was very divisive in terms of opinions and expressed language around it. A finding reflected by Meltzer (2005) during her earlier study of people who were undergoing speech therapy within a support group environment. Prominent speech and language academic Charles Van Riper (1982) expressed concerns that aligning stuttering with the word “disability” could have profound consequences upon the self-identity of a person who stutters. The majority of anti-disability views this study’s participants were in the attempt to distance themselves from disability as much as possible through the use of excuses and ill-informed logic. But when studying how stuttering is accepted and can be applied to disability law, it general common sense that stuttering can fit a range of accept definitions. It is fitting at this point in the study to remind ourselves about the Australian Human Rights Commission’s (AHRC) interpretation of how stuttering applies to the federal Australian Federal Disability Discrimination Act (1992) again:

> *The definition of disability in the DDA includes "total or partial loss of the person's bodily or mental functions". Whatever the origins of a particular person's stuttering (neurological, psychological, or more direct physical causes), it is clear that speech is one of the things we do with our bodies and so partial loss of control of speech is covered* (Australian Human Rights Commission, 2009).

The simplicity of AHRC’s definition in my mind is one that can help not only people who stutter understand how stuttering can be classed as a disability, but also for people who do not stutter to understand (Meredith, 2010). But to be honest, I have written myself on the topic for the online global International Stuttering Awareness Day (ISAD) conference in 2010. This paper was well received in the stuttering world and logically set out the argument purely from a legislative view including tying stuttering back to the World Health Organisation’s definition. Yet still I am frustrated and amazed at the continual debates online and vicious personal attacks towards me due to my personal views. But this avoidance of wearing the label of “disabled” and the perceived associated stigma is leading to what appears to be a large amount of students who stutter not accessing support during their studies from pre-enrolment through to graduation out of pure rejection of the label and resulting identity. This is despite a large majority of these students agreeing that their stuttering had impeded their academic journeys and lead often to under-achievement. This is another example of strategic concessionary bargaining in which they appear to be trading off their academic achievements in order to preserve their normal (non-disabled) identities. Leading at times to some remorse about not making the most of their university experiences, but still resounding with a sense of satisfaction concerning the accomplished results. This is a significant addition to the body of knowledge itself by tying university performance for such students strongly to the rejection of the word "disability" and the possible resulting repercussions linked to aligning to its stereotypical meaning. The word "disability" itself is a strong factor blocking students who may need some assistance with their studies from doing so.

This rejection of seeking formal support appears to be emerging from the points of choosing their intended university and associated degree. But remembering again that partially based on a pre-learned assumption that no support will be available only 2% of students studied sought to seek support information pre-enrolment perhaps negates the immediate need for universities to focus directly on stuttering and more broadly on disability as a whole. I believe there is a strong case for universities to study the affirmation model of disability as proposed by Swain and French (2000) to formulate ways to positively promote disability and shape empowered identities as a result. But this study showed that once the enrolment began, then the rejection of a disability-based identity within a university context became more obvious and concessional bargaining strategies has begun. Students pre to enrolling were anxious and worried about being seen as different to their peers and were working out ways to avoid oral course requirements. Presented here is a significant paradox and dilemma which permeates through the entire student life cycle. The majority of the students studied rejected the ideal of stuttering being a disability and yet their speech problems did lead to under-achievement and lost opportunities. Actions which lend directly to established definitions of disability. This suggests that, for these students, "disability" is not bound up with speech limitations per se, or even in the impact that these limitations might have for their academic achievements, but in concern to how they may be perceived and treated. Their stuttering did in fact stop them from contributing fully to the university experience from classes to their social lives. The ripple effects of their decision-making not to out disclose and seek support negatively impacted their entire academic journeys.

From the moment of filling out the enrolment form the majority of participants rejected ticking the box which asked if they had a disability. A rejection from the very outset of their studies without seeming contemplation or negotiation. As alluded to earlier the clear set of reasons behind this concessionary bargaining was to be not seen as being any different to other students, either in label or through negotiated support. These students did not want to attract attention to themselves or be identified as being different to the norm. Sometimes this was due to the fear of the labelled identity being used against them within more prestigious degrees into the future and for others simply being unsure who and how this information would be used. But these decisions are being made squarely at the point of enrolment and not after actually engaging with broader university life. There are some thoughts that run through my mind at this stage in the discussion. You have learned throughout this thesis about the overt and passionate disconnection of students who stutter with the label and overt identity associated with being “disabled”. I strongly believe that this disconnection itself is causing a widespread problem of propagating the identity of “DisOther” amongst a large percentage of this student population.

It is highly concerning to think that if students who stutter are avoiding aligning with the term “disability”, and in turn missing out on valuable study support when required, then how many other students with a range of different disabilities are perhaps making the same disempowering decision? The numbers of which could be quite large indeed. It makes complete sense that universities have to start to frame and promote “disability” in a more positive and empowering fashion, which I think aligns well to the growingly accepted affirmation model of positive disability framing (Swain & French, 2000, 2008). Perhaps the start of solving this problem is to simply use a different term for a student to align to other than “disability”? To broadly advertise support services and then offer some descriptions of why you would access support, what broad conditions would be included and how. I can understand the need for a university at the point of enrolment to try to estimate the numbers of students that it will have to strategise to offer support for into the future. But I believe then that the option to indicate that you have a difference or condition that may affect your studies needs to be carefully thought out. Perhaps there needs to be a question around the idea of “do you foresee that you will need student support services going into your studies” with clear literature around the support process. This may encourage more students to flag the possible need for assistance in their studies as opposed to indicating having a disability.

I do believe, however, that it is wrong to simply assume that only universities have to address this problem of understanding what is meant by “disability” and providing an empowering social framing of it. As stated earlier, I believe the use of the growingly accepted “affirmation model” of disability is required to understood how to apply in this case as it relies heavily on promoting individual differences as being of value to self and society (Swain & French, 2000, 2008). Stuttering support organisations and programs need to educate their members about how stuttering in Australia can be clearly seen as a disability and how that is not a negative ideal. This will take a great deal or work and I have presented numerous times to the greater stuttering world about such ideals with mixed opinionated feedback (Meredith, 2010; Packman & Meredith, 2012). These stuttering organisations cannot ignorantly shy away from the fact that stuttering is a disability and they in turn will need support from prominent disability activists and organisations to assist to change membership opinions. The key message I give to these organisations is to make members understand how having a disability is different to being disabled by it. But for stuttering to be taken seriously by governments and society the impact and serious nature of its affect to the individual and impacted contribution to society needs to continue to be researched and the resulting findings loudly promoted.

In turn speech pathologists also need to start to introduce this idea of disability into the mindsets of children and adolescents who they treat along with positive modelling. This process itself will have to entail training for such professionals from disability organisations about how to introduce it into the beliefs of young people and to do so in a truly positive fashion. Speech pathologists themselves I believe do regard stuttering as a disability thanks to their largely medical model-orientated approach to therapy. The medical model underlays their general education and training leading to therapy with the hopeful elimination of their client’s stuttering or at least highly successful management of. So in turn the education of Speech pathologists will also have to include the inclusion of different ways of viewing and promoting stuttering beyond the idea of it being a disorder to be eliminated.

For all invested parties the accessing of support services needs to be framed as an empowering strategic decision and not about being a failure or different to others. In a fashion I propose that the current culture of university stuttering support is locked into a large vicious circle that is seemingly hard to break. Students who stutter are not generally accessing support services because they do not want to identify as being “disabled” or any less in character than “normal” people. I would argue that university support services are not seeing many such students enquiring about help. A fact that I verified for you when describing the findings of my university disability web content audit (Chapter 3. The web-based audit). As a result of this cycle it seems on the surface that related university support strategies for students who stutter appear to be lacking to be genuinely informed suffering as a result in appeal and effectiveness. The cycle of ill-informed strategic advice as a result then keeps turning around and around in isolation to the world beyond universities. As a result students who actually access Australian university support services are not feeling overly satisfied or empowered with the negotiated outcomes.

What is also interesting is the timing of when students who stutter actually ask for assistance. When they first accessed support services was generally not early in their studies at all and was commonly during their final year of their undergraduate degree.

This leads you to think more deeply about their journeys up to that stage of study and about the timing of their decisions. It seems that these students are working their way through their initial years of study without generally accessing support services and remaining mostly covert in nature. These students are dodging and weaving through their course requirements and assessment items to avoid vocal interactions and they are perfectly self-aware of these decisions and resulting repercussions of. But just how much of an impact did this environment of anxiety, stress and sacrificed grades have upon the individual student? This question is still unclear. These students at this time in this thesis are often floating within a bubble of DisOthering. The situation itself appears to be supporting and allowing for these students to be disabled, without either acknowledging it or be willing to accept it. Yet have been proven to still be successful within their chosen degrees and most of which appear to be within disciplines requiring large amounts of verbal interactions.

It is time now to divert back to the journeys of those students who stutter who actually sought university support. I proposed to you early in this discussion that the DisOthering within the university context is still occurring despite the good hearted nature of the support providers. These students are continuing to as Boehmer (2005) describes to shape-shift their identities from feelings of being able to that of contextual disability even once formal support has been sought out. The minority of students who actually sought formal support entered this realm with apprehension about what help they would receive, remembering that very little may have been offered to them in earlier education (Butler, 2013). The path through support though was in my opinion one of the most important findings within this thesis and is significantly worrying. These students had decided to take the somewhat brave step to ask for assistance perhaps out of desperation to succeed well in their final semesters of study and this option was a resort that they had avoided up until that point. The support process itself is full of vocal communication steps that require the giving of personal details and are in no form shallow in nature. It is also a process containing confusing steps for these students In terms of the process of proof and stuttering validation.

Another significant finding of this study are the set of problems identified within the journeys of such students once support has been asked for. It is incredibly disturbing to find that of the few students who asked for assistance, all of them experienced a range of negative feelings as a result. Reflected among this cohort were strong feelings of shame, embarrassment and confusion associated with a process that is meant to empower and enable. These feelings themselves may be seeding negative identity shifts within this cohort. There were also strong feeling of helplessness and ignorance around not being allowed to inform the offered support strategies. A surprising but important finding was the shifting of identity for a number of these students as a result of gaining assistance. This was a truly surprising finding because a majority of these students felt more disabled as a result of gaining assistance. This startling finding could be a pivotal point within their identity development leading to these students to as Mishler (1999) describes to question distinctly their place within a university environment and how they are perceived. This support process would have had true impact upon their identity and the way in which they viewed themselves within such a setting. So although satisfied with the results of gaining assistance the process itself appears to have been a negative identity shaping experience.

Once in class, though, the experiences of these students become even more concerning. Although it was felt that their peers cared little about their stuttering, at times they felt that their lecturers did take note with mixed reactions. There appeared to be glimpses of a disconnect between these students and their lecturers in terms of how to manage stuttering in the classroom which was also alluded to by Azio (2017). A finding in itself which this study adds to the growing body of knowledge. But there were few harrowing stories concerning negative peer feedback and this is a positive finding because although there is little evidence of this in the literature there has been a range of studies which indicated that university students generally perceived student who stutter as being socially and academically inferior (Azio, 2017; Dorsey & Guenther, 2000; MacKinnon et al., 2007). It was in terms of their academic achievement that was of major concern. The Australian university students who stutter were very open about how their concessionary bargaining strategies to avoid oral course-based requirements impacted their overall grades. There was little shame reflected over this decision-making process with only a few narrating shame and guilt. This shows a high degree of agency by these students within this setting and they appear to be in strong control of their decision-making which is generally reported within the current literature. It was clear that although not quite satisfied with this decision-making that these students were on track to achieve their degrees or had already done so. Reiterating again that their choice of degrees ranged across a broad group of discipline areas most of which seemingly required strong verbal communication skills. It is also important to note that some of these students were even brash enough to admit that they had used their stuttering as an “excuse” to get an easier path through a course. This itself is an example of a pure strategic decision, if not also unethical. But the resounding message from class-based interactions are that yes, these students are not participating to the degree that they truly would like and at times they are sacrificing grades as a result. But they are perfectly aware of their actions and resulting repercussions. They are not victims of circumstance and are actually very much in control of their academic fates. Now that I have discussed the major contribution of this study, many of which are not supported by the current body of knowledge, I will lead you through a list of recommendations that I have as a result.

Recommendations

To begin with, I will proudly say that this thesis is leading to the development of a website which will be called www.stutterversity.com to inform the invested parties about how to approach and support students who stutter studying at university. The Stutterversity website will be a major artefact arising from this study, acting as a guide for people who stutter to advise them to be proactive when at university to seek support if required and at the same time to inform the support systems in place there more authentically. This will be the first website in the world to in detail express the voices of students who stutter guiding the future of such students into university life and offering universities a unified authentic voice of experiences to draw from.

When deciding to write this section of recommendations it became overtly clear to me that there are handful of different parties to consider. As a result I have framed the recommendations within relevant groups of stakeholders each of whom can help instigate positive change towards the journeys of university students who stutter.

People who stutter

There is an obvious need for people who stutter who are thinking of enrolling within a university degree need to investigate as thoroughly as they can how their chosen university can accommodate any special needs that they may have, in ,terms of their speech. This does not have to be personally conducted and I would recommend seeking the help of the various worldwide stuttering advocacy organisations and support groups (online or face-to-face) for guidance. Often these groups will direct you to established resources and will have members willing to assist finding out more information or have been through the same experiences. I would also recommend joining various social media groups for people and students who stutter. A caveat though when searching social media for help is to look for a balanced range of opinions and keep in mind that often the negative opinions seem to be the loudest voices within topics. When investigating how a university may be able to support speech disorders in times of need, these students need to clearly have in mind what type of assistance that they may require. It important to understand though that degrees will have inherent requirements in terms of knowledge, skills and values for all students to be able to demonstrate and perform. Often these requirements are professionally accredited and mandated. If any of these inherent requirements seem troublesome then a student who stutters must engage in a conversation with degree coordinators and/or university disability support staff to understand what provisions may be available. Students with special needs though have to have expectations that are realistic in terms of accommodation and be open to a range of offered strategies. I cannot iterate enough that before enrolling talk to the degree coordinator or a senior academic in that discipline area to truly understand the communication standards and expectations that will be required of you after graduation. I have seen cases myself of students with special needs enrolling in a degree and then finding out afterwards, sometimes close to graduation, that their differences may make it hard if not near impossible to work within a given discipline area.

University students who stutter

Once enrolled students who stutter need to engage with university support services in order to inform them about stuttering and its needs. In turn this educates the support process and helps to press the need for more fruitful interventions into the future. It is important for such students to clearly understand the definition of “disability” and how stuttering applies to its definition. Although there still are common social stigmas attached to the term “disability”, by not shying from the term students who stutter may be helped to feel more empowered knowing that they are not alone and that there is a strong global disability movement. It is strategically important for universities to know as many of which students may fall under the disability definition as possible in order to budget and plan for the future of provision. Students who stutter must break the shackles of their common covert natures and not be afraid to engage with support. Without more people who stutter asking for assistance, the lack of targeted and advertised accommodation for such students will continue to be generally applied. I see it as a “vicious circle” of support unless the cycle of generally not seeking assistance changes. Students who stutter also need to actively seek accommodation and support when required breaking the sacrifice cycle of the possibility of lesser graded results by not doing so. They must understand that there will be no university discrimination or repercussions arising from asking for assistance and accommodation. There are legislative frameworks within Australian universities to guard against discrimination. To assist students who stutter related support organisations need to actively approach educational providers of all levels to assist to formulate guidelines and to widely educate educators about stuttering and potential accommodations for. Without a strong national push into the education sector the plights of students who stutter will still remain mostly hidden and not taken seriously by educators or government. But in turn such students themselves need to pressure stuttering organisations to take up their plight seriously in order to further empower their future careers beyond university.

Universities

University management need to be highly accountable to ensure that their institutions are accessible as fairly possible. They need to ensure that all web-based disability support information publicly available and is relatable to anyone in need. Universities need to provide potential and commencing students clear and inclusive definitions of what disability means, how it fits into government legislation and broad conditions that it annexes. This will ensure that they seriously strategise about how to promote "disability" more widely and inclusively to attract more students to take up support services into the future and to help their institutions to be marketed stronger in terms of accessibility. In turn, these actions also advertise serious an institution takes discrimination of any form and the processes around raising such problems. Students who stutter must not be concerned about flagging their disability in fear of reprisals from the University and associated staff. To assist this process of disclosure, universities must strongly promote inclusion and anti-discrimination procedures and policies.

Lecturers

University lecturers are at the coal-face of education being the direct conduit between the student and course content. They also work within a stressful and policy driven environment. Lecturers need to be open to the suggestions provided by both disability liaison units and students who stutter in regards to how stuttering could be and should be accommodated in class. This is not to say that lecturers should not provide their own strategies in such cases. Actually it is the contrary as they should be encourage to actively think themselves about strategies to help support student success and not threaten the legitimacy of a course's learning outcomes. They should not doubt the authenticity of students with disabilities who have been offered support provision by their University. These students have already gone through a process of validation which in some cases is not an empowering process to begin with. If lecturers feel that a student who stutters is not feeling empowered by the strategy that has been negotiated, then they should open up a dialogue with such student and together think of ways that assessment and participation needs could be accommodated more satisfyingly for all parties involved. Lecturers by their very nature should harbour a class environment which encourages the students to feel confident enough to more actively contribute to class activities and does not make the student stand-out amongst the class in these activities.

Disability liaison staff

This study has shown that a university student who stutters has an academic journey fraught with strategic decision-making and anxiety towards course-related speaking tasks. It is important for disability liaison staff that once presented with such a student they need to clearly explain and justify the steps required to gain support provision. Disability support staff need to make students who stutter fully aware of the privacy requirements which take place during this support process and that in no way would any university staff use provided information to discriminate against them. By making such students aware, it will less the impact of a perceived university system-based stigma associated with aligning to the term “disability”. As mentioned earlier the term “disability” needs to be clearly defined positively and in an empowering nature. This will require the assistance of both stuttering organisations and the wider disability movement to inform such messages. Both potential and current students need to be able to align their current life situation with a clear and easy to apply definition of “disability”. Disability support staff need to actively listen to the needs of students who stutter and do not automatically assume that they do not want to vocally interact within the classroom. In fact this study has shown that those few who do ask for assistance actually want to speak in class, but they wish to speak on negotiated terms that satisfy both themselves and also the university system. Students who stutter have reflected a feeling of pride being able to contribute in class and to related assessments despite their stuttering. Disability support staff should never suggest any strategies which remove the student's rights to speak in class situations unless the student in question clearly gives this as an option and is comfortable with the associated strategy.

In terms of negotiated strategies, it is important to ensure that as feasible as possible they do not make the student feel ashamed to implement or obviously be seen by their peers as a point of difference. Support staff need to encourage the student who stutters to speak up and be assertive about their needs, while keeping in mind the general covert nature of stuttering. Students who stutter required to understand the processes which drive support decision-making and the need to reasonably be accommodated. In terms of forming a plan to accommodate stuttering into the class, disability support staff should enquire if a student has a current or past speech pathologist that could perhaps offer quick advice about the disorder. This study has revealed that students who stutter have indicated that at times disability support officers seem to lack some general knowledge about stuttering and had not contacted a speech professional for advice.

It is important to note that this study has found a disconnection between the needs of students who stutter, offered support strategies and the opinions of such students by lecturers. As actively as possible the inclusion of academic staff into the negotiations of applied support and the provision of strategies is essential. Academics themselves must feel to be an active part of the entire process in order to be more willing to implement such strategies and to make the support process more satisfying for all involved.

Stuttering-support organisations

Finally, I believe that stuttering support organisations play a strong role within the education and support process for university students who stutter. These organisations should play a large part in assisting university students who stutter to make informed decisions and be better supported through their studies. Such organisations need to outreach to universities and offer public information sessions/presentations about stuttering in order to educate communities more. This would help to educate the general population about stuttering and also encourage people who stutter who have not accessed their support services and associated networks to maybe do so. Stuttering support organisations also need to align strongly with the term “disability” and to promote what the term means within an Australian context. These actions need to be done confidently by not portray stuttering as a defect to eliminate as framed by a medical model approach and perhaps more positively as portrayed by Swain and French’s (2000; 2008) promotion of the “affirmation model”. These actions will educate people who stutter more around the socially stigmatic definition leading to the legally framed definitions which guide and direct Australian equal opportunity legislation. It is stuttering support organisations responsibility to assist to promote evidence-based practise, policy and guidelines regardless of if they personally believe that stuttering is a disability or not. Stuttering support organisations need to be seen as proactive and connected to all forms of education in order to educate and promote. They should be knowledgeable enough to work with universities to enable a potential student who stutters to understand the general provisions of support available to them and the different steps in accessing that support if required.

Avenues for future research

When I first completed my PhD confirmation of candidature, I firmly believed that this study would without doubt contribute to the global body of knowledge and shine the light for a range additional research projects as did the confirmation panel. To add further support to my feelings was the numerous stuttering organisations which supported the need of my proposed study (*Appendix A: Letters of support*). I believe now after the writing of this thesis that without doubt this study will inspire and drive further enquiry. After a lot of thought and contemplation, I believe the following approaches for further studies that I will discuss would be of multi-disciplinary benefit to continue to assist and understand students who stutter not just at university but across different levels of education. I have thought of a large range of future study possibilities to learn more about the education journeys of students who stutter and beyond.

Firstly, I acknowledge that this study only focused on investigated the experiences of university students who stutter with an Australian educational cultural setting. To further understand more about the impact of their university experiences upon their career paths post-university longitudinal studies are required focusing on graduates who stutter while investigating their chosen career paths to see if the negative behaviour found in this study carries on through to their professional lives. For example, do they continue to avoid speaking situations, not look for accommodation for their speech or purposefully avoid promotions? It would be very important to know what challenges these graduates face once put into a real professional setting and what prejudice if any they perceive to have encountered. It is important to judge the levels of prejudicial feelings from peers and especially in the workplace, as it is the levels of support and inclusiveness on offer. How effective are Australian anti-discrimination laws? Do different work cultures and disciplines approach inclusiveness in different fashions? To apply a similar study within work settings will enable researchers to identify if the same high degree of agency and calculated strategic decision-making if applied to careers of people who stutter. It would also be important to replicate this study within the Australian setting to see if there have been any changes in the data since the three studies within this thesis were conducted.

In a similar vein, I believe that a lot more needs to be known about the experiences of students who stutter preceding university at pre to primary to secondary levels. My research has shown that at all school levels there has not been much of a research focus on the experiences of students who stutter unless you count a handful of studies focusing on peer perceptions of. In order to better empower students who stutter their full educational journeys need to be explored and in turn supported. This must include ways to enable students who stutter in being more pro-active, resilient and confident

in their educational journeys knowing that to inform the system they must be actively part of that systems.
To achieve a more holistic view of such educational experiences, the design of this study could using the same methodology could be delivered within different countries and cultures. This could result in showing some unique cultural differences between the university journeys of some students who stutter. Further such mirrored studies may show commonalities of experiences and perhaps distinct demographic differences. It would also give validity to the findings of this study if it were expanded at least in an Australian setting to look at the education experiences of students who do not stutter. This would allow a comparison between broad demographics to occur in terms of barriers to participate and factors influencing outcomes.

With my computer science background in mind, I could imagine studies looking to use social media to data-mine the large amount of existing public conversations and opinions from students who stutter when discussing their educational experiences both and present. It would be very interesting to establish how to data-mine such data and then how to analyse such data in turn extracting useful findings. It seems reasonable in knowing about the large amount of different stuttering forums and groups that exist across a wide range of social media platforms meaning that a wealth of information already exists that could be somewhat accessible and then look at ways to extract meaning from them. Likewise, I would to see more mixed-method style studies conducted to give portray more holistic views of the research question(s). I would envisage the use of both quantitative methods and qualitative methods to complement each other's findings to demonstrate a different views of the data.

It is also clear from this study that more research, education and strategising for university disability support officers needs to take place in order to better facilitate a student who stutter's needs. This would include looking at the disability support officers themselves to understand how to support them more and make them feel more satisfied when supporting such students. I believe also that more work needs to be done to understand how stuttering can clearly align with either the social or medical models of disability. In reality, though I believe for people who stutter that a new model of disability needs to perhaps be created due to their completely mixed beliefs around stuttering being frames as a disability.

In conclusion

To sum up this entire study I will express that it has become apparent that Australian university students who stutter appear to be very much in control of managing their identities and planning their journeys throughout their studies. This is not to say that they are fully satisfied with the overall final outcomes that they achieve during their studentship. But the high percentage who graduate seem to have achieved what they initially sought out to do, which was to obtain a degree in a discipline of their choosing and move into a related career path. This study has completely redefined what being a university student who stutters appears to be. These students have a strong locus of control over their studies. They are fluidly navigating their courses, included assessments and accessing support sparingly in extreme times of need. They are strongly independent during their studies and fully aware of the repercussions of their concessional bargaining in terms of how they wish to interact with classes and assessments, sometimes at the expense of sacrificed grades or social interactions. These students are not helpless victims of their stuttering and how society perceives them stereotypically to be. To better encourage these students to access university support, a more inclusive way of aligning stuttering to disability is required as is a redefining of the overall provision of support process. Just remember to not underestimate my stuttering student brethren, as you now know that they are much more confident that may be stereotypically believed. They are and will be the leaders of the future. They are, and will be, in all echelons of societies influencing and leading great changes. They are, and will be, making large positive contributions to their communities and beyond. They are confident and their academic worth should not be underestimated. They are Australian university students who stutter.

Appendices

Appendix A: Letters of support

The British
Stammering
Association

13 February 2009

Grant Meredith
Room T158
Graduate School of Information Technology and Mathematical Sciences
University of Ballarat
PO Box 663
Ballarat,
Victoria
Australia 3353

Dear Mr Meredith

Thank you very much for informing us of your project about the research into the experience of student who stammer in the Australian higher education system.

We know from analysis of our helpline services that very often it is at crucial transition points in their lives, such as moving into higher education, that people who stammer will feel the greatest need to seek help and support.

Unfortunately, we also know that very often there is very little knowledge of how to support a student in this situation. If you ask a speech and language therapist, you will find that they will not be able to give the academic teacher any specific strategies that will help and allow the student to succeed and realise achieve their full potential.

Indeed, research shows that many teachers hold negative views of the academic and intellectual capabilities of students who stammer – views that are not based on fact as we know that stammering is not an indicator of intellectual attainment.

We very much look forward to hearing the outcomes of your research. As an organisation, we have produced information and training material for teachers and school staff in primary and secondary school settings but are painfully aware of the lack of such materials for the higher education sector.

If there is anything we can do to support you in your research, e.g. with contacts to Universities in the UK, please do not hesitate to ask.

Yours sincerely

Norbert Lieckfeldt
Chief Executive

The McGuire Programme (Aust)

(Fluency And Eloquence Training For Adults Who Stutter)

PO Box 344, Balhannah, South Australia, 5242
Ph: (08) 8388 4663 Mob: 0417 864 460 Email: geoffj@internode.on.net

LETTER OF SUPPORT

To Whom It May Concern

Re: Grant Meredith - Stuttering Research

The research being conducted by Grant Meredith is important to increase the understanding of stuttering and how it affects the person who stutters.

This is especially important in tertiary institutions so that understanding and informed responses can help to attract more people who stutter into advanced study giving them the opportunity to realise their full potential.

The McGuire Programme is fully supportive of this research by Grant and will support the initiative by facilitating surveys and questionnaires within our membership.

Yours sincerely,

Geoff Johnston
REGIONAL DIRECTOR
31st October 2008

The Australian Speak Easy Association

HELPING STUTTERERS TOWARDS FLUENT SPEECH

Grant Meredith
Lecturer
Room T158
School of Information Technology and Mathematical Sciences
University of Ballarat (CRICOS Provider Number 00103D)
PO Box 663
Ballarat, Victoria Australia 3353

Dear Grant,

The Australian Speak Easy Association recognises the value of research into the understanding of and treatment for stuttering. Your proposed study into the experiences of stutterers in the higher education system would be of some value. Many of our members have degrees, and anecdotal evidence indicates that such studies were, to say the least, fraught with difficulty. My own experience with engineering is no exception.

The Association would be pleased to assist with surveys and information from members, and is supportive of your efforts in this research. We wish you every success with your project.

Yours sincerely,

Kevin Nuttall
President
Australian Speak Easy Association

**The Australian
Speak Easy
Association**

HELPING STUTTERERS TOWARDS FLUENT SPEECH

Grant Meredith
Lecturer
Room T158
School of Information Technology and Mathematical Sciences
University of Ballarat (CRICOS Provider Number 00103D)
PO Box 663
Ballarat, Victoria Australia 3353

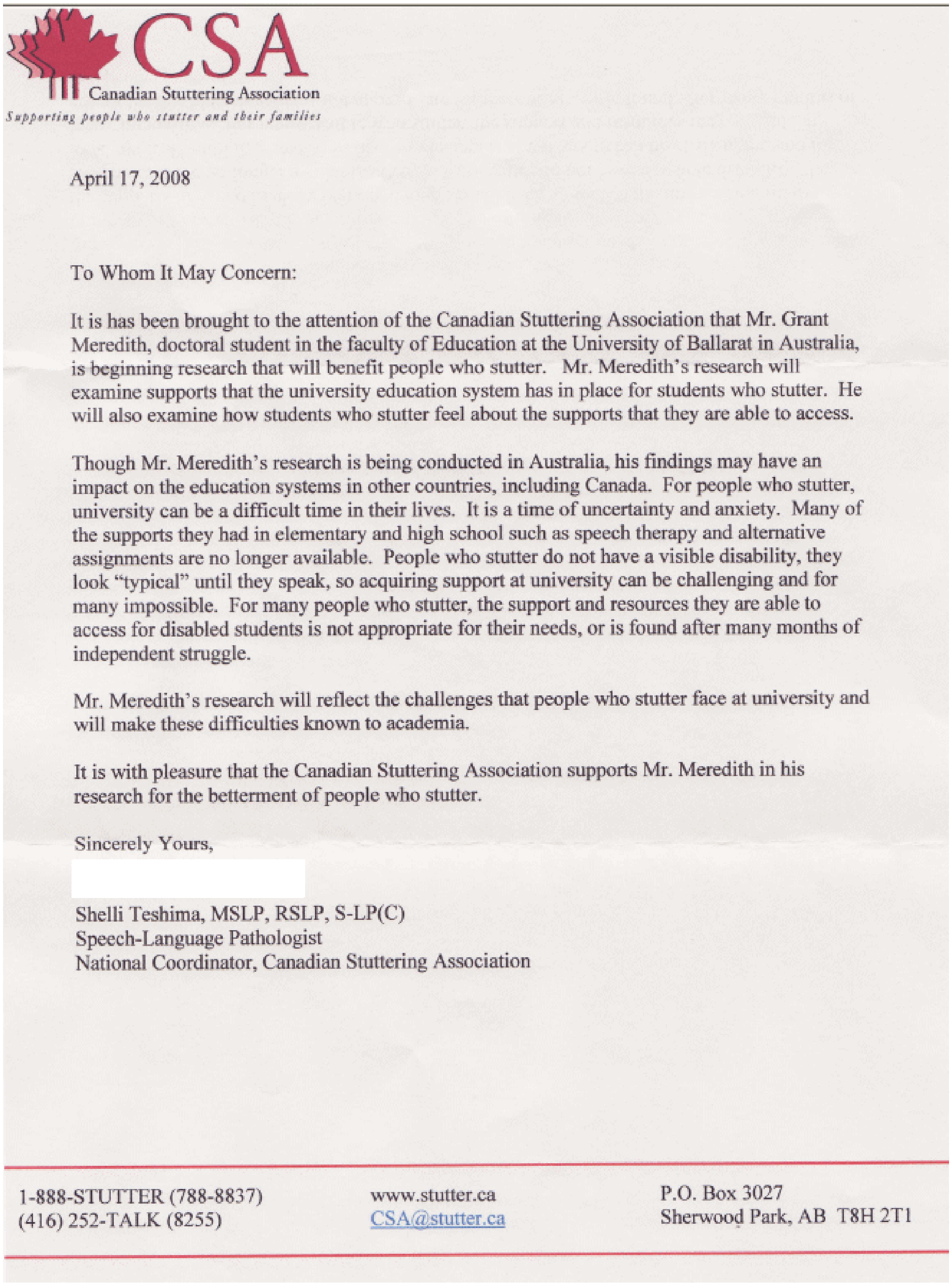
Dear Grant,

As national editor for the Australian Speak Easy Association, I fully support the need for research into the experiences of students who stutter in the Australian Higher Education System. As someone who experienced challenges during this difficult time of schooling, I recognise the value of this study.

The Association and I will be fully supportive in publishing the findings that this research will provide. I wish you every success with this project.

Yours sincerely,

Marcel Morton
National Editor
Australian Speak Easy Association



CSA
Canadian Stuttering Association
Supporting people who stutter and their families

April 17, 2008

To Whom It May Concern:

It is has been brought to the attention of the Canadian Stuttering Association that Mr. Grant Meredith, doctoral student in the faculty of Education at the University of Ballarat in Australia, is beginning research that will benefit people who stutter. Mr. Meredith's research will examine supports that the university education system has in place for students who stutter. He will also examine how students who stutter feel about the supports that they are able to access.

Though Mr. Meredith's research is being conducted in Australia, his findings may have an impact on the education systems in other countries, including Canada. For people who stutter, university can be a difficult time in their lives. It is a time of uncertainty and anxiety. Many of the supports they had in elementary and high school such as speech therapy and alternative assignments are no longer available. People who stutter do not have a visible disability, they look "typical" until they speak, so acquiring support at university can be challenging and for many impossible. For many people who stutter, the support and resources they are able to access for disabled students is not appropriate for their needs, or is found after many months of independent struggle.

Mr. Meredith's research will reflect the challenges that people who stutter face at university and will make these difficulties known to academia.

It is with pleasure that the Canadian Stuttering Association supports Mr. Meredith in his research for the betterment of people who stutter.

Sincerely Yours,

Shelli Teshima, MSLP, RSLP, S-LP(C)
Speech-Language Pathologist
National Coordinator, Canadian Stuttering Association

1-888-STUTTER (788-8837)
(416) 252-TALK (8255)
www.stutter.ca
CSA@stutter.ca
P.O. Box 3027
Sherwood Park, AB T8H 2T1

Appendix B: Glimpses of wider impact

Jennifer Roche with Grant Meredith at Hulme Hall, University of Manchester Halls of Residence.
5 September at 17:10 · Manchester, United Kingdom

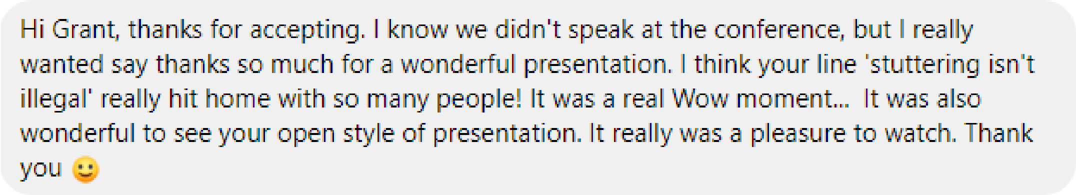
A truly wonderful keynote speaker. Many people had already told me how inspiring you had been throughout the weekend and indeed; it was magic to listen to your keynote on Sunday.
Grant, you also won the award for travelling the furthest 🏆

Gillian Rudd
@GillianRudd

The brilliant Grant Meredith @GrantMeredith1 now speaking (from Australia!) about the importance of being a proactive student who stutters. #SilenceOnCampus #getstucin

6:11 AM - 19 Jan 2019

3 Retweets 5 Likes



Hi Grant, thanks for accepting. I know we didn't speak at the conference, but I really wanted say thanks so much for a wonderful presentation. I think your line 'stuttering isn't illegal' really hit home with so many people! It was a real Wow moment... It was also wonderful to see your open style of presentation. It really was a pleasure to watch. Thank you 🙂

Appendix C: HREC ethics approval

UNIVERSITY of BALLARAT Australia

Human Research Ethics Committee

HUMAN RESEARCH ETHICS APPROVAL FORM

Principal Researcher/Supervisor:	L Angus
Associate/Student Researcher/s:	G Meredith
School/Section:	Education
Project Number:	A08-182
Project Title:	The experiences of stuttering students within the Australian higher education system
For the period:	4/12/2008 to 31/12/2009

NB: The PLS does not mention the interviews. Please amend.

Please quote the Project No. in all correspondence regarding this application.

REPORTS TO HREC:

A final report for this project must be submitted to the Ethics Officer on:
31 January 2010
www.ballarat.edu.au/ard/ubresearch/hdrs/ethics/humanethics/docs/final_report.doc

Ethics Officer
4 December 2008

Appendix D: Plain language statement

UNIVERSITY OF BALLARAT

PLAIN LANGUAGE INFORMATION STATEMENT

PROJECT TITLE: The experiences of stuttering students within the Australian higher education system.

RESEARCHERS:

- Principal Researcher: Prof. Lawrence Angus (School of Education)
- Associate supervisor: Dr. Genée Marks
- Student Researcher: Grant Meredith

EXPLANATION OF PROJECT:

The aim of this study is to understand the experiences of stuttering students in the Australian Higher Education system. Stutterers as a whole comprise around 1% of the general population, yet the focus of research into their general needs and experiences has been very limited, especially of those stutterers engaged in Higher Education based studies.

This study will provide information that will contribute to understanding the experiences of university students who stutter and it is anticipated that it will provide the basis for the development of resources for use by university disability services and other such organisations. This could help universities to encourage stutterers to enrol in their courses, become more educated and make more relevant career choices. It is anticipated that this will have a ripple effect beyond their professional lives and into their personal lives.

You are invited to participate in this study. To be eligible to participate you must be currently enrolled in an Australian university degree course or have been enrolled in an Australian degree course within the past ten years. You will be invited to complete a written questionnaire, which will take a maximum of 45 minutes, and to complete and return the questionnaire as soon as possible in the provided stamp self addressed envelope. At the completion of the survey you will be further invited to contact and participate in a one-on-one interview with the student researcher at a future date/place/time to be negotiated. Participation in this interview will be purely voluntary. To maintain your anonymity you are asked not to include any identifying details on the questionnaire. Information from completed questionnaires will be stored in a password-protected database, and only aggregate data will be used to report results. Participation in this study is voluntary and you may withdraw from participating at any time during data collection. However, after you have completed and submitted the survey, it will not be possible to withdraw as the data you submit will not be able to be identified. It is not anticipated that answering the questionnaire will cause any psychological or emotional distress. Results will be disseminated at conferences and/or be published in professional journals in the future.

You must be over 18 years of age to participate in this research. By submitting the survey, you are stating that you are over 18 years of age and give consent for the information submitted to be included in this study. If you feel that any of the questions in this survey have disturbed you may contact the 24 hour counselling service Lifeline at phone number 131114 or via their website as http://www.lifeline.org.au/ .

This study has approval from the Human Research Ethics Committee and once the results of the study are available they will be issued to both the Australian Speak Easy Association and the Australian McGuire Program to be shared amongst their members.

If you have any questions, or you would like further information regarding the project titled "*The experiences of stuttering students within the Australian higher education system*", please contact the Principal Researcher Prof. Lawrence Angus of the School of Education on telephone number 5327 9741 or email l.angus@ballarat.edu.au

Appendix E: Survey design

Research Survey

Section 1: Demographics

1. **Do you consider stuttering to be a disability?** ○ Yes ○ No
    a. Please elaborate on your answer

2. **Gender:** ○ Male ○ Female

3. **How old were you when you first enrolled at a university? (please round your age to the nearest year)**

4. **In what year (approximately) did you first enrol**?

5. **If you are not currently enrolled in a university course then in what year did you finish your studies?**

6. **How severe would you have rated your stutter in general whilst you were studying at university?**

    ○ Mild ○ Moderate ○ Severe

7. **Do you consider yourself in general to be a covert or an overt stutter?**

(To help you answer this consider a "covert" stutterer as one who employs complex strategies to try to hide or mask their stutter. An "overt" does not)

○ Covert ○ Overt

8. **In what field(s) was/is your main focus of academic study in?**

9. **Did you stutter influence your decision to pursue this field?** ○ Yes ○ No
    a. Please elaborate on your answer

Section 2: Upon Enrolment

10. Did you seek information before you enrolled about how the university could accommodate your stuttering? ○ Yes ○ No

If you answered YES then please proceed through the following questions. If you answered No then please elaborate on the reason for this in the space provided below and go directly to question **11**.

a. How did you initially find this information? (tick as many as apply)

- ☐ University website
- ☐ Email contact with a disability services officer
- ☐ Phone discussion with a disability services officer
- ☐ Personal discussion with a disability services officer
- ☐ From another stutterer
- ☐ From a university staff member
- ☐ University based printed material
- ☐ Other (Please indicate)

b. Please indicate the extent to which you agree or disagree with the following statements.

b1. I was satisfied with the disability support information given to me prior to enrolment.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

b2. The disability support information that I was given before enrolment did not influence my decision to enrol at a particular university.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

You are welcome to elaborate your thoughts on any of these questions in the “Extended Answers” section at the end of this survey.

11. **Did you disclose your stuttering in the enrolment form?** ○ Yes ○ No

    a. If you answered “Yes” then please elaborate your feelings about making this initial disclosure. If you answered “No” then please elaborate why you did not.

Section 3: University Disability Services

12. **Did you at any stage after enrolment ask your university’s disability services for help?**

    ○ Yes ○ No

If you answered YES then please proceed through the following questions. If you answered No then please elaborate this in the space provided below and then proceed directly to question **42**.

12a. How far into your academic course did you first ask for assistance?

○ within your first 6 months ○ 6 months – 1 year ○ 2nd year ○ 3rd year or higher

13. **For what specific reason(s) were you seeking the assistance of disability services for your stutter? (tick as many as apply)**

☐ In class oral presentation
☐ Oral participation in a lab/tutorial class
☐ Oral based examination
☐ Practical based oral task
☐ Other (Please indicate)

14. Did you have to prove to a disability services officer that you had a speech impairment?

○ Yes ○ No

a. If so how?

b. Describe how this process made you feel

15. Did you have to prove to anybody other than a disability services officer that you had a stutter?

○ Yes ○ No

a. If so how?

b. Describe how this process made you feel

To what extent do you agree with the following statements?

You are welcome to elaborate your thoughts on any of these questions in the "Extended Answers" section at the end of this survey.

16. I felt very uncomfortable disclosing my stutter to a disability services officer.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

17. I felt personally empowered by this disclosure.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

18. The formal labeling that I was "disabled" made me feel very uncomfortable.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

19. I did not feel any embarrassment with disclosing to disability services that I had a stutter.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

20. I felt ashamed about disclosing my stutter to disability services.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

21. Did you consider yourself to be "disabled" by your stutter before this disclosure to disability services?

○ Yes ○ No

Please elaborate your thoughts on this question

To what extent do you agree with the following statements?

You are welcome to elaborate your thoughts on any of these questions in the "Extended Answers" section at the end of this survey.

22. I had never viewed myself as being "disabled" until I had to formally disclose my stuttering to a disability services officer.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

23. I felt more disabled after disclosing my stutter to a disability services officer than I did before disclosing.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

24. The disability services officer seemed to be genuinely concerned about my stuttering and related problems.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

25. I felt under time pressures to answer the questions posed to me by the disability services officer about my stutter

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

26. The disability services officer was not open to my own suggestions about possible strategies to help support my stutter during class times

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

27. The disability services officer was very knowledgeable about the effects of stuttering on the individual.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

28. What strategies were suggested by disability services to address your stuttering related issues?

29. What suggestions would you make to disability services to make the whole process of disclosure and assistance provision more friendly, efficient and beneficial?

30. At any stage of your university life did a non-disability services university staff member recommend to you that you go to disability services for help?

○ Yes ○ No

a. If you answered “Yes” then what was your reaction to this offer for assistance?

31. At any stage as a student did you ask a university staff member other than a disability services officer for help?

○ Yes ○ No

a. If you answered “Yes” then what was their reaction to your plea for help?

Section 4: In Class

32. Did you choose to implement, during classes, the strategies suggested to you by disability services?

○ Yes
○ No (go directly to Question **38**)

To what extent do you agree with the following statements?

You are welcome to elaborate your thoughts on any of these questions in the "Extended Answers" section at the end of this survey.

33. Academic staff were not open to implementing strategies to accommodate my stutter as suggested by disability services.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

34. I was satisfied with the strategies suggested by disability services that were put into effect.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

35. The strategies suggested to me did not make me feel empowered in class situations.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

36. The strategies suggested to me lessened my anxieties about stuttering in class situations.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

37. The suggested strategies that I decided to undertake made me stand out from other students in class situations.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

38. The strategies suggested to me complemented the strategies that I had learned in the speech therapy and/or in other programs or support groups.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

39. What strategies would you liked to have had at your disposal that were not suggested to you?

40. Did a disability services officer at any stage ask if you had had any, or were currently engaged in any form of therapy for your stutter?

○ Yes ○ No

a. If “**yes**” then did the disability services officer in any way try to accommodate the techniques and strategies that you may have been taught in therapy?

41. To the best of your knowledge did the disability services officer at any stage contact your therapist/coach/support group for advice?

○ Yes ○ No

a. If “**yes**” then do you think this advice helped the disability services officer decide on a course of action for you?

To what extent do you agree with the following statements?

You are welcome to elaborate your thoughts on any of these questions in the “Extended Answers” section at the end of this survey.

42. My stutter has had a negative impact on my general academic performance.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

43. I have purposely sought out class-based tasks that require little speaking.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

44. I did not verbally participate in all class-based activities.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

45. I have purposely used my stutter as a way of avoiding an assessment task even though I felt I could successfully complete it.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

46. I have never purposely used my stutter as a way of getting an easier road through a subject.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

Section 5: Overall

47. Do you think that disability services staff at your university should have had more understanding about stuttering and related issues?

○ Yes ○ No

Please elaborate on your answer

To what extent do you agree with the following statements?

You are welcome to elaborate your thoughts on any of these questions in the "Extended Answers" section at the end of this survey.

48. My stutter has never hindered my participation in my academic life.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

49. My stutter has impacted negatively upon my overall academic results.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

50. I believe that some of my lecturers underestimated my academic ability because of my stuttering.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

51. I do not believe that some of my fellow students underestimated my academic ability because of my stuttering.

○ Strongly agree ○ Agree ○ Neither agree nor disagree ○ Disagree ○ Strongly disagree

52. Think of 5 tips you would give to help lecturers teach and assess stuttering students. Feel free to add more.

1.

2.

3.

4.

5.

Section 6: Stuttering Impact

To what extent do you agree to the following statements? If you need extra space then please use the “Extended Answers” section at the end of this survey. Your extended responses would be highly valued.

53. “On occasion I neglect my own health to save talking to a medical professional”

○ Agree ○ Disagree

Please elaborate:

54. “If my stutter disappeared overnight I would approach the new day with a sense of fear”

○ Agree ○ Disagree

Please elaborate:

55. **“If a cure for stuttering was found today I would eagerly take it even if it meant a 10 year reduction of my life span”**

○ Agree ○ Disagree

Please elaborate:

56. **“The anxiety involved with the thought of stuttering throughout each day is worse to me than the stutter itself”**

○ Agree ○ Disagree

Please elaborate:

57. **“Stuttering was a major influence on the type of employment that I have undertaken since graduation”**

○ Agree ○ Disagree ○ I have not graduated yet

Please elaborate:

58. “I dropped out of university because of the problems that my stutter was causing me in class”

○ Agree ○ I dropped out because of other reasons ○ I am still studying ○ I successfully graduated (please indicate at what level e.g. Bachelor, Masters etc.)

Please elaborate:

Completion of Survey

Thank you for completing this survey. Your time and effort are highly appreciated.

INTERVIEW
Would you be willing to participate in a one-on-one interview to discuss the issues covered in this survey more personally?

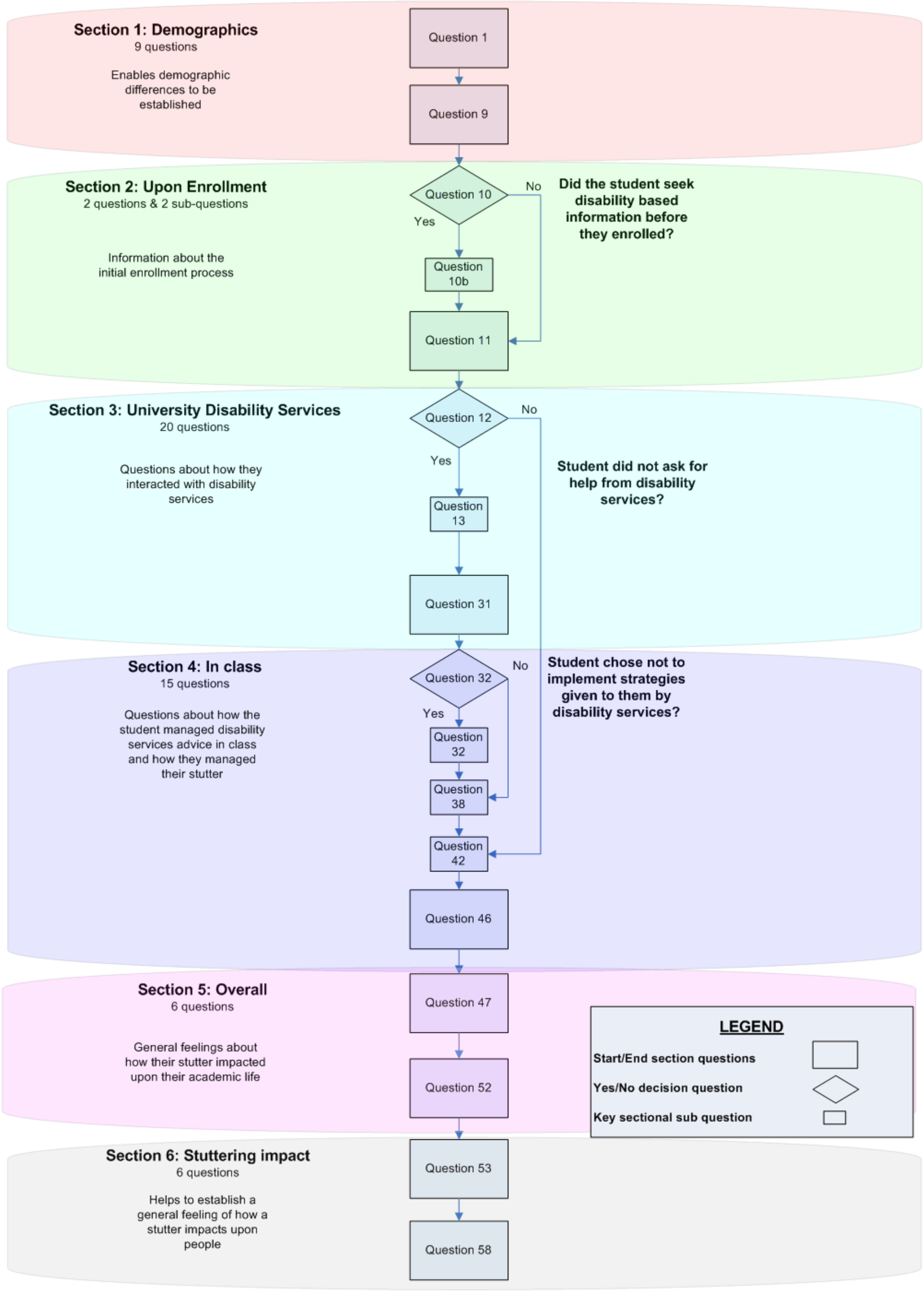
○ Yes ○ No

If you answered “YES” then could you please contact the student researcher at your leisure via any of the methods outlined below to discuss the possibility and requirements of a future interview.

Grant Meredith
Phone (W): (03) 5327 9808
(M): 0423 236 360
Email: g.meredith@ballarat.edu.au
Postal: Grant Meredith, C/O The Graduate School of ITMS, PO Box 663, Ballarat, Victoria, Australia 3353

Survey Finished – Thank you for your time and effort

Appendix F: Survey flowchart



Appendix G: Interview schedule

Please note that this list of conducted interviews is presented in order of initial interview date conducted.

Pseudonym	**State Location***	**Date conducted**	**Date draft sent**	**Date draft confirmed**	**Interview method**
Nigel	QLD	7/09/2009	18/09/2009	22/09/2009	Skype
Arthur	VIC	7/09/2009	25/09/2009	15/10/2009	Home phone
Timothy	NSW	14/09/2009	30/09/2009	26/10/2009	Mobile phone
Malcolm	VIC	12/10/2009	25/10/2009	2/11/2009	Face-to-face
Susan	NSW	21/10/2009	22/10/2009	28/10/2009	Home phone
Conrad	VIC	12/11/2009	2/12/2009	7/12/2009	Skype
Stuart	SA	12/11/2009	30/11/2009	12/12/2009	Home
James	NSW	18/11/2009	25/11/2009	28/11/2009	Skype
Jodie	TAS	18/11/2009	1/12/2009	11/12/2009	Skype
Mary	SA	19/11/2009	20/11/2009	20/12/2009	Skype
Hasaan	VIC	25/11/2009	26/11/2009	28/11/2009	Home phone
Trevor	QLD	7/12/2009	11/12/2009	16/12/2009	Home phone
Justin	NSW	15/12/2009	16/12/2009	17/12/2009	Skype
Cameron	QLD	16/12/2009	17/12/2009	20/12/2009	Mobile phone
Dave	WA	20/12/2009	21/12/2009	22/12/2009	Skype

*State abbreviations:

- NSW = New South Wales;
- QLD = Queensland;
- SA = South Australia;
- TAS = Tasmania;
- VIC = Victoria;
- WA = Western Australia.

Appendix H: HREC final report

1) Project Details:

Project No:	A08-182
Project Name:	The experiences of stuttering students within the Australian higher education system

2) Principal Researcher Details:

Full Name:	Prof Lawrence Angus
School/Section:	School of Education
Phone:	5327 9741
Fax:	N/A
Email:	l.angus@ballarat.edu.au

3) Project Status:

Please indicate the current status of the project:	
☒ Data collection complete **Completion date:**31/12/09	☐ Abandoned **Please give reason:**

4) Special Conditions:

If this project was approved subject to conditions, were these met?		
☐ N/A	☒ Yes	☐ No *** NB: If 'no', please provide an explanation:**

5) Changes to project:

Were any amendments made to the originally approved project?	
☐ No	☒ Yes *** NB: Please provide details:**

	An addition of a new project team member and minor question changes

6) Storage of Data:

Please indicate where the data collected during the course of this project is stored:
On a password protected university server

7) Research Participants:

Were there any events that had an adverse effect on the research participants?	
☒ No	☐ Yes *** NB: Please provide details:**

8) Summary of Results:

8.1. Please provide a short summary of the results of the project (no attachments please):
The findings of this study indicated a large disconnect between students who stutter and the term “disability”. With most of the students refusing to flag their stuttering as a disability on the enrolment form or to ask university-based disability services for assistance during their student life. For those few students who did ask university disability liaison officers for help they generally then found the processes following to be confusing, disheartening and strategically restrictive. Often being unsatisfied with the in-class strategies offered to them to better facilitate their stuttering and felt that the offered strategies did not support any speech or program-based therapy that they had undertook. Students who stuttered in general admitted to using avoidance strategies and sacrifice to avoid potentially embarrassing situations in class. These strategies sometimes impacted negatively individual assessment marks in order to simple gain an overall course pass while feeling under-estimated by university lecturing staff. The majority of these students also admitted that stuttering did negatively impact their studies and university life beyond.

It is clear from this study that the term “disability” needs to be clearly defined and advertised to that less negative stigma is social attached to it. If universities did this then it would encourage more students, including students who stutter, to access support services. Australian universities also need to promote more openly and clearly they disability support services on the World Wide Web so that potential students can make an informed decision about what support services are on offer to the at a given university. People who stutter themselves need to be educated about what disability means and how university-based disability services can help support them. Considering that students who stutter openly admit that their stuttering is negatively affecting their academic performance then these support services must be made more inviting to access, be steered through via process and flexible in possible strategies to assist.

8.2. Were the aims of the project (as stated in the application for approval) achieved? Please provide details.

The aims of this study were all fulfilled with a comprehensive understanding emerging of the experiences of Australian university students who stutter.

9) Feedback:

The HREC welcomes any feedback on:

- **difficulties experienced with carrying out the research project; or**
- **appropriate suggestions which might lead to improvements in ethical clearance and monitoring of research.**

N/A

10) Signature/s:

Principal Researcher:	…………………………….. Print name:	**Date:**	
Other/Student Researchers:	Print name: Grant Meredith	**Date:**	30/10/2010
	……………………………. Print name:	**Date:**	

Appendix I: Web-based audit university List

Abbreviation	University	URL
ACU	Australian Catholic University	http://www.acu.edu.au/
ADELAIDE	University of Adelaide	http://www.adelaide.edu.au/
ANU	Australian National University	http://www.anu.edu.au/
BALLARAT	University of Ballarat	http://www.ballarat.edu.au/
BOND	Bond University	http://www.bond.edu.au/
CANBERRA	University of Canberra	http://www.canberra.edu.au/home/
CDU	Charles Darwin University	http://www.cdu.edu.au/
CQU	Central Queensland University	http://www.cqu.edu.au/
CSU	Charles Sturt University	http://www.csu.edu.au/
CURTIN	Curtin University	http://www.curtin.edu.au/
DEAKIN	Deakin University	http://www.deakin.edu.au/
ECU	Edith Cowan University	http://www.ecu.edu.au/
FLINDERS	Flinders University	http://www.flinders.edu.au/
GRIFFITH	Griffith University	http://www.griffith.edu.au/
JCU	James Cook University	http://www.jcu.edu.au/
LATROBE	Latrobe University	http://www.latrobe.edu.au/
MACQUARIE	Macquarie University	http://www.mq.edu.au/
MELBOURNE	Melbourne University	http://www.unimelb.edu.au/
MONASH	Monash University	http://www.monash.edu.au/
MURDOCH	Murdoch University	http://www.murdoch.edu.au/
NEWCASTLE	University of Newcastle	http://www.newcastle.edu.au/
QUEENSLAND	University of Queensland	http://www.uq.edu.au/
QUT	Queensland University of Technology	http://www.qut.edu.au/
RMIT	RMIT University	http://www.rmit.edu.au/
SCU	Southern Cross University	http://www.scu.edu.au/
SWINBURNE	Swinburne University	http://www.swinburne.edu.au/
SYDNEY	University of Sydney	http://sydney.edu.au/
UNDA	University of Notre Dame	http://www.nd.edu.au/
UNE	University of New England	http://www.une.edu.au/
UniSA	University of South Australia	http://www.unisa.edu.au/
UNSW	University of New South Wales	http://www.unsw.edu.au/
UOW	University of Wollongong	http://www.uow.edu.au/index.html
USC	University of the Sunshine Coast	http://www.usc.edu.au/
USQ	University of South Queensland	http://www.usq.edu.au/
UTAS	University of Tasmania	http://www.utas.edu.au/
UTS	University of Technology Sydney	http://www.uts.edu.au/
UWA	University of Western Australia	http://www.uwa.edu.au/
UWS	University of Western Sydney	http://www.uws.edu.au/
VU	Victoria University	http://www.vu.edu.au/

Appendix J: Common K-12 based tips

Don't tell the child to slow down or "relax.", “think before you speak" "take a deep breath" "stop and start over	SFA, YS, NSA, MP, CCBW, R&R, AT
Don't complete words or finish sentences for the child or talk for him or her.	SFA, YS, NSA, MP,
Help all members of the class learn to take turns talking and listening. All children -- especially those who stutter -- find it much easier to talk when there are few interruptions and they have the listener's attention. Allow plenty of time for student to talk	SFA, YS, BSA, MP, CWP, CCBW,
Expect the same quality and quantity of work from the student who stutters as the one who doesn't.	SFA, YS, CWP
Speak with the student in an unhurried way, pausing frequently. A model of a relaxed and unhurried speech style. Do not model slow speech.	SFA, YS, NSA, SEC, R&R
Convey that you are listening to the content of the message, not how it was said	SFA, CCBW
Have a one-on-one conversation with the student who stutters about needed accommodations in the classroom. Respect the student's needs but do not be enabling.	SFA, SEC, iStutt
Don't make stuttering something to be ashamed of or is a big deal. Talk about stuttering just like any other matter.	SFA, YS, MP, SEC,
Use facial expressions and body language to let the child know you are interested in the content of what he is saying, not how he is saying it	YS, NSA, AT
Keep the child talking so he encounters positive speaking experiences Know that the child will experience greater disfluency at times, especially when tired or stressed	YS, MP, SEC,
Work with the speech pathologist, the child and the child's family	YS, NSA, MP, SEC, CCBW,
Respect the child s decision to participate or not to participate in verbal activities in class	YS, SEC,
Maintain normal eye contact	NSA, MP, SEC, CCBW, R&R
Reduce the number of questions that you ask	BSA,
Don't ask the student to substitute an easy word for a hard one as this will only increase the fear of certain words and phrases.	MP
Keep class predictable and comfortable	CCBW
Do not pretend that the fluency does not exist	R&R
Do not be unusually attentive during times of disfluency	R&R
When asked to be reading aloud call on the child first to decrease anticipation	AT
Encourage the student to indicate to you in some fashion when they are comfortable to speak out aloud	AT
Educate the class if required	AT
Change teaching habits to eliminate time pressure for verbal answers	AT

AT – Atlanta Stuttering Specialists.
BSA - British Stammering Association.
CCBW – Cooper, Chmela, Bennett & Williams.
CWP - Stuttering Centre of Western Pennsylvania
iStutt – Latrobe iStutter
MP – Marie Poulos
NSA – National Stuttering Association
R&R – Rind and Rind
SEC – Speak Easy Canada
SFA – Stuttering Foundation of America
YS – Youthsspeak

Appendix K: Common Australian higher education based tips

Give students the opportunity - but do not compel them - to speak in a group situation.	ANU
Allow students the time they need to express themselves, without interrupting them by filling in gaps in their speech. Don't be reluctant to ask a student to repeat a statement and don't make assumptions on what has been said.	ANU, QUT, SYD
Address students naturally. Don't assume that they cannot hear or comprehend. Difficulty with speech and communication does not necessarily mean the thinking process is faulty or they cannot hear or comprehend.	ANU, QUT, SYD
Consider course modifications, such as one-to-one presentations or a typed presentation read by another student	ANU
Check whether the person uses an alternative communication system/aid e.g. Cannon Printer.	ANU
Maintain eye contact.	ANU, QUT
If difficulties are holding up the flow of the class after a reasonable time, suggest student meets with you after class to discuss the points.	ANU
If you think that the student may like some help - offer and accept the response given.	
Ask a student to repeat a question if you do not understand	ANU, SYD
Provide opportunities for - but do not compel - the student to speak in a group situation.	SYD
Patience is the most effective strategy in teaching students with speech disabilities.	SYD

ANU – Australian National University
QUT – Queensland University of Technology
SYD – Sydney University

Appendix L: Frequency of survey expanded responses

Question 11: Did you disclose your stuttering in the enrolment form?	49
Question 10: Did you seek information before you enrolled about how the university could accommodate your stuttering?	45
Question 12: Did you at any stage after enrolment ask your university’s disability services for help?	39
Question 1: Do you consider stuttering to be a disability?	37
Question 52: Think of 5 tips you would give to help lecturers teach and assess stuttering students. Feel free to add more.	37
Question 09: Did you stutter influence your decision to pursue this field?	34
Question 47: Do you think that disability services staff at your university should have had more understanding about stuttering and related issues?	30
Question 53: On occasion I neglect my own health to save talking to a medical professional	29
Question 54: If my stutter disappeared overnight I would approach the new day with a sense of fear	26
Question 55: If a cure for stuttering was found today I would eagerly take it even if it meant a 10 year reduction of my life span	23
Question 56: The anxiety involved with the thought of stuttering throughout each day is worse to me than the stutter itself	22
Question 57: Stuttering was a major influence on the type of employment that I have undertaken since graduation	16
Question 14b: Did you have to prove to a disability services officer that you had a speech impairment? Describe how this process made you feel.	14
Question 15b: Did you have to prove to anybody other than a disability services officer that you had a stutter? Describe how this process made you feel	14
Question 28: What strategies were suggested by disability services to address your stuttering related issues?	14
Question 29: What suggestions would you make to disability services to make the whole process of disclosure and assistance provision more friendly, efficient and beneficial?	14
Question 39: What strategies would you liked to have had at your disposal that were not suggested to you?	14
Question 44: I did not verbally participate in all class-based activities.	13
Question 15a: Did you have to prove to anybody other than a disability services officer that you had a stutter? If so how?	10
Question 32: Did you choose to implement, during classes, the strategies suggested to you by disability services?	10
Question 14a: Did you have to prove to a disability services officer that you had a speech impairment? If so how?	7
Question 21: Did you consider yourself to be “disabled” by your stutter before this disclosure to disability services?	7
Question 51: I do not believe that some of my fellow students underestimated my academic ability because of my stuttering.	7
Question 43: I have purposely sought out class-based tasks that require little speaking.	5
Question 48: My stutter has never hindered my participation in my academic life.	5
Question 46: I have never purposely used my stutter as a way of getting an easier road through a subject.	4
Question 49: My stutter has impacted negatively upon my overall academic results.	4
Question 58: I dropped out of university because of the problems that my stutter was causing me in class	4
Question 42: My stutter has had a negative impact on my general academic performance	3
Question 20: I felt ashamed about disclosing my stutter to disability services.	2

Question 31: At any stage as a student did you ask a university staff member other than a disability services officer for help?	2
Question 45: I have purposely used my stutter as a way of avoiding an assessment task even though I felt I could successfully complete it.	2
Question 13: For what specific reason(s) were you seeking the assistance of disability services for your stutter? (tick as many as apply)	1
Question 26: The disability services officer was not open to my own suggestions about possible strategies to help support my stutter during class times	1
Question 27: The disability services officer was very knowledgeable about the effects of stuttering on the individual.	1
Question 30: At any stage of your university life did a non-disability services university staff member recommend to you that you go to disability services for help?	1
Question 36: The strategies suggested to me lessened my anxieties about stuttering in class situations	1
Question 38: The strategies suggested to me complemented the strategies that I had learned in the speech therapy and/or in other programs or support groups.	1
Question 40: Did a disability services officer at any stage ask if you had had any, or were currently engaged in any form of therapy for your stutter?	1
Question 50: I believe that some of my lecturers underestimated my academic ability because of my stuttering.	1
Total responses	536

Abbreviations

ABS: *Australian Bureau of Statistics.*

AHRC: *Australian Human Rights Commission.*

ANSWD: *Australasian Network of Students with Disabilities.*

ANU: *Australian National University.*

ASCED: *Australian Standard Classification of Education.*

ASEA: *Australian Speak Easy Association.*

ASHA: *American Speech-Language-Hearing Association.*

ASRC: *Australian Stuttering Research Centre.*

ATA: *Applied Thematic Analysis.*

AVCC: *Australian Vice-Chancellor's Committee.*

BSA: *British Stammering Association.*

CAPS: *Canadian Association for People who Stutter.*

CIAO: *Centre for Informatics and Applied Optimization.*

DAP: *Disability Action Plan.*

DDA: *Commonwealth Disability Discrimination Act of 1992.*

DSE: *Disability Standards for Education, 2005.*

DSO: *Disability Liaison Officer.*

GPA: *Grade Point Average*

HREC: *Human Ethics Committee.*

ICF: *International Classification of Functioning, Disability & Health.*

ISA: *International Stuttering Association.*

ISAD: *International Stuttering Awareness Day.*

K-12: *Kindergarten to Year 12.*

NSA: *National Stuttering Association.*

PWS: *Person Who Stutters.*

QUT: *Queensland University of Technology.*

SDAC: *Survey of Disability, Ageing and Carers.*

SFA: *Stuttering Foundation of America.*

SLP: *Speech & Language Pathologist.*

SWS*: Student Who Stutters.*

TATS: *Teacher Attitudes Towards Stuttering Inventory*.

TEPPS: *Technologies for Empowering People for Participation in Society programme.*

UKDDA: *Disability Discrimination Act (UK).*

VAK: *Visual-Auditory-Kinesthetic*.

WHO: *World Health Organisation.*

WWW: *World Wide Web*.

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