The Significance of Staff Decision Making and Awareness
in Acquired Brain Injury Outreach Contexts

Suzanne Leigh Snead, M.S.

Doctor of Philosophy
August 2004
I hereby certify that the work embodied in this thesis is the result of original research and has not been submitted for a higher degree to any other University or Institution.

Signed: _____________________________________________________________
Acknowledgments

“Nothing worth having comes with out some kind of fight,
You’ve got kick at the darkness until it bleeds daylight” - Bruce Cockburn

At the risk of scaring off future PhD scholars, the above quote summarizes my feelings about the past three and half years. It has been a struggle - from my days in as a therapeutic recreational therapist in outreach practice to grappling with the intricacies of this weird insane endeavor called postgraduate research. Why on earth does anyone put themselves through this? Ah, but while the lows may sometimes be low, the highs are high. The joy of when an idea clicks and suddenly new information is revealed in a way you never dreamed, the excitement and stimulation of intelligent discussion and debate with colleagues and mentors, the amazement of going from “I can’t write 300 pages on anything!” in my early days to now looking at a cohesive thesis of 300 pages and thinking, “Wow, I wrote *that*!” I have numerous people to thank and embrace for supporting me on this adventure.

Foremost to Kevin Lyons, supervisor extra ordinaire and all around good Aussie bloke. Your guidance and encouragement kept me on track, and your friendship is irreplaceable. And hey, we didn’t kill each other! Good job, cap’n! Also thanks to Wendy Gunthorpe and Ros Giles, who each “bookended” the project. You both brought fresh perspectives to the research, challenged me to expand my own perspective and enriched the research.

Thanks to all the participants in the research, who shared their time and thoughts with me, and the organizations which permitted me to seek volunteers from their staff. You guys are the ones out there making it happen. Thanks for your dedication and honesty.

Thanks to John Davis, my friend and mentor. You have offered unwavering support, encouragement, and been my biggest fan, which flatters me beyond belief. I miss working with you, and I am counting the days until you take that sabbatical in Australia.

Thanks to Rick Green, also my friend and mentor. I wouldn’t have even dreamed of pursuing a PhD if I hadn’t been so inspired by your teaching and supportive encouragement. This whole thing, therefore, is all your fault! You’ve created a monster.

To my Newcastle/Aussie family, and I fear if I start to list names here, I will leave someone out as well as incriminate a few people! You all know who you are - fellow postgrads, neighbours, flatmates, friends, colleagues. Thanks for feeding me, loaning me furniture, giving me a lift, inviting me over, including me, listening to me, and supporting me. One of the reasons I love Australia so much is because of you mob!
To any **Australian who pays taxes** - a big thank you. Your government supplied the full scholarship that enabled to come Down Under to study in, live in, and explore this amazing country. Support your local ABC.

Thanks to **Shaun and the SMOWAH gang** - one of the most important factors in completing a thesis is the respite you take from it. Thank you for allowing me to embark on a “second career”, for providing an exciting distraction, and being a general fun bunch (of BANANAS!) We miss you, Meatboy.

**BIGGEST, HUGHEST, MOST ENORMOUS LOVE AND GRATITUDE** to my family - **Mom, Dad, and my sister**. You have always supported me in whatever I have chosen to do, and I couldn’t have done any of the things I have done in my life without the independence you taught me and the confidence you gave to me. I love you, always.

Finally, a **special thank you to all the clients with ABI and other disabilities I have known and worked with over the years**. You have taught me to think outside of myself, to practice patience and compassion, and inspired me to try and do something to “change the system”. Because at the end of the day, we all just want to live our lives the way we want to, not as others tell us. This work is for you. I hope it makes a difference.
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**Introduction**

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Abstract

Staff who work in front line, direct contact support positions with community based clients with acquired brain injuries (ABI) hold unique responsibilities, and face unique challenges in their work due to the combination of three key factors: autonomous work environments, socially sanctioned power status over clients, and the decision making deficits of clients with ABI. These factors further contribute challenges to staff in the presently complex and ambiguous outreach context, where the embedded ideologies of the medical model of treatment remain in tension with the purported ideologies of the social model of disability and client self determination that drive outreach services. Using constructivist grounded theory methods and narrative and interpretive analysis strategies, this research interviewed fifteen (15) ABI outreach support workers to explore and examine their perceptions of the outreach context, how they negotiate decision spaces, and how they deal with the central ethical dilemma of outreach - achieving balance between their duty of care and the client’s dignity of risk. The thesis documents decision making strategies used by the interview participants, examines the factors that influence their decision space when in the field with clients, and explores the role staff awareness of professional and personal values plays in making decisions in the best of interest of the client. Staff awareness is shown to be a critical, yet oft neglected factor in consideration of staff ethical decision making in ABI outreach. Implications for best practices in the field are discussed.
The Significance of Staff Decision Making and Awareness in Acquired Brain Injury Outreach Support

Chapter One

Chapter Abstract

This chapter introduces the main themes of this thesis. Foremost is the concept that members of front line staff working in outreach contexts are in a position of power over clients with acquired brain injury (ABI). The power in this capacity is potentially exacerbated by the diminished ability of some clients with ABI to be self determined or to make autonomous decisions due to the nature of their cognitive impairment. The autonomy of the outreach environment means the burden of responsibility is upon the staff members to make ethical decisions in the best interest of the client. However, the nature of decision making itself is a subjective, biased process. It is established in the literature from related helping professions that staff awareness of personal values, professional ethics, and ideological tensions are essential elements in staff decision making, and that the level of a staff member’s awareness contributes to the quality of services offered to the client. However, to date this argument has not been specifically applied to ABI outreach contexts. This chapter outlines this absence of knowledge in the ABI literature as the rationale for investigating staff decision making and awareness, from the perspectives of a sample of staff working in the field of ABI outreach, and to theorize about the significance of decision making and staff awareness as it applies specifically to ABI outreach. This will achieve a synthesis of knowledge not previously made before (the significance of staff decision making and awareness + working with people with ABI in outreach environments), and add empirical evidence to demonstrate the applicability of the new synthesis to the specific context (ABI outreach).

Introduction to the topic

This thesis investigates a very unique and unusual job. People who hold this job are paid to go into people’s homes and help do things most of us do on our own without much of a second thought. Sometimes these workers help people get showered and
dressed, sometimes they help people fix meals, sometimes they take people shopping or
to the movies. They may go to a baseball game with someone. They may help organize
a party or teach someone how to keep a diary. These workers may take a group of
people on a picnic. They may help someone figure out his/her finances. They may just
sit and talk with someone, be a good listener and offer companionship and company.

Sometimes these workers may have to stop the people they are paid to visit from doing
things they want to do. They may have to stop someone from riding a bike, or a horse,
or a motorcycle. They may have to tell someone what he/she can and cannot eat. They
may have to prevent someone from going swimming or smoking.

Sometimes these workers may have to help someone make up his/her mind. They may
have to explain specific choices to someone, such as telling him/her they can choose to
go to the park or the beach. If the person they are helping cannot decide, these workers
may suggest they go to the beach for the day. They may work with some who is non
verbal, has communication difficulties, or just says “I don’t know” whenever asked
what he/she would like to do.

These workers are staff who work with people who have acquired brain injuries (ABI).
They work with clients with ABI in what is termed outreach or community settings,
meaning they do not work with these clients in hospitals or clinics, but in the homes and
communities where the clients with ABI live their lives.

The experience of working with a person with ABI varies, sometimes greatly and
dramatically, from staff to staff, depending on the personalities of the staff and client,
the nature of the client’s injury, and numerous situational factors. The client with ABI
may seek only minimal assistance with managing his/her monthly budget and learning
to use some compensatory memory aids, such as a daily diary/note planner to remember
what he/she has done and needs to do. The client may have numerous and great needs,
such as requiring constant guidance to be prompted and cued by a staff member to
remember and be guided through basic daily life routines such as getting dressed,
making a phone call, or remembering how to get around his/her own neighbourhood
(Ponsford, 1995; Story, 1991).

The staff in these environments emerge as major figures in the life of a client with ABI, often with as much, if not more influence in the client’s life than the client’s family and natural support circles. It is because of this powerful pivotal role in the life of people living in the community with ABI, and my own experiences as a former staff working in ABI outreach, that I wished to focus research on staff in these contexts.

Staff who work in helping professions are regarded as being of high social worth and therefore accorded powerful status (Hugman, 1991). It is socially acceptable and socially legitimated that clients of a helping service defer to staff authority (Drew, 1986; Marks, 1999; Reiff, 1974). The impairment of ABI can impact autonomous client decision making, resulting in diminished ability to be self determined. This has potential to increase the already socially sanctioned power position of staff in the staff/client relationship.

Outreach is a work environment in which staff perform their jobs, supporting clients with ABI. Yet it is unlike typical work environments, due to the location and nature of the work being in the homes and neighbourhoods of the clients they support. This blending of work and home environments (Beckett and Wrighton, 2000), which traditionally in Westernized nations are demarcated and emphasized as separate domains of human life (Goodale and Godbey, 1989; Stormann, 1989), creates a unique context which impacts upon the way staff support clients with ABI. That is, the environmental cues that influence decision making, often in subtle or subconscious ways, can become ambiguous and conflicted in the blurring of work and home contexts.

The outreach environment does not adhere to many traditional work-space cues or identifiers. Front line staff workers often wear casual, non uniformed or non professional clothes, work autonomously or away from direct employer supervision in the homes and/or neighborhoods of the clients they support, and tend to facilitate or assist clients in domestic and recreational/leisure activities. To an uninformed observer,
A staff-client interaction in a grocery store may appear as one friend helping another friend fill her shopping cart. A staff and client may appear to uninformed observers as two mates at a footy game, a mother and daughter having lunch in a café, or a group of friends out for a night at the movies. The blurring of work and leisure boundaries has already been problematised in analyses of industrialised societies. The job task of facilitating leisure activities for a client further problematises this distinction, as staff engage in behaviour that typically is contained within domestic and other non-work domains of human life (Brown & Ringma, 1989).

This can, in turn, affect how staff assess situations, select an approach and course of action, and the manner in which they carry out their job duties. It can affect the attitude staff bring to their work and the client. It can impact the way staff evaluate choices, and the final decisions they make, either for themselves as staff acting on authority, or on behalf of clients where the client is unable to be self-determined.

This is a potent combination: the diminished capability for autonomous self deterministic decision making in a significant number of clients with ABI which exacerbates existing staff power, and an ambiguous, autonomous work context that looks, feels, and for all purposes, is a home environment. This combination warrants the closer examination of the ABI outreach support context. How do staff perceive their working environment, what are the types and nature of the decisions (exercises of power) they make, what decision process they use, and what is the role of their own awareness of their power and the values - personal, occupational, and societal - that influence those decisions? That is, what is the significance of staff decision-making and awareness within this particular outreach context?

While the conclusions of this thesis may have relevance for staff in working across many other helping profession contexts involving other client bases, this study has deliberately focused on staff in this particular context for a number of reasons. Clients with ABI in community outreach have unique support needs resulting from the particular sequella of brain injury (Sherry, 2002; Rowlands, 1999). Research specific to acquired brain injury outreach settings and situations is a burgeoning field, but lacks the
longitude and proliferation comparable to research in other related disability fields (McColl, Carlson, Johnston, Minnes, Shue, Davies & Karlovits, 1998; McColl, Davies, Carlson, Johnston, Harrick, Minnes, & Shue, 1999; Ylvisaker, Hanks, & Johnson-Green, 2002). Within the field of ABI outreach research, emphasis on staff experiences is marginalised and practically non-existent (McCluskey, 2000). It is one of the purposes of this work to redress the dearth of research specific to staff supporting clients with ABI in outreach settings. This is achieved by firstly examining the role of decision making in the ethical performance of a staff member’s work, and secondly, by determining if there is a relation of staff awareness to the decision making process and outcome. This introductory chapter will explain why this research is focused on ABI outreach staff, and outline the key issues and themes of inquiry which set the foundations for the study.

**Community Integration in Acquired Brain Injury Support**

The re-integration of people with acquired brain injuries into community environments is a widely endorsed client support approach (Higham & Phelps, 1998; Ponsford, Sloan & Snow, 1995; Powell, Heslin & Greenwood, 2002), stemming from ideologies of mainstreaming and inclusion in the 1970's (Meekosha, 2003; Shapiro, 1994; Wolfensberger, 1972). Historically, individuals with disabilities have been institutionalized, and kept away from mainstream inclusion in the community (Barnes, Mercer & Shakespeare, 1999). The deinstitutionalisation and mainstreaming movements of the 1970's in countries such as the United States, Britain and Australia, meant that people with disabilities, including ABI, who may have once been cared for in segregated schools, hospitals, and institutions, were now moving into independent or supported living accommodations, and participating in community life (Schleien, Ray & Green, 1997; Shapiro, 1994). The generalized ideology of self determination was central to this paradigm shift, advocating that people with disabilities have the ability and right to make their own decisions regarding how they wish to live their lives (Hagner, 2000; Schloss, Alper & Jayne, 1993). Disability advocates emphasized that independence for people with disabilities was not so much relevant to physical independence, or the ability to perform functional life tasks unassisted, but rather independence was regarded in terms of being able to manage and control one’s own...
life, even if physical or functional assistance may be needed to do so (Priestley, 1999; Reindal, 1999).

It is the hired staff who largely fill this role (or supplement/support the role of family members) in providing physical or functional assistance in implementing the self deterministic, community integration ideology for people with disabilities (McCluskey, 2000; Ponsford, Sloan & Snow, 1995). For people with ABI, their inclusion in this support modality follows after the success of applying this type of support to people with similar impairments in developmental disability and mental health populations (Ducharme & Spencer, 2001; McColl, Carlson, Johnston, Minnes, Shue, Davies & Karlovits, 1998; McColl, Davies, Carlson, Johnston, Harrick, Minnes, & Shue, 1999). However, ABI presents a unique sequella of challenges and support needs not adequately addressed by support models designed for other cognitive impairment disability populations (Sherry, 2002). ABI is a relatively young disability population, with more individuals surviving acquired brain injuries due to increases in high risk activities and technologies (such as faster cars contributing to more car collision incidents) and increases in medical technologies, resulting in more people surviving what previously would have been fatal injuries (Krefting, 1989; Webb, 1998).

The field of ABI support stands on the evidence and knowledge from the fields of developmental disability and mental health, but does not have the benefit of longitudinal research specific to the unique sequella of brain injury, and the particular challenges and issues people with ABI face in their daily lives. The borrowing of philosophy and programmatic structures from non-ABI specific disability fields has resulted in inconsistencies in the ABI field regarding staff training, organizations of services, and implementations of outreach programs and supports, as well as gaps in knowledge about how best to support people with ABI in the community (Ylvisaker, Hanks, & Johnson-Green, 2002). Research specific to ABI outreach is a rapidly developing area, but is still nascent and fragmented compared to the knowledge bases in mental health and developmental disability. This begs the question of what implications does adoption of support models and ideologies not specifically designed for clients with ABI have on the context of ABI outreach? Also, how does this
transference of support models and ideologies from related fields affect the staff who are central in implementing these supports and ideologies?

**Staff in ABI Outreach Contexts**

The staff who work with people with ABI in clients’ home and community settings are as unique as the clients they support because of the specific context of their work, a context partially contingent on the nature of the client’s personality and injury (McCluskey, 2000). Staff are in a position of influence and power over the clients they work with (Hagner 2000; Marks, 1999; Reiff, 1974) because of three factors contributing to the context - the socially sanctioned status of the staff role, the autonomous work environment compared to traditional work settings, and the variety of decision making deficits usually present in clients with ABI.

**Socially sanctioned role**

People who work in human services, or helping professions as they are often collectively called, are associated by society with the expertise of medical professions (Hugman, 1991). Helping professions originated from the medical profession, and continue to mostly follow the same organizational structures and procedures (Hagner, 2000; Priestley, 1999). Modern medicine and its related services are one of the most highly regarded occupations in Westernized societies, and those within such professions are often accorded high social worth (Hagner, 2000; Hugman, 1991, 1998; Marks, 1999). In this circumstance, staff have come to be acknowledged and viewed as experts in a discipline or field, and clients are seen as subordinate to the staff. Clients, like patients, have been reinforced to relinquish power and control to staff figures in exchange for recovery, healing, or receiving the favour of the staff (Anderson, 1981; Barnes, Mercer & Shakespeare, 1999; Schorr & Rodin, 1982). This historical power relationship between staff and clients has been transferred to the modern outreach environments of ABI supports, and is maintained through the embedded medical model structures within organizations that provide ABI services (Hagner, 2000; Priestley, 1999). This point is to be revisited below and more thoroughly examined in chapter two.

**Autonomous work environment**
A distinguishing feature of outreach services is that the support of clients occurs in natural settings, namely the client’s own home (or community based semi-supported residence) and the surrounding community (Higham & Phelps, 1998; Ponsford, Sloan & Snow, 1995; Powell, Heslin & Greenwood, 2002). The staff in this context usually work one on one with the client, or with a small group of clients, alone, away from direct supervision and other staff. Sometimes the staff may work in small groups with other staff, such as on recreational outings, but here, the group may split up and a staff member may spend a large portion of the outing alone with one or a few clients. Responsibility and decisions to be made while in the field with the client fall to the individual staff member, who relies partially on his/her own experience, resourcefulness, knowledge of policy and procedure, as well as knowledge of the client to work effectively while in outreach settings. Staff hold the power to make judgement calls as they see them at the moment of decision making in the field. Staff also are often unobserved by other staff or supervisors and have the power to choose to behave ethically or not. There is a notable absence in the literature of addressing specifically the nature of autonomous work environments, the understandings staff have of such contexts, or the influence working autonomously has on a staff member’s decision making process with clients.

**Client decision making deficits**

Some people with ABI may manage their lives with minimal to no noticeable decision making difficulties, some may have noticeable decision making deficits but are able to use compensatory strategies and assistance from others to make their own self-determined choices. Some may find decision making very difficult and taxing, requiring assistance in taking decision making steps, or having choices narrowed down and presented to them in a comprehensible manner, and yet others with ABI may not have the ability to comprehend choices and make self-determined decisions at all. The abilities of individuals post-injury to perform this cognitive function is wide and varied from person to person, depending on the nature of the injury, the pre- and post-morbid cognitive skill level, and the insight of the person with ABI into his/her own cognitive impairments (Fischer, Gauggel & Trexler, 2004; Sloan & Ponsford, 1995; Wesolowski & Zencius, 1994). The likelihood that staff working with a person with ABI will have to
assist in some manner with that client’s decision making is high, as most people with ABI will encounter decision making deficits in some manner and to some degree (Kneipp, 1991; McCluskey, 2000).

For example, a person with ABI may have difficulty in deciding the sequence of events in a morning hygiene routine. I worked with an individual once who could only remember activities such as tooth brushing, hair combing, dressing, and breakfast preparation in short, brief scripts. To assist him with getting ready in the morning, I would stand at his dresser and closet with him and ask him what he wanted to wear that day. Often, this was an overwhelming question, with so many clothes to choose from, so I would say something to the effect, “Well, the weatherman said it was going to be very warm today, so you could wear your short sleeves and shorts today if you wanted”. I may even have framed the options as “Would you like to wear this shirt, or this one?” if he was stuck deciding. Left alone, he could then dress himself after all his clothes for the day were laid out on the bed, but upon completing dressing himself, he would become confused and lost with no idea what to do next. I would help him find the bathroom, and say something like “Now there is your toothbrush”, which was his cue to brush his teeth. This he could do as long as he had help with the segues from one morning activity to another, but he was unable to segue himself. He could not make decisions about how to structure his morning routines autonomously.

Power is manifested and used in the process of decision making, as the one who makes the decisions has the power (Friedson, 1987). Sometimes the level or extent of decision making deficit in a client with ABI is difficult to determine with certainty (Beresford, 1996). Staff may under or overestimate a client’s abilities to be self determined, just as a client may under or overestimate his/her own abilities as well. Staff have the challenge of discriminating between when they need to make choices on behalf of clients (often under the guide of following a duty of care to a client) and when to encourage self determination (regarded as the client’s right to the dignity of taking risks). This staff decision alone, of whether to make a decision for the client or encourage/allow the client to decide, immediately determines who holds the power to make subsequent decisions relating to the matter being decided. Staff hold the power to
veto client decisions at any time the staff feels the client’s decision is risky or may harm
the client or someone else (Mattison, 2000). In the example above, this could be played
out in staff action such as if the client chose a ragged, flannel shirt to wear to a
restaurant and I overruled his choice, asking him to pick another shirt because I may
feel the shirt is inappropriate for the venue to where he is going to eat. I may be
concerned for him to not be excluded socially because of the way he has chosen to
dress, or I may really be concerned about being embarrassed by being seen in a
restaurant with someone who is shabbily dressed. What ever the reason, my staff status
enables me to veto his choice.

These three factors contribute to the inherent power position of staff over clients with
ABI in outreach settings, and warrants investigation into how this power is being
recognized and used by staff working in the field.

**Professional Ethics, Values and Awareness in Decision Making**

In addition to the immediately recognizable factors that may inform a staff member’s
decision making in the field, such as weighing the risks of the situation towards the
client, and evaluating the client’s capacity to understand the nature and consequences of
the choice he/she wishes to make, staff are also influenced in their decision making by
the personal and professional values they hold and the degree to which staff recognize
and are aware of these values (Corey, Corey & Callanan, 1998). Values are beliefs and
attitudes that “provide direction to everyday living” (Corey, Corey & Callanan, 1998,
pg 3), while ethics, more specifically, are guidelines to what constitutes correct or
proper conduct (Corey, Corey, & Callanan, 1998; Mattison, 2000.) In a work context,
ethics specifically refer to professional conduct (Freud & Krug, 2002a).

Decision making is a value laden activity (Plous, 1993). Likewise, helping professions
are value laden occupations (Hugman, 1998). Garcia-Serrano (1994) states "It is
generally recognized that behaving ethically is full of philosophical and value-laden
issues" (pg. 1). A lack of awareness regarding these values and their impact on service
delivery can be detrimental to the helping process as staff may make unethical decisions
against the client, such as inadvertently abusing the inherent power they have in the
staff/client relationship to meet their own needs rather than the needs of the client. (Corey, Corey & Callanan, 1998; Roberts, 1994). While this has often been addressed regarding major life decisions in ethical codes (Freud & Krug, 2002b), it has received lesser attention in more mundane, routine actions between staff and clients, such as in everyday interactions in ABI outreach. Worthley (1999) emphasizes:

Healthcare professionals exercise considerable influence and power over the lives of patients, subordinates, and colleagues—often in routine and subtle ways. (They) can . . . double-check procedures or not check them at all . . . emphasize harmony in the office or tolerate interpersonal squabbles . . . greet (clients) with honor and respect or hardly acknowledge them. Because such routine actions are a daily part of healthcare delivery, the ethical dimension of ordinary professional life must be explored. Healthcare ethics must probe the ethical significance of seemingly inconsequential situations and help healthcare professionals use their power responsibly within the hectic contexts of their daily tasks (pg. 7).

Decision making is regarded in this study as a self determined voluntary behaviour (McGrew & Wilson, 1982). However, conscious awareness of decision making processes in mundane, routine actions is not common. As Hogarth notes "judgement is an inevitable part of living. However, for the most part, judgements are made intuitively—that is, without apparent reasoning and almost instinctively" (1980, pg. 1).

Combs and Gonzales attest to the importance of staff decision making and its implications for clients: “Although many professions are heavily dependant on the use of various kinds of tools, the success or failure of most helpers often rests, almost exclusively, on their own thinking and behaviour, on how effectively helpers use themselves as instruments in the helping relationship” (1994, pg. 19). In some helping profession literature, developing higher awareness within staff has been advocated as a device for staff to improve their decision making skills and improve best practices in the staff client relationship (E.g. Anderson, 1981; Combs & Gonzalez, 1994; Schaefer, 2002; Schorr & Rodin, 1982). Other literature has suggested the notion that self-awareness about one’s values and behaviour is not just a prerequisite for effective helping, but is also an ethical concern for staff conduct with clients. (E.g. Corey, Corey & Callanan, 1998; Drew, 1997; Wegener, 1996; Worthley, 1999). As MacLean and
Gould (1988) emphasize, “Self-awareness is extremely important, and is a part of the helper’s armamentarium. It seems to make sense to suggest that if you are not aware of or sensitive to yourself as a person, or how you function and affect other people, it is unlikely that you will be sensitive to the needs and feelings of others!” (pg. 44).

Yet this emphasis on staff awareness of values and decision making has not been sounded specifically in the ABI outreach literature, and is not a prominent feature in existing, albeit inconsistent, training protocols for ABI outreach staff in the field. This research seeks to empirically close the gap between assumptions about staff awareness and decision making in related fields and its applicability to the specific context of ABI outreach support.

**Models of Support: Ideological Tensions**

A staff member brings his/her own experience, personality, opinions, emotions, and thoughts to the job, each of which helps to shape or is a product of that individual’s value system of beliefs (Combs & Gonzalez, 1994; Elizur & Sagie, 1999; MacLean & Gould, 1988). These individual values are then combined with more encompassing organizational, cultural, and societal values that are embedded in the structures of helping profession organizations, including ABI outreach services. The historical significance of the medical model of services towards illness and disability will be substantially explored and charted in chapter two. Here it is highlighted as the dominant ideology from which most helping professions, including ABI rehabilitation sprung (Boake, 1991; Hagner, 2000; Priestley, 1999). In essence, the medical model of treatment is based on illness or disease being viewed as embodied within the client, and is treated as an individual problem (Barnes, Mercer, & Shakespeare, 1999; Priestley, 1999). The practitioner is viewed as an expert in their field, and clients submit to the expertise, opinions, and knowledge of practitioners in exchange for treatment and recovery (Barnes, Mercer & Shakespeare, 1999; Illich, 1976).

This ideology may be appropriate for curable illnesses and disease, but has been criticized as an inappropriate modality of service for people with disabilities and chronic illnesses, for whom there is no ‘cure’ or recovery from their condition or
impairment. Some disability advocates have proposed a competing social model of disability, in which it is contended that disability does not lie in the individual but rather in society. It is the way society neglects, marginalizes, and omits people with impairments that creates disabling conditions for them (Barnes, Mercer & Shakespeare, 1999; Oliver, 1990, 1996; Oliver & Barnes, 1998). The self-deterministic ideology, which is the US companion to the UK born social model of disability, is a challenge to the authority of the medical model, contending that the client is the expert, since no one can know his/her life better than him/herself (Sands & Wehmeyer, 1996; Schloss, Alper, & Jayne, 1993). Outreach supports for people with impairments, such as developmental disabilities, or mental health issues, grew out of this client-centred philosophy (Barnes, Mercer & Shakespeare, 1999; Oliver, 1996; Sands & Wehmeyer, 1996; Shapiro, 1994).

The disability movement in Australia has followed an emancipatory path similar to those in the US and UK, albeit at a slower pace, and sometimes with less direct advocacy (Newell, 1999). Australia is uniquely positioned to draw upon the ideology and service support literature from both the US and UK, rather than be negatively divided over ideological debates as scholars between the US and UK sometimes are (Meekosha, 2003).

Outreach service modalities from the mental health and developmental disability fields were adopted by the ABI field in lieu of a knowledge base specific to ABI community reintegration. However, while outreach is based on a social model of disability philosophy, the medical model structure is embedded in the organizational structure of many ABI community outreach services (Hagner, 2000; Condeluci, 1998). For example, a common practice is the keeping of a client chart in ABI outreach, where regular documentation about staff-client interactions, and client progress towards client selected goals is recorded. This is often regarded as a necessary protocol, for liability protection and to allow consistency between different staff working with the client. Documenting is usually required to also demonstrate outcomes, often at the insistence of third party payers reimbursing the service.
From a social model and self-deterministic viewpoint, the keeping of a client chart may be an invasive and unbalanced practice. In four of the various healthcare/rehabilitation agencies I have worked in (a hospital, two group homes, and a community integration agency), every intimate detail about the client’s life was recorded by the staff for other staff to read. Clients could not read their own chart without permission from staff. There was one-sidedness in that staff were allowed and often expected to know significant amounts of personal information about a client in order to effectively pursue their work, but clients were not allowed to know personal information about staff. A staff member who shares too much personal information with a client may be viewed as being unprofessional (Fox, 1995). Under the current structures of outreach organizations, chart keeping may be a necessary endeavor. However, the practice may be viewed as continuing to reaffirm the medical model legacy from which it sprung, and emphasizes a power imbalance between staff and client.

That something as basic as chart keeping may be unquestioned by staff working in outreach services contributes to the speculation that without an operational awareness of the historical and ideological origins of helping professions and outreach, staff may be unwittingly contributing to the dominance of the medical model in disability services. This dominance impedes the implementation of truly client self determinist supports. This observation applies to all disability groups, as well as ABI.

Another feature present in the ABI outreach field is the support organization or agency itself. The ideologies of the medical model and the self-deterministic/client centered model filter into organizations and are manifested in the hierarchy, organizational structure, policies, procedures, and programming of the organization (Condeluci, 1998; Hagner, 2000). All organizations, regardless of occupation or purpose, contain an organizational climate and culture, which are environmental factors and group behaviours that come to define an organization’s ‘personality’, and affects the behaviours of the individuals within that organization (Jennings and Wattam, 1994). Decision making is one such affected behaviour, as decisions are rarely made in isolation, but are influenced by the structure, climate and culture of an organization, and the behaviours and opinions of others (Jennings and Wattam, 1994). Tensions between
support ideologies may manifest as ethical or moral conflicts at the individual staff level, particularly if the staff is unclear or unaware of the influences of the ideological tensions underlying the conflict.

**Research Question and Approach**

Patton (1990) states “decisions about design, measurement, analysis, and reporting all flow from purpose” (pg.150). The issues raised in this chapter provide a justification for this study, of which the purpose is to examine the role of decision making and the significance of staff awareness upon decision making within acquired brain injury outreach support. This issue is best explored by examining the challenges staff working in ABI outreach face in trying to implement ideologies that are in tension and may be ambiguous, by describing how personal values and professional ethics impact what staff do, and by demonstrating how awareness of values may be a useful device for staff to improve their ethical decision making process. This is accomplished through using a constructivist theoretical approach to conduct and interpret the research. Specifically, this research is situated in a constructivist/interpretive paradigm with a symbolic interactionist focus, using constructivist grounded theory to collect and analyze the data, and present the thesis report.

Symbolic interactionism and social constructivism are intertwined in a shadow-foreground interplay, each coming to the fore depending on the sensitivities and intent of the researcher (Schwandt, 1994). Both theoretical positions reject the problematic notion of a single, objective, measurable reality (Denzin & Lincoln, 1994; Ife, 1997), espousing instead the view of subjective, individual realities (relativism), created by individuals through meaning making of symbols and action. The meanings individuals have created defines their understanding of their reality and guides how they act and behave within that reality (Denzin, 1978). Individual meanings are then shared through collective symbols and institutions, such as language and cultural practice and knowledge (Duong, 2001; Gergen, 1999). The umbrella paradigm has been termed both interpretive (Baumgartner & Strong, 1994; Lincoln & Guba, 2000) and constructivist (Charmaz, 2000; Guba & Lincoln 1994; Schwandt, 1994) in social sciences. Smith (2002) notes that extensive debate regarding qualitative paradigms and assumptions go
beyond the parameters of a doctoral study, and cites Gadamer (1975) in justifying his position to utilize the paradigmatic and theoretical positioning that best explain his own research assumptions and world view through which research decisions and interpretations are filtered. For my purposes here, the symbolic interactionist concern with how individuals create and experience meaning takes the fore to the backdrop of social constructivist views of the historical/socio-political/cultural and organizational interpretations which create context for individual meanings. The constructivist paradigm envelopes the symbolic interactionist focus and positions my ontological and epistemological sympathies.

Denzin (1994) states, “Interpretive research begins and ends with the biography and the self of the researcher” (pg. 510). Thus, symbolic interactionism is equally relevant and appropriate for understanding and conducting the research process, since it is from my own personal experiences in ABI outreach that launched the inquiry, and contributed to my understandings and analysis of the data. In this research, I am engaged in a series of meaning-making, interpretive relationships - with the past literature, with the interview participants, and with the data. Each of these relationships and interactions are filtered through my own world view which influences and shapes the meaning and interpretations I derive from the research process. Rubin (1981) reminds us that “there is no meaning without context” (pg. 104) and “The quest then (in research) should not be for the fool’s gold of objectivity but for the real gold of self-awareness. For it is not our subjectivity that entraps us, but our belief that somehow we can be free of it” (pg. 103). Denzin (1994) concurs, “In the social sciences, there is only interpretation”(pg.501). Therefore, symbolic interactionism positions both the content of data as well as the method and process as to how I interpret the content, specifically using constructivist grounded theory methods (Charmaz, 2000). The theoretical positioning of this research and methodological frameworks and techniques will be elaborated upon in chapter four.

New South Wales as a Research Location
New South Wales has one of the highest disability populations in Australia, with the Hunter Region having a higher average of people with disabilities than the New South
Wales state average (Keene, 2004). All the features of ABI outreach service required for this study are present in New South Wales, making it an ideal location in which to recruit criterion based, purposive sampled research participants for a qualitative study. Additionally, conducting the study in Australia allowed me as a researcher to remove myself from the personal context of my own work experiences in ABI outreach in Canada, allowing for reflective research.

**Significance of Study for Theory and Practice**

Phillips and Pugh (2000) list fifteen ways in which research can contribute knowledge in an original manner, one of which is to make “a synthesis that hasn’t been made before” (pg. 63). In this thesis, I draw on research and theory from related disciplines and fields to argue a position that has not been previously addressed in the specific context of ABI outreach. I also introduce qualitative evidence that documents staff experiences in the field, and demonstrates the applicability of the argument to the context of ABI outreach. Theoretically, this research contributes to the body of knowledge regarding best practices, specifically tailored to ABI and not from the related bodies of knowledge in developmental disability or mental health fields.

Simultaneously, this is applied research, with immediate practical application for staff working in ABI outreach contexts. The review of literature on the medical model and self deterministic ideologies highlights of embedded conflicts in the ABI outreach field. Awareness of these ideological contradictions contributes to understanding what may cause tensions or ethical conflicts in a staff member’s work in ABI outreach. Descriptions, and anecdotes from interviewed staff about the strategies they use in working with clients, and in developing their own self awareness may have current application for other staff working in similar contexts or struggling with similar issues.

Chapter two, the first half of the literature review, will examine the development and dominance of the medical model of health and illness as the source of staff power in staff/client interactions. The chapter will also chart the historical and ideological evolution of contemporary ABI outreach contexts and review the support needs of clients with ABI to illustrate the central role staff hold in supporting clients with ABI in
outreach settings. The second half of the literature review in chapter three will examine various challenges staff encounter in implementing outreach principles with client with ABI, and review a selection of the literature regarding decision making to illustrate how a brain injury may impede a client in making self determined decisions, and how staff may be influenced in their decision making by personal values, professional ethics, and situational/social/cultural factors.

Chapter four will elaborate upon the theoretical and methodological positioning of this research, while specific method procedures appear in the first appendix. Chapter five descriptively introduces each of the staff members interviewed for this research, and discusses their perceptions of the ethic of practice they aim to achieve when working with clients. Chapter six presents an inventory of strategies the interview participants use which represent the way they negotiate their ethic of practice. Chapter seven examines some factors of influence that inform and compete for the staff’s attention in the decision making process and potentially affect which strategies are used. Chapter eight examines how aware the participants are of these factors of influence impacting on their decision making, and how they may use awareness as a means for monitoring their decision making (and therefore their power) in staff/client interactions. The conclusion in chapter nine summarizes the research, and revisits a constructivist perspective that frames the symbolic interactionist focus upon the meanings expressed by staff. This contextualises the research and emphasizes the role of awareness as an agent of change. Some future research and practice directions are identified for resolving problematic gaps between staff’s ideological intentions and actual decision making practices and awareness.

A Word about Words

There is much debate over proper terminology to use in regard to people with disabilities, which appears to fall largely along cultural lines (Priestley, 1999). Disability scholars and advocates in North America have endorsed the use of people first language, which has been used in the thesis thus far. Darcy (2002) notes that people first language is also standard and acceptable in Australia. People first language is utilized to emphasize that people should be recognized for their individual
personalities and are not defined by their disability. Instead of stereotyping someone as a “brain injured man” or a “disabled man”, people first language emphasizes an individual’s commonality with humanity over their difference through disability. Western European advocates and scholars have argued that disability is not “with” the individual but that social conditions and social environments are responsible for disabling someone. To be referred to as a “disabled person” indicates that social policies, environments, and attitudes create the barriers an individual experiences in community life, rather than his/her individual impairment (Barnes, Mercer, and Shakespeare, 1999; Oliver, 1990; Priestley, 1999).

Disability advocates adopting the social model of disability also ascertain that disability is a central tenet of the self in a disabled person. To imply that disability is an addendum after one’s personhood (as “person with a disability” would infer), is to deny the centrality of disability to one’s self identity in a disabled person (Oliver, 1990). Fine and Asch (1998) however have found that this is not necessarily how all people with disabilities may see themselves.

I am sympathetic to the position that having a disability may be central to one’s identity and self-hood, but also that a person should be viewed in a holistic manner and not labeled solely by his or her impairment. I do not theoretically agree that people first language implies disability as an addendum to the person. In this thesis, clientele of helping professions is not the subject population being researched. In this text, acquired brain injury is regarded as a condition within an individual, which in turn indicates a series of particular circumstances that create a unique work context for staff. This unique context defines and justifies the subject population of the research study. This thesis will discuss the relevance of medical and social models of disability to helping professions and the work context of staff in chapter two. However, terminology such as “clients with acquired brain injury” will continue to be used throughout the manuscript as an appropriate reflection of the medical condition that contributes to the distinctive work context of the staff. It will also be used as it is the most appropriate terminology in the Australian context (Darcy, 2002), where this study was conducted.
The word “client” is also a term of controversy for some disability advocates and scholars. It has been contended that use of the term “client” for someone who seeks services from a helping profession is illusory, as traditional ideologies of expert authority in helping professions undermine true person-centered services (Marks, 1999). However, “client” is a widely recognized term, pertinent in most helping professions to denote which party in the therapeutic relationship is the seeker/receiver of organizational services. Again, due to individuals with acquired brain injury not being the central subject population of this research, the term “client” will be used for its purpose to differentiate its counterpart, the staff providing client services, which are the subject of this research.
Chapter Two


Chapter Abstract

This chapter examines closely the origin of power in the staff role and why staff hold a socially sanctioned power position over clients in helping professions. It is because of this power position, exacerbated by client decision making deficits in ABI, that how staff recognize and use this power in autonomous outreach environments is of concern for ethical practice. The medical model has been conceptualized by disability advocates as the source and ongoing apparatus of staff power. The social model of disability is presented as an alternate ideology to the medical model, and also as a key catalyst in the origin of outreach models of support being developed for people with disabilities, including people with ABI. ABI is presented as a young disability population in the spectrum of disability support services, and it is noted that longitudinal and field specific research for ABI is lacking compared to other disability populations. This has meant the outreach model of support was adopted by ABI rehabilitation on principle and not on empirical evidence of effectiveness as a best practice. An overview of the impairment of ABI is given to demonstrate the critical role outreach staff often play in supporting a client’s quality of life.

Introduction to the chapter

This research is an investigation into the role of decision making and staff awareness in ABI outreach support. Chapter one outlined the justification of the value and need for this avenue of inquiry, noting in particular the power position of staff in largely autonomous work contexts with clients, and the tensions between medical model and social model/self deterministic ideologies that may manifest as conflicts or dilemmas in the staff-client relationship. The unique sequella of brain injury that can create vulnerabilities in clients unlike those seen in similar but different disability populations, and the sparsity of theoretical and practice knowledge about best practices exclusive to the ABI field create a critical need to fill the knowledge gaps about staff practice in ABI outreach settings, as staff practice impacts the quality of life for clients.
In this first half of the literature review, I draw on selected past literature and research to simultaneously illustrate the origin and source of power in the staff role, and explain how contemporary ABI outreach contexts evolved. This is achieved through examining and contrasting two significant ideological models, the medical model and the social model of disability. The latter half of the chapter introduces people with ABI as relatively new in the spectrum of disability populations utilizing support services. A review of some of the challenges a person with ABI encounters, and the ways in which staff are conceptualized as a means to address those challenges is presented to underline the central role a staff member may fulfill in the daily life of a client with ABI. In the next chapter, literature and research regarding current challenges and issues in the contemporary ABI outreach setting will be reviewed, along with a review of decision making literature.

Contextualizing this research through a literature review serves the purpose of locating where the current research sits among the existing literature, as well as emphasising pertinent themes which are utilized in the understanding and interpretation of the data collected in the current research. Reviewing the literature also serves the educational purpose of bringing awareness to the social, political, and historical precedents that impact contemporary outreach contexts and ABI supports. While much of this literature sits outside the specific realm of ABI literature, this thesis synthesises the information and presents its relevance to the ABI outreach context.

The Rise of the Medical Profession and the Medical Model of Health and Illness
In the disability advocacy movement, academics with disabilities such as Mike Oliver and Colin Barnes in the United Kingdom, were among the first to identify that the traditional ideology in society and in helping professions under which people with impairments and chronic physical conditions were regarded (the medical model) was disempowering for people with impairments and chronic conditions. It is largely from their and their colleagues’ work that I draw upon to illustrate the concept of the medical model and its power structures as a foil to the social model of disability (to be presented later in the chapter). The UK social model theorists are largely from a social Marxist background, and their argument centres on the theme that people with impairments have
devalued status in society because of their exclusion from or inability to join in the economic workforce. This positioning takes into consideration the effects empiricism, industrialization, and capitalism have had in changing social attitudes towards disability, and the way people with disability are incorporated into (or excluded from) social life. These three ideological/cultural movements are briefly reviewed here only in relevance to the critique of the medical model.

In this social Marxist vein, the development of the medical model is understood in relation to social and political factors and events in Westernized nations. The rise of empirical science and a positivist paradigm towards the world, the belief that only observable phenomena could construe knowledge, challenged long held religious beliefs about the operation of events in the physical world (Foucault, 1975; Freidson, 1970b). Previously, people were mystified about the causes and effects of disease and illness, through superstition and folklore, often believing that impairment was a manifestation of evil spirits or the devil. These beliefs often meant individuals with disabilities were shunned, taunted, feared, and sometimes even killed (Barnes, Mercer, & Shakespeare, 1999; Schleien, Ray, & Green, 1997; Wolfensberger, 1972). Sociological analyses have drawn parallels between the sequestering of individuals with disability and a human fear of death and disfigurement (Wolfensberger, 1972).

Individuals with disabilities remind us of our own mortality. This is antithetical to the natural survival instinct in humans, so society tends to hide away and avoid any icon of inevitable morbidity. Hunt observed (as cited in Barnes, Mercer & Shakespeare, 1999) that disabled bodies threaten able-bodies by representing ‘tragedy, loss, dark, and the unknown’ (Hunt, 1966, pg. 155), and thus are devalued as ill, deformed, and diseased.

The new science in medicine helped to dispel such myths, and to develop technologies that would help alleviate illness and improve health for individuals (Freidson, 1970a). Empiricism/Positivism would mean that for individuals with disabilities, including acquired brain injury, scientists would take interest in the causes and symptoms of their conditions and seek rational explanations rather than superstitions to understand them and treat them. Science instigated humankind’s mastery over the human body. Science in other fields led to other technological developments that contributed to
Industrialization.

Industrialization in the Western world had profound impact on the nature of community and family life in the 1900's (Goodale and Godbey, 1988). The nature of work changed, becoming more routinized, faster, and often requiring intricate performance of tasks, thus limiting the eligibility of individuals with impairments from the workforce. Agrarian ways of life were fading against urbanization and fast paced manufacturing employment, two trends that removed many individuals from their rural homes and into factories and cities. Family and friends were no longer available to assist those in need, and individuals with needs often could not be integrated into the new workforce as they had been on farms or in labor of a more artisan nature (Barnes, Mercer, and Shakespeare, 1999; Oliver and Barnes, 1998).

In Marxist tradition, industrialism and the economic theory of capitalism are also closely linked. Central to capitalism is the control of the worker, and the ability to maintain a productive workforce (Barnes, Mercer, & Shakespeare, 1999). Individuals unable to work were subsumed into the capitalist state through the industry of helping and welfare (Hugman, 1998). The birth of helping professions occurred from both humanitarian and economic interests in this era. "The origins of the caring professions are placed in the context of capitalist and middle class concerns about the productive labor force of the working classes" (Hugman, 1991, pg. 20). As the welfare state developed, helping professions evolved as agents of the state to address the needs of individuals unfit for the workforce, due to disability, illness, or the effects of poverty (Hugman, 1991; Macdonald, 1995; Pollak, 1976). This resulted in an industry of helping, which, some critics contend relies “on the troubles and miseries of other people” (Freud & Krug, 2002a, pg. 474) to sustain itself. This criticism will be more sharply reviewed during the discussion in this chapter regarding power in professions and professional self-interest.

The Industry of Helping
Helping as a social act has existed as long as there have been social connections
between individuals. Informal helping is a staple of social life, while helping in a more formal manner, such as performing charity work, or volunteering, can be traced back to over 2000 years ago (Pollak, 1976). Up until the mid-nineteenth century, helping was focused primarily on providing assistance to people without wealth and property. Religious dogma and moral convictions of the middle ages in Europe contributed to the social sentiments that the rich should divert a percentage of their wealth to the poor. Churches were initially the providers of assistance to the needy, but as they grew overburdened with the demand of the disadvantaged, churches turned to the State for assistance with providing welfare (Pollack, 1976; Topliss, 1975). The Elizabethan Poor Law of 1601 in Britain is the first state social policy regarding the provision of welfare (Oliver and Barnes, 1998; Pollack, 1976).

The secular rise of science, particularly medicine, shifted the focus of helping from ecclesiastical charity to humanistic determinism, in that people with illnesses or disabilities were seen as being able to be treated and therefore, it was the responsibility of those with the knowledge and expertise to do so (Barnes, Mercer, & Shakespeare, 1999; Freidson, 1970a; Priestley, 1999). This perspective led to the formation of professions. Helping professions are borne from and serve both humanitarian and economic purposes. As medical science allowed mastery over the human body, the medical profession organized to allow practitioners mastery over medical knowledge and its use with patients. As medicine grew more specialized, numerous offspring therapies, such as physical therapy, occupational therapy, or social work developed, with the same goals in mind (Hugman, 1991; Johnson, 1972; Macdonald, 1995; Wilding, 1982).

Zins (2001) recognizes a distinction between helping professions and human services, noting that “Human service workers are usually presented as generalists, namely they are trained to perform as variety of tasks within the field of human services but are not considered specialists in any specific helping profession” (pgs.18-19). This has significance for acquired brain injury services and this research in particular. The field of ABI outreach is an integrated mix of professional and generalist workers with varying degrees of education and speciality. ABI services rely on this diversity of
occupational and professional players, with no uniform approach or overall theoretical framework guiding services in the field. There is dispute and difference regarding best practices in ABI (Ylvisaker, Hanks, & Johnson-Green, 2002). Thus, ABI services as a whole cannot be considered a singular profession per se, yet the nature of the caring work places the field under the larger umbrella term of “helping professions” (Zins, 2001). It is this generalizing of the term “professions” to encompass generalist workers as well as truly professionalized workers that is used throughout this thesis to extrapolate how the power associated with traditional professions also comes to be associated with generalists working within a helping profession, such as ABI outreach.

**Power in the Medical Model**

Power is an ever present dynamic in human relationships (Garcia-Serrano, 1994). The structuring and control of power has been hypothesized as a central feature of the medical model (Barnes, Mercer, & Shakespeare, 1999; Hugman, 1991; Illich, 1975; Reiff, 1974). I draw upon this critical view of the medical model, which has also been applied to helping professions stemming from medicine, to illustrate the inherent power position staff in ABI outreach are have over clients. This critical view also considers the ways in which staff-client power hierarchies and imbalances which are embedded in medical model structures have transcended into ABI outreach settings.

**What qualifies as a profession?**

The sociology of professions seeks to examine what precisely determines one occupation to be able to make a claim to being of professional status, while another does not (Macdonald, 1995). More detailed examinations debating whether the occupations of medicine and related helping occupations (under which the field of ABI community support falls) are indeed professions have been discussed elsewhere (See Freidson, 1970a; Johnson, 1972; Hugman, 1991). What is key to understand about the debates regarding the legitimacy and veracity of a profession is the central concern with the possession and control of power, which in turn has implications for the manifestation of power in ABI outreach settings. It is a central tenet of this thesis that outreach staff, by virtue of their status and job role, are in a position of power over clients with acquired brain injury. It is also important to understand the conceptualization medical and
affiliate helping professions as monopolies of power and control. These monopolies are the catalyst for the resistance against the medical model by disability advocates, and the alternate conceptualization of the social model of disability. The following discourses on power as a process and structure within helping professions are relevant to demonstrating and illustrating these tenets which bear on the ABI outreach context.

**Professional power**

It is widely agreed that a primary feature of a profession is possession and control of knowledge exclusive to the occupation in question (Macdonald, 1995; Wilding, 1982; Hugman, 1991; Johnson, 1972; Reiff, 1974). Professions dictate who has access to that knowledge (professional membership), how the knowledge is passed on (educational credentialing and certification), and how the knowledge shall be used (standards of practice, codes of ethics). Exclusivity to particular cannons of knowledge afford professionals status as experts in their fields, and thus are granted power to diagnose problems in individuals and determine how to address and treat such problem (Hugman, 1991; Johnson, 1972; Macdonald, 1995; Reiff, 1974; Wilding, 1982). In medical and helping professions, practitioners are the ones who determine the type and nature of illness, disease, or impairment in an individual, what the best courses of action are, and how they are to be administered. This hierarchal structuring of the practitioner dominating over the patient because of expert knowledge has largely gone unchallenged and been legitimized by the administrative and social structures that surround helping professions (Hagner, 2000; Reiff, 1974; Schorr & Rodin, 1982).

**Criticisms of professional power**

One criticism of this power relationship has been the self-serving nature of medical labeling and treatment (Barnes, Mercer, Shakespeare, 1999). Professions are interest groups (Macdonald, 1995), and the helping professions are constructed upon the problems, and suffering of individuals (Freud & Krug, 2002a). A continual requirement for the helping professional’s service is assured as long as the helping professional continues to locate and identify individuals deemed in need of help (Hugman, 1991). Numerous instances can be cited where individuals have been identified as requiring treatment, and then been treated against their will, particularly in the history of
psychiatry and mental illness (Guggenbuhl-Craig, 1971). Critics have posited that some medical diagnoses are contextual, and reflect dominant cultural values rather than true impairment (Hugman, 1998; Priestley, 1999). This is evident in the helping professions’ ideological shift in attitudes towards homosexuality, once diagnosed as a deviant psychological pathology, but now regarded as an alternate lifestyle, not requiring intervention to return the individual to ‘normal’ sexual functioning (Corey, Corey, & Callanan, 1998). These criticisms are central to understanding the formulations of the social model of disability (discussed later in the chapter), which helped spawn outreach modalities adopted in the ABI field.

ABI outreach employs a mix of specialized professionals, including but not limited to psychologists, neurologists, social workers, occupational therapists, physical therapists, and therapeutic recreation specialists. Each of these staff has professionalized training in their specific discipline and work within the ideologies, practice standards, and code of ethics of their profession as well as under the mission and objectives of their employing agency/organization. ABI outreach also relies on front line generalist workers, such as described above by Zins (2001), who tend to not be professionalized, usually have basic or limited higher education, and tend to have their work duties and tasks assigned by the professionalized staff (though generalized staff may not necessarily be directly supervised by professionalized staff when implementing their duties). While guided by professionalized ethics or agency policy, staff may still encounter difficulties in deciding what is ethically sound due to the ambiguousness and unpredictability of the ABI outreach context. In exploring the significance of staff awareness in ABI outreach contexts, one of the aims of this research is to examine what values guide staff, how they manifest in outreach contexts, the level of awareness staff have about these values, and how levels of awareness influence staff decision making and behavior.

Helping professions are value laden entities, and are an interest group in society (Corey, Corey & Callanan, 1998; Freud & Krug, 2002a & b; Hugman, 1998; Wilding, 1982; Wolfensberger, 1972). Helping professions emerged out of particular values for humanitarian and capitalist interests, which shaped the founding structures and ideologies and remain persistent features to this day. A positivist medical model of
diagnosis and treatment, professional authority, and a duty of care to clients are central value features underlining helping professions, evident in the training of practitioners, the administrative structure of services, and the social worth given to helping professions (Hugman, 1991, 1998). The context and history of helping professions cannot be ignored when challenging their structure and processes, as will be discussed when examining the social model of disability further in this chapter.

The practitioner/client power relationship is further legitimized by the mental and emotional state of the client in the patient role. For one to seek help is to admit to having a problem, and not having the capacity, skills, or knowledge to cope with it. Clients have traditionally accepted the practitioner’s expertise and relinquished control of the relationship to the practitioner in return for potential success in recovering or coping (Anderson, 1981; Schorr & Rodin, 1982). Phipps (2000) and Beresford (1996) both note the difficulty practitioners in the ABI field have in ascertaining true informed consent in some clients, due to the complexities in decision making and diminished insight a person with ABI may have. Fischer, Gauggel, and Trexler (2004) observe that a practitioner’s judgement tends to be the dominant method for assessing the level of insight and decision making capability a client with ABI may have.

Critics of professions claim control within a profession is maintained by the occupation’s uncontested claim to professionalism and the authority therefore granted by society to the profession (Hugman, 1991; Johnson, 1972; Macdonald, 1995; Wilding, 1982). Control is also maintained and recognized in the way language is used by professionals (Fairclough, 1989; Freidson, 1970b; Hugman, 1991). A client who challenges a practitioner’s authority may be labeled as uncooperative or difficult, aligning the resistant behavior with a moral judgement of good or bad. Diagnosis involves a process of designated language or jargon to label individuals’ deficiencies or abnormalities, even when the individual in question may not agree or may not perceive a problem at all (Barnes, Mercer, & Shakespeare, 1999; Freidson, 1970b; Hugman, 1991). This has particular resonance with mental and psycho-social disorders which can vary in validity through various cultural and historical contexts (Again, the psychological perspective of homosexuality demonstrates this idea.) Jargon may also be used to
mystify and remove laypersons from the meanings specialized medical language infers between professionals in the know. This insider language can serve to help medical professional retain their expertise status.

**What is normal? The medical model as a dominant social paradigm for regarding and treating disability**

In order to understand the paradigm shift that the social model of disability advocates, one must understand how the medical model of health and illness has transcended the immediate practitioner/client relationship into a wider social phenomenon that has been termed as a “medicalisation of life” (Illich, 1975). This has several consequences, which act as the catalyst for the resistance to be discussed below regarding the disability advocacy movement.

Conrad and Schnieder (1980) assert that medicalisation of human issues results in moral issues becoming medical diagnoses. Historically, social problems become individual problems, and therefore are addressed in absence of the wider social, political, and economic contexts in which they occur. In ABI contexts, this may be seen in the social behaviors that can lead to an individual acquiring a brain injury. The majority of individuals with ABI, both in Australia and in most other Westernized nations, are males between the ages of 18-35. The most common cause of ABI are car collisions with alcohol a mediating factor in three out of four of these collisions (Fortune & Wen, 1999; Rowlands, 1999). The acquiring of a brain injury becomes an individual problem, where societal attitudes and structures related to drinking and driving, and masculinity rituals among youth are lesser examined or hold lesser responsibility to the individual’s condition. Brain injury becomes an individual’s ‘misfortune’ under a culture of personal tragedy (Barnes, Mercer & Shakespeare, 1999; Priestley, 1999). Ironically, individualizing social issues can also abdicate the diagnosed individual of responsibility for his/her behavior because it is attributed to be caused by impairment and not personal character. Such social issues become depoliticized when viewed and treated in the realm of individual human bodies, and enterprises and social structures which benefit from such issues, such as the alcohol and liquor industry, or government liquor taxation, are left largely unexamined in their contribution to the problem (Priestley, 1999). Recently
however, there has been a paradigm shift in appropriating responsibility of social issues (Barnes, Mercer, & Shakespeare, 1999), as demonstrated in the public example of backlash against the tobacco and cigarette industry. A series of lawsuits displays the pressure the public is placing on such industries to take responsibility for their contribution to social issues.

This medicalisation of life has particular impact for individuals with disabilities. It is in resistance to this medical model paradigm that the disability rights movement mobilized. Medicalisation of disability served to place clients with disabilities in a subordinate position beneath health professionals and eventually, support service providers. Individuals become dependant on the expertise and guidance of others, weakening an individual’s sense of self and responsibility for their own care. Citing Illich (1975), Barnes, Mercer, and Shakespeare (1999) highlight that “doctors mystify the real causes of ill health, and exaggerate their own capacity to provide solutions. This is the basis for the expanding power of medicine, as well as for its augmented role as an agency of social control” (pg. 59). It also has consequences for the individual to be subjected to new regimes of social control in the form of professional experts applying intervention and treatment. Social issues become individual issues, with social influences and factors being disregarded or minimalised (Barnes, Mercer, & Shakespeare, 1999).

Medicalisation of life also has consequences for individuals with disabilities, or impairments of a permanent nature, such as ABI, from which there is no recovery in the typical sense. Using a medical model of care, practitioners subjugate clients to expert control and systems of surveillance to maintain control (Barnes, Mercer & Shakespeare, 1999; Hugman, 1991; Reiff, 1974). This subjugation to control is particularly of concern in regards to people with ABI, since an individual’s autonomous decision making and self determination abilities is either genuinely impaired, in question by practitioners, or both. Well-intentioned substitute decision making on behalf of a person with a brain injury potentially runs the risk of subjugating the individual to further controls and restrictions than may be necessary or desirable.

Control and caring
Power and control may be more difficult to recognize when enveloped in an industry of caring or helping, of which ABI outreach staff are agents. It has been widely acknowledged there are two general types of caring; "caring about" which reflects an emotional empathy for another’s struggles, and "caring for", which indicates a more direct involvement between individuals in which one provides direct help or support for another (Hugman, 1991).

Dancy Jr. and Wynn Dancy (1995) express the characteristics of caring help as the helper being able to empathize with the cared-for, to empower the cared-for, and to engage on behalf of the cared-for in an advocacy role. MacLean and Gould (1988) point out that formal helping is informed and purposeful, and that it is "primarily aimed at enabling the person being helped to help himself" (pg.9). Such distinctions clarify the area between emotive forms of care and more task oriented caring that has been the basis of most helping professions’ models of service. This however is not without its difficulties when the natural compassion of caring is transmuted into the business of caring. Phillips and Benner (1994) notes how the medical model structure subverts the natural instinct of humans to care for each other:

Many caregiving professionals experience a conflict between the vocation to care for persons, and the industry of caring for manageable parts and aspects of human beings....Increasingly in the helping professions, personhood and caring have been eclipsed by the depersonalizing procedures of justice distribution, technological problem solving, and the techniques and relations of the marketplace (pg. 2).

Fox (1995) hypothesizes the concepts of ‘care-as-vigil’ and ‘care- as-gift’. He terms care-as-vigil is a ‘technology of surveillance’ , "which is more to do with power and control than values of love, trust, and giving" (pg. 108). The vigil is an interpretation of the dominant medical model in helping professions. The practitioner is viewed as the expert and the role of the client is to be submissive and obedient to the practitioner’s treatments. Surveillance is both direct and indirect, from clients being visually watched by staff, to systems of documentation (such as client charts) and intrusive exploration into clients’ personal lives through assessment, to routines of structure requiring compliance on behalf of the client.
Fox’s ‘care-as-gift’ is a conceptualization of resistance to the ‘care-as-vigil’ system. Care-as-gift is more akin to the emotive ‘caring about’ combined with the tasks of ‘caring for’, in which care and help are given unconditionally, with no expectation of reciprocity. Care-as-gift may be interpreted as a threat against the vigil, as "it establishes an inequality or an imbalance in power" (1995, pg. 118). It is noted how care-as-gift interactions are often viewed as unprofessional behavior, when a practitioner ventures outside the strict defined boundaries of what is appropriate in a client/professional relationship. Care-as-gift subverts the traditional roles of professional as expert and client as dependant, and is threatening to the traditional practitioner maintaining a medical model ideology.

ABI staff in outreach contexts may be affected by these various interpretations of caring interactions, without being explicitly aware of their influence or structures. Staff who form interpersonal relationships with clients may be viewed as being unprofessional for not maintaining strict professional boundaries. Technologies of surveillance, such as client documentation, physical supervision, restrictions on client behavior, or having to seek family/doctor clearances on client stated preferences and choices are regularly used in ABI outreach contexts without consideration for alternative methods of providing support. I should note I am citing provocative criticisms of the medical model structures and ideas to highlight the concept that blind acceptance of the medical model eradicates discourse on alternate paradigms. This unquestioned domination of a single ideology which maintains an absence of conflict illustrates what Lukes (1972) conceptualized as radical power. Power, in this sense, is demonstrated by one interest group’s ability to put forth and maintain their ideological paradigm as the uncontested norm in society.

The Legacy of the Medical Model
As medical advances led to more highly specialized knowledge about the body, illness, and impairment, affiliate therapies and professions evolved to address specific aspects of the growing fields of medical theory and skills (Hugman, 1991). The medical model has been the basis for related helping professions to organize their approach, training, structure, and services. Interdisciplinary and multi-disciplinary approaches to treatment developed, maintaining the medical model as the primary infrastructure for care of
clients. Despite paradigm shifts to social models of disability and care, it is this infrastructure of the medical model that presents complications and contradictions to fully realizing client centered services in outreach and community care contexts (Cohen, 1998; Hagner, 2000; Priestley, 1999), a point which will be further examined in the discussion regarding the social model of disability.

As a result of traditional social reverence of helping profession practitioners as experts (Hagner, 2000; Hugman, 1991; Marks, 1999), staff at any level in a helping profession organization inherently carry a dominant power position over clients as ascribed to their helping profession status. Formal professions, such as social work or counseling psychology, may address the issue of power dynamics in therapeutic relationships when educating practitioners, or in outlining codes of ethics (Freud & Krug, 2002a; Steinman, Richardson, & McEnroe, 1998), while generalized workers may lack guidance in attenuating to this power imbalance. Staff at any level may be unaware they hold the dominant power position over clients, especially when placed in the ambiguous outreach context, or they may not view it as problematic. As Wolfensberger (1972) states:

Many benevolent, humanistic clinicians see themselves as servants of the public, offering themselves and their services in a non-controlling fashion. They see their clients as free agents, free to accept or reject the offered services. Their self concept- in part due to indoctrination received during training - is frequently incompatible with action perceived as controlling, directing or dictating client behavior. Yet, here is where so many human service workers deceive themselves, because their roles are not almost always societally sanctioned, but in an endless array of encounters between the server and the served, the server is the interpreter of and agent for the intents of society, and wields a truly amazing amount of power and control, even if he may not consciously perceive himself as so doing. (pg. 1).

Clients, socialized into the role of subordinates to practitioners, relinquish personal control and accept the guidance and directions of staff (Schorr & Rodin, 1982; Wegener, 1996). Staff in helping professions are also indoctrinated into helping ideology, in that their purpose in interaction with the client is to change, improve, or alter the client’s condition, or behaviour in some way (Hagner, Helm, & Butterworth, 1996; Wegener, 1996). Staff are given authority to re-direct or correct client actions when re-direction and intervention is regarded as treatment. Even in client centered practices, where
clients play a role in defining self goals and exercise self-determination in articulating expectations of support services, elements of support interventions which could be construed as intrusive to the client are legitimized under the staff’s obligations to observe a duty of care to the client (Hagner, 2000; Hagner, Helm, & Butterworth, 1996; Marks, 1999; Schorr & Rodin, 1982, Mattison, 2000). That is, power can licitly be exercised over the client, even against the client’s will, if such action is perceived as in the best interest of the client. This is a crucial point when placed in the context of ABI support, in which some clients may have diminished cognitive capacity to be self-determined, or lack personal/social insight. Wolfensberger’s concerns with a staff’s unawareness of the power they hold over a client because of societal sanctioning is a key theme of this research.

Up to this point, the discussion has been reviewing a traditional, historical view of the medical model and its influence upon modern helping profession practices. It is important to remember that this model remains embedded in many helping professions, even though a significant paradigm shift has occurred with respect to disability (Hagner, 2000; Hagner, Helm & Butterworth, 1996). The social model of disability has been developed in direct resistance to the medical model of care, and the oppressive implications medicalising disability experience has had for clients with disabilities.

**Resistance to the Medical Model**

In the social model of disability, impairment, which is “lacking part or all of a limb, or having a defective limb, organ, or mechanism of the body”, is distinguished from disability, “the disadvantage or restriction of activity caused by contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (Oliver, 1996; Priestley, 1999). Damage to the brain that results in mental, emotional, and behavioural deficits or difficulties would qualify as a physical impairment, since the physical structures of the brain have been altered.

According to the social model of disability (also known generically as disability theory), social myths and cultural views about people with impairments contribute to the
sociological phenomenon of disability. The culture of tragedy assumes that disability is a tragic misfortune that affects an individual, and therefore the individual should be pitied, or feared. It also presumes that care must be administered to people with impairments, because such individuals are incapable of caring for themselves (Priestly, 1999).

The culture of embodiment assumes that disability is caused by the individual impairment, thus creating the life difficulties an individual with impairment encounters. This addresses directly the medical model assumption about disability. The culture of otherness assumes that people with impairments are somehow qualitatively different from people without impairment and therefore should be regarded and approached differently. Otherness emphasizes the differences between people rather than commonalities (Priestley, 1999).

Otherness is established by a dominant group determining the experiential and cultural norms. “Where this occurs the normalcy of the dominant group’s perspective leads alternate perspectives to be judged as deviant; to be characterised as ‘other’” (Priestley, 1999, pg. 28). Dominant groups establishing their perspective as the norm is also an interpretation of power in society (Lukes, 1972). The medical model of treatment and control is the dominant discourse of helping professions, legitimated by the high status accorded medical and helping professions in Western society. As medical model discourse and practices are taken to be the norm, so is viewing people with disabilities as ‘others’ (Wolfensberger, 1992).

As mentioned in the introductory chapter, there has been a division in disability studies circles regarding disability theory, most blatantly manifested in the preferred language of disability scholars. North American writers tend to have approached disability studies from humanistic perspectives, while European scholars tend to have used a sociological approach. Meekosha (2003) notes the tension between UK and US academies in disability studies, and identified that “In...Australia...the approaches tend to be rather more eclectic, drawing on both metropoles...” (pg. 3). The legacy of the medical model is prominent in North American approaches, which focus on helping people with
impairment reach their potential through community supports, still incorporating an individualized treatment approach. European advocates insist people with impairment are held back by society, and it is society which needs to change (Marks, 1999; Priestley, 1999).

The social model of disability has been met with some criticisms, most notably the absence of discourses on impairment from disability. Critics have put forth that the experience and reality of impairment for individuals cannot be divorced from the experience of disability, since the nature of impairments often determine the type of disability experiences one encounters. Also, issues such as chronic pain, or psychological effects of impairment (both of which people with ABI may experience) are not addressed by the social model (Oliver, 1996; Thomas & Corker, 2002). Mike Oliver, one of the originators of the social model responds that the social model of disability is not intended to be a social model of impairment, and that a social model for impairment needs to be developed to sit in tandem with the disability model (1996). Others have contended this is ineffective however, as it is the physical mark of impairment that signals difference and acts as the catalyst for disability experiences (Koch, 2001; Thomas & Corker, 2002).

The social model has also been criticized for its emphasis on and apparent perspective from physical impairments, and not fully accounting for mental, cognitive, and psychological impairments, which sometimes may be accompanied by no outer physical impairments at all (Marks, 1999; Oliver, 1996). This has particular repercussions when attempting to utilize a social model of disability within an ABI context (Rowlands, 1999). Sherry (2002) notes that acquired brain injury has been “neglected within the social model” (pg. 14). Relative to the first criticism, the nature of brain injury impairment is central to the disability experience, often as the most difficult issues are regarding social relations and behavior. Specifics of brain injury will be detailed further in the chapter.

The social model runs the risk of undercutting the legitimate benefits the medical model and medicine in general has offered to society. Medical technology has served to reduce
death rates and in general, increase quality of life standards for much of the population (Barnes, Mercer, & Shakespeare, 1999). Oliver (1996) again responded to critics that the social model is not intended to explain everything about disability, and is still in a process of development. The social model certainly has played a significant role in shifting the thinking about how people with impairments are regarded and treated in society, and has contributed to self-determination and independent living movements (Hagner, 2000; Koch, 2001; Priestley, 1999; Schloss, Alper, & Jayne, 1993).

**The Growth of Outreach as a Service Modality**

Independent living, community care, or outreach supports are a departure from previous ideologies of care that have dominated the lives of people with disabilities. Normalization emerged as a concept in the 1970's directly contrasting dominant institutionalism policies. The definition of normalization is the “utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behavior and characteristics which are as culturally normative as possible” (Wolfensberger, 1972, pg. 28). Wolfensberger notes that “normative” is used in the sense of statistical trends rather than moral judgements.

Normalization became a widespread human services ideology in the same timespan as numerous liberation movements in the US, which helped to spawn independent living movements and disability advocacy in the 1970's and 1980's (Meekosha, 2003; Shapiro, 1994). This led to mainstreaming, and integration, moving people from segregated environments in educational, vocational, and housing domains, to inclusive environments. Independent living movements, often spearhead by people with disabilities themselves, were based on ideologies of self-advocacy and self-determination, that individuals with disabilities should control their own lives and make their own decisions utilizing whatever supports they deemed necessary, rather than being subject to what others deemed necessary for them (Schleien, Ray & Green, 1997; Shapiro, 1994). Again the humanistic and sociological split in perspectives is manifested in the language of the movements, as self-determination is seen as a goal of independent living in humanistic contexts, but viewed as the starting platform in sociological contexts (Priestley, 1999). This could be construed as bias towards the physically
impaired and against cognitive impairments as self-determination skills, such as decision making and problem solving, may be inalterably compromised in the individual with acquired brain injury. Willer and Corrigan (1994) note that most consumers of independent living centres (ILC’s) in the US were survivors of spinal cord injury and that “ILC’s have been criticized for not meeting the needs of individuals with emotional or cognitive disabilities, such as those with mental retardation, brain injury or mental illness” (pg. 649).

In Australia, deinstitutionalization grew slowly over the second half of the 20th Century. In New South Wales, a 1983 inquiry into the status of health services for individuals with mental illness and developmental disabilities, known as the Richmond Report (Department of Health, New South Wales), recommended more comprehensive community based services for clients, and further dismantling of the institutional systems. The result was the majority of clients with cognitive needs were discharged into community settings, but the practicality of deinstitutionalization, mandated in the 1991 National Mental Health Strategy, was not met by adequate government funding (Gray, 2002; Lucas, 2001). The ideology of community integration was further enhanced by the Disability Services Act in 1986, which was a landmark of disabilities rights legislation in Australia (Daruwalla, 1999). The 1994 Burdekin Report (Human Rights and Equal Opportunity Commission), which examined the national mental health system, revealed that numerous individuals with mental illness who had been deinstitutionalized without proper community supports were homeless and at risk of human rights abuses.

Lucas (2001) noted that the bureaucratic realignment of health services at the state levels was poorly planned. He also notes that the concept of community is oft mentioned in the 1991 National Mental Health Strategy, but never defined explicitly. Essentially, rather it is negatively determined as something that is not an institution or other such space.

Brain injury as a disability is not specifically mentioned in either the Richmond or the Burdekin reports. Brain injury was specifically addressed by the Commonwealth Government of Australia in 1994 with the National Policy for Services for People With
Acquired Brain Injury. In the policy, the diversity and unique nature of the support needs people with ABI require are recognized, and rationale for support in community living is upheld. The policy also is a recognition of the difficulties people with ABI may face in falling between the cracks of service provision, and outlines the needs to better coordinate existing services, since “it is not feasible for a dedicated program to meet the variety of needs or offer the necessary range of expertise and specialised services required” (pg. 4, Commonwealth Department of Human Services and Health, 1994b).

Mixed Signals: Paradigm Shifts

Community integration is widely supported ideologically as the best practice and most appropriate support modality, both for individuals with disabilities in general (Hagner, 2000; Priestley, 1999; Schleien, Ray, & Green, 1997; Shapiro, 1994), and specifically for individuals with acquired brain injuries (Higham & Phelps, 1998; Ponsford, Sloan, & Snow, 1995; Powell, Heslin, & Greenwood, 2002; Willer, Button, Willer, & Good, 1998). Yet numerous issues arise between ideologically stated beliefs and implementation of practices into community contexts, most of which can be directly traced to the stronghold of medical model influence on helping profession structure.

Hagner (2000) describes the move to outreach supports as a paradigm shift in ideological thinking on disability, and attributes the difficulty in applying contemporary ideology into practice on the rapidity of a previous paradigm shift. The facilities paradigm was the dominant form for much of the 20th century, the institutionalizing and segregating of people with disabilities. Rationale for such practices included that segregation was for the safety of the individuals as well as the general public, and that individuals with disabilities could have access to more specialized care and professional attention.

A major paradigm shift occurred between the facilities paradigm and the programs paradigm. In the late 1970's and during the 1980's, normalization and mainstreaming became the dominant ideology in disability studies and services. It was recognized that people could be included in the community through specialized programs. However, in effect, the program paradigm in many ways was a facilities approach without walls. Specialized services were created to address needs for people with impairments, even
though generalized services for all had been in the community. But individuals with disabilities were not thought to be able to use such services in functional or satisfactory ways due to their impairments. The program paradigm still operates from a medical model approach, that disability is located within the individual, and this disability sets the individual apart, requiring a different mode of service (Hagner, 2000).

Paradigm shifts occur slowly and over time if at all (Kuhn, 1970), so such a swift move in ideology from facilities to programs has been somewhat overwhelming for workers in human service industries. Organizational culture often determines how receptive or resistant to change the organization is, and a change in disability ideology does not always result in a accompanying change in service practices (Hagner, 2000). Now another paradigm on the heels of the programs model has evolved, the supports model. In the supports paradigm, in concert with the social model of disability, the commonalities between individuals with and without disabilities are emphasized. Individuals with disabilities are capable of utilizing any service or good in the general community, given an appropriate amount of support as to be determined by the individual him/herself. The supports paradigm recognizes autonomy, self-determination, and the human rights of individuals with impairments (Hagner, 2000).

Hagner (2000) expostulates several challenges with implementing supports ideology at the practice level of services. The primary barrier is the pervasiveness of the medical model, which is the foundation upon which helping professions and human services were founded, and designed. The structure of human services agencies reflects this embedded philosophy, from the way funding is granted, to the organization of staff, job descriptions, outcome measures, documentation, and scheduling. According to Hagner, human service agencies operate on filling places in their programs with clients, rather than individualizing supports as directed by the service user.

Contributing to this barrier of incompatibility is the ease with which the language of the social model of disability and the supports paradigm can be adapted to the program model with different interpretations. A client may have a goal setting or life planning meeting with case managers and program coordinators in an organization, and from the
goals set by the client, the organization staff then decided which programs fit the client’s goals. This is an illusion of person centered planning. In a supports model, the individual decides what he/she wants to achieve or needs assistance with and then contracts with services to get appropriate supports. Specialized human services may not be required, but rather general services that all the public uses may be accessed, resulting in a more inclusive supports model than one that relies on disability specific services (Hagner, 2000; Hagner, Helm & Butterworth, 1996).

Hagner (2000) and others point to the socialization of helping profession workers into the medical model of service as another major barrier to shifting to a supports paradigm (Hugman, 1991; Schorr & Rodin, 1982; Wilding, 1982). Professions are accorded a high social status in capitalist societies, legitimizing and reinforcing their control over designated client groups (as previously discussed). Medicine and related fields are highly valued professions in contemporary Western society, creating an insular, rarely challenged stance to the methods and theories of the helping professions. The training of new professionals and generalist workers is designed with a medical model approach. Being the dominant value, the medical model system of operations is often viewed as the norm by workers, who have been trained to believe in their professional authority because of specialized expertise, and feel they are obligated under a duty of care to exercise judgements about and over the client out of best interests for the client (Hagner, 2000; Hugman, 1991, 1998; Marks, 1999; Priestley, 1999; Reiff, 1974; Schorr & Rodin, 1982; Wilding, 1982). The supports model and current disability theory challenge this thinking though with the belief that the individual with the impairment is the expert, as that individual know his/her own life, experiences, fears, dreams, and hopes better than anyone else. This discourse is outside the realm of medical model discourse and therefore is literally inconceivable to many professionals and helping profession workers. It is often a misinterpretation and mis-application of the supports paradigm language and ideas when workers socialized in the program paradigm believe they are applying client centered programing (Hagner, 2000; Hagner, Helm & Butterworth, 1996).

Hagner (2000) offers three suggestions for disability advocates to assist with the
process of paradigm shifting. One is realizing that a paradigm shift is not a rational, logical process, but a serious upheaval of dominant norms and routines. Resistance to change is often strong in organizational cultures, which is necessary for the stability and maintenance of the organization (Jennings & Wattam, 1994). More useful than educating and offering technical assistance to organizations willing to adapt to change is a process mentor, who will guide and offer reassurance to the staff of the organization during the shift. Secondly, how organizations are funded must be changed, since currently, so much organizational structure and bureaucracy is directly tied to the way monies are given to and accounted for by the organization. Finally, it is suggested sometimes starting up a new organization is the best way to go, as existing organizations come with a lot of baggage in terms of culture and history. A strong staff allegiance to organizational culture and status quo will create numerous barriers to a paradigm shift.

So while the current practice of outreach community support operates under the guise of being client centered and client driven, it is borne of a medical model approach, and remains strongly rooted in medical model ideologies, ideologies that are focused around power and control over clients. It is now that I turn to the specific impairment group of people with acquired brain injury, and examine the implications the preceding discussion carries for both their disability experience and the experience of the staff hired to support them in the community.

A New Disability Population
Acquired brain injury (ABI) is the disability that should not exist. Webb (1998) notes the irony that technological advances in both leisure and medicine have increased the prevalence of head injury in Western cultures. "Prosperity, mobility and the (particularly masculinist) cultural adulation of speed, cars and motorbikes" along with "medical intervention in life expectancy as well as design improvements that give greater driver and passenger safety to motor vehicle mean that there is now a far greater chance of surviving those accidents which in the past would have resulted in death" (pg. 543). Webb highlights the contradiction of medicine’s propensity and ability to save life at all cost without proper consideration for the full long term implications of such
measures, and required supports. ABI has often been called the ‘silent epidemic’ (Chamberlain, 1995; Coburn, 1992; Man, 2002), due to its mosaic, unpatterned nature, and the insidiousness with which the impairments of ABI cause or contribute to major life disruptions (Chamberlain, 1995; Hubert, 1995; Krefting, 1989).

The technological changes that have helped to create ABI as a disability (Krefting, 1989) developed in the same era as the disability movements origins (Barnes, Mercer, & Shakespeare, 1999). Disability as a concept has been applied across all contexts and forms, despite numerous variability across impairments (Bickenbach, Chatterji, Badley, & Ustun, 1999). As a result, the ideas of the disability movement influenced the design of services provided to survivors of ABI. The dearth of available empirical research on ABI resulted in programming and therapy techniques being borrowed from the related fields of developmental disability and mental illness, particularly in regard to community reintegration strategies (McColl, Carlson, Johnston, Minnes, Shue, Davies & Karlovits., 1998; McColl, Davies, Carlson, Johnston, Harrick, Minnes, &Shue, 1999). Despite similarities, acquired brain injury is not a developmental disability or mental illness. The sequella of impairments from ABI and the related impacts it may bear on functioning in all major life domains sets it apart from other disability groups (Sherry, 2002; Ylvisaker, Hanks, & Johnson-Green, 2002), and requires exclusive enquiry into its nature and effects.

In order to understand the ambiguities and challenges a staff member in ABI outreach may face, it is crucial I discuss the impairment of ABI itself. This will illustrate some of the support needs which ABI outreach staff are expected to address.

**What is Acquired Brain Injury?**

Different entities in different countries have adopted various definitions of brain injury for specific purposes, such as legislation, rehabilitative identification, and insurance coverage benefits (Fortune & Wen, 1999). Terms such as ‘acquired brain injury’, ‘traumatic brain injury’, ‘head injury’, and ‘brain damage’ may be used synonymously by non-professionals, though this is usually seen as erroneous by medical professionals.
In general, acquired brain injury is regarded as an umbrella term which encapsulates traumatic brain injury and brain damage. Traumatic brain injury refers to an impact against the brain that causes damage, while reference to acquired brain injury includes damage incurred from disease processes, or other internal factors. Head injury denotes an injury that affects the head but may or may not affect the brain, though injury to the head is likely to have an accompanying brain injury. Inversely, a brain injury can be incurred sans any injury to the head (Chamberlain, Neumann, & Tennant, 1995; Fortune & Wen, 1999; Ponsford, Sloan, & Snow, 1995).

For rehabilitation purposes, it is important to distinguish a brain injury that occurs before, during, or immediately after birth, and a brain injury that occurs later in life. Birth related brain injuries are akin to developmental disabilities, and are treated as such. The individual does not encounter major life changes from acquired brain injury if the injury has been present since birth. Individuals sustaining an acquired brain injury after personality formation has begun require different resources and supports than individuals who have always experienced life with an acquired brain injury. One of the complications of acquired brain injury is the process the affected individual and his/her family and friends experience adjusting to the affected individual’s post-injury personality and behavioural changes.

In Australia, the National Policy on Services for People with Acquired Brain Injury (Commonwealth Department of Human Services and Health, 1994b) defines the condition as:

...injury to the brain which results in deterioration in cognitive, physical, emotional, or independent functioning. ABI can occur as a result of trauma, hypoxia, infection, tumor, substance abuse, degenerative neurological diseases, or stroke. These impairments to cognitive abilities or physical functioning may be either temporary of permanent and cause partial or total disability or psychosocial maladjustment (pg. 29).

**Causes**

A brain injury can be acquired traumatically, or non-traumatically, and is classified as such. The most common cause of traumatic brain injury is car collisions, particularly
among males aged 18-35. In 75% of cases, alcohol has been a factor in the accident causation. Other traumatic causes may include other accidents (such as a fall), or sporting injuries. Non-traumatic brain injuries can be caused by viral infections to the brain, anoxia, and stroke (cerebrovascular accident or CVA) (Fortune & Wen, 1999; Rowlands, 1999).

Incidence and Prevalence
A significant portion of the population in Australia is affected by brain injury. As of 1999, it was estimated that nearly 370,000 individuals Australia wide had an acquired brain injury. 114,735 of these individuals reside in New South Wales, of which 54,348 require daily support or assistance. It was also estimated that every year, 45,067 new incidents of brain injury, both traumatic and non-traumatic, occurred in New South Wales. 70% of traumatically incurred brain injuries happened to males, as did 53% of non-traumatic brain injuries. The largest age group in New South Wales sustaining ABI was 5-14 years olds (20%) followed by 20-29 year olds (19%) (Fortune & Wen, 1999; Rowlands, 1999).

Services and support for individuals with ABI is administered at the state level in Australia. Contact information for ABI agencies provided by the Brain Injury Association of Australia revealed there are approximately 30 agencies in New South Wales which serve clients with ABI, 14 of which are located and networked within in the Newcastle and Hunter region.

Effects
The effects of ABI on an individual and their family are wide ranging and diverse, affecting physical, psychosocial, emotional and cognitive functioning. These effects are often interrelated and interactive, with deficit in one area affecting, exacerbating, causing or resulting from deficit in another area (Chamberlain, 1995; Higham & Phelps, 1998; Johnson, 2000; Ponsford, Sloan & Snow, 1995). For example frontal lobe damage (physical) may result in loss of inhibition (cognitive) which can affect judgement and behavior. The individual may irrationally act in ways that cause other people to avoid or chastise him (psychosocial), leading to isolation and the individual feeling lonely and
depressed (emotional). Functioning deficits and impairments from ABI are rarely as linear and direct as the example, but its point is to keep in mind the overlap and entanglement of ABI difficulties. Exhaustive reviews and discussions of the impairment of ABI are available elsewhere (See Chamberlain, 1995; Higham & Phelps, 1998; Ponsford, Sloan and Snow, 1995; Sherry, 2002). Presented here is a brief review to demonstrate the life altering effects and unique life long support needs a person with ABI may experience, which outreach staff are usually expected to address.

Physical
Physical damage or alteration to the structure of the brain results in numerous aberrations in behavior, thought, affect, and mood. Physical effects from ABI can include difficulties with balance, coordination, fine and gross motor skills, paralysis, chronic pain, weakness and sensory deprivation or loss affecting all the major senses (sight, hearing, olfactory, taste, and touch). Physical injuries to other parts of the body may also accompany ABI when injury has resulted due to trauma, such as a car collision (Higham & Phelps, 1998; Johnson, 2000; Ponsford, Sloan & Snow, 1995). On average, 10% of individuals with ABI also have at least one other significant physical disability (Fortune & Wen, 1999). This is due to either trauma incurred to other parts of the body at the time the brain injury occurred (such as in a car collision) and/or due to the particular area of the brain injury having a role in physical functioning (such as damage to an area resulting in hemiparalysis on the right side of the body).

Alternately, individuals with a brain injury may have a typical physical appearance, and their impairment is not immediately apparent (Krefting, 1989; Ponsford, Sloan & Snow, 1995). This tends to have different consequences in the psychosocial realm, as aberrant behavior or mood shifts have no visibly obvious etiologies to observers unaware of the brain injury in the individual. Public reaction to such individual can be more harsh or impatient when the person’s impairment is invisible (Willer, Johnson, Rempel, & Linn, 1993). Krefting’s (1995) ethnographic study of individuals with brain injury revealed that often individuals with ABI will engage in concealment of their impairments in an effort to further the perception that they are ‘normal’ and without disability in an effort to fit in.
Psychosocial

Often the most devastating effects of ABI are psychological and social in nature. Often the personality of the affected individual is altered, frequently in negative ways. Individuals may have difficulties with initiation, motivative, sustaining interest or focus, disinhibition and impulsivity. Individuals may become self-centered and have difficulty with empathy and reciprocity, making social and intimate relationships difficult to maintain. People with ABI may have difficulties interpreting and responding to appropriate social cuing and customs, also contributing to social isolation and the withdrawal of previous friendships. People with ABI tend to have few if no friends, due to such deficits in friendship/social skills (Higham & Phelps, 1998; Hubert, 1995; McCluskey, 2000; Ponsford, Sloan & Snow, 1995; Rowlands, 1999).

Family relations tend to change, as the individual with the ABI tends to be reverted to the adult child role by caretaking parents (Webb, 1998). An individual often loses much autonomy and independence. Financial matters are usually an issue due to medical and support service expenses, as well as the individual’s limited capacity or limited opportunity to engage in gainful employment. The individual may also be isolated by lack of transport options to access work or leisure options (Higham & Phelps, 1998; Hubert, 1995).

Emotional

People with ABI may experience irritability, aggression, anxiety, depression, feelings of loss, mania, apathy, and fatigue. Some individuals are emotionally labile, shifting between a range of emotions suddenly and without provocation. Emotional difficulties may be organic in nature, resulting from the injury, and be beyond the control of the affected individual, or they may be in concert with insights the individual has about their injury. Some individuals may have flat affect and appear to experience very little range of emotions or any depth of feeling. Sexual interest may be heightened or flattened (Johnson, 2000).

Cognitive
Difficulties include memory loss, remembering, learning, language comprehension and formation, information processing, maintaining attention and focus, problem solving, and decision making. Individuals may require scripts, or cueing by others to complete mundane routines. Complex operations requiring multitasking, such as operating a car, may be extremely difficult for the affected individual (Johnson, 2000; Kreutzer & Wehman, 1991). Decision making deficits in people with ABI will be examined more closely in the next chapter, as this diminished ability for the client to be self determined is hypothesized to be one of the primary sources of staff power exacerbation in ABI outreach contexts.

Depending on which area of the brain is injured, to what degree, and the pre-morbid components such the client’s previous personality, all factor into the post injury state of the individual and their deficits. Any combination of the examples of deficits given often have serious and interrelated impacts in the various domains of life - family, work, education and leisure. How these needs are addressed by staff in outreach will be discussed theoretically later in the chapter, and examined as practice strategies as part of the qualitative results of this research.

**History of ABI rehabilitation**

Modern ABI rehabilitation has its origins from the two world wars in the early and mid-twentieth century (Ylvisaker, Hanks, & Johnson-Green, 2002). Corwin Boake in Kreutzer and Wehman’s *Cognitive Rehabilitation for Persons with Traumatic Brain Injury* (1991) offers a comprehensive overview of the development of ABI rehabilitation. Here, I will summarize the key points of his discussion.

Both World Wars saw high returns of servicemen with head injuries, instigating various programs and philosophies in Great Britain, Germany, Russia and the United States regarding head injury rehabilitation. German head injury researchers recognized a need between balancing head injury patients’ abstract functional performance in artificial environments and concrete performance in real world settings, since generalizing of skills from an artificial laboratory environment to a real world job placement is a difficult task for many individuals with ABI. In Russia, it was thought that creating
special living and working environments for survivors was the best method to reducing the stress and disorientation survivors often experienced in natural life settings. Segregation was reinforced as the best way to redirect and control behavior of the affected individual.

In Great Britain, a continuum from the acute treatment phase to community living was recognized as necessary to the rehabilitation of the individual with head injury. Meanwhile, the military hospital system in the United States largely took on the role of developing treatments and programs for head injury rehabilitation, and evolved into a separate specialized medical and surgical field that became head injury rehabilitation (Boake, 1991).

Interest in post acute long term ABI treatment lay dormant from the immediate post war years until the early 1970’s, when the Yom Kippur war in Israel and several key head injury conferences raised the issues about what to do with survivors of head injury (Boake, 1991). Political and social changes such as deinstitutionalisation, normalization, inclusion philosophies and the social theory of disability certainly have contributed to the evolution and growth of supported employment programs and independent living centres. Yet, there remains a pervasive question of how to address lifelong support needs and especially, who is responsible to provide them to individuals with ABI.

From the Medical Model to Community - Rationale for Outreach Supports in ABI
Several researchers and proponents for ABI supports have written about the ideological appropriateness of community reintegration as a goal for individuals with ABI, and advocate for supported community living as the best care options for individuals with ABI when it is possible. Early outreach program models and strategies were based upon literature from the developmental disability and mental illness field (McColl et al., 1998; McColl et al., 1999). There is a rise of research that seeks to understand community integration from the unique perspective of ABI, as well as a growth in long term studies regarding the outcomes of current dominant outreach supports models.
One of the most pervasive reasons for supporting individuals with ABI in community/outreach contexts is due to the lifelong effects of the injury across various or all domains of that individual’s life (Minnes, Buell, Nolte, McColl, Carlson, & Johnson, 2001; Ponsford, Sloan & Snow, 1995). While improvements in functions may be achieved in acute care and immediate rehabilitative settings, there is no complete "recovery" from ABI. The injured individual is irreversibly altered often in significant ways, and must learn to live with their impairments in a realistic and adaptive manner (Chamberlain, 1995). The alternate to community living is permanent warehousing of the individual in an institution, a historical precedence which is no longer ideologically sound, nor proven to be an effective strategy for wellness (McColl et al., 1999). Freeman (1997) notes that medical treatments and medicalised routines can be intrusive to an individual. Clients need their own personal space for self-esteem and sense of control. Advocacy for community living is targeted to all individuals with disabilities (Shapiro, 1994). Because of the need for ongoing supports to successfully negotiate daily community living, outreach services are one logical way to address the daily needs of individuals with ABI.

Another important reason community/outreach supports and services are favoured is the common issue of individuals with ABI being unable to generalize skills. That is, skills learned in one environment may not transfer to different environment (Freeman, 1997; Fussey & Giles, 1988; Kreutzer & Wehman, 1991). For example, an individual who learns the sequence of how to use an ATM machine in one location, may not recognise how to use an ATM machine in another location, due to different stimulus in the environment distracting from the task, and the individual not having the ability to apply past knowledge in the new situation. It is best to teach practical skills in the environment in which they will be used, that is the client’s own home and neighborhood. Additionally, artificial environments, such as workshops, training spaces, and institutions tend to be more organized and sterile than in natural settings, which are constantly subject to numerous stimuli and influences (Freeman, 1997). Once it was thought best to shield individuals with ABI from such environments by segregating them and removing them from natural environments (Boake, 1991). Currently, the philosophy is to teach skills to the person and offer them necessary
supports to negotiate the natural environment of the community.

Often in rehabilitative settings and therapies, the emphasis is initially on aiming to restore the individual’s physical, cognitive, emotional, psychological and behavioural skills and functions to pre-inury levels (Doig, Fleming, & Tooth, 2001). When restorative strategies do not work, compensatory strategies may be used. Some of these may require extensive training and repetition to gain permanence in the individual’s repertoire of skills, while some may never take and always require cueing or prompting for every day routines and functions. Even when some level of independent mastery of living skills may be achieved in some skill areas, there may remain deficiencies in other skill areas (Fussey & Giles, 1988; Ponsford, Sloan & Snow, 1995; Wesolowski & Zencius, 1994). One to one personal support, such as offered by outreach staff, may compensate for these deficiencies.

Studies have shown that individuals who receive personal outreach support tend to be more successful in integrating in the community than those who merely receive information about community resources and referrals (Powell, Heslin, & Greenwood, 2002). This may be due to individuals and their families not knowing how to access or properly use the information, the individual lacking capacity for initiation or self-motivation, or related difficulties with finances or transportation. The amount of sequencing and processing of information and choices are often taken for granted by individuals with full mental capacities, but such process can be overwhelming when an impairment in one or more of the many required cognitive capacities for such tasks is present. Having a personal support, such as an outreach staff member, can help an individual with ABI negotiate information and decision options.

When individuals with ABI are asked what they prefer, like their other disability counterparts, they state they want to be at home, want to live in their own housing or apartment, and want to live in community (McColl et al., 1998). Ideally, service providers respect these wishes and work with the individual to make them a reality. The ideologies of self-determination and client centered services create the heart of most outreach supports organizations (Hagner, 2000; Hagner, Helm, & Butterworth, 1996;
Young & Lehmkuhl, 1993).

Studies specific to ABI commonly reveal one of the greatest difficulties of ABI survival and the issue most individuals with ABI cite the most frustration with is high social isolation (Johnson & Davis, 1998; McColl et al., 1998; Rowlands, 1999). Individuals with ABI tend to lose older friends post injury due to personality changes in the injured individual. Often individuals have complications in making new friends and maintaining friendships. These are the result of cognitive impairments, in which the affected individual may have any range of difficulties with recognizing social cues, fulfilling the reciprocity expectations of friendships, inappropriate expressions of language and/or behaviour towards others, poor personal hygiene and grooming, lack of comprehension or application of social norms, and general misunderstanding of the nature of brain injury impairment by members of the public unaware of the individual’s condition (Higham & Phelps, 1998; Johnson & Davis, 1998; McColl et al., 1998; Rowlands, 1999).

Complicating the social deficits of an individual with ABI is the sometimes lack of apparent physical impairment in the individual, leading others to regard their social deficits as personality related, and not as symptoms of impairment. Individuals in the public may view an individual with ABI as rude, arrogant, aloof, or merely strange, perhaps even frightening, dependant on how much the individual’s behavior deviates from the expected norm of contemporary society (Willer, Johnson, Remple & Linn, 1993). Direct support in community settings, such as through one on one staffing, is a strategy to address these issues, and to assist the individual with ABI to make new friendships and maintain existing ones.

On a similar note, research has found that the nature of the environment of the individual with ABI is key to the success of that individual’s community integration and satisfaction. The importance of relationships, particularly with family and staff is underlined in this context (McColl et al., 1999). This discussion of outreach support rationale demonstrates the logic of using personal staffing in community and home settings, and illustrates the critical role outreach staff fulfill in addressing daily living.
Chapter Two - Literature Review Part I

support needs of clients with ABI.

**Medical model structures as barriers to true client centered supports**

This demand for ongoing, usually lifelong support by hired staff is in a constant state of tension with healthcare policy trends towards funding cutbacks and more rapid turn around rates of discharging clients from programs and therapies (Phillips & Benner, 1994). While community support is typically not a therapy per say, it is often budgeted and treated like one, with limits placed on hours of service and a requirement for some type of outcome or progress to be demonstrated with the client in order to secure ongoing funding. Services to a variety of populations often compete with each other for what limited grant funding is available, while third party payers may insist on time limits for services, contingent on outcome measures. Everywhere, helping professionals are expected to get the most result for the least cost. The need for permanent supports for some individuals with ABI can mean they receive the most minimal amount of attendance by paid staff, whereas greater support could perhaps enable the individual greater success in community integration. Fussey and Giles (1988) cited Jennet’s (1982) claim:

> that greater resources are required to meet the needs of the brain injured adult. To effectively change the structure service provision for the brain injured, the policy makers at the higher levels in health service management must be made aware of both current and future needs. Unfortunately, considerable financial allocation is required to create even the minimal acceptable level of care. (pg. 197).

It has been suggested that the move to deinstitutionalisation was hastened before proper evaluations and estimates were made of what resources individuals would need for successful community living (Belcher, 1993). This is a key criticism in the Australian mental health arena (Commonwealth of Australia, 1993).

Staff may be indoctrinated with the philosophy of self determination and client centered services, but then are pressured to produced outcomes and other such treatment oriented results that are at odds with self-deterministic principles. Supporting a client in what that client wants to do emphasizes a process, where as producing a measurable result emphasizes an outcome. Staff may feel pressured, under time and cost restrictions or
resource limitations, to emphasize client outcomes at the expense of processes in order to conform to supervisor, or funding body expectations. Staff may also become frustrated with client processes if they are particularly slow (such as teaching a client to prepare his/her own meal) and shortcut the activity to achieve a goal and move on to the next task (such as making the meal for the client, to save time, and be able to attend to other shift tasks that may be assigned). The pressures of medical model/treatment type expectations within a process oriented, client center orientation may affect the way a staff makes decisions and the types of choices they make when engaging with clients.

**Chapter Summary**

In this first part of the literature review, the evolution of contemporary ABI outreach contexts has been traced, with particular attention to the conflicting ideologies of the medical model of health and illness and the social model of disability. The source of staff power has been located within the power structures of the medical model. This chapter has also demonstrated how the tenets of each of these ideologies has shaped the work structures and approaches of staff in ABI outreach contexts. The impairment of ABI has also been reviewed to demonstrate the critical supports outreach staff provide in the daily lives of clients with ABI. The second part of the literature review will examine more closely the issues and challenges in implementing ABI outreach supports, anchoring the medical model and social model as two paradigms from which to understand the manifestations of conflicts and challenges in ABI outreach support. The next chapter will also specifically discuss the challenges of implementing a self deterministic ideology with a client population for which many member have decision making impairments.
Chapter Three
Decision spaces and ethical dilemmas: A review of the literature - Part II

Chapter Abstract
This chapter examines challenges in implementing outreach ideologies with clients with ABI as cited in the literature. The major ethical dilemma to emerge is how to implement an ideology of self determination with some clients that may have diminished ability to be self determined, due to cognitive decision making deficits. How brain injury may affect decision making is examined to illustrate why greater decision making responsibility may be placed on staff in outreach. This is then considered in light of facts that demonstrate decision making itself is a subjective, biased process, influenced by values at various levels (personal, occupational, social, cultural) to which no staff member is immune. This information reinforces the concept that power in the staff role necessitates staff vigilance in how they make decisions, since staff subjectivity and bias can inadvertently impinge on client preferences and self determination. It is noted the call for staff to develop awareness in decision making and staff/client interactions has been advocated in numerous other helping professions, but there is a notable absence from the ABI outreach literature, and ABI outreach training regarding concern for the issue. This reinforces the importance of this research to redress the gap in the literature, as well as for the need for this literature to document what is actually happening as staff practice in ABI outreach.

Introduction
The first part of the literature review in the previous chapter traced the evolution of ABI outreach contexts, and highlighted significant events, issues, and ideologies that impact the contemporary field of ABI outreach. In particular, the dominance of medical model ideologies and structures was shown to be the source of socially sanctioned power in the staff role. In this chapter, some of the challenges of implementing self determinantistic ideologies in the medical model structures of ABI outreach will be explored, as well as
the key staff duty of ethical decision making and its role in ABI contexts.

The context of ABI outreach includes the physical environment in which outreach staff perform their jobs, and the conceptual understandings, expectations and attitudes they have regarding their work. This context plays a direct role in creating the decision space which informs the staff’s modus operandi when interacting with a client. McGrew and Wilson (1982) discuss the concept of decision space:

No decision is made without some pre-conceived ideas of what to aim for, what possible means there are for attaining it, and the costs to be incurred in choosing one means rather than another...The idea of a decision space, where the decider forecloses nearly all options and goals and proceeds directly to rapid evaluation of only a limited range of possibilities, seems a very convincing description of what happens in practice (pg. 3).

In this thesis, the idea of decision space is expanded to include the options a decision-maker considers as well as the resources available that will bear on a decisional outcome. As the following discussion will reveal, the types of possibilities the decision maker considers are informed by decisional influences inherent in the human decision making process, as well as environmental cues, such as found in social cultures and climates.

Ambiguities in ABI outreach
"Effective outreach is simple in concept but complex in execution (Young and Lehmkuhl, 1993, pg. 33). Outreach services for individuals with ABI have existed as long as outreach services have for other disability groups. ABI has a unique distinction however as becoming a prominent new disability group, while related groups such as developmental disability and mental illness have existed with much longer histories of various treatment strategies and ideologies of support (Ducharme & Spencer, 2001). The rise in the self-determination movement for individuals of all disabilities caught individuals with ABI in its net without ABI having gone through the same progression of trial and error approaches as other comparable disability groups. What seems to work
for developmental disability and mental illness seemed like it would work for ABI, without the benefit of ABI specific research, or even the longevity of ABI as a population group to merit the effectiveness of such strategies. The result is inconsistent approaches across the field of ABI outreach support (Ylvisaker, Hanks, & Johnson-Green, 2002), and confusing ambiguities not addressed in the literature regarding other cognitively impaired populations.

There are several factors which contribute to the ambiguousness of ABI outreach contexts and create difficulties for staff to define clear boundaries regarding the decision space in which they conduct their work. The major factor stems from the role staff have in making ethical decisions in their work, combined with potential client decision making deficits which may hamper clients from making autonomous decisions. This will be examined in detail later in this chapter. Firstly, other factors to be considered include a lack of definition as to what constitutes community integration, the lifelong support needs of many individuals with ABI, the enmeshment of staff into family dynamics and situations, and the tensions of using medical model program designs and strategies within a client centered, self determinist ideology on which the concept of outreach is based.

Definitions of community integration
Foremost to the issue of ambiguity in outreach is the lack of conceptual clarity of "community integration" (McColl, Carlson, Johnston, Minnes, Shue, Davies & Karlovits, 1998). What is it exactly? The lack of definition also relates to the difficulty in operationalizing the concept of community integration, thus making it difficult to research specific outcomes of various integration strategies and outreach programs (Doig, Fleming & Tooth, 2001). Measurement of outcomes is a routine expectation of outreach organizations from their funding sources, so it is crucial the support organizations can demonstrate that their services are achieving the objectives of the organization (Phillips & Benner, 1994). In a client centered philosophy, the objectives of an organization are to address and support the goals of the client (Hagner, Helm, &
Butterworth, 1996). McColl et al. (1998) have researched into a definition of community integration through interviews with clients with ABI to gain an understanding of how the clients themselves define the concept.

McColl et al. (1998) examined what features of community life clients with ABI regarded as important and found that the people they interviewed tended to include nine categories, grouped into four overall categories. Conformity (understanding and following the rules of society), orientation (being able to find one’s way around), acceptance (by other community members), having close relationships as well as diffuse relationships, being active in leisure and productivity/vocational activities, being self determined in making life choices, and having choice in one’s own living situation emerged as the defining aspects of community integration for those interviewed. It was found that the more broad a definition of community integration an individual with ABI has for himself/herself, the more positive they tend to feel about their own community integration success. It is interesting that while a correlation between broader conceptualization of community reintegration by the individual and their positive regard for feeling integrated is noted, the researchers did not speculate if a cognitive incapacity affecting the ability to conceptualize more abstractly may have been a factor in individuals with narrow, concrete definitions and more negative views of their own integration successes or failures. This type of research is promising for yielding consistent definitions of community integration but it is still in its infancy and not yet a standard of support services.

Without a clear concept and mandate for staff to recognize as the definitive purpose of their involvements with clients, or to use as a measure of their efficacy and success in supporting clients, staff may turn to their own value systems to apprise their work (Steinman, Richardson, & McEnroe, 1998). They may look towards professional values/ethics, such as iterated in codes of ethics or service delivery standards to guide their work with clients. Staff may also adopt a ‘follow orders’ approach to lessen confusion in ethical or decisional dilemmas, and place responsibility for their own
actions upon the people who supervise them. It is important to investigate how staff in ABI outreach define this context for themselves, and then in turn, explore how their individualized perceptions of the context inform their ethical decision making with and for clients.

**ABI for life**

There is no recovery from acquired brain injury. While people with brain injuries may be able to regain pre-injury skills, or improve their functioning in various life domains, the majority of individuals with ABI require some form of support that will last their lifetime.

Staff come to fulfill a valuable and often indispensable role for many individuals impaired by ABI.

Daily living can be stressful for anyone, particularly as negative life events may occur and disrupt daily expectations (Kleiber, 1999). Stress is enhanced for individuals with ABI who encounter the same daily life stressors in addition to the stresses impairment and disability bring to their life (Hubert, 1995; Karlovits & McColl, 1999; McColl, Davies, Carlson, Johnston, Harrick Minnes & Shue, 1999). Staff play a role to help clients address and manage the daily events of their lives (McCluskey, 2000). Often training regimes are employed to help clients cope with the dual stressors of daily life and disability. However, as Johnson and Davis (1998) note, there is no explicit evidence that social skills training is effective. More often than not, the results of training and therapy are lost once formal therapy ends (Powell, Heslin, & Greenwood, 2002). It seems successful maintenance of coping and living skills in clients with acquired brain injury results more from environmental structure and the ongoing relationships and contacts of individuals in the client’s life. This often includes staffing, a necessary support for some clients who cannot function minimally without one on one attendance (Karlovits & McColl, 1999; McColl et al., 1999).

For staff, offering life long support means the task of supporting clients never ends or
reaches a conclusion. Unlike other work type tasks and duties, there is no completion date. There may also be clients who do not functionally progress or do not demonstrate growth and improvement in skills. Staff may not be able to see or sense that the work they do has any effect, or may not find much personal satisfaction in facilitating ongoing domestic routines. In many health care settings, and therapeutic models, there is an expectation that a client will learn, improve, recover, change for the better as a result of intervention. This is not an expectation that can be applied to all clients in all settings in the ABI outreach field. Staff may lose focus as to what their purpose in working with the client may be, or may fail to challenge clients to attempt improvement if the routinization of the work becomes an emphasis over goal setting and accomplishment. It is important to understand how staff view their role in the support of a client, and how that view may affect the way the staff will approach the work, and shape their decision space.

**Lifelong support and family dynamics**

The cognitive inability for some clients to independently master living skills creates the need for ongoing personal supports. Often family are recruited and sometimes thought to be obligated to fill this role for clients with ABI. In many situations, family members, particularly parents (most often mothers) do adopt the caregiver role (Hubert, 1995; McCluskey, 2000). This situation in itself however brings its own complexities. Webb (1999) points out the psychological reversion ABI creates in parents of an adult offspring with ABI, in which the parent treats the individual as through he/she were a child again. Too easily, adults with ABI succumb to this role, and the tribulations of adolescence are played out again in the family dynamic, this time without resolution. The family becomes arrested in cycle of old parent/child dynamics. Often, both parties are resentful of having to fulfill such turbulent roles, without realizing how to adapt to a more healthy approach to relations. Ponsford, Olver, Ponsford and Nelms (2003) note:

> the major source of stress to families appears...to be the presence of cognitive, behavioral, and emotional changes in the injured relative. Provision of ongoing assistance in dealing with these changes at the community level following discharge from rehabilitation should, thus, be a priority. (pg. 466).
Parents have their own issues and grief to experience and deal with regarding their family member’s injury, but the process is often pushed aside as they fulfill the caretaker duties. Carers may feel they can never take a break from caring, feeling both resentment for this role thrust upon them, as well as guilt for wishing they did not have to care. Carers also often feel isolated and overworked (Frosch, Gruber, Jones, Myers, Noel, Westerlund & Zavisn, 1997; Hubert, 1995; Man, 2002; Marsh, Kersal, Havill, & Sleigh, 1998). Staff support is an essential element not only to support the individual with ABI, but to assist with lessening the burdens of family caretakers as well (McCluskey, 2000).

Ponsford, Olver, Ponsford and Nelms (2003) conducted a study measuring family adjustment when one member of the family has a brain injury and comprehensive community supports have been provided, such as attendant carers. They found that family caregivers with reduced burden of care tended to have lower rates of anxiety and depression compared to family caregivers with less comprehensive support in other studies. Ponsford, Olver, Ponsford and Nelms note that support, such as that of attendant carers, can help to alleviate some of the family member’s caregiver burden. "Clearly the emotional burden of being in a direct caregiver role is significant, and that emotional burden, in turn affects family adjustment. Every attempt should be made to develop models of long term care that alleviate this burden on relatives" (2003, pg. 466).

The intimate nature of staff working with clients in their homes places staff inside the family dynamics. Staff may come to be viewed as a member of the family, as it is difficult and most likely not preferred to avoid interpersonal attachments when one works so closely among other people for long periods of time. Staff may also become caught between parents and the client if the parents and client are in disagreement over an issue. Staff may have to tread a fine line between family wishes and client wishes if they are at odds. The unique placement of staff with a family dynamic as work context may further confuse boundaries and muddle the focus of the staff’s purpose in supporting the client.
These aforementioned factors are some of the situations and issues that contribute to the challenges staff face while working in ABI outreach contexts. Staff negotiate through this environment with their decision making skills, a process further complicated by the problematic marriage of client self deterministic principles in outreach philosophy and the autonomous decision making deficits associated with many clients with acquired brain injury.

**Self Determination in the Context of ABI**

The self determination movement that led the way to outreach/community supports advocates that people with disabilities have the right to make mistakes and fail (Oliver, 1990; Shapiro, 1994). The philosophy emphasizes that people should be allowed to take chances, even if those choices seem risky to others. At the same time, staff have a responsibility to ensure serious harm does not come to the client. Staff working in outreach contexts constantly balance the issue of dignity of risk (client autonomy) with duty of care (beneficence). This emerges as one of the key ethical dilemmas in helping professions (Banks, 1995; Corey, Corey, & Callanan, 1998; Freud & Krug, 2002a; Mattison, 2000; O’Sullivan, 1999; Wegener, 1996), and will be examined in this thesis as a key dilemma specific to staff decision making in ABI outreach contexts.

Often it is a difficult task to know how well a client with ABI may truly understand the consequences and implications of his/her choices, especially when the impairment is of mild to moderate severity (Beresford, 1996). A client may appear to comprehend his/her choice implications, but also may overestimate his/her own abilities, or lack insight to his/her own impairments and limitations (Fischer, Gauggel & Trexler, 2004; Krefting, 1989). Aside from ethical and moral obligations to avert harm from clients, staff also may have to be concerned with legal implications of not intervening. In some situations, staff may be forced to intervene or even prevented from intervening under legal restrictions and guidelines (Steinman, Richardson, & McEnroe, 1998). Put together, these two issues - self determinism and supporting clients with ABI - create a unique and critical challenge for staff working with people with ABI in outreach contexts:
How best does one apply a philosophy of client self determined decision making to a person who has an impairment which may adversely affect decision making?

Decision making is a consistent thread through interrelated aspects within the staff/client relationship in ABI outreach contexts. Decision making holds relevance to both the role of staff as well as the impairment of ABI. In regards to this research, decision making needs to be regarded from two distinct, yet overlapping perspectives - that of the client, for whom decision making will be qualitatively affected to some degree by brain injury and that of the staff, for whom decision making is an aspect of their job duties and role function.

For the client, injury to the brain impacts, to various degrees, the processes involved in decision making, such as sensation, perception, memory, emotion, awareness, knowledge, and abstract thinking. Any of these cognitive functions may be damaged by brain injury (Johnson, 2000; Kreutzer & Wehman, 1991; Ponsford, Sloan & Snow, 1995).

**Decision making and brain injury**

In this section, I review some of the literature that discusses what happens when injury to the brain, resulting in deficits to executive functioning essential for decision making, occurs. However, first, I want to be explicit that having a brain injury does not automatically render an individual with ABI unable to make decisions. It is not my intention in this chapter, or indeed this research, to create the impression that anyone with a brain injury is unable to make decisions. Sherry (2002) emphasizes that individuals with brain injury are often conceptually grouped (and sometimes physically grouped in rehabilitative situations) together by practitioners and in public perception, regardless of individual ability levels. He also notes people with brain injuries are often erroneously likened by the public to be the same as people with intellectual disabilities. Sherry goes on to argue that practitioners often fail to recognize the agency of individuals with ABI and their right to be self determined.
I recognize and respect the problems that arise from considering "people with ABI" as one collective group in this thesis. It is not my intention to imply all individuals with ABI have identical characteristics, identical personalities, or identical decision making deficits. Rather, the issue that is being explored in this section concerns firstly understanding where difficulties in decision making may possibly lie with individuals with brain injuries, and secondly, to recognize that an individual’s ability to be self-determined has to be taken on an individual basis. There are individuals who do not have brain injuries, nor any other physiological impairment, who encounter difficulty decision making, or make what some people may regard as poor or dangerous decisions. I recognize that on the one hand, many people, including staff, erroneously equate brain injury, or even general disability, as automatically rending an individual unable to be self determined in any capacity or form. However, on the other hand, I also recognize that there are individuals with brain injury for whom decision making is a genuinely impaired process, and that a constant ethical balance between dignity of risk and duty of care exists for the staff member who role it is to assist such individuals.

The recent work of Antonio Damasio and his colleagues has focused on decision making and brain injury. By studying what does not work in the decision making process when injury is present, Damasio has been able to learn more about how the actual process of decision making occurs in non-injured brains. One of Damasio’s studies (Blakeslee, 1999) found that research participants incurring brain injury in infancy resulted in those individuals being unable to conform to social norms and expectations. The limbic system, responsible for emotions, plays a role in decision making by providing a reference to feelings an individual may have had about a past experience and therefore providing feedback and influence as to how the individual may choose to act in a new, yet similar experience. Individuals in the study who had damage to the prefrontal cortex since infancy displayed difficulty in adjusting appropriately to social situations, had little concern with long term outcomes of their immediate behaviour, and tended to behave in impulsive and sociopathic ways. Damasio explains that these particular individuals seemed to have never learned common social cues and
expectations and what is considered morally appropriate behaviour in social contexts. Individuals with prefrontal cortex damage incurred later in life also had difficulties with social adjustment and impulsive behavior, but seemed to be able to at least recognize what was considered right and wrong behavior in social situations and could adjust.

This study is significant to illuminating the biological manifestation of emotions and their role in decision making, and demonstrating one manner in which physical injury to an area of the brain may significantly alter the decision making process. Age of onset as well as location in the brain of the injury are two of the many factors that contribute to determining the extent and nature of injury and its effects on executive functioning.

Another of Damasio’s studies (Vogel, 1997) focused on intuition in decision making. By studying individuals with brain injury, Damasio and his colleagues found that a key factor in their subjects’ inability to make good decisions was attributable to a lack of intuition, "which many cognitive psychologists think may be based on memories of past emotions" (pg. 1269). This study underscores an important finding for clients with ABI as well as the general population. In the individual with brain injury, damage to areas of the brain that are involved in emotions and memory can result in the missing component of intuition, which seems to be an important facet in decision making. For non-injured individuals, such as the staff who may be working with the client, this research highlights how intuition is a critical aspect of decision making, that "non-conscious emotional signals may well factor into decision making before conscious processes do" (pg. 1269). This finding lends more justification to the argument that an individual’s own feelings and beliefs influence their decision making at an unconscious level.

A third study (Bechara, Damasio, Tranel & Damasio, 1997) by the same team looked at similar themes by detecting what strategies individuals, both with brain injury and without, use to make the best decisions. Their findings suggest that a "nonconscious biasing step that uses neural systems other than those that support declarative knowledge" (pg. 1293) is accessed before conscious knowledge in the decision making
process. The importance of these studies are to underscore the large role that non-rational factors, such as feelings, intuitions, and unconscious processes play in the decision making process in non-injured individuals.

These findings have twofold significance in the current argument. For the client with brain injury, so many minute and complex brain functions are involved in decision making that injury to any neuromechanism will inevitably create disruption to the typical decision making process. Again, it must be emphasized this does not mean that any individual with brain injury is unable to make self determined decision, but rather that awareness of how the decision making process may be disrupted needs to be better understood, and understood as it relates particularly to each individual with brain injury.

Secondly, in order to recognize what is atypical, we have to know what is typical functioning in individuals without brain injuries. What is found is the process of decision making is not a factual, rational, computational process, but rather a largely irrational, emotional, subjective process. Research into general decision making in individuals without brain injuries further supports this, as discussed in the next section.

**Daily Decision Making: Not as logical as it may seem**

In order to understand the role of decision making in the performance of an ABI outreach staff at work, some general concepts and research related to the nature of decision making itself needs to be explained. The purpose of this review is not to canvass an exhaustive report of decision making literature, but rather to give a basic understanding of general decision making processes. There is a need to understand these processes to extrapolate the implications such processes may have for how staff in ABI outreach contexts form their decision space and make decisions.

Decision making is often conceptualized as a rational, systematic process by most laypeople. One of the earliest theories of decision making was called the Expected Utility Theory. Proposed as a normative theory of decision making, it states that rational
decision making should occur if the following conditions are met (from Plous, 1993, pgs. 79-80):

- Alternate choices should be compared and the decision maker be able to rank them by preference, or be indifferent to the choices.

- The decision maker should not select a choice that is dominated by a superior choice, that is if another choice yields a better or more efficient outcome.

- There should be a difference in outcomes between the choices. If the outcome is the same for both choices, then the choice options cancel out.

- Preferences for choices should be transitive over a series of choices. If the first choice is preferred over the second and the second is preferred over the third choice, it follows that the first choice should also be preferred over the third choice.

- Preferences should be for a choice with greater disparity between outcomes, given the odds favor the better choice, over a choice that has minimal difference between outcomes.

- Decisions should not be affected by the way the choice outcomes are presented to the decision maker.

The research discussed below examines some of the factors that influence the decision making process, making expected utility theory problematic as an explanation of daily human decision making.

**Decisional Influences**

"Psychological research into perception has identified a range of factors which impact upon individual decision making and which generally have the effect of limiting
rationality in information processing," (Jennings & Wattam, 1994, pg 104). Jennings and Wattam list these factors as including attention, memory, heuristics, and bias. This section will briefly review these factors as illustration of how typical decision making in everyday life is logically problematic.

**Attention**

The amount of stimuli in the environment around us is infinite. It is impossible for our brains to take in and register consciously every single sound, site, smell, tactile sensation, and taste all at once that our bodies are in contact with at any given moment. Our perception of the environment and what is happening in it is selective and limited. What we attune to and which details we give meaning and focus upon will shape the content and types of decisions we will make, as well as affect the actual choice made. Alternatives have to be recognized as an alternative before they can be considered in a decision making process (Hogarth, 1980; Plous, 1993).

A very simplified example may be of a staff working with a non-verbal client with ABI. The staff may typically assist the client in a routine of taking a walk to a nearby park and feeding birds which the client seems to enjoy. Suppose the staff perceives that the goal of the activity is for the client to get exercise, or participate in community activities outside the house. The staff may consider alternative activity choices to offer the client, such as a drive to the beach, walking to a location other than the park, going shopping, and such. However, suppose the staff perceives that the goal of the activity is to go to the park, (or is directed by another to only go to the park), or the client never autonomously indicates he would like to do something other than go to the park and feed birds. Options for alternate choices may not be considered or offered to the client. Before a decision can be made to assist the client on an alternate outing, the staff has to recognize other activities as an alternative. This alternative only presents itself if the decision maker perceives of it as an alternative. Where attention to options is directed plays a role in the formation and recognition of choice.
Memory
Memory plays a crucial role in all human functions, because it is memory that gives continuity and consistency to our lives. Our decisions about what to do next are informed by what we have done before, or seen others do (Plous, 1993). Memory allows us to recognize objects and behaviors and reconnect them to meaning created in the past. The meanings then give worth to the alternatives before us, and we make choices based on those meanings (Freeman, 1999).

Initial memory is sensory memory, when stimuli in the environment impress upon our senses. Short term memory uses the sensory memory to connect meanings to the sensory stimulus, though recall of the sensory impressions are short and impermanent. Short term memories that are rehearsed, though repetition, are transferred into long term memory. Experiences are compared to existing memories in the long term memory, and then categorized accordingly (Freeman, 1999; Hogarth, 1980; Plous, 1993).

Memory is never exact, as it is the interpretations of sensory experience that are retained in the long term memory. Also, memories are not like photographs that can be retrieved in the identical form of which they first entered the mind. Rather, memory is reconstructed, based on the meanings and interpretations stored in the mind (Freeman, 1999; Plous, 1993).

Memory can distort the way alternatives are interpreted and recognized by the decision maker, and likewise, various meanings of event stimuli to various decision makers can create vast differences in the way decision makers interpret choices, thus influencing the choices they make (Hogarth, 1980; Plous, 1993).

Heuristics
Because the amount of environmental stimuli and sensory experience is infinite, and the need for the mind to organize selected interpretations into meaningful categories, people often use heuristics in judgement and decision making. Heuristics are shortcuts, or
personal guidelines people use to consider and evaluate information. The use of heuristics "lead to predictable bias and inconsistencies" (Plous, 1993, pg. 107) in decision making.

Heuristics may originate from a person’s schema, or personal interpretation and organization of the world in a manner that the individual can make sense of his/her environment (Hogarth, 1980). Schemas are uniquely personal, as "meaning is closed from the outside by virtue of its very uniqueness and complexity," (Freeman, 1999, pg. 14). Freeman continues to state, "the meaning in each of us is a quiet universe that can be probed but not occupied" (pg. 14).

Heuristics in an ABI outreach context may concern how a staff views their role and purpose within an outreach support context, and what their responsibilities to a client may be. The concept of value hierarchies is a related concept, as a person’s individual schema of the world is informed and shaped by values and belief systems, personal and social. The order in which a person ranks values may affect the way he/she considers decisional outcomes and makes decisions. (Panzarella, 1980; Rokeach, 1973). In the context of a work environment, "work goals or values are specific expressions of general (human) values in the work setting" (Ros, Schwartz & Surkiss, 1999, pg. 54). Panzarella (1980) points out the specific influence of values as represented by professional ideologies upon the work decision-space:

The unique demands of a particular profession may accentuate the importance of certain values with the effect of producing distinctive values hierarchies. The position a given value holds in a hierarchy determines the degree to which that value succumbs to or overrides other values when conflicts arise and decisions have to be made (pg. 10).

These aspects are all part of the influences that create the decision space from which staff decisions are made in ABI outreach. Later in this discussion, the idea of organizational climate and culture will be reviewed when examining decision making.
and the formation of decision spaces within social contexts. At this stage, the discussion is still focused on individual decision making and individual biases and influences.

**Bias**

Bias cannot be avoided, as memories and meanings are subjective, and perceptions about options and choice will be filtered through each person’s own particular worldview and personal bias (McGrew & Wilson, 1982). As Hogarth (1980) states: "Limitations on human memory capacity force people to use cognitive simplifications mechanisms which - although often efficient in terms of dealing with the complexity of the environment - do leave one open to biases" (pg. 94). Information processing is limited. As mentioned, our perception is selective, and anticipation regarding what may happen influences what we actually attune to. Memory also seeks to incorporate perceived information into existing information, rather than generate entirely new categories of information (Hogarth, 1980). This can contribute to one of the decision making traps known as self-fulfilling prophecy (Plous, 1993), in which perception and behaviors are targeted at confirming what one believes to be true. Hogarth (1980) also notes the self confirming bias, in which information or experiences that counters one’s beliefs are disregarded or viewed as erroneous, in order to preserve the perceptions a person has about a particular situation, ideal, or person.

These biases can be detrimental to staff-client relationships, if a staff member expects particular behaviours or routines of a client, and does not attune to potential growth, change, or regression in a client’s functioning. Opportunities may become limited for the client by the staff’s own limited conceptions and expectations of client potential; conversely, staff may also push a client too hard in a direction the client may not wish to go, and not attune to the expressions or communications of the client for a different preference. Numerous authors (Banks, 1995; Corey, Corey & Callanan, 1998; Mattison, 2000; Schaefer, 2002; Steinman, Richardson, & McEnroe, 1998; Worthley, 1999) suggest that staff need to be aware and explicit in understanding their own values systems, and professional ethics and recognize how these beliefs, and decisional
influences impact upon the way they formulate, process, and make decisions in the field.

This sampling from the decision making literature demonstrates some of the ways the individual decision maker can be influenced and biased by his/her own perceptions, experiences and values. But what about the influence of other people on our decisions? Staff in ABI outreach may largely work autonomously with clients when on shift, but they also engage in interactions at many levels with numerous stakeholders, from the client and client’s family, to fellow staff and supervisor in the employing organization, to general members of the community. The next section build upon the concepts previously discussed, but from the perspective of the individual within social contexts of organizations, general society, and cultures.

Decision making within groups

While staff working in outreach contexts are, in practice, working in autonomous conditions, staff are not complete free agents in the work they do. Their actions are guided by numerous factors that include the mission and philosophy of their employer, the organization’s hierarchal structure, policies and procedures, and the goals of the client and their families, which overtly guide behavior, as well as organizational climate and culture that carry influence on individual decision making. I do not wish to give the impression that these organizational and group influences only happen in ABI outreach contexts. These influences which affect decision making have been researched and recorded in the general population. These concepts can then be extrapolated to the specific context of ABI outreach organizations. This review of organizational context on individual decision making draws largely on the writings of David Jennings and Stuart Wattam’s (1994) Decision making: an integrated approach.

Jennings and Wattam state:

Traditional approaches to decision making assumed the individual decision maker operated rationally and in isolation from any possible group organizational influences...any look at business decision making in practice will
dispel the validity of this perspective. To understand decision making and to improve decision making skills, it is necessary to be aware of the group and organizational contexts in which decisions are taken (pg. 54).

There are explicit forms of organizational structure that inform a staff’s individual behavior and the way they make decisions, including organizational mission statements, (which espouse the overarching values and aims of the organization within which decisions should abide; Campbell, 1997), policies and procedures (which define or establish limits to or expectations of programs and staff and the ways in which they operate), and job descriptions (which also define role boundaries and task expectations of staff, outlining areas in which they may have authority to make decisions). Less explicit but perhaps more potent in the formation of staff decision space is the organizational climate and organizational culture.

Organizational Climate
Jennings and Wattam (1994) define organizational climate as "attributes which can be perceived about a particular organization and/or its subgroups that may be induced from the way that organization and/or its subgroups deal with their members and the environment" (pg. 87). This can range from the physical structure of a work space (Do staff work in an office environment or in another person’s home?) to managerial policies and leadership style (Are employees allowed to personalize their workspace? How relaxed is the dress code? Are supervisors autocratic or democratic in involving staff in organizational decisions?). Also included are the policies and procedures of the organizations, which outline the way in which organizational tasks and operations should be conducted. All the factors affect both the types and the way decisions are made within the organization (Hemingway & Smith, 1999). Organizational climate has also figured significantly in studies of organizational burnout (Deckard & Present, 1989; Hemingway & Smith, 1999; Vallen, 1993) across a range of organizations, which job stressors perceived as being from the climate of the organization contributed to job dissatisfaction, employee withdrawal behaviours (such as absenteeism and tardiness), and resignations. This highlights the significance of organizational climate to the decision space of staff and their ability to operate effectively and productively.
Organizational Culture

Related to climate, but harder to pin down is organizational culture. Denison (1996) cites that research on organizational climate and culture actually overlap in a paradigm conflict. He compares and contrasts literature on both organizational climate and culture, calling attention to similarities. For the purposes of this thesis, it is only significant that general concepts of climate and culture are understood in order to recognize their roles in forming decision spaces. Jennings and Wattam (1994) compare the culture of an organization to that of the personality of an individual. They state that "decisions have to be seen in their cultural context. They will be affected by the norms, values, and shared perceptions of organization members" (pg. 92). A short hand definition of organizational culture is the way things are done.

The concept of organizational culture is that organizations are like little societies, in which the social bonds and influences of the members of the organization impact how and what kinds of decisions are made. In Jennings and Wattam’s (1994) book several examples from the literature about group influence on individuals are cited to surmise that: informal group norms tend to govern group actions; dominant group opinions tend to influence individual judgements; groups have the power to bring about consensus; and there is a tendency for individuals to conform to group expectations or opinions. Whyte (1956) first proposed the ‘social ethic’ as replacing the ‘work ethic’ in organizations, in that members of an organization may place emphasis on making decisions that facilitate good relations with co-workers and fitting in with the culture, rather than decisions that pursue optimal outcomes for the work goals of the organization.

Jennings and Wattam (1994) also comment on group cohesion factors, factors that can enhance or impede harmony in group situations, such as an organizations. Large groups tend to break into sub groups. Sub groups can also be formed by diversity or similarity of tasks and duties performed by members of the organization. This could contribute to factors such as the divisions between staff who work in outreach and staff who work in
group homes such as in the ABI organization I worked in. Continuously changing membership in a group, such as the high staff turnover rate common to numerous social service organizations, contributes to group instability, as does lack of work space proximity, where staff tend to work in physically separate work spaces. Outreach workers perform the majority of their jobs in the community, often away from other staff members.

Lack of group cohesion can contribute to conflicts in organizational settings. Jennings and Wattam observe that conflict in groups is inevitable and can not be eradicated, but it can be managed, particularly if people are explicit about it. "In some way, decision making is seen as a rational and logical process above such things as departmental rivalries and personal quests for power. In practice, these sorts of factors frequently play a role in decision making" (1994, pg 80).

Three statements in Jennings and Wattam’s work make explicit the relation between organizational culture, and the role of power in decision making. The authors state: "There is a political dimension to most decision making..."(pg. 82). "Politics is concerned with the competition for power and power is a necessary attribute for any individual or group wishing to take and implement a decision" (pg. 84). "There is a long tradition of seeing decisions as a product of a dominant coalition" (pg. 85). The latter quote resonates with Lukes (1972) radical view of power as the unquestioned dominant ideology propagated as the cultural norm by the dominant interest group. McGrew and Wilson (1982) point out that theorists such as Lukes propose that "the agenda of decision making always contains an inherent bias towards the dominant interests in society, and in consequence more can be garnered about decision making if one has a concern for why certain issues never arrive on the public agenda" (pg. 6). As explained earlier, the medical model of disability is one such example of a socially sanctioned and accepted ideology. Similarly, staff in helping professions work in a organizational culture of which the values of the dominant members of the organization will determine what is considered the norm or status quo. Often, these organizational cultural norms in
helping professions may collude with larger social acceptance of medical dominance and staff-as-expert over clients-as-needy roles.

Staff in ABI outreach contexts using ‘common-sense’ principles to make decision in their daily interactions with clients will be liable to the subjectivity biases and decision errors that are common to human decision making, as illustrated in this discussion. This decision making premise for staff is then made more challenging by the decision making deficiencies, regardless of scale, of the clients they work with. There is concern for how staff are making decisions in the field with clients due to the exacerbated power status this decisional context creates in ABI staff/client relationships, and if the decisional processes and outcomes are ethically sound.

**Decision making and professional ethics**

For staff, decision making is a key facet of their job duties. Gambrill (1990) states that decision making is at the core of clinical practice, clinical practice being both the predecessor to outreach as well as a contemporary allied health service. Staff are working in outreach contexts as facilitators to make self determined decision making a reality for clients with ABI. Staff are also charged with a duty of care to clients, which requires they make decisions about how to best perform their jobs in a way that will be most beneficial and safe for the client (Commonwealth Department of Human Services and Health, 1994a). Mattison (2000) cites Lowenberg and Dolgoff’s (1996) observation that "increasingly, individual practitioners are being held responsible for their choices of action" (pg. 201). Staff are accountable for how they make decisions in an effort to balance the client’s dignity of risk with their duty of care towards the client.

Part of the ethical concern for how staff are making decisions is related to the power in the staff role. Friedson (1987) highlights that "decision making is an activity that requires some sort of power" (pg. 1). As discussed previously, staff possess both legitimate and social/professionally condoned power over clients. The types of decisions and the way decision making is exercised by staff is one manifestation of the power
dynamics within the therapeutic relationship.

Issues related to balancing client autonomy and beneficence have been identified as one of the key ethical dilemmas in helping professions (Banks, 1995; Corey, Corey, & Callanan, 1998; Freud & Krug, 2002a; Mattison, 2000; O’Sullivan, 1999; Wegener, 1996). Corey, Corey, & Callanan (1998) state that ethical issues are:

Often complex and multifacteted, and they defy simplistic solutions. There are many grey areas that require decision making skills. This process entails not only learning information about ethical standards, but also learning how to define and work through a variety of difficult situations (pg. 4).

In discussing rehabilitation ethics, Wegener (1996) states, "ethical issues and values play an integral role in decisions made by both staff and patients"(pg. 7). Ethics are related to professionalism (Lane, 2003), but Corey, Corey, & Callanan (1998) point out the two are not the same, as one may be unprofessional but not necessarily unethical in a particular action. However, staff may have difficulty in determining what is ethically and professionally sound when the boundaries of their decision space is not clear, or other factors distract them. Brennan & Coles (2003) note they have found practitioners "working in the frontline of medicine...may find that stress and lack of experience, support, and training can lead to uncertainty about professional behaviors and attitudes" (pg. 1506).

**Ethical decision making and awareness**

At a generalized level, decision making is one of the most pervasive and necessary human activities (Hogarth, 1980). It permeates all intentional human behavior, or "All behavior involves at least simple decisions." (McGrew & Wilson, 1982, pg. 53, citing Jabes, 1978). However, despite the constant occurrence of decision making in our lives, "for the most part, judgements are made intuitively - that is without apparent reasoning and almost instinctively," (Hogarth, 1980, pg. 1). In other words, much common daily decision making is not actually considered decision making at all by most people. "We
perform most daily activities that are clearly intentional and meaningful without being explicitly aware of them," concurs Freeman (1999).

Corey, Corey, & Callanan (1998) similarly note that in professional practice "most violations of ethics probably happen quite inadvertently" (pg. 5). Worthley (1999) contends that staff "must develop the ability to think ethically - to focus on the process of making decisions rather than on the decision per se" (pg. 7). This view is shared by numerous other scholars in helping profession literature (Banks, 1995; Corey, Corey, & Callanan, 1998; Drew, 1997; Freud & Krug, 2002a; Mattison, 2000; O’Sullivan, 1999; Schaefer, 2002; Wegener, 1996), though none specifically from the field of ABI outreach.

Steinman, Richardson, & McEnroe (1998) assert "staying out of (ethical) traps requires a strong sense of ethical self-awareness, a subject that most of us spend little time examining" (p. ix). Mattison (2000) concurs: "Pragmatic approaches to ethical decision making must be better linked to daily practice and the decision makers themselves should develop insight into how they typically respond to value conflicts" (pg. 201).

Staff in ABI outreach have the unique challenges of applying a self deterministic decision making ideology towards a client population with decision making deficits, within a helping profession structure that retains a medical model dominance which is in tension with a philosophy of client autonomy and self determination. Staff negotiate this challenge through their decision making. Given the evidence of the importance of awareness to ethical decision making when considering the influences that impact decision space, it is important to investigate staff decision making and awareness specific to the ABI outreach context to understand how staff balance the client’s dignity of risk with their duty of care.

Summary of Literature Reviews
This review of the literature, both in chapter two and here in chapter three, has been
presented to give a clearer understanding of the environment in which outreach staff who support clients with ABI work. Understanding their environment and the various factors that bear influence on how the staff regard and perform decision making in their work context will help the reader understand subsequent themes and relations that I will present in the results descriptions and interpretive analysis. The key tenets of importance as illustrated in the two literature review chapters are:

1. ABI community rehabilitation and support has developed as part of the family of helping professions, which originate from the medical model of disability and illness.

2. Power is a key theme in the dominance of the medical model, and socially sanctioned status given the medical and related helping professions. Staff are socialized into roles of power over their clients, which staff themselves may not be aware of.

3. Disability advocacy has introduced the notions of a social model of disability and the rights of self determination for clients with disabilities, both ideologies which have informed and been adopted (theoretically) by outreach support programs (including ABI).

4. ABI is a relatively new disability population, and many support program models and theories have been applied to ABI without the benefit of longitudinal knowledge of best practices for ABI.

5. The ideology of self determination is embedded with the assumption that the client has decision making abilities, while some individuals with ABI may experience a unique array of decision making deficits. This creates an ethical dilemma for staff of how to balance the client’s dignity of risk with their duty of care towards the client.
6. Front line outreach staff are placed as the conduits between the ideology of self
determination and the realities of supporting clients with decision making
deficits, yet nothing is known of how staff actually perceive this task and
attempt to accomplish it.

This thesis gives a voice to a selection of those front line staff, some who are
specialized in particular professions but more who are not (Willer and Corrigan, 1994).
This research fills a unique niche in trying to understand and interpret experiences that
fall between the experiences of the clients and their families and the theories and/or
prescriptions/directives of the scholars, professional experts and administrative
managers: the experiences of generalist workers who show up at the client’s home and
directly support clients with acquired brain injuries in the ambiguous and conflicted
context of outreach.
Chapter Four
The Research Method

Chapter Abstract

This chapter justifies the use of a constructivist paradigm and symbolic interactionist approach to conducting the research.

Theoretical Frameworks

“Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter” (Denzin & Lincoln, 1994, pg. 2). Qualitative methods are ideal to investigate and interpret social phenomena as it occurs within its natural setting, (Baumgartner & Strong, 1994, Denzin & Lincoln, 1994), such as staff-client interactions and staff decision making in outreach contexts. In particular, this study fulfills the aims of applied research, in that it contributes “knowledge that will help people understand the nature of a problem so that human beings can more effectively control their environment” (Patton, 1990, pg. 154). Qualitative studies in the specific area of ABI rehabilitation and community reintegration have been conducted, with the focus largely on clients and their families (Eg. McColl, Carlson, et al, 1998; McColl, Davies, et al, 1999; Higham & Phelps, 1998; Johnson & Davis, 1998, Kelleher, 2000; Sherry, 2002). It is important that the voices of outreach staff be included in this picture, to gain a fuller representation of all the key players in the outreach environment. These voices include my own, as a practitioner with experience in ABI outreach contexts. “Applied qualitative researchers are able to bring their personal insights and experiences into any recommendations that may emerge” states Patton (1990, pg. 154).

Some narratives offered from clients or family members of individuals with disabilities have criticised much of the existing literature as being of a medical discourse written by self styled experts and ignoring the voice of clients (Kelleher, 2000; Ribner & Knei-Paz, 2002; Sherry; 2002). This client/family representative narrative literature tends to fault helping professional literature as prescriptive and dominating over client agency
and self-determination. While much disability related literature has historically been from a professional prescriptive view (Darcy, 2002), what is lacking are narratives from staff expressing their experiences in the field as they perceive them. Willer and Corrigan (1994) note that most staff in community contexts are not from medical or professional backgrounds, having mostly a layperson’s sensibilities about their work and relations with clients. It is this curious mixture of an everyman sensibility socialized into a helping profession discourse (Wolfensberger, 1972) and structure within the field of ABI outreach that I explored with this research and present in the results. One of the interview participants of this research, who is specialised in a profession, commented:

I think that generalist workers might actually be luckier than those of use who were trained in a discipline, because you’ve got a more normal society viewpoint. Does that make sense to you? Like you’re not trained to look at a specific area, you’re just looking at it as a member of the community who is working with the population, and sort of comparing this population with community and would they fit in? Maybe they’ve got a better view point than we have. We tend to be a bit nit picky maybe at times. You know, you see the small deficits and the things that have gone wrong. - Felicity

Symbolic Interaction: as an interpretive tool
Since this research is concerned with social interactions (between staff and client) and the meanings staff create from those interactions, I have taken a symbolic interactionist focus within a construtivist/interpretive paradigm. Clarke (1997) states, “A basic assumption of symbolic interactionism is that rather than acting instinctively, human beings manipulate symbols, and through ‘minded behavior’ or creative thinking, the individual interprets, defines, and attaches meanings to symbols in his or her environment” (pg. 297). It is from these meanings that individuals decide how to act in their environments. Symbolic interactionism describes a constant flow of information and meaning-making occurring between the individual and their environment which Stryker (1980; 1981, cited in Clarke, 1997) identified as "reciprocal effects between self and social interaction"(Clarke, 1997, pg. 297)

Guba and Lincoln (1994) point out, “Questions of method are secondary to questions of
paradigm, which we define as the basic belief system or worldview that guides the investigation, not only on choice of methods, but in ontological and epistemological fundamental ways” (pg. 105). Symbolic interaction is an interpretive approach within the constructivist theoretical paradigm (also called an interpretive paradigm; Guba & Lincoln, 1994; Lincoln & Guba, 2000). Denzin (1994) notes, "A good constructivist interpretation (text) is based on purposive (theoretical) sampling, a grounded theory, inductive data analysis, and idiographic (contextual) interpretation" (pg. 508).

Staff in ABI outreach are located within a culture of understandings and meanings specific to the outreach context. Individual subjective meanings are expressed and developed though the process of cultural acquisition and institutions (Lal, 1995), which theoretically can be applied to the socialization of staff into existing outreach cultures. Lal (1995) notes:

The acquisition of culture, which plays the crucial role of orienting the individual in his or her activities by transmitting to him or her "a pattern of symbolic meanings through which the members of a collectivity grasp their worlds," is available in and through communication (Higham, 1984, p. xi). Put slightly different, the process of communication, and in particular language, socialization, and education, transmits the experience of the group (or groups) into the subjective world of meaning and value that directs individual effort and activity (pg. 424).

Building on the theory that staff are socialized into a medical model ideology in ABI outreach contexts, the acquisition of ABI outreach culture by staff can be conceptualized as a symbolic interactionist process. This theoretical approach allows me to explore the way staff look at their jobs and their relationships with clients, and to interpret their narratives as subjective experiences which inform them how to act in a daily context with their clients and within the culture of outreach support. This subjective experiential viewpoint from staff on the front lines has not previously been documented in the context of ABI outreach support.

Symbolic Interaction: as a research process
According to Baumgartner and Strong (1994):
“How individuals interpret some phenomenon, how important or unimportant it is, the words used to describe it— all are indications of how people impart meaning to objects, people, and events, and this in turn determines how people act” (pg. 179).

This observation has relevance not only to the content of the narratives shared by interview participants, but also to the manner in which they shared their stories in the research interview with me. The interview participants and I were involved in a social interaction in the conduct of the interview, and therefore subject to the same symbolic interactionist dynamics as found in any other human interaction (Fontana & Frey, 2000). The features of the interview process, my private reactions to the interview, what was not said as well as what was, and discussions that revealed interview participants holding differing definitions of abstract concepts are all vitally important elements to understanding and interpreting the narratives as obtained in the interview process. Charmaz (2000) states, “What respondents assume or do not apprehend may be much more important than what they talk about. An acontextual reliance on respondents’ overt concerns can lead to narrow research problems, limited data, and trivial analyses” (pg. 514).

Denzin (1994) similarly states, “The methods of making sense of experience are always personal. Life and method are inextricably intertwined” (pg.501). Likewise, Altheide and Johnson (1994) posit, “We do not apprehend anything without connecting it to something else and that ‘else’ turns out to be everything in our life world and its appropriate zones of relevance” (pg.492). There is an appealing duality in this research in that not only does symbolic interactionism frame the research process, but also captures the theoretical understanding of the decision making processes staff use in ABI outreach contexts.

Some tangible examples of symbolic interaction occurrences in the research process seemed like interview “problems” to me at the time of the interviews, but revealed later in analysis to be significant pieces of information about the interview participant’s subjective experience and meanings. The specifics of these occurrences will be discussed in the results. Applying symbolic interactionism to the research process and
the analysis of the data content contributes to a logical consistency that supports the trustworthiness of the research. Altheide and Johnson (1994) remark, “As long as we strive to base our claims and interpretations of social life on data of any kind, we must have a logic for assessing and communicating the interactive process through which the investigator acquired the research experience and information” (pg. 485).

**Interviews and other data collection methods**

Lal (1995) notes, "The symbolic interactionist is required to employ methods that capture the actor's point of view and that enable him or her to speak for him- or herself. In this sense, symbolic interaction ‘empowers’ those it seeks to describe and understand" (pg. 421). The current research is an attempt to describe a phenomena from the perspective of the individuals who know it best: the people living it. Staff members who work with clients with acquired brain injury are the most qualified to speak about their own interactions, feelings, beliefs and opinions on the nature of their work.

Interview was selected as the optimal method for me to gain access to the participant’s inner thoughts. In trying to explore staff’s personal meanings about their own work, what interview participants told me about their understandings and personal meanings was more important than witnessing how they actually behaved. Observation occurred in the interview process itself, where my own observations of how the participant responded and behaved in the interview contributed to my interpretations of their narratives.

Interviews were also favored because of the difficulty in gaining access to observing participants in their work environment. There were concerns with participants modifying or monitoring their own behavior in the presence of a research observer. I felt social desirability could negatively influence natural observations of participants engaged in interactions with clients (Bradburn, 1983). Observation is problematic, in that the presence of the researcher invariably affects the observed environment and subjects, despite efforts to reduce researcher influence on naturalistic inquiry (Adler & Adler, 1994). An ethnographic approach was not needed to understand the general nature of ABI outreach environments, since I have worked in ABI outreach contexts,
and my own personal experiences in the field were the impetus to launch this research. There were also legal issues of client confidentiality restricting my access to observe staff during client interactions. The data collection method of semi structured interview allowed for interview participants to voluntarily share their narratives with me in a non-threatening, open manner, and to offer forth information in their narratives which they perceived as important or significant to the topics under discussion (Kvale, 1996). The participants’ freedom to answer open ended questions however they wanted to answer, contributed to the symbolic interactionist process of my interpreting the meanings the participants’ attached to their work through the meanings they attached to the questions.

**Constructivist grounded theory principles in guiding the research**

The principles of constructivist grounded theory were applied in the formulation of the research design, the conduct of the fieldwork, and the interpretive phase of the data analysis. Grounded theory is an exploratory process appropriate for investigating the nature of phenomenon in the social world. The theory is emergent from the data collected, and the direction of the research is in response to the information revealed in the data. Through the investigation of a phenomenon, the researcher seeks commonalities and themes, which the researcher eventually interprets into a meaningful theory about the nature of the phenomenon (Strauss and Corbin, 1994). This method is more about exploring possibilities than proving a hypothesis. Maiocco (1999) notes that grounded theory is about the exploration of social processes. This research is concerned with the social process that occurs in the staff-client interaction in ABI outreach.

Charmaz (2000) proposes a constructivist modification of traditional grounded theory to address the criticisms that the traditional approach is too closely tied with positivistic paradigms and a belief in an objective observable reality. She explains:

> A constructivist grounded theory assumes that people create and maintain meaningful worlds through dialectical processes of conferring meaning on their realities and acting within them (pg. 521)....a constructivist approach recognizes that categories, concepts, and theoretical level of analysis emerge from the researcher’s interaction with the field and questions about the data (pg. 522).
This view is in concert with the symbolic interactionist positioning of this research and my own worldview as a researcher. Along similar lines is the proposition of framework analysis, though it appears to attempt to adhere to the positivist paradigm. Framework analysis uses the premise of grounded theory, but allows for prior assumptions to be incorporated into the research design (Lacey and Luff, 2001). In framework analysis, the researcher seeks data regarding a priori assumptions and themes, often with practical outcomes resulting from the data that can be applied in practical settings. Framework analysis allows for focused investigation into themes of interest to the researcher, while still permitting emergent theory to come forth from the data collected (Lacy and Luff, 2001). Both framework analysis and constructivist grounded theory acknowledge and allow for the subjectivity and sensitivities of the researcher. I acknowledge being responsive towards themes I anticipated I would find in the data, as well as being open to unexpected or new themes that I did not anticipate. My prior assumptions formed the frame around which I designed the research, but grounded theory principles allowed for theoretical generation of concepts not found in prior assumptions, or concept which did not conform to prior assumption expectations.

From my experiences in the field of ABI outreach, I came into this research with some distinct assumptions about the nature of staff-client interactions in ABI outreach contexts. Those assumptions included the following:

1. A staff member’s personal values affect how he/she performs his/her work.
2. Staff hold positions of power over clients.
3. Power dynamics are exacerbated in staff-client relationships when the client has ABI due to client cognitive deficits and vulnerabilities.
4. A staff with low awareness, of his/herself, of power dynamics in the staff client relationship, and of features of the psychological exchange in therapeutic relationships can potentially be a damaging influence on the client.
5. Principles of self-determination or inclusion sometimes seemed at odds or an inappropriate match with the capabilities and interests of the client.

These assumptions arose out of direct experiences I had with other staff members,
observing other staff with clients, or from reflections on my own engagements with clients in the course of my work. Here they are mentioned as provocateurs which engaged my interest in the current research and acted as starting points in investigation.

Grounded theory principles also guided the fieldwork interview process. As they were being collected, I regarded the interviews as a continuum of narratives about working in ABI outreach, and not as separate individual cases of thematic occurrences. Since the purpose was not to quantify the number of times a particular theme emerged, it did not matter if a theme was mentioned once in one interview or numerous times across a large number of interviews. Once a particular event, concept, or theme emerged in a narrative, this was license to either question other interview participants about the theme to search for differing narratives, or to change the questioning towards other themes to seek theoretical saturation. In this research, theoretical saturation is understood as seeking data from different angles and perspectives until no new information or understanding is forthcoming about a particular theme or theoretical line of reasoning within the collective data (Strauss & Corbin, 1994). Charmaz (2000) points out that theoretical saturation can be problematic in its loose definition of what constitutes saturation, and that grounded theorists may be duped by their rapid categorizing of data into thinking they have saturated it more fully than what actually could remain. This seems not to be as much a concern in constructivist grounded theory, since data is acknowledged as “narrative constructions” (Maines, 1993, cited in Charmaz, 2000), and the best we can do as researchers is recreate and reconstruct the data in our own telling of the research (Charmaz, 2000; Denzin, 1994). The results presented in this research are a snapshot, based on what data was gathered with a specific group of individuals, within a specific time and space. It is a telling of their stories about their experiences as they saw them at the time of the data gathering.

As an example of concepts emerging in the data collection process, one prior assumption I took into the research was that staff hold inherent power over clients in their interactions. This assumption was anchored from my personal experience in the field. It was corroborated by sources in the literature that speak of the legacy of the
medical model and society’s value in helping professionals, (examined in chapter two). This literature support legitimated the issue of power to be sought as a potential theme to emerge in the data. In an early interview, the following exchange occurred:

*Me:* When, you’re in that autonomous situation, and you’ve got sort of that awesome decision making responsibility, how did you carry that, or how did it make you feel?

*Melanie:* Yeah, that’s right. Yeah, it makes you feel good because you knew that you were responsible for yourself and I think, and you’re responsible for another person, so it does. It gives you a bit of control, and a bit of authority, which sometimes I worry about that (Laughs) with some people...

Melanie’s spontaneous mention of control and authority introduced and legitimated the theme of power as a relevant interview topic in subsequent interviews. Using grounded theory, the concept emerged naturally from an interview participant, but since the interviews were being regarded as a collective of narratives within the overall story of ABI outreach, the emergence of the theme needed to be discussed with other interview participants to seek differing perspectives and explore alternate potential meanings power may have in the ABI outreach context. When no new information was forthcoming about a particular theme, the theme was considered theoretically saturated (Strauss & Corbin, 1994).

**Applying an Inductive Method to Deductive Approach**

Baumgartner and Strong (1994), citing Marshall and Rossman (1989) remark that qualitative research begins with the curiosity of the researcher sparked by an event or phenomenon the researcher has experienced or observed. “A plan begins to form from hunches” (pg. 182), they write, and continue to note, “Intuition about the importance of the problem, a feeling of ‘how interesting it will be to learn about this!’ often plays an early role” (pg. 182). Denzin (1994) also notes, “If a paradigm is constructivist, the writer will present a text that stresses emergent designs, and emergent understandings,” (pg. 502), reflecting the interactive nature of the research process.

Awareness of my own biases, in terms of my assumptions and thematic interests, has never been outside of my concern for the duration of this project. Through the course of
learning how to conduct and understand qualitative research, I realize much of my efforts were still performed under the influence of empirical positivistic thinking. As I have become involved in the writing stages of the thesis, I acknowledge and allow that I never could be entirely objective in my research, as the positivist model would have one believe. According to Phillips and Pugh (1990), the Ph.D. process is not so much about completing a mammoth tome known as one’s thesis or dissertation, but it is about learning how to do research. Hanrahan, Cooper, and Burroughs-Lange (1999) criticize traditional empirical reporting of research that does not account for the interaction and involvement of the researcher, as well as the impact of learning how to do research upon the researcher-in-training. They encourage openness from the researcher-in-training to acknowledge this impact:

We believe that it is more consistent with recent developments in educational theory for factors such as subjectivity and discussions of changes in epistemological beliefs to be accepted and reported as a legitimate part of the learning process in a doctorate (pg. 401).

Hanrahan, Cooper, and Burroughs-Lange (1999) also cite Walkerdine (1994) that “subjectivity in social research is ‘impossible to avoid’” and therefore it should be “a feature of the research itself” (pg. 405). This is in concert with the symbolic interactionist framework which threads all aspects of this research. Thus, admission to changes in my own epistemological understandings and beliefs are viewed as part of the learning process.

What I initially saw as problematic actually is an inevitability of interpretive, qualitative research. As Denzin’s biographically situated researcher, I am encouraged by Denzin (1994) to place myself into the text, “to engage writing as a creative act of discovery and inquiry” (pg. 504). Denzin cites Lather (1991), “Writers create their own situated, inscribed versions of the realites they describe (1994, pg. 505). My subjectivities are manifestations of the world view and ideological positioning through which I filter and interpret my experience of the research, as well as the research content. Rather than make excuses for them, I make them explicit and include them in the research process.
My assumptions resulting from personal field experience lay the foundations for the research project. I deduced tentative themes that I felt would be relevant to the ABI outreach context based on what I had personally observed and reflected. This also established a potential bias in the collection and analysis of the data. While interpretive research does not pretend to be objective and allows for the relevant personal perspective of the researcher, it is still critical to demonstrate trustworthiness in the data that presents a logical symbiosis threading the theoretical positioning, conduct of the research, and analytic interpretation of the data (Altheide & Johnson, 1994). Since “a text and an author’s authority can always be challenged” (Denzin, 1994, pg. 506), it is through demonstrating this theoretical and procedural logic that permits the reader of the thesis to judge its trustworthiness (Attheide & Johnson, 1994; Baumgartner & Strong, 1994).

Adopting grounded theory principles for the data collection and analysis was an appropriate inductive approach for two reasons. It helped to guard against my ‘leading’ the participants; that is to allow their own stories to emerge without imposing my story and perspective on them. While some disclosure and story sharing on my part did occur, this was for the purpose of rapport building (Kvale, 1996), and not to engage a mutual view of a shared narrative. I wanted their narratives to take centre stage in the data collection, with the purpose of my own narrative to be the story that set the research in motion. This also fits with Glaser’s (1978) assertion that “any existing concept must earn its way into the analysis” (in Charmaz, 2000, pg. 511).

The other reason this method worked was it allowed significant themes to emerge as understood by the interview participants, rather than my having to operationalize abstract constructs such as ‘power’, ‘values’, and ‘awareness’. Fontana and Frey (2000) assert that “the use of language, particularly the use of specific terms, is important in the creation of a ‘sharedness of meanings’ in which both interviewer and respondent understand the contextual nature of specific referents” (pg. 660), and warn of misunderstanding when interviewer and respondent believe they are speaking to the same concept but actually are not. I was aware directly asking questions about power
dynamics in a staff-client relationship or personal values could also be contentious when speaking with staff. The risk of staff viewing our conversation as somehow judgmental of their job performance created the possibility of staff offering socially desirable responses to questions. In my experience in helping professions, the term ‘power’ has tended to be viewed in a negative context, unless one is speaking of the power of the client. I was hesitant to be the one to introduce these terms into the interviews. However, such terms and constructs were open for discussion if introduced by the staff member being interviewed. Ultimately, for the purpose of reducing my own influence on interviewees responses, it was more appropriate to define constructs from an interpretive phase.

As stated and demonstrated in chapter two, a plethora of evidence and theory from past literature substantiated much of what I had experienced in my own work, and also served to better focus the research questions and design of the current study. The literature review was an essential phase to connect my personal assumptions from experience to larger more universal issues in ABI outreach support that would hold greater relevance and implication for the field. Focusing on the narratives of others reinforces the universality in the themes under investigation. Denzin (1994) notes that utilizing a multi-voiced approach in the text guards against the researcher completely dislocating or eclipsing the voices of the subjects being researched. The narratives represent individual stories within a context of ABI outreach support, and highlight issues and themes that potentially may be experienced by anyone else within the same context.

Remaining open to a multiplicity of discourses in the narratives, and highlighting rather than minimizing contradictions allows me, in Lather’s (1982) words, to: “present alternative, conflicting representation, juxtapose disparate textual styles and forgo the unresolvable tensions between them in order to understand what is at stake in creating meaning out of data” (pg. 9). Jones (1992) reminds us that “contradictions, complexities, and competing discourses” are often at “the heart of important issues” (In Kelleher, 2000, pg. 51).
Thematic Representation: Anecdotal vs. Evidence

This research is clearly not universally representative of every ABI outreach worker. There are limitations on how widely the results of this research can be applied. This raises the question about how to present the results of my data. Are the narratives I gathered from other outreach staff workers anecdotes, merely descriptions of staff experiences as perceived by staff? Descriptive data is valuable in the depth and specificity it can give to understand a particular phenomena or life world experience (Denzin & Lincoln, 1994). In describing and presenting what interviewed outreach staff experience in their daily work, this research adds a dimension of comprehension that cannot be captured in quantitative research alone. Kelleher (2000) raises the concern in her work about the tension between respecting the narratives of others by remaining faithful to a pure descriptive approach and the temptation to apply an analysis to highlight significant themes and issues. Analysis runs the risk of imposing meaning upon other’s narratives which was not intended by the storyteller (Charmaz, 2000).

Researchers inscribe rather than describe the data they have collected (Lather, 1991; Denzin, 1994), since it is impossible to describe without some degree of interpretation. As previously explained through the symbolic interactionist framework, the collection of data for this research has occurred through my interactions with other outreach staff. In talking to me about their own experiences and perceptions, my understanding of their meanings is at best my own interpretation - my engagement in the process of spoken discourse with another person (Fontana & Frey, 2000). In reporting data in the thesis, yet another layer of interpretation occurs - this time my engagement with the written text which is representative of the spoken discourse. New meanings and associations may become apparent which were not so during the time of the interview. Patterns emerge across interviews, which are more fully recognized away from the immediacy of conversation. Anomalies also appear where a situation or occurrence appears in one person’s narrative but does not in any of the others. Anomalies are as provocative as patterns, begging the question of why has there been an exception to what appears to be common to the other participants (Fontana & Frey, 2000).
Denzin (1994) comments, “Fieldworkers can neither make sense of nor understand what has been learned until they sit down and write the interpretive text, telling the story first to themselves and then to significant others, and then to the public.” (pg. 502). Richardson (2000) also notes that “writing is a way of ‘knowing’ - a method of discovery and analysis” (pg. 923).

In the process of learning qualitative methods, I grappled with how to elicit empirical evidence from anecdotal data. Different approaches to data analysis were employed to offer a range of perspectives on the interview transcripts. My difficulty however remained with trying to apply my prior knowledge of quantitative methods to the qualitative data. I worried about rigor and being able to prove that I was right about the conclusions I was drawing. Of course, there is no way to be “right” about one’s interpretation. One can only build a case for why they have interpreted in that way (Denzin, 1994; Baumgartner & Strong, 1994).

Kelleher (2000) notes that to be selective in what to present in a descriptive approach is a type of analysis, as certain themes and patterns will dominate the thesis over others. In this research, my intention has always been to both describe and interpret the narratives offered me through the interviews I conducted with other outreach staff members. The descriptions are presented to better understand what staff are experiencing and conceptualizing while in the field. Simultaneously, analysis occurs for significant themes of interest, as established through my own personal experience and support from the literature. Even if the voices presented in this research are a minority in the field, the fact that they encounter these issues is substantive. Ethical issues of conduct for staff which affect quality of life issues for clients are applicable to all.

Throughout the research process, I thought at different times I was investigating values, power, or decision making, all within the context of ABI outreach. I knew these themes were linked but I did not know quite how. Denzin’s (1994) and Richardson’s (2000) observations became overwhelmingly apparent to me upon the completion of writing my first results draft, and the central issue of staff awareness emerged as the overall theme
and core of the research.

Familiarity and greater understanding of the constructivist paradigm and interpretive approaches has alleviated many of these concerns. I am no longer trying to be “right”, but rather I am offering perspectives from a particular group who work in a particular context. The perspectives I am offering are corroborated by theoretical and empirical support from the literature. This approach serves to highlight and raise awareness about decision making and power issues, and the significance of staff awareness to both in ABI outreach, which has a direct bearing on client support services and client quality of life issues.

Detailed accounting of the methodological procedures used to conduct this study are located at the back of the thesis in Appendix A.
Chapter Five
Staff in ABI Outreach Contexts and The Ethic of Practice

Chapter Abstract

This chapter presents brief profiles of the fifteen individuals (henceforth called participants) interviewed for this research. The purpose is not to compare their experiences, attitudes, and personalities to each other, but rather to offer a sampling of a cross section of people who work in ABI outreach, and to demonstrate the diversity of staff roles, outreach structures, and staff duties that may occur in ABI outreach settings. Literature on role definitions is offered to further corroborate the perspectives of the participants as not being atypical of other roles, duties, and perspectives held by staff in other helping professions. The lack of training in ABI outreach, first noted in the literature reviews, is corroborated by the participant’s own testimonials to their own lack of ABI specific training in their outreach positions. Elicited from the perspectives of the interview participants, the ethical dilemma of balancing a client’s autonomy (dignity of risk) with beneficence (a staff’s duty of care) emerges as the central aim of the participant’s ethic of practice. This ethic is corroborated in the literature as a common dilemma across a variety of helping professions.

Introduction

In order to understand the role of ethical decision making and the significance of staff awareness within acquired brain injury outreach support, there is a need to be sufficiently acquainted with an understanding of the context of ABI outreach and those who work within that context. In keeping with a symbolic interactionist positioning, this context is described in this thesis from the perspective of those interviewed, in the form of a collection of narratives, or stories about working in ABI outreach contexts with multiple voices and actors. My biographically situated perspective is also voiced in the chorus of ABI outreach staff, contributing to the perspectives in this context, as well as providing insight to my own worldview and interpretive filter regarding this research.
Probably the most consistent feature of outreach settings is how inconsistent the structure of outreach can be from one organization to another. As noted in the literature review, what underpins outreach as a context is that clients are not supported in institutions or artificial, controlled settings, but rather in home and community environments familiar to the client. This is a negative definition, in that outreach, or the community setting is defined by what it is not, rather than being able to pinpoint what it is (Lucas, 1999). This may be part of the challenge in trying to bring consistency and philosophical alignment among service providers in the field of ABI services, which in current times are not unified (Ylvisaker, Hanks, & Johnson-Green, 2002).

Understanding the various work settings and the various positions of the staff interviewed for this research (participants) as related to the overall ABI outreach environment and structure will contextualize the challenges and strategies used by the participants in these environments. Often, particular work issues arise from the very nature of the way ABI outreach support is structured. Understanding outreach structures in ABI support will also contribute to understanding the role decision making and staff awareness may play in these environments.

This chapter will introduce fifteen individuals from New South Wales who volunteered to share their stories about their experiences in ABI outreach through describing their backgrounds and attitudes towards their work, the structure of their working environments, and key challenges they identify as encountering in their work. While the sample size in this study is too small to infer generalisability of the participants’ self-described experiences, or to compare individual differences in any meaningful manner, this collection of participant profiles does demonstrate a diverse cross section of ABI outreach staff whose described perceptions and experiences are consistent with outreach descriptions in the literature (e.g., Clegg, Standen & Jones, 1996; McClusky, 2000; Ponsford, Sloan & Snow, 1995).

Who We Are and Where We Work

The opening query of the interviews with each of the research participants was “Why did you decide to work with people with acquired brain injuries?” This was a
deliberately worded question, my intention to uncover if indeed participants felt their involvement in ABI outreach was a choice, foreshadowing the discussions and interpretations of decision making to follow in the interview. The variety of responses I received to this opening inquiry offered insight into the participant’s background and some of their personal motivations to work in the field, as well as opened the discussions for many of topics that emerged as significant themes in this research. The question and accompanying response also gave me an informal initial indication of the potential ability for the interview participant to demonstrate self-reflexivity.

**Jeff**

Jeff works in a respite house in a regional city. He began as a volunteer during a period of unemployment. He felt his experience with having a developmentally delayed daughter could be useful in a helping profession, and signed up for a training course with a local ABI support agency. His volunteering led to his eventual employment with the agency. Jeff described his purpose in his work as being a facilitator for the clients.

> Probably the most important service is that they are able to access, and to do the things that they would actually like to do themselves as long as it’s not within, you know, any risk to themselves or anything. To be able to just, help them to be able to do the things they basically would like to do, you know, just as a normal person would like to be able to do, and to be there as an assistant to them in doing that.

In his summation of his working philosophy, Jeff touched on two themes to be further examined in the results, that of the client’s dignity of risk balanced with the staff’s duty of care, and a view of clients as “others” (Priestley, 1999) rather than as the same with differing abilities. This distinction is recognized in the interviews when participants make references such as “just as a normal person would”, implying that the client is not a normal person.

Jeff described his duties in the home as being concerned with facilitating activities of daily living (ADL’S) which include domestic chores and recreational outings.

> It was a matter of making sure they go through their normal routines, and you
know, showering, changing to clean clothes, that they’re available for them, and making sure that they have had their breakfast. Making sure they have had their medication, and, again, it depends on the time whether they’re medicating, whether they have to have it or whether they’ve already had it from the previous service worker. Seeing first of all, whether we’ve got service vehicles available, and whether or not we can get out to go somewhere. We might just go out for a drive, we might be for a walk somewhere, and there are chores that gotta be done within that, at the house. The cleaning and the washing, and all that sort of business, just like running a normal household \textit{(laughs)} and just make sure that they are safe and that they are doing, you know, what they, would like to do. The ones that are in the moment, they just like playing cards and dominoes \textit{(laughs)} so they pretty well entertain them, themselves at the moment. There are others that aren’t in the...we do community respite too so we actually go to their home, rather work in the (respite) home with them or pick them up from their home, and, might be just a matter of going for a drive, or going to a shopping centre or be something like that, just to help them out with some thing they might want to do.

Jeff offered an overview of group home life, and spoke to logistical concerns in terms of transportation and assisting clients with pursuing activities they would like to do. He also mentioned the teamwork approach in group homes, in which staff need to consult with each other for consistency in routines and how they work with the clients.

Jeff said the least satisfying aspect of his job is the physical and emotional drain it can put upon him. The most satisfying aspect for him is seeing someone be discharged from the service. He said he hasn’t seen it happen often but when it does, “it’s a great feeling, you know, that now that it actually has happened.”

Loretta
Loretta works in the same respite home as Jeff, and conducts the same duties as Jeff described. She has been employed with the agency for four years, but her prior experience with people with disabilities was her own family, which she suggests, “makes you a little bit in tune with people who, you know, have difficulties. I guess I’ve always been a bit interested in that area”. She volunteered in her daughter’s school, sometimes assisting other children with disabilities as well as her own child. In stating her guiding values, Loretta remarked:

I think the most important thing that I can do is to let them be as independent as
possible. That’s always...I think that, the companies I work for, I think that’s what they think, but I definitely think. Sometimes it’s much harder. You could do everything for them and tell them what to do, and that. To me, it’s really important to give them the independence.

In Loretta’s comments, two more themes emerge that will be examined more closely in the results, that of personal values and agency ethics in the work setting, and power/control dynamics present in a staff client relationship.

Loretta emphasised the importance she feels in teaching skills to clients to enable the clients to be more functionally independent in their daily lives. She stated:

Like getting someone to dress themselves, I could dress them, you know that, the time with no frustration, but it’s so important if they have those skills to keep them.....I have one client who lives in a nursing home, she’s only a young woman so they dress her, because it’s quicker, and that was a skill she had that was really good and it’s quite painful now, because it’s only once a week she dresses herself.

She explained that the hardest aspect of her work was dealing with unprovoked outbursts and occasional abuse from clients. The most satisfying aspect of her job was being able to teach new skills to someone, to see them learning and being able to do new things.

Felicity

Felicity is a physical therapist working with a community reintegration agency in a regional city. She cited having a long standing interest in neurological disorders, but found her move to the field of brain injury a major shift from her previous experience and knowledge.

Yeah. It’s about the mystery of the brain, I think. I just find it so fascinating about stuff that can go wrong. You just, you don’t even stop to think about in terms of your everyday function. It goes wrong and the whole thing falls apart and you think *WHOA* how did that happen? And it’s just really fascinating trying to, trying to unpick people’s neurological problems, like in terms of understanding what’s causing what. So you can actually get through to the bottom of it, if you can, if such a thing is possible......I have a family member who’s got a disability as well (Down’s Syndrome), so I guess I’ve been exposed
to it over a long period of time. So, the issue of working with severe disability wasn’t an issue, I think, I think the issue is more coming face to face with exactly what the cognitive and behavioral sequella of brain injury.

She stated she felt “plonked into the deep end” when she moved into ABI, since it is so much more unpredictable than other intellectual disabilities she has worked with. Signing on as the physical therapist (PT) with her current employer, Felicity is also required to take on case management duties in her role. She deals better with the PT aspects of her work because it is "black and white", whereas she constantly struggles with the lack of boundaries and grey areas of case management in outreach. The autonomy of her position creates as many dilemmas as it does freedoms.

....Where does it end? Case management is one of these thing that, you know, it can be small, just report writing if that’s what you decree case management is, or it can balloon out to, bang, your involvement in the entire of this person’s life is needed, and there’s no, in our unit at this point in time, there are no guidelines...

She cited having a holistic view of the client as being central to her work, even though she struggles to maintain a holistic viewpoint.

Felicity described a lot of varied activities and environments in one shift. Some of her work is with groups of clients who meet at the office for an exercise class, some of her work is one on one consultations with clients who come in to see her. Her time is also spent in planning and organizing duties, such as preparing the weekend exercise course, or reviewing a client’s file. Time is also spent in consultation with other staff to coordinate team efforts around each client.

Felicity stated that the physiotherapy aspect of her job was the most satisfying, particularly when she is able to see the immediate improvement in a client’s physical functioning as a result of her intervention. The case management aspects of her job are the least satisfying because “it doesn’t finish, because there’s no boundaries, I think it’s inherently unsatisfying.”

Jane
Jane also has a family member with a disability, and is also specialized in a profession, social work. She is part of the same team of professionals as Felicity with a community reintegration agency in a regional city. Her son has an intellectual disability, which has led to her having “been involved on various committees and things over the years” in advocacy work, but had no specific experience or training in ABI prior to her current position. When asked why the move to brain injury, Jane replied “There was no altruistic motive there really.” The position was closer to Jane and her family’s home and ceased the need for commuting a long distance to work. She cited listening to clients and validating their feelings and experiences as the most important service she can provide to the clients she works with.

Jane conducts most of her consultations with clients in her office at a centralized agency location. However, she has a high level of direct contact with clients, as well as consultations with team members to perform her duty of addressing issues the client has at home and in the community. She described her roles as providing a “very broad psycho-social assessment”, as well as establishing:

.....whether counseling’s required...... We tend to try and divide between psychology and social work. Social work tends to take the family as the client and psychology tends to take..., the person who’s had the TBI (Traumatic Brain Injury). At the moment we don’t have a psychologist however, so that role’s fallen very much to me, and then, of course, the third aspect is the practical assistance. If they’re, if in the assessment we identify for example, that, you know, people’s houses, payments are falling behind, you know, that really pragmatic stuff, that’s kinda my job as well.

Jane does not generally accompany clients into the community, except if it is directly related to something in her social work capacity, such as taking the client to a solicitor. She remarked working to time lines and pressures set by insurance companies and third party payers is the least satisfying aspect of her job because, “sometimes you just think, you know, this person, three more months, which would, in the scheme of things, not cost a lot of money, would make a lot of difference to this person for the rest of their life.” The most satisfying aspect of her work was "to see people do things that you never thought they would be able to do."
Karen

Karen works as a case manager with an ABI support agency in a regional city. She has seven year experience with her current employer. Karen cited her family experience with disability as an influencing factor to enter the ABI field. Her experiences as a family member in the disability support system sparked her interest in helping profession work. She singled out brain injury because, “it’s something that’s so common but you don’t hear a lot about it. It’s not one of the really well known, media covered type disabilities.”

Karen stated “allowing (clients) the chance to make decisions” as guiding her work with clients. Like Jane, she understood the trials clients and families go through in rehabilitation, and recognized the client may have lost some autonomy and control in their own life. She emphasised, ”it’s all about the decision being a process”, rather than the end result taking priority.

Karen spoke to involvement in tasks such as rostering worker shifts, completing costing reports, and addressing major decision making with clients, such as money management, or guardianship. She described her role within her agency as a liaison who networks with and on behalf of the client, and coordinates support for ongoing functional needs a client may have. One on one contact with clients tends to be more consultive in nature, and less direct front line work. She will occasionally accompany a client into the community to assist with or assess a functional task. If the client’s goal is short term, Karen may act as the support worker for that client, but longer term or lifelong support needs are addressed by support workers supervised by Karen.

My job is to work, I mean as overall, to work as part of a team to help the person with the brain injury decide on goals that they’d like to reach and then work with them on setting out a plan on how those goals will be worked towards. So the emphasis isn’t so much on the outcome, it’s on the process involved....My contact with people is mainly over the phone to set up things, and then I go and do home visits to talk with people, or it might be that they come in here, into the office to do things, so I’ll talk with them then.

Karen spoke of needing to keep her own values in check when making decisions
concerning clients and its relevance to her supervisory role. She said she is “very conscious of my own, not putting my own values on the person.” When she detects personal values or emotions in her subordinates may be interfering with their work with clients, it is in her supervisory role to address it with the staff member.

Staff personal values is another major tenet of this research. Karen’s narrative expresses her need to be aware of those values, as well as to assist staff under her supervision with recognizing value conflicts that may affect how they work with clients. Upham (1973) reminds us “The practitioner uses values and principles to guide the helping process” (pg. 10), meaning our work is value laden, whether we recognize it as being so or not.

Karen cited “red tape” as a dissatisfying aspect of her job as well as “feeling I guess a bit helpless and not being able to intervene more, or not being able to offer more, where you can see families need it.” Her most satisfying aspect and "biggest motivator" is "enjoyment I get out of just the personal contact with people. Working with people, and personally, I get a real buzz when people achieve something that they wanted to do."

**Gregory**

Gregory coordinates a recreation service geared specifically for clients with ABI in a large metropolitan city. He has over 15 years experience working with clients with various disabilities. His first encounters with clients with ABI occurred when he worked as a nurse in hospital. He recalled making a connection with the people he met there, drawing on their similarities rather than differences:

> The clients that were there for the rehabilitation were mostly males about my age. So it was sort of, yeah, we connected on that level, they were sort of my peers so I found that interesting and there was a few motorbike riders as well and I ride a motorbike.

This connection spills over into Gregory’s philosophy in his work towards clients. I treat people the way I like to be treated myself if I was in their position, basically. That’s my philosophy. If I had a brain injury similar to theirs, I’d want to be treated in a humane way, encouraged to do as much as I can for myself. I
only do for people what they can’t do for themselves, not what they want me to do for them, only what they can’t do for themselves. If they have a good time, that’s a plus, especially because it’s a recreational leisure service. Giving choices, let them make their own choices.

Gregory’s philosophy is very much in line with the ideologies of self determination as set forth by disability advocates, in that he seeks to maximize client choices and accommodate client preferences. As he said about himself and tells his staff: "The service is here for the clients, not for the staff."

Gregory described the process of planning the recreational group. Outings and events are planned in advance through consultive group meetings with clients, in which clients express the types of recreational pursuits they would like to do. Clients sign up for the events they want to attend once the agency has completed and distributed an events calendar comprised of the clients’ suggestions. The day of the event, some clients supported by Gregory show up at the agency location to then be transported in a group to the event location. Other are picked up in the agency van by Gregory and his assistant, Tess (who will be introduced later in the chapter). Gregory mentioned some of the many details he has to be attuned to in organizing and facilitating an outing.

We just sort of have a coffee and have a chat, see how their day’s gone and their week’s been since they were last at the centre, if they are having any major issues they want us to sort of help with, even though that’s not our role, but we do help in certain circumstances. Make sure everybody’s got enough funds to cover the day. That they’ve got appropriate shoes, if they need specialist equipment, whether it be frames or chairs, make sure that’s serviceable, because sometimes they could be an issue. Yeah, and then basically we drive, we load up the bus, oh make sure everyone goes to the toilet, make sure we’ve got everybody on the bus, and then drive to the museum, and then split up into individual groups.

Gregory mentioned many of the factors that he must consider in making decisions about the activity, which suggests that the structuring and logistics of the outing can constrain the options available to him to make choices from. He stressed opportunities for social interaction among the clients are more important than any sort of specific goal attainment.
Like Karen, and Felicity, Gregory is frustrated by seeing the needs of clients and not being able to prove more support, “because of lack of funds. I really get annoyed that there’s so much need out there and there’s not enough money to accommodate it.” It is the least satisfying aspect of his work, while the most satisfying is seeing the clients have a good time, and telling him they are happy with the service.

Lois
Lois came to be involved in ABI support work though her previous community volunteer work. Prior to joining the agency, Lois voluntarily cared for an individual with a developmental disability. Through her work with him and connection with community support groups, she was recruited to work for her current agency. She now works one on one with a single client in a rural region. At the time of our interview, she had been working with the ABI support agency for approximately eight years. The particular client she works with has initiation and motivational issues, with no overtly stated goals. Lois said her reason for supporting the client, “is to keep the company. Make her feel that she’s important and special, which I’ve grown to develop a relationship with her over the years.” Of all the interview participants in this study, Lois works in the most autonomous and isolated of environments, away from other workers and supervisors. Her narrative is also unique in her difference in attitude and approach to the client-staff relationship and professional boundaries. Lois’s perspective offers a competing discourse to the dominant themes to be explored on staff-client emotional involvement in the results.

Lois currently works one on one with a client in that client’s home. Lois arrives at the client’s house twice a week and spends two hours with her. She described her role as mainly providing companionship for the client: "She just wants me to talk to her. She’s craving for people to visit her because she’s lost a lot of her friends that she had before, so she really just needs the contact, one on one talking." As noted in the literature review, loss of friends is a common occurrence among survivors of ABI.

One of the major consequences of this client’s brain injury is the loss of initiation and motivation to engage in almost any type of task, aside from self care activities. While
the client’s lack of motivation does not impair her ability to function daily, it does severely limit the client’s realm of experiences and heightens her social isolation. Lois said the client came into the ABI outreach service because the service recognized the near total isolation of the client. Lois has been matched with this client for eight years.

Lois is not expected to work on goals with the client, but she still tries to tap into the client’s interests to motivate her into engaging in a few more or different activities. Lois will also occasionally engage in some domestic duties while in the client’s home because "I just feel dreadful. I’m just sitting there. I could be talking and ironing, so I do a little bit of other stuff, but I don’t have to do it.” Lois is expected by her supervisors to keep documentation of her interactions with the client, which is a common procedure in healthcare and rehabilitation settings.

I do documentation. I just, yeah, the hours in. At the end of each month, I’ll write, they’ve got questions they ask. "Has the client made any achievements?” "Has, Have any goals been fulfilled that we’ve been trying to make?” "Has there been any problems", and I sort of answer all the questions and all the tasks that we’ve done together. I write all that down each month, that goes in with my time sheet.

The client’s lack of motivation is the source of the least satisfying aspect of Lois’ work since she sees “no great achievements” the client. However, the most satisfying aspect is the emotional reward of seeing the client and her husband happy when Lois arrives at their house. “When I show up,...(they) think it’s fabulous that I’m there, and yeah. And that’s very rewarding.”

Lynette

Lynette works with a recreation group specifically for clients with ABI in a metropolitan city. Unlike other people who cited previous experience working with clients with disabilities, she had no prior disability experience. She described her foray into ABI support as wanting a change in careers. One of her work experiences prior to entering a helping profession was working with computers. She stated she "didn’t ever like working with computers" and moved through stints in recruiting and real estate. Lynette sees her role as providing " A link to the outside world, because our clients are
very isolated. We just ensure they have a good time”. Lynette emphasised enjoyment and fun as being central to her work with clients. Her philosophy closely aligns with the ideology of diversionary recreation, echoing the theme of clients as “others”, in that her work provides an escape for clients from their less than satisfactory daily lives.

The group is organized and planned in the same manner as Gregory described his group, with a client-participatory, democratic process used to select and program outings and events, and then program information is distributed on a calendar of events for clients to choose from. Clients supported by Lynette are picked up from their homes by the agency.

Recreational activities in Lynette’s job may be elaborate such as taking a group of clients to a concert or sporting event, or may be simpler, such as going on picnic or spending an afternoon at the beach. Lynette described her previous shift as

We went to the beach, we sat on the water, and just sat around and talked. Had lunch, had fish and chips or some clients brought their own. Just sat there and spoke to them, and, it was just like a picnic, like a family picnic kind of deal. And then we just got on the bus and went back home again.

She cited riding the bus to pick up clients as the least satisfying aspect of her job, as the trips often were long and covered a great deal of areas. The most satisfying is “knowing that these people are having a good time”.

Tess
Tess works as Gregory’s assistant in a recreation agency specifically designed for clients with ABI in a metropolitan city. As a student in a welfare course, she accepted a placement with the agency because there were no options left. Convinced she would not like working in ABI, she surprised herself by enjoying the placement and remaining on as volunteer. Eventually the volunteering turned into a permanent placement. She attributes the fun and camaraderie in the group as what she liked most about the job and changed her mind about working in ABI. She has been with the agency for six years. She cited providing an atmosphere for socializing as the most important service in her
work with clients. She additionally commented that she felt there was special value in clients with acquired brain injury being able to relate to other individuals with the same impairments:

Just the fact for some of the higher functioning ones, they’ve got other people who they can talk to about their frustrations, who understand. Well, as even us, who worked with them and we know what they’re going through, it’s still not the same as them talking to each other.

Tess implied that the actual activity in the group is less important than the opportunity for clients to just be together to talk and maintain relationships.

We’ve been trying to put it back a bit more on socializing, you know, having more picnics. Some days we’ll go out and have some fish and chips there and just letting them that social contact instead of working out at the gym where their not really socializing that much, I think..... Summer, we spend more time at the pool, which is nice, and again, some of them think of that as a work out as well, but at least in the pool, they can still talk, and it’s more relaxing and a bit more fun.

This notion was expressed by most interview participants in regards to improving the client’s quality of life. In Tess’s narrative, it is demonstrated as simple as creating opportunities for clients to just have friendly interactions, and a social life. Both Tess and Gregory demonstrate and articulate that this is the key reason for their involvement in the lives of the clients they support. In turn, this plays a role in the types of activities they pursue with clients.

Tess spoke to the fun she has with the clients as being one of the more rewarding aspects of her work, but admits the emotional strain and stress can be difficult and dissatisfying aspects to the job.

Nicole

Nicole is an occupational therapist who works with young adults and teenagers with ABI as part of an outreach team of a major hospital in a regional city. Her perspective and experience are differed by the fact she works with clients who have more substantial support networks around them in the form of parents, siblings and educational providers, which may or may not be part of support circles for fully adult
clients with ABI. Nicole cited the interest in seeing opportunities to influence positive change in the lives of people who had experienced trauma.

That’s something that I thought would be interesting. I suppose because, initially there’s so much change that goes on, so as a therapist, you can shape that change, and also, I think because families are often going through such traumatic times, you can, you become involved in that and can be, and sometimes see yourself as a support person for them, and helping them.

Her remarks echo Karen’s and Jane’s in her understanding of families’ need for support after trauma and rehabilitation, and contrast Felicity’s frustration with the unpredictability of ABI. Nicole found her previous work in hospitals somewhat limiting and prefers her current outreach work since it is more relevant to "every day, it’s more what affects the families and kids from an everyday point of view". Nicole draws on self deterministic principles in her philosophy towards working with clients:

I think it’s important to work on goals that they want to work on, and increasing their independence or self-esteem in their skills, because I see that if they feel more successful, then they begin, more likely to give things a go and so on

Nicole works in the field, both with clients and with the client’s support network, such as parents and teachers, to implement programs and lifestyle changes in the client’s routine that will enable greater client autonomy.

The more you educate the teacher’s aide, or the teacher, or the parents, or whoever the significant others are for that child, because compared to what you can do with a one on one with the actual child, if you can get the others around them sort of on the right track, it makes so much more of a difference then coming and then doing therapy for half an hour.

While there may have been overlap between discipline areas, Nicole, as an occupational therapist, had a wide and varied range in terms of skills she would work on with clients.

It’s a bit of everything. You end up being a bit of a consultant, I suppose. As an occupational therapist, we’re involved in dealing with sort of the functional everyday tasks, and they tend to be, how the kids are coping at school in terms of, you know, following instructions or, handwriting, or accessing the school or, you know, their self care needs at school, and at home, it tends to be more, you
know, self-care routines, or just routines in general.

Nicole is contracted as part of an outreach team of a hospital. This arrangement results in client referrals and funding allowances coming to her in a different manner than clients who are part of agency based programs.

Basically, the clients get referred to our team from the inpatient, they tend to be an inpatient at the hospital, and then get discharged, and then get referred to the community team, and then the, inpatient therapist or the inpatient clinical nurse consultant will realize that that’s an issue and then ask the insurance company at discharge, they need ten hours of OT, three hours of physio and five hours of speech pathology or something, like that, and then you’ve got that time to work with.

Nicole identified herself as a consultant with clients and their families and offers support within that context, but not as "someone who’s there everyday, sort of helping them" such as an attendant carer or generalist outreach worker. She cited documenting and “working within financial constraints” the most frustrating and least satisfying aspects of her work, while “thinking that you might have helped somebody” gave her the most satisfaction.

Kody

Kody is a case manager with a respite house for clients with ABI in a regional city. Her education is in social science welfare. She described taking a job with the ABI agency because it offered full time work. To her, it was a logical extension of previous disability support work she had been involved in. She has been with the agency for six years. When asked what was important about her service towards clients, she remarked:

I think, well I guess probably the respite in itself, because it sort of like two ....when I first started up, it was always being, sort being pleasant and respectful, because you’re going in with families and you’re leaning a lot of them and they give you a lot of information. So I felt that having that rapport was vital to be able to do any good, and the other thing was, is the actual service that we provide. Like I realize that is was so good for them. That’s the thing that was so good in my job right? We were constantly given this great feedback, because the service was new, and they’re getting respite, it was like they were all so appreciative of it. It was like, it’s lovely feedback all the time. So that was really good.
As mentioned by others interview participants, Kody touched on the theme of escape for clients and families, seeing the respite they need from their daily life routines and relations. However, her reflection of positive family feedback and her own appreciation of it touches on the theme of staff needs at work, and the concept of valency, which is related to the theme of personal values. Valency is the idea that people are drawn into professions in response to unmet psychological needs or desires, such as a need for approval or to control (Roberts, 1994). It will be explored further in the results the concept of valency, its manifestations in the current narratives, and possible influence on staff decision space and practice ethics.

Kody has been involved as a coordinator of a community respite house since the inception of the service. She described the formation of the agency resulting from "heaps" of consultation with clients and their families to design an effective respite service. The duties and purpose of her role grew organically from the needs expressed by clients and their families.

Kody also reflected on differences in how she approached clients when she started out in the field and her approach now:

"Back then, it was definitely doing the right thing, and what was sort of, it was black and white to me then. Whereas now, I think because I've had the experience, it's become...it's like, does it really matter? Like you know, I'd be asking myself those sorts of questions, like does this really matter. It's not life threatening, what's the worst thing that could happen?...It's only now as I have moved along a little bit and I understand consumers a lot more and...that I think, well no, I don't have to do that, you know. Like that was sort taking away a bit from her, in a sense."

Kody attributed her body of experiences as influencing her approach from being task oriented to a goal/process oriented approach. She finds the administrative aspects of her job, such as doing costings or scheduling staff shifts as “tedious” and the least satisfying aspect of her work, as “I could never actually finish anything and feel satisfied in it” (which is similar to Felicity’s frustration of not being able to see an end or get closure on ongoing work and tasks). She cited the personal contact with clients and feeling
appreciated as the most satisfying aspects of her job.

Melanie
Melanie works along side Kody as a case manager with a respite house for clients with ABI in a regional city. She explained her move into ABI support as by chance, in response to a job advertisement. She moved up the ranks in the agency from a casual worker to her current position. She has been with the agency for over three years. Like several others, Melanie advocated self deterministic principles in her approach to her work with clients.

Being able to give them a bit of independence, being able to provide them with a choice, give them some option because often with people with a disability they’ve lost that, you know. They have to rely on family, friends, whatever. So if I can you know, I mean, a lot of times you’ve got to encourage them a lot. (laughs) But at least you’re giving them a few options so they’ve got control of their own lives.

Melanie worked a couple years with individuals with disabilities other than ABI prior to the current work in ABI. She reflected on how her approach to working with clients has changed over the years.

I think there’s been times in the past when I probably first or second year I started working with clients, where I would go out for … you’d take them out of coffee, or something, and rather than encouraging them to do everything themselves, I would maybe baby them a little bit too much, you know. Just try and help them and really, that’s not what I was there for. I’m there to encourage them to be independent.

It is this insight into how she used to feel in her work, and how her approach has changed that allows her to understand some of the experiences of support workers she supervises, and to direct them towards approaches that align with agency philosophies of encouraging client autonomy. As Melanie specifically stated, knowing what it was like to be a front line worker influences the trust she places in her subordinates to perform their jobs:

Now that I’m on the other side of the fence, I put a lot of faith into our support
workers, and I know that if they’re in a situation, they have to act a certain way and they have to be responsible for that consumer.

The least satisfying of her experiences were doing personal physical care with clients. “Just helping” the clients and giving them choices were the most satisfactory aspects of her job.

Alexia
Alexia works as a case manager in the same ABI support agency in a regional city as Karen. Alexia requested the interview not be audio recorded. While my preferred method of data collection was to audio tape and transcribe all interviews so I could use the interview text as raw data for analysis, I respected Alexia’s choice to not be taped. Field notes are recognized as a legitimate source of data collection in qualitative research (Baumgartner & Strong, 1994), and therefore the data from Alexia’s interview was recorded via note taking. Alexia’s decision not to be audio recorded led me to speculate she felt a degree of suspicion or anxiety about the interview process.

Alexia described her decision to work with ABI as a matter of moving to town and seeing her current job advertised in the paper. She noted that she was surprised to discover someone she had known from school had a brain tumor and is now one of the consumers of her agency. She had previously worked with intellectual disability and mental illness. Alexia started part time work with agency about 4 and a half months before our interview, and had been in current full time position for three months at the time of our interview. Previously, she worked in the hospitality industry before becoming involved working with people with disabilities in a residential setting. She had also worked for a state Department of Community Services, which she described as challenging work, and not a good situation.

Alexia said she really enjoyed working with people with disabilities. There was no particular attraction to people with ABI. She commented that she has been fascinated by the nature of the disability and the diverse ways in which it affects different individuals.
Alexia clarified her position in her agency as having three roles. She coordinates an 
education team which consists of clients with ABI making public speaking 
engagements to tell their stories. They visit places such as traffic offenders classes, 
some high schools, and nursing homes. She is also beginning to do some case work with 
some consumers, and she occasionally does some front line support work as well.

Alexia’s previous front line experience was with clients with developmental disabilities. 
She feels she is still learning about ABI in her new position with a different agency. She 
noted how different the population is in terms of their individual independence as 
compared to when she worked with client’s with intellectual disabilities. She feels the 
people she works with now are much more independent in their daily lives, and she is 
still getting used to working within that context. She compared her current job to her 
previous job by saying her previous setting was much more structured than what she is 
working within here. She felt she had to be in more of a guardian role, whereas in her 
current role "This is much better". She feels more is up to the consumer in terms of 
choices and the direction her work takes with them.

Alexia cited the paper work and dealing with bureaucracy matters as the least satisfying 
aspects of her job. Early in the interview, she referred to not liking the structure of 
dealing with government agencies and the frustration that occurs along with red tape 
type interactions. She finds the consumer contact and working with the ABI population 
in general the most satisfying. She finds it very enjoyable, and likes the variety of her 
job.

Gary

Gary works in a residential group home in a large metropolitan city. He has been 
working with clients with acquired brain injury for just over a year at the time of our 
interview. He came to the job via a welfare work placement, having no previous 
experience working with people with disabilities. He did receive on the job training and 
was in the midst of completing a certificate in community services at a local Technical 
and Further Education (T.A.F.E.) Institution. Unlike the others, Gary did not express 
any personal reasons for doing the job he does, but rather seems to view it as a way to
make a living. The least satisfying aspect of his work is “getting up in the morning”, and the most satisfying is “just going in and work and coming home.” He cited making sure the clients “have a good time” as his prime role in his work.

Gary described his work in a group home as "Personal care, take the guys out, take the guys out on camps, do craft activities". He stated he does not work one on one with clients, but that there are always other staff present when he is on shift. He mentioned the importance of being client centred, by making the client’s preferences and satisfaction with what they were doing a priority. Gary stated that making sure the clients were happy and having a good time was the most important service he could provide.

The particulars of my experience interviewing Gary will be discussed under my results interpretations in chapter seven. His was the shortest interview (20 minutes) and the least articulate. His responses were very concrete in nature, and when prodded to elaborate, he often replied he could not or did not know anymore. The discourse of interview was such a dramatic contrast to the more verbose and reflective conversations with other interview participants, that I derived great richness from the absence of comments in context of what he was being asked, in addition to the actual responses he gave.

Violet
Violet is a former front line worker in ABI who came into the research study via snowballing, that is she was told about the research by a mutual friend and recommended to me as a possible participant. Her perspective is valuable as someone no longer active in the ABI field. At the time of our interview, it had been 18 months since she left the ABI field, though she remained involved occasionally on a volunteer basis with a few individuals with ABI. Her previous volunteer work eventually led to hired positions with two ABI agencies within a regional city community, and later led to her promotion to case manager. She was enrolled in a social science major at university at the time of our interview, and had a certificate in nursing. Her reason for leaving ABI: “it was too stressful”.

Chapter Five - Staff in ABI Outreach & The Ethic of Practice
Violet had experience both in one on one in home and community environments of clients, away from direct supervision or other staff, as well as work in a respite house environment. Violet described a client-case manager-front line worker triad in her one on one settings - The case manager would work with the client to establish goals the client wished to work towards with their support workers. Such goals and objectives would be documented in a service plan for the client, and Violet would use this service plan to guide how she worked with the client and determine what activities they would pursue with the client. Sometimes her activities with clients were predetermined by individual service plan (ISP’s) goals that the client and case manager had established at a prior date. Her role was to act as a coach or supervisor in these circumstances to assist the client in learning or following the activity protocol:

If it was community respite, more community activity, re-integration, it (the activity) would either be a regular thing, that they’d go to the gym or go to whatever activity on a regular basis..... I’d take them to the gym, but it would be their responsibility to present their card, or pay, pay whatever they needed to pay. What they were doing on the equipment, make them as independent as possible in their routine, and that type of thing.

Teaching independent functioning was a key goal in Violet’s work with clients. Even with unstructured activities, Violet kept the emphasis on framing choices for the client to make and direct the outcome:

I would tend to sort of offer some suggestions, that type of thing. Then it would really be up to them to sort of guide, even if there was a structured activity, it would be up to them to sort of guide the process of it....Some of it was unstructured, and then it was up to, it was a discussion, like you’d have an idea of what it (the shift) was about. It was about, I guess most of it was about them becoming independent, and increasing their independence, working on some skills. So, like, one person I was working with, it was a matter of increasing her skill ability in terms of community living and, like, in terms of hygiene and in terms of ...just, I guess, proper eating manners and things like that, so we did thing like go out to dinner and it was that preparation and getting her prepared to, you know, we’re going.

Goals were reviewed and updated at regular intervals with the client and case manager, in which Violet’s feedback about her progress with the client would factor and contribute. However, Violet felt she was not allowed to contribute much in terms of
specifying goals with the client, rather that she was constrained to work within a
definitive framework the case manager set. This will be examined more closely in
chapter seven under a discussion of staff autonomy at work.

Violet’s attitude towards teaching skills and her feelings of disempowerment regarding
being able to influence client goals was the source of her dissatisfaction in the field:

I think, I guess when we see that there’s potential in an individual, that that
potential’s not, sometimes it wasn’t allowed to be explored. Going back to that,
you know, you know, very set way of doing things, like yeah, I mean choice was
involved in the activity that they did, but it was also continuously offering the
same activities, so it wasn’t giving them a range of activities, and I guess, I
thought that there was, you know, I probably see the potential to try new things
and to do new things, but as a support worker, you don’t have any, you know,
you just do as your told to do, and you don’t, and you’re not involved in that
decision making process of what will happen, or what activity will be done, so I
thought that was, yeah, it probably was the biggest thing is that repetitiveness in
activity.

Most satisfying was the interpersonal relationships, and rapport with clients. Violet
seems to be able to indulge in this satisfaction by now occasionally interacting with
clients as a volunteer without having to deal with the dissatisfying aspects associated
with being a paid employee and having to follow directives from an employing
supervisor.

**Summaries**

**Who We Are**

This introduction to the individuals who shared their narratives in this research
expresses a diversity of personalities, experiences, attitudes and job roles in a sampling
of staff who work in ABI outreach. While none of the profiles of the interview
participants are presented as typical or representative of ABI outreach workers,
collectively they paint the larger conceptual picture of examples of staff who work in
ABI outreach.

Each of the interview participants spoke to believing in client self determination as part
of their work ethic or purpose in the client’s life. There was a commonality among the
interview participants in their stated commitments to improving quality of life for the clients they work with, to different degrees and interpretations as to what exactly constitutes quality of life (which will be discussed further in the chapter seven.) The commitment of each staff to their clients ranged from curiosity about the impairment of ABI to personal identification and empathy for the client.

This suggests that in this group of staff workers, there is a general ethic of implementing the ideology of client self determination in their work with clients, as well as the ethic of beneficence towards clients - promoting the good, which is the basis of the duty of care. How the participants negotiate a balance between these ethics (the client’s dignity of risk and the staff’s duty of care) will be described in the section on strategies in the next chapter.

It is interesting to note there was a strong pattern of dissatisfaction and frustration among the interview participants regarding bureaucratic and administrative matters, while direct client contact and a sense of making a difference or reaching an achievement is the commonly identified most satisfying aspect of the job. It seems as though the bureaucratic matters, such as funding limitations, or resource constraints, or the administrative matters, such as having to complete paperwork, were perceived as barriers or obstacles to the more satisfying aspects of the jobs. Lack of resources emphasized discrepancies between what the interview participants saw as needs of the clients, and what they can really do, while administrative matters, like the time it takes to complete documentation, took time away from the staff to engage in direct client interactions. These frustrations and barriers will be reconsidered when discussing factors that may influence the formation of staff decision space and may act as detractors or distractions in decision making.

Where we work and what we do

This introduction to the interview participants also illustrates some of the variances in different ways outreach may be structured, and the variety of roles contingent upon a staff’s position or professionalization within an outreach structure. This includes staff who work one on one with a client in the client’s home or local community
environment, staff who organize and facilitate community recreation groups, staff who work in agency run residences located in community neighborhoods, specialist staff who consult with clients and other staff, and case/mid-managers of outreach supports who largely coordinate individualized client programs or agency services. The discussions of a staff’s duties and approach towards clients can be interpreted in terms of a range of roles staff may fulfill in their relationships with clients.

The positions of the staff participants within the employee hierarchy of their agencies, the structure and environment of their outreach settings, and the nature of the tasks each attend to are elements that influence the decision space each participant forms regarding particular decisional situations. It is interesting to note that the higher a person’s job status in the organization, the less frequent and direct their contact with clients became. Yet, the major decision making responsibilities regarding service plans for clients or organizational policy rests with the higher status employees, such as professional specialists or mid/case managers, while front line workers seemed to attend mostly to mundane daily decision making. Decision space influences will be explored more closely in chapter seven.

Role definition

Ponsford (1995) offers a broad generalized description of the typical duties of outreach staff:

Attendant carers can be trained to implement specific therapeutic exercises, aimed at assisting or maintaining physical or cognitive recovery, or assist the TBI person in pursuing home bases activities of interest. They may provide transport and/or accompany the injured person to ongoing centre-based therapy activities, or assist in involvement in community based activities of a social, recreational, or work-related nature. Above all, an attendant carer may become an important friend to the TBI individual, actively assisting them to reestablished previous activities or social contacts, or establish new ones (pg. 202).

McClusky (2000) notes that “paid attendant carers spend many hours assisting people with a brain injury. Despite this considerable responsibility, most carers receive little support or training and their roles are often ill defined” (pg. 943). In her study, she
identified five emergent roles that support workers fulfill in work with clients with acquired brain injury: Attendant, Protector, Friend, Coach, and Negotiator. (See Table 5.1 for details on paid carer roles).

Often these roles overlap, and staff may fulfill different roles in different situations and/or with different clients. I have found this role identification useful in categorizing some of the staff behaviour and values interview participants in this research expressed, as the following examples illustrate:

I take people to aqua-aerobics, and part of that is dressing them afterwards. (Attendant) - Loretta

Every week that he comes, he wants to go to a different club, and alcohol’s an issue, because the behavior gets worse with alcohol. So we’ve got a rule, the driving rule. You know, you can have two drinks your first hour, one drink every hour after that.....we go to a club, there’s alcohol there so that straight away lead to the issue of us trying to stop them from drinking. (Protector) - Tess

I look upon her as a friend in need at the moment. (Friend) - Lois

If there wasn’t a structured activity, I would tend to sort of offer some suggestions, then it would really be up to them to sort of guide the process of it, so whether it was attending the gym, or whatever, it would be their responsibility to present their card or pay whatever they needed to pay. What they were doing on the equipment, make them as independent as possible in their routine and that type of thing. (Coach) - Violet

Some of them may want to go somewhere else that the others don’t, so, you know, sometimes there’s a compromise that’s got to be made (Negotiator) - Jeff
Categorizing role definitions as identified by the experiences and perceptions of staff working in ABI outreach may be one way of understanding how staff view their jobs and form their decision spaces, which in turn could lead to better understanding the most appropriate support approaches and training protocols to use in ABI outreach.

**Training in ABI Outreach support**

The lack of a unified staff training approach can contribute to the ambiguousness of ABI outreach contexts, leaving staff without a consistent foundation of philosophies and approaches across the field of ABI outreach support. Ylvisaker, Hanks, & Johnson-Greene (2002) note there are no unified approaches or theories regarding best practices and modalities of service for people with ABI post acute rehabilitation, with research devoted to the topic lacking in the field. This sentiment is echoed by McCluskey (2000), Ponsford (1995), and Fussey and Giles (1988). The majority of narratives expressed in this research echoes this trend of staff receiving a minimal amount or complete lack of deliberate training and specialized education specific to acquired brain injury for staff working with clients with ABI. This absence of consistent training and support models may mean the participants utilize widely differing approaches, some of which may originate from their own personal philosophies in instances where direction from the agency is unclear or ambiguous as well.
Jane commented on the differences in work with clients with ABI and the lack of models to guide her practice:

Yeah, it’s less cut and dry, it’s less cut and dry. It’s…prior to this I worked in torture and trauma, and that, you know, there are set models that you work to, and it’s a lot of PTSD (post traumatic stress disorder) and mental health, and there are no models for TBI clients, you know. You get a model that works with somebody, and you think, Yes, I’ve got another aneurism, I’ll use that same model, and it doesn’t work. You know, for whatever reason, because of they’re different people, or because their support networks are different, or whole, their injury is different, whatever, and that, but that’s what I find challenging.

Gregory, Lynette, Tess, Jane, Felicity, Alexia, Melanie, Karen, and Kody all expressed having no formal training in acquired brain injury support, learning on the job and from experience. Kody commented, “There no real training in brain injury though, it’s more or less learning it as you go.”

Gary, Jeff, Loretta, and Lois, all direct front line outreach staff, each referred to receiving ABI training from their agencies, but the content of the training seemed to be related to general helping profession issues rather than ABI specific strategies. Gary said his agency training consisted of education in "communication, duty of care". Loretta said that "yes we’ve had lots of training in brain injuries", but when asked to elaborate, she described her training as:

Yes, you know, lifting procedures and medication and all that, all that sort of thing. Nothing formal, but it’s…it’s probably more just that sort of the on the job stuff that you learn.

Nicole spoke to taking related courses to increase her skill level, though none were specific to ABI.

I’ve done a lot of sort of one day courses or two day courses, sort of short courses. Either in, in specific therapy skills or generally different subjects that are, would be related to brain injury but aren’t specifically brain injury courses.

Only Violet of all the interview participants had taken an ABI specific course.

I did a psych degree. I don’t, we didn’t, I suppose we did all the neuropsych type stuff, then I did, through Charles Sturt University, they were offering an ABI
Both Nicole and Violet sought further ABI education on their own and not as part of a requirement for their jobs. Looking at the course Violet took, her training included learning “key principles and practical strategies in assisting a person who has had ABI” and how to “identify individual client needs, demonstrate skill in negotiating goals with the client, and describe appropriate strategies to assist the client” (CSU website, 2003). Speaking with course representatives, I learned this was a distance education course, largely theoretical in nature and providing numerous resources for students to pursue on their own initiative. The benefit of such a course is in its availability to motivated, self aware individuals who are pro-active in improving their effectiveness in ABI support. The disadvantage is that how students actually apply the theory cannot be evaluated or monitored.

Felicity described the difficulty she encountered reconciling her training in physiotherapy with the reality she encountered in ABI support. She noted her formal training in physiotherapy “which is reputedly black and white” did not prepare her for the necessary flexibility required in approaches to ABI support. Working with clients with ABI, she said:

required more in terms of thinking globally in terms of a person’s life, so more far reaching consequences and effects.... more holistic, and I mean, I used to think I wasn’t too bad at being holistic, but I look back on it now and think, Awww, I knew nothing. (Laughs)

Felicity commented she feels this is an issue in general for staff with specialized training, where the staff’s focus must expand from looking only at the aspects of the client that fall under their speciality to having a global, holistic view of the client’s life. Nicole spoke to professional territoriality that may impede a holistic approach towards clients:

There’s some therapists or professionals who are really concerned about boundaries and, you know, "you shouldn’t comment on that because you’re not
speech pathologist. "...I think, a transdisciplinary approach is quite useful, and I think, the bigger the overlap between boundaries, the less likely that the people are to fall down the gaps between the boundaries of professionals.

For myself, I also did not receive any training specific to ABI, but rather learned on the job from other staff members and supervisors. I was given specific training on matters such as preventing violent behaviors and what to do in situations when client violence occurs, but there was no training or universal techniques in day to day encounters with clients. As Jane noted, because each situation is different, and each person has a unique personality, training specific to ABI support techniques may not be possible. As Felicity remarked:

There’s no clear guidelines about this is a higher priority than this, except in this circumstance when that prevails, or you know, you almost need some sort of a diagram to do that, but there isn’t one because there can’t be because the number of situations that can arise are too numerous to actually put down in a policy.

This canvassing of interview comments regarding training demonstrates that not only have the participants experienced a disparity in levels and types of training, but there is also a disparity in the level of awareness different participants have toward the role and relevance of training towards the performance of their jobs. Participants such as Felicity, Violet, and Jane expressed concerns with training issues, while individuals like Loretta and Gary did not seem to feel the training they received was insufficient to do their jobs. It is important to note however that Felicity, Jane, and Violet were involved in case manager type duties, while Loretta and Gary work in front line generalist positions. There may need to be consideration for the amount of training needed as per the breadth or types of responsibilities the staff may be involved in regarding clients.

It is not known wholly what is truly guiding staff in the formation of their decision spaces and affecting the manner in which they interact with clients. There is also a question regarding which principles and concepts should future training protocols be based upon. It is unlikely staff training and support models could follow rigid treatment intervention protocols, as is often found in medical model philosophies, due to the
mosaic, unpatterned sequella of brain injury in each individual with ABI.

**Dignity of risk versus duty of care: The ethic of practice**

A constant across all the narratives in this research is the participants contending with allowing a client the dignity to take risks versus that staff’s duty of care towards the client. Here is one manifestation of where values and the use of power in the staff client relationship is played out. It also represents a tension between staff authority and client autonomy. Dignity of risk versus the duty of care is complex in the context of ABI, since cognitive impairments may cloud a client’s judgement or insight, or staff may hold the perception that a client lacks insight or sound judgement when the client’s capabilities are actually sufficient.

Gregory described it as a balancing act.

.....it’s a really difficult question because you like them to make choices but then we are responsible for their care as well. Yeah, it’s very fine balancing of an act.

Jane commented:

What’s going to be safe? Yeah *(laughs)*. What we think’s a risk, they sometimes don’t think is a risk at all, but, yeah, I mean, I don’t know, it’s, it’s a tough one. It’s a tough question.

Lynette reported that knowing when to intervene with a client is constantly a difficult decision for her.

We had a client, we’re in a restaurant and he was eating something and, his face started going red, and lots of, as you know, lots of them do sort of stuff the food in, and I think, is this man choking? Do I make this big deal out of this man and do the whole first aid thing on this man, or do I let him go? And as it turned out, he was actually choking, so it’s very hard to know when to step in and when to leave it.....Do I step in and make a fool out of him? Basically, who has very limited language and might be saying, oh I’m fine, I’m fine but he can’t say that because his mouth is full and he has limited language anyway, or do I take the
risk? But we stepped in and, he was choking, so he was fine. Other things, lots of instances do I step in when people are moving around, or do I let them keep going because they want to keep trying? There’s lots of those little, many times. Do I wipe this person’s face or do I leave it there? Do I, do I help, when to help, and when not to help is my biggest problem and particularly when I started. I’d sort of watch what other people did. That was my big problem.

Lynette described the grey areas of making decisions about and with clients, particularly in everyday, mundane situations, and recognizing the balance she tries to maintain between allowing clients their autonomy and dignity, and stepping in to avoid any harm occurring to the client. For her, rarely are the situations clear cut. Loretta took an opposite attitude:

To me, most things are reasonably black and white. Yes, you can have a crack at it. You know, the worst thing that will happen is you’ll fall over, or, no, just can’t happen. Too dangerous, too scary... just leaving myself wide open for repercussions. Yeah, I don’t really, I’m not an iffy person. Most people, even, even the clients, would know, she would let you do that, or she wouldn’t. I’m probably fairly..., and I think... with people with a brain injury, you’re better to keep it, fairly... you can do this stuff, you can’t do that stuff. Even things like, sometimes they will tell you get F’ed and all sorts of things, and I would straight away say that that was inappropriate, and... they would know.

Loretta expressed concern for how decisions may come back on her, and adheres to a strict sense of what is allowed and what is not with the clients she works with. She also spoke to legal obligations, illustrating that certain duty of care interventions are dictated by law. Steinman, Richardson, and McEnroe (1998) point out that when ranking decision choices in an ethics hierarchy, the interests of the client actually come third. They state the first principle is that staff must ensure their decisions do not place themselves in a position where they can no longer work in a helping profession, since "they are important assets to all their clients specifically and to society as a whole in general" (pg. 10). Next are the interests of society, of which legal obligations are a part. The interests of clients should not come before the laws and interests of society. This proposed ethical hierarchy follows a medical model structure and the power mechanisms of professions by emphasizing the importance and worth of professionals over society and the individual client. Society as the second tier of interests represents
rational models of social control, that the individual conform to the greater good. However, it is unlikely many people would advocate on the individuals’ behalf for the right to murder or abuse another person. In the instances of major legal transgressions, such as child abuse or intentions to harm another, there seems to be little to no ethical conflict. But more minor, subtler scenarios where it is questionable if the client’s choices may be risky to themselves or others, it seems to be a more difficult situation for the participants to assess and make a decision.

Gregory gave an example of subjective risk.

When we have lunch, we try and....most people are quite independent and can decide what they want for themselves, but we have a few that are on quite strict diets, or diabetics so we’ve got to supervise what they eat. One particular guy is on a quite strict diet at the moment. He’s very overweight and he’s on a pre-prepared meal plan and he wants to eat junk, and so we’ve got to be quite....it’s a bit of a balancing act of his rights and our duty of care to him about what he should eat, and when we explain to him that he is on a diet and the best thing for him to do at the moment is to lose the weight, he sort of gets the program and says ‘yeah, fair enough’ and doesn’t carry on about any chocolate or biscuits or cake, and stuff like that, so yeah. That’s a bit of a battle, but that’s just the way the service is, some people with brain injury are.

Gregory spoke to having to balance what the client wants with what is in the client’s best interest. This is an ethical challenge echoed in several of the other narratives, and which frames the heart of the conflict between the medical model of treatment versus the self deterministic ideology of outreach support. Gregory deals with this by offering as much information as he can to the client about why staff are making restrictions on his meal choices. His comment that this is the way "some people with brain injury are" spoke to the compounding of the duty of care versus dignity of risk debate by the cognitive deficits that can contribute to a lack of insight or lack of effective decision making on the part of the client. "It’s a bit of a battle, but that’s just the way the service is..." spoke to the legitimized power staff hold over a client’s choices. In this case, staff have authority to tell a client what he can and can’t eat. Gregory expressed his awareness that this authority has ethical implications by his terming it a balancing act, but also revealed his belief in staff authority with his belief that this is how it has to be.
We have another guy who’s been in a wheelchair since he had his injury and he has a frame... ... and he’s been at the same level for basically ten years now, and hasn’t progressed at all... and he said, ‘I’ll be fine’, but we have to convince him that because he probably will fall, and the chance of him falling is probably, you know, 80%, that we have to restrict him to his wheelchair on specific days.

The duty of care concerns the client’s overestimation of his own physical abilities, and the greater concern is for him receiving an injury due to a fall rather than being able to exert his independence by attempting to walk. Having witnessed the client previously fall from walking attempts, staff decide the best strategy is to restrict the client. However, in another situation, with another client, Gregory based his decision on the client’s assertion that he understands the implications of his choice.

We were down in the Rocks in Sydney and they wanted to go for a ride on one of the Harley Davidson things, and I actually said to him, ‘Well, if you can state to me and another staff member that you’re doing this on your own back, and that you understand the implications and things like that, then I’ll permit you,’ and they did all that, so...it’s basically covering our back if anything happens, that they’ve made the decision by themselves and yeah, it’s a really difficult question because you like them to make choices but then we are responsible for their care as well. Yeah, it’s very fine balancing of an act.

Gregory felt the client who uses a wheelchair does not understand or accept the level of his physical impairments and risks harming himself if permitted to attempt walking solely with a frame. He felt the client wishing to ride motorcycles has a better capacity to understand his physical abilities, and Gregory showed more confidence in the client’s expression of understanding. Even though motorcycle riding is considerably more high risk than walking, the insight and physical impairments of the clients contribute to the scales in Gregory’s balancing act between duty of care, and dignity of risk.

Loretta spoke about various situations with tension between her duty of care and dignity of risk. Some approaches are determined by agency policy, such as dangerous house items, like knives, and medications being locked away and restricted from client access. In autonomous approaches, Loretta’s experience with various clients...
guides her in deciding to simply avoid some situations that could become contentious. Different client personalities, and different situations require different approaches.

Well, if they want to do something, I will talk about them...like, this fellow wanting to go to the hardware shop, and I probably would have to say, "Is that something you would normally do?", and he would probably say...(laughs) he might say yes, he might say no. So I would have to say to him, "Ok, it’s just down there, can I trust you to be back in fifteen minutes because that’s...just for starters, we’ll see how you go". And he’s fine with that, and turns back up, and it’s always a bit of a risk. We’ll go for lunch somewhere and you can bet that one doesn’t want to go where everyone else is going, so then yes, you have to think, is he capable of going down to that other shop, deciding what to buy, buying it, paying for it, getting his change? And you do...you do take that risk sometimes,

Loretta allows a client to engage in a situation that could be risky, such as going off alone in a public place when the client typically has not done so in the past. She weighs the client’s insight and ability with the level of risk in the situation. Whether the client with acquired brain injury demonstrates the capacity to learn from his own actions is a factor which weighs into the staff’s assessment of how much risk the client is capable of taking. Like Gregory and the client wishing to ride a motorcycle, Loretta talks thoroughly the decision with the client to assess the client’s understanding and insight of his choice.

Tess acknowledged the power authority of the staff as she discusses "pulling rank" at times with clients.

Well as much as we can, we’ll let them decide what they want to do. But, as I said, a lot of the time, well, maybe not a lot of the time, but there are definitely times where, you know you just have to veto what a few people want and make the decision for everyone...One man... every week that he comes, he wants to go to a different club, and alcohol’s an issue..... So we’ve got a rule, you know, the driving rule. You know, you can have two drinks in your first hour, one drink every hour after that. If it doesn’t interfere with any medication that you’ve got with you.......and not everyone wants to go to the club every week...... And my supervisor and I have talked about it, and we both feel, Well if that’s all you want to do, you don’t need to come to the group, because you’re not socializing anyway. You know, you can just go to the club and blow all the money you
want on the pokies by yourself, you know, and not cause all this stress every week...... So a lot of the time we have to, you know, ‘no, we’re not going to that club, we’re going to here’, and my supervisor puts that out of bounds which it helps to deal with that...... Negotiating if it can be negotiated, otherwise you know we just have to pull rank.

The situation described by Tess is a duty of care issue, with concerns about clients on medications drinking in a pub, as well as a group conflict issues, with the client in question seeking transportation to a pub rather than participation in the social objectives of the group. Here, the risk is not only to the client wanting to go to the pub, but to all the other clients in the groups as well. The final decision is guided by the objective of the recreation group to emphasise socializing during leisure activities.

Violet had to juggle duty of care versus dignity of risk issues as well, with a combination of suggestions, negotiations, and sometimes outright restriction.

There was one individual who used to hoard a lot of things so she’d..... find things and she’d just, yeah, pick them up and keep them. She used to hoard things in her room to no end, so even food and stuff like that used to be stashed away in her room, and things like that, so that was stuff to work around and every time we sorta saw her and things like that, which was on a fairly regular basis, we’d, you know, encourage her to, you know, get rid of some of her stuff, and, and I think, I mean, that was an issue, an issue when she was in respite, because she used to hoard things in her room, and sometimes if, if it was food items, it used to get pretty disgusting, so that used to have to be put to an end.

Like Tess’ "pulling rank", Violet recognized her authority as a staff member over client. However, this approach did not sit well with her therapeutic coaching philosophy.

Some of the stuff that was done, I don’t think was terribly appropriate. Sometimes cupboards would be locked and things like that for her not to have access to the stuff so she wouldn’t take it, which I don’t really think is, whereas my view on it is it’s not really teaching her anything. I used to just talk to her about it, and, you know, we used to just work, work it through, and that type of stuff, so.
Condeluci (1998) states, "When a person is denied the right and opportunity to take chances, he is denied a vital outlet to learning," (pg. 105). He recognizes liability is a genuine concern for organizations and agencies, but voices his own concern that agencies preoccupied with avoiding liability sacrifice the ethic of client self determination critical to community integration and outreach programs. "Most of this action only leads to oppression and domination of the recipient of the services," (pg. 105). Abramson (1989, cited in Mattison, 2000) noted this course of action is called paternalism.

Felicity spoke to being aware of not threatening the integrity of her relationship with the client during negotiation and balancing her duty of care with the client’s dignity of risk in the following two examples.

That’s a big problem, because, you know, if you notify a parent, notify a child because their parent is brain injured, which the legislation basically said you have to do now, then, and DOCS comes in and removes the child or something, well, sorry but you can just kiss that therapeutic relationship goodbye. They’re gone. And that’s a real tension, a real problem for me, especially if I don’t think from what I see of this person, that they do pose a risk to their family, so I think it’s a real problem.

Another example has been "don’t get on your bike, please don’t get on your bike, you will fall off" (smiles) "Aw come on", so they go out and they try it anyway. They come back in the next week, "aw, I fell off my bike". "I told you so!" (laughs), and, I mean, that’s a lighthearted example but that actually does happen quite a bit....... And they know that, they know there’s nothing that can stop them from getting back on their bike and hitting the road, and we can’t stop them. We can advise against it, but we actually can’t physically stop them, and you know, that’s sort of, that one’s a problem.

In the first narrative, legal obligations require Felicity to notify the Department of Community Services of a client’s injury, which could lead to the child being removed, and destroying the trust in the staff-client relationship. In the second narrative, Felicity spoke to the legal protection of the client to not be prevented from riding a bike post injury, even if evidence indicates that the client is likely to incur further injury because
of physical or cognitive impairments. It seems in both scenarios, the law can potentially be a catalyst for negative consequences in the client’s life. In the first situation, the client’s family may be separated. In the second, the inability for staff to intervene in a high risk situation where a client demonstrates a lack of insight about his/her true abilities may allow for an additional serious, yet preventable, injury to occur to the client.

Karen incorporates her own values and feelings when negotiating through a dignity of risk versus duty of care situation. She explores options with the client.

I guess it’s a process of negotiation.....there’s only a couple of instances I can think of where I have actually come out and said, "Well, no, I’m sorry. I can’t partake in this, or I can’t allow you to do this while you’re with our service because..." and it always comes back to duty of care, about a person wanting to put themselves into a physical situation that’s not safe...., it might be saying to the person, "Well, I’m feeling a little uncomfortable about this or I have some concerns about this because, or I can see a hiccup with the goal because of whatever reasons." It’s ultimately the....unless it’s something that goes against legal reasons, or duty of care, or the policies of the service, I don’t actually have the right to make a decision for somebody else, so I might put forward, as I said, "I have concerns about this, I’d really like you to think about these things, but ultimately, the decision is yours."

In ambiguous situations, staff may have to determine their own markers for what constitute the limits where they should ethically intervene. As Melanie explained:

Usually, when I feel like a situation’s escalating, where I feel if I don’t stop it now, it can only get worse, to the point where the consumer is not going to be able to bring their behavior back. They’re just going to get out of control, and I don’t really...if we’re in their own home, whatever, I’d just let run wild, as long as they’re safe, whatever, but in a public situation, often other people get a bit scared, or whatever - Melanie

The ethical implications of balancing duty of care with dignity of client risk is a concern to Felicity:

That really worries me. The level to which we impose conditions on people’s
autonomy, because how do we know from a pen and paper neuro psych test that this deficit that we’ve identified actually transfers to this function in another setting? And I think that’s really difficult. I have a lot of problems with those sorts of decisions.

**Dignity of risk versus duty of care summary**

Balancing the duty of care with a client’s dignity to take risks is a difficult, complex dilemma in ABI outreach, as well as in helping professions in general. The boundaries of care are usually demarcated in regards to major legal issues, such as child protection and guardianship, but are less defined in mundane, daily situations, such as client wishing to ride his/ her bike or a client exhibiting unpredictable anger and frustration in a public location. Gauging the level of risk is subjective, as clients, staff, agencies, families, and society in general may have various definitions and limits to what is considered a risk. What someone considers a risk is relevant to what that person values. Balancing dignity of risk with duty of care seemed to be the prime objective in the practice ethic of the interview participants. Negotiating dignity of risk with duty of care is the challenge they must meet when facing a decisional situation with or about clients.

**Chapter Summary**

This chapter introduces the interview participants in this research. In explaining how each came to be involved in ABI outreach support, the diversity of responses indicated some of the significant themes and issues that will be examined in chapter seven: staff autonomy, boundary setting, personal and agency values, power and control dynamics, emotional involvement with clients, staff personal needs (valency), and definitions of independence in practice. These particular issues have been brought into focus by the participants themselves, either through their own perspectives that these are critical issues in their jobs, or through interpretation that these factors play a role in decision making by analysing their descriptions of their own work behaviour. A lack of adequate and consistent training was common to the participants in this research, as also noted in the research literature. This absence of consistent training may increase the participants’ reliance upon their own interpretations of their job roles, duties, and personal approaches to clients.
This chapter also described some of the outreach settings the interview participants work within in: One on one in home and community settings, recreational groups, respite/group homes, and professional/specialised consultant, with the additional context mid-management administration considered as part of the structure in which front line workers operate. These environments play a role in the scope and limits a staff member works within, influencing the nature of the relationship the staff has with the client, the role they may fulfill, and the types of decisions they may make with or for the client. Here, outreach contexts are introduced, but will be referred to in subsequent chapters as specific issues in outreach are further explored.

The discussion of balancing the duty of care (beneficence) with the dignity of risk (client autonomy) explores the complexities and challenges embedded in the query of how staff implement a philosophy of self determination in outreach settings with a client population that commonly experiences autonomous decision making difficulties and deficits. This tension between risk and care epitomises the tension between self determinist ideologies advocated by the disability movement and stalwart medical model structures that permeate the outreach environment, often unbeknown to staff. How the participants negotiate a balance between these ethics (the client’s dignity of risk and the staff’s duty of care) creates their ethic of practice. The practice strategies the participants select to achieve this practice ethic will be the focus of the next chapter.
Chapter Six

How we do our jobs: Practice Strategies in Outreach

Chapter Abstract

This chapter lists an inventory of practice strategies used by the participants as named or described in their narratives. These strategies represent the ways the participants decide to engage in a staff/client interaction in order to achieve their ethic of practice - balancing dignity of risk and duty of care. Strategies of how the participants care for themselves or cope with work issues are also listed, as the literature documents that staff stress can negatively affect staff practice and service delivery. This information is relevant for practical purposes as it documents staff behaviours and decisions as a sample of ABI outreach staff have described them, giving a snapshot of ABI outreach practice as it potentially happens in actuality rather than as prescriptive idealism. This information is important theoretically as it explores the strategies in terms of the values each decisional outcome upholds, and what values the staff adhere to in selecting one particular strategy over another. The role awareness plays in some of these strategies is evident. Awareness itself seems to be a factor in many of the self-care strategies, which the participants seem to use to clear their decision space to be more effective in selecting client strategies.

Introduction

What is interesting about this research is despite the variances in background, experiences, education, and outreach structures of each interview participant, the challenges they face as staff and the strategies they use to deal with these challenges are not limited to any one type of staff role, staff personality or outreach structure. That is, the challenges and strategies can be found threading though multiple narratives from diverse situations and different interview participants. This is significant in light of fact that there is no dominant model of ABI support or ABI specific outreach training being used in the contemporary ABI field (Ducharme & Spencer, 2001; Fussey and Giles, 1988; McCluskey; 2000, Ponsford, 1995; Ylvisaker, Hanks, & Johnson-Greene, 2002). While some strategies are standard agency protocols found widely in helping profession
structures, many listed here are intuitive, organic responses to in-the-field situations and dilemmas.

To date, there has not been any systematic exploration or documentation in the ABI literature which examines the actual practice of outreach staff. In this section, an inventory and examples of strategies that the interview participants have expressed or described as using in their work with clients is presented. These strategies represent decisional outcomes, that is, the results of how participants negotiated decisional situations with clients in the field. This information is insightful in developing an understanding of how the task of implementing outreach ideologies are actually taking place among a selection of individuals currently in the field. These strategies represent the choices participants made in attempting to balance the ethic of client autonomy with the ethic of staff beneficence - their ethic of practice. These strategies also represent how values, both personal and organizational or ideological, are being actualized in the decisional outcomes.

Strategies could be interpreted as being in two separate categories. *Client strategies* refer to behaviours and tactics staff engage to directly address client behaviours, issues and challenges. *Self-care strategies* refer to the ways in which staff deal with their own issues within their work, which could also be defined as coping strategies. Self-care strategies are as important to consider as are client strategies, as the psychological and emotional health of the staff impacts the way they work with clients, and their ability to be effective in their work (Combs & Gonzalez, 1994; Corey, Corey & Callanan, 1998; McLean & Gould, 1988). Some self-care strategies also reveal directly the relation of staff awareness to their job performance, as will be discussed below. Both types of strategies have formal structures as designated by the employing agency, and informal structures as created and used by staff under autonomous conditions.

**Client Strategies - Formal**

Formal/Agency strategies to deal with client issues and behaviours as discussed in the interviews include individual service plans (ISP’s), established client routines, checklists/documenting, and planning sessions. Formal strategies provide a framework
for participants as to how certain decisional situations should be negotiated.

Individual service plans - An ISP is a common tool used in rehabilitative treatment and community integration support services. Wesolowski and Zencius (1994) describe the plan as:

- a process of identifying a desired outcome; specifying current performance abilities and inabilities (those skills needed to function in the desired community, educational and vocational domains); and defining the necessary interventions, services, and environments that will assist an individual in achieving the desired objectives (pg. 31).

Typically, ISP’s are formulated after an assessment of the client’s needs and preferences. The ISP sets out objective and goals that guide the staff’s work when with the client. The objectives can range from very specific directives, such as following through on a physiotherapy plan to assist the client with rebuilding muscle strength, to broader general goals to frame overall interactions with the clients, such as a goal to make friends, which could encompass strategies to increase social skills, recreational skills, and learning to use resources in the community. An ISP will often spell out ways for a staff to go about facilitating particular activities with the client in order to achieve ISP objectives. ISP’s are usually reviewed at regular intervals and updated or revised as needed in accordance with the client’s progress. Violet described a typical client-case manager- support worker triad in terms of goals and implementation:

It was very much guided by the case worker as to what, I mean, you were out there in the community, you’re obviously doing the work, so, but it was very much, very specific as to what your goal was and what you were to achieve, and the manner, I mean, we used to have regular meetings as to how to approach things and how to work with people..... Some of it was very well structured.

Gary cited the ISP file as his primary source for information about the clients:

- It’s mainly their contact information, emergency contacts, past history, like all their past incidents and accidents, like behaviour problems, whether they need personal care, ...things like that.

ISP’s make explicit for staff the goals they should be working on with the client, and sometimes also detail the procedures staff should follow, thus providing a framework.
for the types of decisions the participants will make regarding clients, and offering some direction as to what the decisional outcomes should be.

**Routines** - Sometimes included in ISP’s, or perhaps in place even if something as formal as an ISP is not, are client routines. Due to cognitive deficits in logical processing and critical thinking, a client with acquired brain injury may rely on memory aids, such as several scripts or routines to enable their daily living to have some semblance of continuity (Wesolowski and Zencius, 1994). A routine usually consists of a set of instructions or steps, sometimes called task analysis, that the client follows to accomplish basic activities of daily living (ADL’s), such as personal grooming, meal preparation, or using public transport. Sometimes staff is required to cue a client in these routines. A client may not have the ability to initiate a routine, but once cued by the staff, they may be able to complete the steps of the activity in the sequence they have learned as part of their rehabilitation. The sequence and timing of routines in the client’s life could potentially impact the level of freedom clients and staff have in varying their daily schedules as Jeff stated:

> Then we’re stuck with time tables, that the vehicles are due back at certain times, or you’re even due back at a certain time, you know, for staff change over and that.

Violet voiced concerns over staff falling into routines with the client, and performing work in a type of auto-pilot mode. She had expressed feeling the clients she worked with were too stuck in routines, and opportunities to expand or diversify skills were missed.

Routines provide the participants with an expectation of what they need to facilitate for the client, but may still leave open space for the participants to decide how to actually implement the routine and assist the client in meeting routine objectives.

**Checklists/Documenting** - Writing progress reports, shift notes, or maintaining a checklist of concrete tasks to be accomplished on shift with clients are ways to evaluate
client progress on their ISP goals, as well as enable staff to monitor their relationship with clients. Documenting was often the least favored aspect of ABI work among the interview participants. Felicity remarked on both the positive and negative aspects of documentation in the scheme of her work with clients:

That’s the mundane, and to be quite honest with you, at times, it’s a really good breakaway from the other things as well, and it’s satisfying that you can cross things off your list of things to do, but it doesn’t give you that feeling that you’ve actually contributed to somebody’s life. I guess you’ve documented what’s been done, but it doesn’t seem like a very positive thing, it doesn’t seem like a useful thing at the time, so I think that’s probably what I would nominate there. It is an important reflective tool as well, and I can see positives from there...

Felicity’s mention of documenting as a reflective tool indicates the value in having a record of client interactions, which documents, among other things, the outcomes of past staff decisions and influences how future decisions may be considered. Documentation acts as a type of shared memory among staff, so even workers who did not actually engage in the interaction with the client, or were not present when decisional situations occurred with the client, can still be informed of the outcome of those decisions, and use that information in forming their decision space in future decisional situations.

Planning sessions - Often, with interview participants who worked among group situations, such as group homes or recreational groups, formal planning sessions with the clients were held on a regular basis to formulate activity calendars and events with the clients’ input. The concept that client involvement was tantamount to the creation of client activities was a frequently held attitude among participants. As Gregory stated:

I used to work at services where it was always the coordinator who made all the decisions of what the activities were, and things like that, where I run it opposite to that. I don’t make a decision about what the activities are going to be without actually consulting the clients, because the service is not there for me. It’s for the clients, and I’ve worked at services where staff said, like when we go to the movies, ‘Oh, I don’t want to go to that movie.’ Well, that’s not your problem, you know. The clients want to go see it, I don’t care what it is, you’re going to see it, because that’s what the client wants to see. The service is here for the clients, not for the staff.
Planning sessions with clients incorporates the ethic of client self-determination, as the clients (with the assistance of staff) select and plan their course of activities. The intent is to place as much decision making responsibility as possible with the clients.

**Client Strategies - Informal**

Informal/Autonomous strategies are forms of behaviour used by staff when dealing with clients that are not necessarily spelled out in agency directives. Often such strategies were taken for granted by interview participants as just routine manners of interacting with clients and were not spoken about as if they were deliberate strategies used with clients. I interpreted the following informal strategies from discussions of staff behaviour and attitudes in the interviews: persuasion/suggestion, avoiding, distracting, redirecting, humour, consultation, negotiation, consensus, consultation, teamwork, giving information, seeking information, rule bending, clients helping clients, failure, utilizing client deficits, and knowing.

**Persuasion/Suggestion** - Persuasion was a dominant strategy used when participants felt that a client was making a decision that would put the client, or other individuals at risk. Persuading a client towards making a different choice was often seen as a legitimate and ethical response towards maintaining a staff’s duty of care towards a client. Making suggestions along side offering options, or determining the types of options to be offer to clients was one method of persuasion used to influence client decisions.

Someone’s got a weight problem, you wouldn’t take them to McDonald’s, you’d encourage them to buy a salad sandwich somewhere. If you’re at a kiosk, you would encourage them to get the salad sandwich and not the sausage roll. - Melanie

If we were going to have lunch, before she said anything, I’d say, ‘Oh, I’m having a salad sandwich’, so it wasn’t me telling her to have a salad sandwich, but often with people with brain injury, if one has a meat pie, everyone has a meat pie, because it’s just that suggestion to them. - Loretta

Some are easy to get on with, you could just suggest anything to them and they would be quite happy to turn around and do them. - Jeff
One reason persuasion may work so well as a strategy for shaping client behaviour is the traditional hierarchical role staff hold in the staff-client relationship. The designation that one individual is ‘staff’ and the other is ‘client’ automatically assumes particular features are ascribed to the individual filling the role. The role of ‘staff’ comes with connotations of expertise, knowledge, and authority, while the role of ‘client’ implies neediness, helplessness, and deficit. The opinion and suggestions of staff, by virtue of title alone, are often given more credibility and worth than those of clients, and therefore carry more power and influence (Reiff, 1974; Schorr & Rodin, 1982; Hagner, 2000).

**Avoiding** - Another oft used strategy was the deliberate avoidance of situations that had previously been confrontational or resulted in conflict in the staff/client relationship. Avoidance was used more often in staff/client relationships that had more history than newer staff/client relationships. A sense of "knowing" the client needed to exist prior to selecting the strategy of avoidance as the most effective way to shape client behaviour.

Experience tells you the person that’s going to try and jump out of the car as you’re driving along, or the person that might attack someone else because that happens in a group situation, so yes, you’ve just got to always be thinking. People who have lack of insight, lack of balance, well then you don’t let them walk anywhere near the water, you know. You make that your walk is over there, because if it comes down to you telling them they can’t do it, well then you’ve got a real problem on your hands, because like anybody, no one wants to be dictated to, so I find I tend to, if it comes to confrontation, you’re lost because legally you cannot force that person to not do something, so I tend to avoid the situation. If you know and it’s only from experience that certain situations will spark off anger or problems, well then you tend not to go there, if you can.- Loretta

Avoidance would also include preempting an undesired behaviour with a more desired, incompatible behaviour, making it difficult for the client to engage in the negative behaviour.

I know she’s not supposed to smoke indoors.....I try and take her for doctor visits and we arrange the doctor visits to be when I’m there....she’s not allowed to smoke in the doctor’s surgery so I get around it that way in a lot of cases. - Lois
Participants deciding to use avoidance in a decisional situation have chosen to align with the ethic of duty of care, while sensitive to the ethic of the client’s dignity of risk. The strategy averts direct confrontation between the two ethics by not allowing a situation to arise where the client may become directly aware that he/she is being prevented from engaging in a particular choice.

**Distracting/Redirecting** - Another form of avoidance is distracting or redirecting the client. Distracting involves the participants refocusing the attention of the client to a different stimulus to avoid the client fixating on a confrontational matter, while redirecting is a more direct command to maneuver the client into behaviour deemed more appropriate.

One of them is very cognitive with his needs. Gets very fixated with wanting to go to the toilet all the time, and eating, so you sort of basically encourage him to have a look around (in the museum), because he’s quite interested in cars and music, he was a musician before his accident. And he was studying an arts degree, and things like that, ...but he gets quite fixated with going to the toilet so you try and avoid toilets and encourage him to have a look at things he finds interesting and not just charging off to the toilet and losing him, which can be a bit of a problem. - Gregory

This strategy is used in situations where the participant has deemed his/her duty of care supercedes the client’s autonomy, and like persuasion, may be an effective strategy due to the cognitive limitations common to most clients with ABI, and the socially sanctioned role of staff to direct client behaviour.

**Humour** - Humour was cited by several participants as an overall approach to how they worked with clients, and indicative of the social environment they endeavored to maintain with clients.

We have a fair bit of fun....we muck around a lot with the clients. We joke a lot, you know, like we tease them, they dish it back, you know. It sort of keeps things light and you know, fairly enjoyable for most of us. - Tess

(The clients) crack up, and the support workers are there, and they crack them up. It’s a lot of joke telling. - Melanie
Humour was also an effective tool for deflating inflamed or tense situations with clients.

If that behaviour is inappropriate, I’ll stop them, explain what is inappropriate, try again. If that doesn’t work, they’re out of my office. If they’re just being a bit of a pain in the bum, I tend to get away with a fair bit by joking with them through a lot of things, and it works with most people. A few it doesn’t, but with most people you can get through it using humour.- Felicity

The decision to use humour may allow the participants to deal with confrontations directly but with less hostility, or it may allow the participants to deflect confrontation by changing the subject or distracting the client.

**Negotiation** - Negotiation is common when working with clients with acquired brain injury (McClusky, 2002). Client preferences are not always able to be facilitated for a variety of reasons offered by interview participants, including constraints on physical resources, time, staffing resources, and the level of risk in the activity the client is likely to be exposed to. Negotiation is required to best meet the client’s needs and preferences within the realistic constraints of what the staff can facilitate.

Some people want to go out, and when you’re, well then you’re stuck with time tables, or even due back at a certain time, you know, for staff change over and that. They may be still enjoying themselves and you’ve got to actually coax them, you know, to ‘ok, we gotta go back, you know,’ and they can’t understand why. They’re there all evening, but you aren’t there all evening, and, but again, after a little bit of negotiating, a bit of explanation, yeah, things work out. - Jeff

Negotiation often seems to occur around safety and risk issues concerning the client.

If there’s no physical danger to the person, it’s not an issue or an activity that’s going to be emotionally damaging. It’s usually a negotiation process with the person. If it’s something that I don’t feel is maybe a particularly good idea, I would come out and say, ‘Well, look, I personally have some concerns about this. Are you happy for me to raise those with you? Are you happy if we have a talk about it a bit more, because I’m feeling a little uncomfortable.’ So it’s usually a negotiation process. - Karen

Negotiation engages the client into the participant’s decision process, and respects the client’s expression of self-determination, while also accommodating the participant’s
concerns and responsibilities towards client. Negotiation can be seen as a direct manifestation of a staff member actively evaluating and balancing between the client’s dignity of risk and the staff’s duty of care, seeking the optimal resolution to the decisional situation.

**Consensus** - Negotiation was dominant in group situations, where the participants rely on democratic consultation and consensus from the group to determine which preferences and activities to facilitate for clients.

We have a planning meeting for, we set out the program for every month in advance, and we have a planning meeting every three months so they (the clients) can give me ideas of what they actually want to do in the next three months period, and then we sort of, we take votes on, because it’s such a large group of ten people usually on a weekly basis, we take a vote on what people want to do, because some people will say they want to go to the races every week and some people will want to do something like ab-sailing, or things that are totally not appropriate for everybody else in the group, and some people are quite physically able and some people are not so physically able. - Gregory

Offering alternative choices is one strategy of balancing client preferences with concessions to the group.

So sometimes the more physically abled people want to do the rock climbing or the ab-sailing and that, and we just say sort of say, ‘well maybe we could organize for you to go an do that with (another) group by yourself’ but it’s not appropriate to (this) group to do. - Gregory

**Consultation** - Consultation occurred both between the participants and clients regarding client made decisions, and also occurs between participants and fellow staff regarding decisions made about the client. At the staff-client level, the participants use consultation with clients to ensure that the client is being as self-determined as they are capable of being, and that the client has as much control over their own daily activities as possible.

We talked about what he wanted to do, and we ended up going for a drive. ...we went for a bit of a drive and we chatted the whole way....I was saying, ‘Do you want to stop or are you happy to just keep driving?’ and he was so happy to
drive because it was a really cold wintery day and it was sunny and it was nice in the car, so we just went for a drive and then he was keen to head back, so I guess he was making decisions about what he wanted to do. He was able to tell me so I really didn’t need to give options. - Kody

Decisions that the participants are unsure about or that carry potentially larger consequences are usually made with the assistance of supervisors or peer staff.

If we have any problem with any (client) at any time, we can always go either face to face with our respite planners, or phone them up at any time within working hours, talk to them. The regular staff meetings we have, we can talk about various clients that we’re working with, and someone, you know, might just hit on something really great, you know, that can work really extra well with a particular person. But hopefully, at the same time, they’ve also consulted with the respite planner and told them that, and written it up in the notes also. - Jeff

Consultation also may involve other members of the client’s circle of support, such family members or medical personnel.

Depending if the person wants to do a particular activity or something, we might seek a medical clearance. If we’re not sure about something, we would then take it the next step to the coordinator, who might the take it to the management committee. Possibly checking with family or whoever is the key person in that (client’s) life as to, you know, are they happy to have the person go ahead with these things. - Karen

Consultation was one method by which a staff member may cope with the uncertainties of particular situations that occur when working with clients with ABI.

If you feel a bit uncomfortable, that would, you’re more likely to run it by the team then. If you think ‘hmmmmmm’, well you know, ‘uhmmmm’. I think we all try to do what the client wants as much as possible, and that can be hard. Some clients want to take a risk...Sometimes I’d like a policy and procedure that says, “In this situation, you do that, and in this situ- but we can’t, there’s not, you know, you just can’t have that for every situation...So that’s where your colleagues are really important. Supervision’s important. - Jane

Consultation as a form of staff coping will be discussed further under the Self Care section of this chapter.
Teamwork - Consultation can be considered as a facet of teamwork, in which staff collaborate to provide the resources to facilitate client preferences or deal with client behaviour. Moving beyond discussions about clients, teamwork may also involve strategic cooperation between staff to meet logistical demands of client decisions and resource constraints.

We might go to a large venue like the museum and we split up into individual little groups. We don’t stay in one big group, and we usually split into about four groups. There’s usually 12 people so we split up into four groups of about three and we go our separate ways, but we usually see each other and we all have mobile phones, so if there is an issue or if we’ve lost someone, we usually, you know, we pull together another group and make a larger group of say six people and two staff members...so generally you are by yourself (in the field) but with easy access to pull another staff member. - Gregory

Participants working autonomously in the field may still utilize teamwork to work through reoccurring client issues on the job.

I have the freedom to decide (what client strategies to use), but at the training days, we each say something about our client that we’re dealing with or any of the problems we may have, and sometimes I’ve brought up the (client’s lack of) motivation. I usually do bring that up because it’s very difficult. It’s the main problem with her. And people give different viewpoints of what I could try, which I have done. - Lois

Like consultation, teamwork is also a Self-Care strategy which will be further discussed in the self care section of this chapter.

Giving information - Giving information to the clients could be considered part of the negotiation process. When circumstances dictate that a course of action must be taken that conflicts with the client’s preferences, explaining the reasons for such decisions is usually the first manner in which the participants attempt to help the client understand what is happening.

Just explain to the client, there’s no wheelchair access or the reason why there is a problem. They’re quite understanding. They’re all adults, all our clients. They’re all good that way. We’ve been to venues and not been able to get into the toilets and things, so we’ve had to get back on the bus, so they’ve
Reasoning with clients can be frustrating at times if the client’s incapacity to understand interferes with the process.

I think one of the most difficult things is to reason with clients, like to get them to...because sometimes they had very extreme thoughts, ideas or, which sometimes was acceptable, if that’s what they wanted, but in other settings, it wasn’t. ...another person for example was in regard to managing money. He was really, could not manage his money, and it was very hard to work with him in managing his money, and reasoning with him as to, you know, like what he had to do and what bills he had to pay and when I used to do all his budgeting with him, and he used to just not want to pay bills or see that bills weren’t important when they were overdue, that type of thing. So fairly important things, yet you couldn’t reason him into paying them.....If they didn’t pay rent or if they didn’t pay bills, then they’d be evicted and that type of thing, but for them to actually get that understanding, until it happens, it’s very difficult. - Violet

Giving information occurs after the decision is finalised and is a strategy intended to remain sensitive to the ethic of client self determination. By explaining to the client reasons for a particular decisional outcome, the participants seem to feel they are still including the client in the decisional process.

Seeking information - Some interview participants find it beneficial to seek further information from their clients in order to better understand the client’s viewpoint and how that may be influencing the challenging behaviours.

A bit of delving can usually reveal that something is not going right at home, or they’re having a few problems financially, or they’re probably being a bit more frustrated with their life, or sexually frustrated or whatever, so yeah. If you don’t go with your gut feelings, you tend not to find out what is going on. - Gregory

Seeking information is part of the information gathering the participants conduct to assist in forming a more coherent decision space, and the nature of the information obtained will likely influence the decisions the participants will make in a decisional situation.

Rule bending - Some staff spoke to bending the rules when ideologies about client
centeredness seemed to conflict, or even when the staff’s wish to gain approval from a client superceded the staff’s need to adhere strictly to the policies pertaining to the client.

We talked about what he wanted to do, and we ended up going for a drive and then making his sandwich. I know he’s not meant to have butter, right, and he wanted butter. And I gave it to him. And we both just laughed about it and said we wouldn’t tell his mum. - Kody

I don’t necessarily like having to make those choices for that person, saying ‘No, you can’t eat that food, you have to have this’, but that comes back to how we have to be…..You can see how much they want that McDonald’s hamburger, or whatever. - Melanie

We do break our policies, because being a church based service, they’re very anti gambling, but my clients choose to go to races and want to put bets on the races, horse racing, or come to the club and have a go at the pokies, and that’s their choice, and I don’t think it’s my duty or my responsibility to restrict them in that way, as long as they’re doing it in a sensible way and not in a destructive manner. - Gregory

Rule bending is one way staff deal with conflicts, both personal and ideological, in the workplace. By bending the rules, staff may be able to avoid confrontation with the clients, or may be able to perform in what they see as the best interest of the client, such as Lois giving her home phone number to her client, or facilitating a better relationship between the client and the client’s husband, as Lois explains:

I don’t feel that I go by the book.. I go away from the book a lot of times (laughs) a lot of times I know I shouldn’t. No, I feel I have my own freedom to decide what we do, and if I feel it wouldn’t be good for her, I would suggest that we not perhaps go that way and do something else.....It’s generally all within the guidelines of the book. The only way I differ from the book is that I do stuff for them, like I might clean the windows, which I am not supposed to do. I am only supposed to be there for her, but I just feel I’m so able bodied and they’re not, and if I can talk to them and chat with them and be doing stuff as well, and he’ll (the husband) come out as well and have a chat and we might talk, you know, and I think that’s good, because that gets them going together and harmonizing and talking over a problem between themselves, which is what’s lacking in their relationship, as well. So I sort of try to get them both involved and that in turn will benefit her.

Rule bending may be seen as an option when it is not clear which ethic should prevail -
dignity of risk or duty of care, or in situations where a participant’s own values and personal ethics are chosen over those of the agency or profession.

Clients helping clients
Lois and Tess each spoke to utilizing the bonds between clients to resolve issues.

These two clients have known each other for a lot longer than I have known them, and I was actually hoping that this other high functioning client might be able to make a bit of a difference with the other one, because she’s been there, and I thought, no matter what we say, they can still always turn around and throw in our faces, well, how do you know? It hasn’t happened to you, and they’re right. And this other client, I’ll go and talk to her, and I thought ok, you know, maybe you’ll be able to get through where I won’t be able to. - Tess

In this example, Tess indicates she is hopeful to attain the same outcome she may have gotten, through the different means of letting a client assist another. Her intentions are the same, but she has decided on an alternate approach upon not being successful with persuading the client herself.

Lois spoke to the benefit of her client having responsibility for another person, Tess also acknowledges the self-esteem benefits for clients involved in a group of mixed ability levels.

I think it’s a positive in that you know, the variety...... it’s also a positive for the clients, because they, because they’ve formed their friendships, they will sometimes step in and help others, where they can. So it’s good for them.

This strategy is sensitive to the effects of giving a client responsibilities, which includes the clients’ making decisions about how to help each other.

Failure - A couple of interview participants discussed using failure as a way to illustrate to clients or families the true nature of the client’s limitations. Sometimes a client with ABI lacks the insight to gauge his/ her own skill and ability level, and may overestimate what he/she can do. Differing from suppressing client autonomy or dignity of risk,
harnessing a situation that will demonstrate the deficit areas in the client’s ability may be an important or perhaps the only way to make clear to the client and family the nature of the client’s ability.

Even if the outcome’s not good, it’s proved to him that he’s not up to it. It’s not just you telling him he’s not up to it. Sometimes I do blatantly let someone do something that I know that’s going to turn into a disaster, just to prove to them, rather than me saying, "No, you can’t do that," So that they can think to themselves, even if it’s only for that minute, oh bugger, that didn’t work. You know, that wasn’t a good idea. - Loretta

There’s some situations where it’s the opposite and it’s, especially if the client doesn’t have insight into their own abilities, you might be saying, say for a young child, "This child really needs to go to the special school", or really don’t have the ability when the parents are hoping, or thinking that they do. So, I think sometimes, as therapists, you’re the one to actually make the parents realize that their child’s abilities are actually less because you’re, you’re challenging them, and you’re putting them in situations where they would have to adapt and they can’t. So, I think that’s, that’s an awful part of our job, is by challenging the client and trying to get them to do better, you’re sometimes making it more obvious for the family and the client that their skills aren’t that good, whereas they, because they tend to support them in the home environment or whatever. They think, "ah yeah, you know, he’s alright", and they don’t realize how much they actually compensate, for their clients. So you feel like a mean, mean, nasty person, because you, you’re aware of their lack of ability but sometimes the family or the client isn’t. - Nicole

A client or family’s overestimation of client abilities could create a potentially hazardous precedent in the tension between client autonomy and a staff’s duty of care, especially in situations when the client’s overestimation results in the client wishing to take risks that are physically or cognitively beyond the demonstrated capacity of the client. The decision to allow a client to fail is not so much one to engage in the client’s dignity of risk as it is a measure to demonstrate the logic behind a participant’s duty of care concerns towards the client.

Utilizing client memory deficits- A few interview participants related stories that involved strategies which involved using a client’s short term memory deficits to the advantage of finding a resolution to a conflict.
We were going to the movies and there was, I think, eight clients, two workers, and they had the choice of “Spiderman” or “Scooby Doo”, so we generally that we would divie it up somehow, but there was only one person who wanted to see “Scooby Doo”, which would make it very difficult because the other person would have had seven people, and we have a really bad epileptic, and a few things like that, so we said to the person who wanted to watch “Scooby Doo” that we’d had to change the plan and it would have to be “Spiderman”, and we had this big argument. She just chucked a big wobbly, but then in her frustration, or she forgot, she asked for a “Spiderman” ticket. And so, because the others, some of the others in the group were saying, ‘She bought Spiderman’ (Puts finger to lips to demonstrate staff reaction) Shh, shh, it’s cool, everything’s ok’.” - Loretta

The client’s cognitive deficit provided an opportunity for Loretta and the other staff to find resolution to the conflict of managing a group of clients with different interests. Like Jeff and Gregory’s group experiences, compromises are often made to accommodate client interests when there are not enough staff to support clients individually. In this narrative, the client’s actions inadvertently resolved the conflict, whereas for the client to be alerted to her error would have possibly caused more stress and conflict. On an individual level, it may seem ethically unsound to exploit a client deficit, such as faltered short term memory, to obtain a desired outcome, (getting everyone to go to the same film), but on a group level, participants may have felt forced to deal with situations within the resources they had, and at times, a utilitarian outcome was the chosen path of action.

As cited in the sections regarding persuasion/suggestion and avoidance, client memory issues seems to be a subtle key factor in the success of some persuasion/suggestion or avoidance strategies. This is revealed in Melanie’s quote:

Often she would want to go to (the RSL) for lunch....but it’s a huge area, and it’s too much for her to take in, I think. So what I ended up doing was saying, ‘Ok, we can go to McDonald’s or we can go to Subway,’ because there’s a complex (there) which has three or four different types of food in there. And I knew every time she’d pick McDonald’s without a doubt. Because she loved McDonald’s, but it was giving her that choice to make.

For Melanie, her actions are legitimized since she offered choices to the client. However, at least one choice offered was pre-emptive, relying on the client’s penchant
for choosing McDonald’s, allowing Melanie to avoid the more difficult environment of the RSL, and also increasing the probability she would engage in a predictable routine with the client in this instance.

Sometimes it takes time, but you got to remember people with a brain injury got such short term memory they often forget, and they just ..a lot of them just go with the flow (laughs), so it’s a benefit in a way. (Laughs) - Melanie

Avoidance of difficult situations, or conflicts relates to the notion of knowing in the staff/client relationship, as knowing allowed a participant to be aware of triggers that may instigate challenging client behaviours. Avoidance, and pre-emptive choices will be addressed further in the discussion on knowing within this chapter.

Knowing - Several interview participants, such as Gregory, refer to knowing, such as by their ‘gut feeling’ or just having a sense of ‘knowing’ what to do with clients. Knowing is a sense about the client and their potential through direct experience of working with that client. Knowing can only be gained through experience, and builds a sense of confidence in the participants about the appropriateness of their decisions and actions. Knowing is often abstract and unable to be succinctly described or explained by subjects when asked about it.

Well, lots of our regular clients have been going the whole time so I understand the personality, and I know some people *always* want you to step in, no matter what it is, and they want you to step in and be their servant almost, and other people, no, let me be, and they’ll get quite upset if you do step in, so I know their personality now. I know when to step in. .....And knowing their personality, and knowing what to expect is a big thing. And you know we’re going to an all-you-can-eat restaurant and she’s like that every time. She won’t be any different this time. So you know, so that’s how I deal with it, I guess, it’s just to understand that, who they are. - Lynette

There seems to be a trusted reliance on knowing by experienced staff members.

If you’re smart enough, you’ll know the triggers of people, what, what will, what they’ll want to do......It’s just experience. Initially, everyone has a report, a file that you read before you take that person out, but often it’s not enough, but experience tells you the person that’s going to try and jump out of the car as you’re driving along, or the person that might attack someone else because that
happens in a group situation, so yes, you’ve just got to be always thinking....If you know, and it’s only from experience that certain situations will spark off anger or problems, well then you tend to not go there, if you can. - Loretta

You really need to be here a long time to really get to know all of them because they are so individual and the short term memory is the only thing that is pretty much across the board. Yeah, so it takes a long time to get to know all of their strengths and weaknesses and to be able to think, well this person’s going to react this way so we’ll plan for it....... if two new people came into the job, then God help them (laughs). .......Because I found even after being here for years, sometimes, occasionally, very rarely, but sometimes something will happen that I still think, shit, I thought I knew these blokes! Or there’s one particular person and you know something totally unexpected can happen, and I think, oh, ok, well, I’ll have to remember that one. - Tess

Knowing does not necessarily preclude staff being open and aware of changing possibilities in the client. Tess stated that sometimes unexpected occurrences happen that can catch her off guard. Violet accesses her knowing to prepare for the potential for the unexpected to occur.

I used to prepare myself for it, so I used to go into it knowing what the situation would be like and knowing what my possible reactions would be so that when I was in a situation, I’d be aware of it.

Jane referred to the concept of practice-wisdom to describe her incorporation of knowing into her decision process.

Is it practice- wisdom? Is that what they call it? (Laughs) I’ve seen some recent papers, social work papers where that’s what they call this, what I would call a gut instinct, so they are calling it practice- wisdom. I mean, you do base it on past experiences, on an assessment of the client from, what you know of other clients and what you know of this client, and, and how you feel...... Some clients.....want to take a risk, you know, might want someone that wants to go back to horse riding, or has had a head injury, and wants to go back to, you know, motorbike riding, bull riding, you know. I mean, it’s not a joke, they do, "That’s what I want to do, that’s what I do”, and, and so we have to balance that, but we certainly assess, well is that possible in any way? Yeah, yeah, it’s not easy, it’s hard.

Practice-wisdom is defined as

a system of personal and value driven knowledge emerging out of the
transaction of the phenomenological experience of the client situation and the use of scientific information. Central to this system of knowledge is a set of principles that incorporates values of the worker and the profession and serves as rule to translate empirical knowledge, prior experiences, and other forms of knowing into present professional actions (Klein & Bloom, 1995, pg. 801).

Zeira and Rosen (2000) note this is also termed as intuition or tacit knowledge. Along with Schon (1983) and Scott (1990), they assert that practice-wisdom is a significant influence and aspect of the decision making process, which may take precedence over formal or technical knowledge used in practice (Reber, 1993; Rosen, 1996 cited in Zeira & Rosen; 2000).

Lynette spoke to the importance and use of knowing a client when deciding how to approach them.

One of our clients wants, like as I’ve said, wants you to be their servant and do everything and if we go to an all-you-eat restaurant, she’s like ‘peel my prawns’, ‘get me my soup’, and you’ve got other people to get food for and it’s dinner time and I, you want to eat as well, so, I’m just like, it’s a bit, sorry, Jude, we’re going to be here for quite a while. And knowing their personality, and knowing what to expect is a big thing. And you know we’re going to an all-you-can-eat restaurant and she’s like that every time. She won’t be any different this time. So you know, so that’s how I deal with it, I guess, it’s just to understand that, who they are. I know where to go, and little things that might upset different people, like crowds or things I’ll avoid, certain things, just little, little things.

Knowing was regarded by participants as something that must be accumulated and acquired through experience on the job with clients.

**Self-Care Strategies - Formal**

Human services are stressful occupations (Combs & Gonzalez, 1994; Corey, Corey & Callanan, 1998; Edelwich, 1980). Staff’s primary tool of the trade is themselves, interacting with the clients in a therapeutic relationship (Combs & Gonzalez, 1994; Corey, Corey & Callanan, 1998; Upham, 1973). The psychological and emotional health of the staff, as well as the staff member’s awareness of their own psychological and emotional status, directly impacts the manner and efficiency in which they perform their jobs and make decisions (Combs & Gonzalez, 1994, Corey, Corey & Callanan,
1998; McLean & Gould, 1988). It is as important to look at how staff deal with the personal stresses in ABI outreach as it is to look at how staff deal with clients. It is logical and necessary that staff will have developed a myriad of ways in which they cope with the daily difficulties of their jobs, both formal and informal. From an organizational perspective, formal avenues often used to address staff stress include formal debriefing, rotating workers, boundary setting, and documenting

**Formal debriefing** - Formal debriefing includes mechanisms such as staff meetings and training days, when the participants can share ideas or discuss issues and stresses they are experiencing with particular clients, as well as individual one on one supervisory meetings, in which the participants can process with their supervisor challenges they may be experiencing with the client. Alexia related that sometimes in supervisor meetings, her supervisor would help her sort through the issues that were "her stuff" versus issues that were "client’s stuff", to sort through personal feelings and reactions that could be impeding her work. Most of interview participants spoke to similar conversations with supervisors or formal staff meetings. Violet did not feel the level of debriefing she received matched the level of stress she encountered in her job.

I’d have to say there probably wasn’t enough formal debriefing, I think in some of those situations, like, the guy that I used to do budgeting with on a fortnightly basis, like that went on for ages and ages and it wasn’t an easy situation, yet I didn’t, in my view, I didn’t receive, it was like I was told to keep going and doing, do it, but it wasn’t an easy task to complete, so, yeah, I mean, I guess that’s a different issue but I do feel that more supervision does need to be requires to most services, because it is very draining work.

Violet expressed a desire to have had more formal debriefing from the agency to cope with the stress of the job. The recurrent theme of feeling as if her supervisor did not listen to her is present as well.

Supervisors may guide the staff through a challenging decision process regarding a client, or even make the decision for the staff member. Formal debriefing may also help the staff member critically examine his/her own decision making processes and decision space ‘blind spots’ to help the staff member improve upon their own critical thinking.
Rotating workers - One of the issues staff in helping professions face is the blurring of boundaries between professional status and friendship with clients. Emotional over-involvement with clients can be detrimental to the staff/client relationship, and can contribute to emotional exhaustion and burnout in staff. (Corey, Corey & Callanan, 1998; Huggard, 2003) According to the participants, one way some agencies they work for address this issue is by making sure a variety of staff work with each client so that emotional closeness between one staff and one client is less likely to develop. Rotating workers is seen as a strategy in the best interest a client’s emotional health as well. Most agencies are open to switching workers in scenarios where there is a personality conflict between the staff and client. Either the staff or the client can request to work with someone else if either party feels the relationship is not conducive to the client’s goals.

The policy of rotating workers to decrease the stresses related to staff emotional involvement with clients is affirmed by Kody as being in use in her agency.

If they want a particular support worker to come every week, but we say, "We’ve got a policy now that it has to be a rotation thing of all support workers so there’s no dependency issues", that’s a really important thing. Sometimes the families aren’t as happy about that, but you just think, well that’s how it is.

Tess, Gregory and Lynette were exceptions to this as their contact with clients is less frequent and focused on leisure activities. Lois was also a major exception as a direct front line worker. She works in a rural area, with the closest regional city 30 kilometers away. She also lives in the same community as her client. Lois and I speculated the agency’s cost considerations for paying other workers to travel to the client’s house may be one reason Lois is not included in a rotation with other staff from the agency. The role of emotions in decision making and the potential for emotional closeness with a client to cloud decision spaces is one of the issues to be examined in more detail in the next chapter.

Boundary setting - In the vein of rotating workers, some agencies are also explicit about
professional boundaries and what is considered appropriate or inappropriate behaviour within the staff/client relationship. Many of the larger taboos are often addressed in code of ethics statements (Freud & Krug, 2002a & b), as set forth by the agency or professional disciplines. An agency may address more subtle issues regarding the staff/client relationship, but it is less often the case than more.

Kody’s agency has other policies in place to further assist with setting service boundaries. Kody admits though that there are relevant subjective elements to consider when defining individual service that concern the client’s life situation.

Well, it’s sort of like...those standards come back to the policies and our criteria, like entry criteria, and what we can and can’t provide, but then, so what...it always backs onto that, that sort of ground that’s black and white, but then it’s also, it’s sorta like having to think through things as well, like to look at the whole family, and the needs and stuff.

She also comments that sometimes external factors come into the fold of defining service limits, like agency funding.

But, and we’ve had to do it with some of the nursing home consumers, because they’re not, they’re not in our funding guidelines anymore, so, I’ve had to stop services there. But because it been cut it’s been alright, like I can just say, "It’s not in our funding guidelines, we can’t do it", so ......yeah.

Setting boundaries assists in demarcating clear parameters regarding some aspects of a decision space for the participants, but even within the parameters, there may remain numerous other factors that influence the decision making process and final outcome of the decision, as Kody indicated.

**Documenting** - As previously discussed, documentation can serve as a reflective tool for staff to clarify issue in the staff/client relationship and become more aware of how the relationship is progressing. Documentation primarily serves the practical purpose of recording client progress towards goals, or objective outcomes, which can also be rewarding for staff if they can realize some achievement in the client from their efforts. However, Felicity feels the documenting does not accurately reflect the work she has
done with the client.

I just had to submit occasions of service to our area physio manager, for perusal, and I look at it and I think, Ok that really doesn’t speak to what I did. I mean, in most other physios, you’ve got your appointments on the half hour, you shot around the ward and you see a patient every twenty minutes, but here, you know, you might be seeing somebody for an hour and then you’ve got to work for another hour liaising with people to sort them out. Yeah, the complexity, the overarching complexity.

Felicity also spoke to harnessing documentation to monitor her emotional involvement with clients.

I find that very, very difficult, especially with a client who grates on me or I think, "you’re a mongrel". (Laughs) You know, there’s just some people you think " I don’t like you" and I find it really hard to be objective there, and I’ve actually got to force myself to sit down and do really good progress reports for them, so that, I think if you put it down on paper, you can be a little more objective about it.

Documentation was often looked upon as a necessary evil of the job and often was regarded as a stressor, since many interview participants perceived it as time spent away from the client. This may have implications for the decision space around the task of documenting as a participant’s mood or attitude towards the task may influence what they actually write in the document. As a record of client progress and/or behaviour, what is written in turn may influence future staff/client decisional situations.

**Self-Care Strategies - Informal**

I find the informal ways staff cope with stress at work fascinating. I could relate to some of the ways interview participants discussed how they dealt with difficulties at work, as well as be surprised by some strategies they had each adopted informally to deal with the stress and difficulties of the job.

**Informal debriefing/soundboarding** - Pulling a colleague aside to express one’s thoughts and feelings was common among the participants who had access to peers in the course of their working day. Just being able to get frustrations off one’s chests was found to be
cathartic, while informal problem solving and brainstorming among staff peers could also occur to address immediate client decisional situations that were not necessarily of a crisis nature.

Our team leader’s very good at being somebody that you can go and say, "Do you believe this!!" (laughs) and have a big verbal vomit and go back, and "Ok, I can do this now." - Felicity

It might be that I talk with another staff member, you know, "I’m really getting frustrated with this, it’s obviously not working. Can you help me see another way around it?" - Karen

Self-talk - Several participants described self-talk, or mental rehearsing, as a way they prepared to deal with an upcoming client encounter that was likely to be challenging. From past experiences with particular clients, the participants could predict the likelihood of how a client interaction would go under a particular circumstance. This relates to the concept of knowing, discussed in client strategies section. The participants would mentally rehearse what they planned to say to the client, and imagined potential client responses to which they could rehearse additional answers or behaviours. This helped the staff to have more options at the ready for dealing with challenging decisional situations if they arose.

I did have to remind myself that that was just the way they were going to be for basically maybe the rest of their lives, and you know, yeah. It can be frustrating, yeah, I do find it frustrating, but, yeah, I don’t know. Yeah, I do have to remind myself that it’s, that they are, they are people with a brain injury and that that is their, why they’re part of a group and stuff. - Gregory

Gregory discussed self-talk and self reminding as strategies for dealing with personal frustration. He adjusts his perspective on the client that this is behaviour the client has little ability to stop doing, and reminds himself that his reason for assisting the client is because of these cognitive and behavioural difficulties. He noted self talk in other situations as well.

Yeah. I, I...he does push, this individual does push my buttons so I tend to really, be really aware that he can do that, push my buttons and set, and...he tends to be very racist and things like that and I find that really frustrating, and I
usually just sort of say to myself, ‘well, he’s entitled to his views’. I usually correct him and say, ‘well, that’s not quite right’, and things like that, but I do find it frustrating, and but then again, he is entitled to his views and his choices, so, it’s a real balancing act.

Self talk also helped participants to calm down and refocus when aware of their own frustrations in an immediate situation with the client, when other staff may not be immediately available to soundboard or trade places with. Participants would remind themselves of the reasons for the client behaviours and reshape their frame of mind to view the client behaviours as symptomatic of the brain injury and not as a personal attack.

I guess frustration’s probably fairly high on my list (laughs), given the repetitive nature of a lot of the stuff. Once again, I tend to use, for me personally, you know, if I’m getting frustrated with this, imagine how this person’s feeling. I really try and take a step back. If I can feel myself getting frustrated, I try and take myself a step back. - Karen

Self talk is a very clear example of some participants being aware of factors that may influence how they form their decision space. The participants in these situations then harness that awareness to mentally rehearse optimal decisional situations and outcomes that are flexible and responsive to whatever situation that may occur when involved in a particular staff/client interaction.

Removal/Avoidance - When staff/client interactions become too stressful, some participants noted they may remove themselves from the situation. If another staff is present, the participant may trade off positions with them. Otherwise the participant may just time out from the client altogether until the disruptive behaviour has subsided. Some participants may also avoid a problem client in a group situation and allow another staff to work with the client if there is a conflict of personalities.

If they’re doing something that’s not appropriate and it’s gets frustrating, I just refer that to another staff member, and let them deal with them, with the client. - Gary

Trading off with another staff member to take a time out from a client can allow a staff
member to defuse negative emotion that may affect decision making or work behaviour. Avoiding certain clients or removing oneself from certain situations also was also used as a strategy to avoid favouring clients overtly.

I do have my favorites as well, so you try to, you treat everybody as equally as you can. You try to give as much time to each individual. When we split up into groups, little groups, I tend to rotate myself around and not be with the same people all the time. - Gregory

This strategy, like self talk, also indicates an awareness in some participants that the staff/client interaction is clouding their decision space negatively, and they need to pull back and take care of themselves emotionally before re-engaging with the client and/or decisional situation.

**Boundary setting** - While the agency may offer guidelines or explicit policies about professional boundaries, some participants add their own standards of boundaries, usually according to what they are personally comfortable within the staff/client relationship.

Loretta is very firm on maintaining clear professional boundaries between her and clients, which she says the agency encourages and supports.

Well, they....I’ve been out with one girl, and she’ll run into someone she knows, and she would say, "This is my friend", and would say, "No, I’m actually the carer", and just to make sure that’s the basis that person is thinking of me.

Setting personal boundaries may help distance a participant from getting too emotionally close to a client, which could cloud the participant’s ability to effectively make decisions. Setting personal boundaries also may help demarcate parameters for forming decision spaces, and may help lessen ambiguity in particular decisional situations.

**Teamwork** - Teamwork would include previous themes such as soundboarding, and trading places with another staff when avoiding challenging client behaviours or
staff/client relationships. More crucial to the idea of teamwork is the sense of trust important to being able to perform one’s job with colleagues.

Tess spoke to the emotional toll of working with clients with ABI, and the trust and support of fellow staff used to cope with it.

I think we’re lucky as well in that the staff get on well. You know, we support each other as much as we can. You know, one staff member had a death in the family recently, and you know, I saw it as, I suppose a testament to the strength of our friendship and working relationship that he knew he could come and say to me, that he could come to me and say ‘ah look, I don’t feel very good’ so I’ve been able to pick up a bit for him, you know. If the clients have been getting a bit difficult, I thought, ok, well I’ll try and keep them away from him. I’ve had times when I’ve been really down, and he’s, you know, pretty much pulled my weight for me. It makes it easier to work with each other, I think, when you know you can trust the person that you’re working with, you know, while as if we didn’t work well together, it would be a lot harder to go to each other and say, ‘I’m having a really low day. I’ve had this happen, you know. I’m not functioning really well’ yeah, so it makes it easier I suppose to work together.

Tess describes a supportive environment between the staff, in which co-workers and clients are aware of personal staff issues outside the workplace, and are given more insight to what may be affecting a staff member’s mode, energy level, or decision making. This contrasts with the agencies in which personal information about staff is to be left outside the work environment. A trusting, supportive work environment may allow fellow staff to recognize when another staff may be having difficulties forming a clear decision space, or may help an individual staff to feel secure in asking for help when needed, rather than feeling they must carry the stress and responsibility of the job alone.

Seeking guidance - Akin to soundboarding, outside the formal mechanisms of staff meetings and scheduled supervision, staff may continue to seek guidance about how to deal with difficult decisional situations from supervisors or co-workers. Usually such guidance seeking is informal and casual, by means of asking for a moment of a colleague’s time to quickly discuss an issue and create some on the spot ideas for decision options.
Prioritizing - Prioritizing relates to hierarchies of values. The myriad of situations that can occur while a staff is working with a client can occasionally result in a conflict between two equally relevant principles or ideologies relevant to the ethic of practice. Often there are no clear cut directions as to what principle should take a higher precedence over another in any given situation, such as when the ethic of the client’s dignity of risk is against the ethic of the staff’s duty of care. Some participants spoke of how they prioritize for themselves what matters most to reduce the conflict between different principles or ideologies in the course of their work with clients.

Lois weighs the health risks to her client from smoking against the integrity of her relationship with the client.

I know she’s not supposed to smoke indoors ....and I think that we go for walks and I try and keep away from it, I try and keep her away from it as much as I can, so I think rather than hassle her and have me, I mean, I’m the only contact she has. I don’t want anything to stop that because she needs it. I try to take her for doctor visits and we arrange the doctor visits to be when I’m there, and it saves her husband having to take her, in the wheelchair and everything, and it also, she’s not allowed to smoke in the doctor’s surgery, so..I get around it that way in a lot of cases.

Lois mentions the importance of the relationship between herself and the client, since she is the client’s sole support person. Sometimes integrity of the relationship is more important that addressing client issues, such as the health risk of smoking. Lois deals with this by engaging the client in an incompatible behaviour - going to the doctor’s where the waiting room disallows smoking, rather than risk rupturing the interpersonal relationship in a conflict. She also speaks to the client about her feelings about her daughter smoking rather than confront the client directly about her own smoking.

Felicity attempts to apply a general principle to guide her prioritizing but recognizes that there are more exceptions that rules.

I’d be looking at probably a harm avoidance model. Ok, what harm is going to come to this person if I don’t do that? What harm is going to come to this person if I don’t do this? Who can, you know, is this person going to have a crisis if I don’t do that? If the answer is no, then the other things come ahead of it. So
yeah, harm, I think harm avoidance before harm minimization actually would sort of come into play there, and yeah, there’s no straight answers of them. You’d be juggling someone with an accommodation crisis with somebody with an eminent significant other relationship breakdown and where do you go there? Is it, is it the psychological distress of this or is it somebody out on the street, and where do you put that? Is that a referral on to somewhere else? Not that there is anybody to refer onto but, you know, it’s a real juggling act there.

Prioritizing is a direct effort by participants to lessen decisional ambiguity by establishing some parameters to their decision space and rank decisional outcome preferences.

**Chapter Summary**

The strategies reported in this chapter are the ways in which the interview participants implement their ethic of practice. The strategies they report or describe using have been presented to allow understanding of what is occurring in ABI outreach between these staff and their clients. These strategies are the results of a decisional process, and represent decisions the participants have made in how to process or navigate further through other particular decisional situations. Collectively, these strategies represent the modus operandi of staff practice for the interview participants.

These strategies are manifestations of the values and ethics the participants draw upon to decide the optimal course of action. Values underpin the manner in which staff may perform their jobs, how they may approach the client, how they may regard and make decisions (Elizur & Sagie, 1999; Schon, 1983; Zeira & Rosen, 2000). The level of awareness a staff has about their values and the influence of those values on their behaviour also affects the way a staff may perform their jobs (Corey, Corey, & Callanan, 1998; Worthley, 1999). Many of the informal strategies appear to have developed organically, with little direct awareness from staff regarding the nature of the strategies they are drawing upon. Some interview participants did articulate an awareness of the types and application of strategies, and seemed to harness this awareness to improve their own decision making skills. The next chapter will examine factors the participants feel impact upon their decisions.
**Chapter Seven**

**Forming the Decision Space: Factors that affect staff practice**

**Chapter Abstract**

This chapter looks at decision space factors particularly pertinent to the ABI outreach contexts, as nominated by the participants either directly or as revealed in their descriptions of and attitudes towards their work in ABI outreach. These factors are considered in terms of how they manifest in ABI outreach environments and how they potentially enable or restrict the selection of practice strategies by the participants. Instances of when participants were aware of their decision space being affected are noted, highlighting the role awareness plays in minimizing or harnessing decision space factor influence on decision making and the selection of practice strategies.

**Introduction**

In chapter three, the second half of the literature review, it was asked how best does a staff member apply a philosophy of client self-determined decision making to a person who has an impairment which may adversely affect autonomous decision making. In chapter five, it was established that there is an ethic of practice among the interviewed participants consisting of balancing the client’s autonomy/dignity of risk with the staff’s duty of care/principle of beneficence among the decision making strategies they used as discussed in chapter six. This chapter focuses on some factors which influence the formation of decision space and enable or restrict such strategies in the pursuit of the ethic of practice among the participants. The factors discussed in this chapter do not represent a comprehensive catalogue of every factor that potentially can influence the formation of one’s decision space. Rather, these decision space influences were elicited from the issues the participants either themselves raised in the interviews as important, or issues that I interpreted as being influential from their descriptions of decisional situations. The primacy of these issues and related decision space factors suggests the particular relevance they have specifically in an ABI outreach context for the participants interviewed in this study.

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Decision space, as established in chapter three, has been conceptualized throughout this thesis as a mental space in which a person considers and forecloses on options and resources that will bear on a decisional outcome (strategies). The themes of client independence/independence, clients as “others”, staff autonomy, valency (staff needs), emotional involvement/boundaries, and stress/burnout will be discussed in terms of how these issues may impact upon staff decision space, and affect which strategies are implemented at the practice level. Examples of strategies used from participant narratives will illustrate the relation between strategies and decision space factors. Firstly, though, consideration must also be extended to two additional decision space factors.

**Individual differences**

Shiloh, Koren, and Zakay (2001) state: “In natural decision situations, the decision space and structure are based on the decision maker’s subjective perceptions” (pg. 699). This is consistent with the literature presented in chapter three on decisional influences based on cognitive processes, such as bias, memory and heuristics. Shiloh, Koren, and Zakay (2001) note that decision making research in the past has tended to concentrate on how decision tasks are framed and how complex a decisional situation may be, while neglecting the role of individual differences. I cite their research here to highlight the fact that individual personalities and subjectivity do play a role in how individuals, such as those interviewed for this research, form decision space. However it is not my intention in this chapter, or in this research, to investigate the complex terrain of individual differences within the small sample of staff participants I interviewed. Rather, this chapter is focused on additional decision space factors which are pertinent to the context of ABI outreach that may play a role in forming decision space.

**Resource Access and Availability**

When asked directly, “What factors influence your decision making?, the first response from most of the participants related to tangible, resource related factors, such as time, money, weather, and/or if other staff were available to share duties. Further discussion revealed these responses were offered in consideration of decisions regarding surveying resources available for specific activities, usually recreational in nature. It is noted here
as factors that do affect the range and types of options available to the participants to engage in one activity choice over another.

For example, both Gregory and Lynette relayed tales of complicated and often long van routes they drove to supply clients with transportation to and from recreational events - a story I am well familiar with as I have endured the same many times myself when I coordinated recreational activities for an ABI agency. Logistical demands and needs of the clients, such as requiring transportation in order to be able to participate, constrain the amount of time that could be devoted to the actual activity, since part of the staff’s time would be used in transit to and from client’s home. This may also affect the choice of activity location, as driving to a more centralized location would cut down transit time and allow for more direct activity time, while driving further would lessen the amount of time clients’ could spend at the activity location. The remainder of the decision space factors elicited from the participants and discussed in this chapter are more specifically targeted at understanding intangible or conceptual influences that factor into which strategies are selected by the participants in pursuing their ethics of practice.

Values of independence/client autonomy among staff

A key factor that appeared to contribute to how the participants formed their decision space is the way they understood and regarded client independence and autonomy. The concept of independence has been contested between helping professionals and disability advocates. Reindal (1999) summarizes the debate:

Professionals tend to define independence in terms of self-care activities. So, independence is measured against skills in relation to performance of these activities. Disabled people however, define independence as an ability to be in control of and make decisions about one’s life. Independence is then not linked to doing things alone or without help, but by obtaining assistance when and how one requires it (pg. 353).

Messages about client independence and autonomy are mixed and ambiguous in ABI outreach. How a staff member interprets independence for their client will likely affect the strategy the staff uses to facilitate independence - whether it be in relation to
functional performance or decisional autonomy or a combination of both. The way
independence is understood by staff will also likely affect the types of decisions staff
make towards the client. As previously discussed in the literature review, client
autonomy for the individual with ABI is a complex area, due to client deficits in
executive cognitive functioning used in human decision making. Even staff who
recognize independence for the client as being able to make their own decisions will
face challenges to support this ideology with some clients with ABI.

Most of the interview participants said that teaching or encouraging independence was
one of the most important services they could provide to their clients. Tess described
facilitation of functional independence:

One particular client who will walk through the door and say ‘make me a
coffee’, and we’ll say to him, ‘go and make it yourself’. You know, we’ll carry
it back for him, because we know if he carries the cup back, he would have spilt
half the coffee all over his hands, but he’s capable of making it. So we’ll say,
‘you go and make it yourself and we’ll carry it back for you’. You know, or
even if it’s buying a movie ticket, for some of them, you know, they might
forget what movie they were going to see, so we’ll go with them, but get them to
ask for the movie ticket themselves.

Loretta emphasized several times that she felt developing and encouraging use of
independent skills was the most important aspect of her job, even though it would be
easier to do everything for the client. "Easy is not my job", she remarked. She explained
how the public’s misguided charity for people with disabilities can unwittingly undo
efforts to facilitate independent functioning. She described a common encounter when
she takes a couple of clients swimming at a community pool:

I have one client who lives in a nursing home, she’s only a young woman so
they dress her, because it’s quicker, and that was a skill she had that was really
good and it’s quite painful now, because it’s only once a week she dresses
herself, and I have people in the change rooms wanting to help, wondering why
I’m not helping. Even though I walk her through it like saying , ”Now come on,
I’ll put your legs in your pants, you have to do the rest.” And I have a fellow that
I take as well, so I use the excuse where I’ll say, "I’ll go an check on him, while
you put your undies on", and I’ll come back and some other woman has put her
undies on (laughs), and even some of them have said to me, you know, months
later, "I thought you were being mean"...the other people who are going to the
class, yeah, they think I’m being mean. And that’s something I’m always aware of, and so I will say things to the client, like, "Now you put your socks on because I know that you can," so that the other people will, you know, will take that cue, but I, quite often they don’t, and when I go out of the room they’ll come over and try to put her shoes on for her. So I find that hard.

This scenario illustrates the good intentions of others to help someone they see as in need can unintentionally deter someone from performing tasks independently. The value in charity or helping, seen as one form of beneficence by the member of the public in this example, undermines the ethic of client self-determination. Loretta’s use of redirection and suggestion to instruct the client to dress herself while Loretta excuses herself from the room acts as both a client cue, as well as a signal to others that the client is capable of dressing independently and just needs to the space and time to do so. This enables Loretta to maintain the ethic of teaching her client self-deterministic skills, while gently educating members of the public without direct confrontation or embarrassing herself, the well intentioned observer or the client.

Some interview participants recognize client independence as client autonomy, encouraging clients to make their own decisions. However, decision making itself is a type of functional activity. Many of the interview participants, like Kody, recognize that some clients with ABI may be overwhelmed by too many options to choose from, or may have difficulty in recognizing options. She referred to presenting limited options to facilitate client choice in routine, everyday situations.

I guess they’re encouraged to make decisions about where they want to go for their respite, and sometimes they find it so hard, because they have no idea what they want to do. So then there, they ultimately have to make the decision because we say to them "Well, you can either go to this place or go to that place", but they still have to make a decision. Like we might help them by making those choices smaller or something, not as many options.

This is an overlooked area in the disability advocacy literature, as was discussed in the literature review. Sherry (2002) writes that individuals with brain injury are marginalised in the social model of disability, while Willer and Corrigan (1994) note that independent living movements from which disability advocacy sprung were largely founded by people with physical disabilities. People with physical impairments (non-
head related) are unlikely to face the same type of decision making challenges as people with cognitive impairments. Phipps (2000) reminds us "individuals with cognitive related injuries, such as head trauma present along a broad continuum of disability/incapacity when it comes to decision making" (pg. 1184). So for staff working with clients with ABI, even encouraging client autonomy may still entail encouraging the functional skills of decision making.

Melanie seemed to combine understandings of independence as both functional skills and autonomous expression of interests and preferences.

I see that there is room for improvement always, and it depends on the consumer, how far they want to go..... It’s got a lot to do with their brain injury, how far they can go, but I just think there’s always potential to do more, and to learn more..... Just help them. Encourage them, push them that little bit. Don’t push them until they frustrated and annoyed with you (Laughs). Because that has happened on a few occasions. They’ve already have that ability to make decisions. So, it’s more to assist them to make them.....Give them the choices....yeah, give them..rather than giving them ten, try and narrow it down to two or three, because they, they could spend all day thinking about ten different things. Two or three, half an hour (laughs) Hopefully.

How a staff views client autonomy can affect decisions the staff makes towards the client. In Gregory’s narrative, clients who participated in selecting an activity for the group but then declined to participate in the activity when it came around were not forced to participate. For Gregory, this may be an example of respecting a client choice. For Loretta, however, learning to take responsibility for one’s choices was a more important lesson.

With something that’s been...decided on, a vote type thing before hand, like these activities, we tend to say, "Well, you guys voted on it, we said you were going, and that’s the activity, that’s how it is."....they need to take some responsibility, because they’ve suggested it, they voted.

Loretta may see the issue of taking responsibility for one’s choices as related to being able to make autonomous decisions and accepting the consequences of those decisions. In both of these situations, Gregory and Loretta are valuing the ethic of client
autonomy, yet their different interpretations of what autonomy entails (personal choice vs. personal responsibility) resulted in two different strategies in similar situations.

This was an issue I faced many times in my role as a recreation specialist, where much effort would go into planning and organizing events clients had suggested, and then some would decide on the day not to participate. In the most extreme example, one client would sometimes sign up for a dinner outing, in which he had to be picked up by the agency in the agency van, along with other clients, along a transportation route prior to the event. More than once, this client would tell the van driver when he arrived at the client’s apartment that he changed his mind and did not want to go. This was a problem in our scenario because if he had called to cancel, it would have avoided the driver going all the way out to his apartment, making other clients ride along, and extending the length of the pre event transportation. It also meant an extra seat on the agency van was lost to someone else who may have wanted to go but couldn’t sign up because all the seats were full.

I struggled with the issues of this client’s right to change his mind, and the complications changing his mind caused to the over all outing. There was also the recognition that the client suffered clinical depression and often made rash choices to isolate himself out of social insecurity. Sometimes, the client was told he had to attend, since he had booked the space and the driver, with other passengers, had already made the trip out to get him. Invariably, the client would enjoy himself on the outing and be glad he came. So I have had an empathy for the "hold clients to take responsibility for their choices" line of thought. As illustrated though, with some clients with brain injury, this is not a cut and dry solution, or approach. As much as I value personal autonomy, I recognize that I also value the responsibility that comes with choice. This ethic guided me to hold clients to their decisions more often than not.

Sometimes in adapting the coaching role, the goal to teach independent skills could bring up tension between encouraging new skills and activities with a client, and respecting client choices, especially if said choices were routinized. Violet saw this issue as partially stemming from the way the case manager programmed service plans
with the client, and expressed frustration with it:

I guess most of it was about them becoming independent, and increasing their independence, working on some skills..... I think sometimes it would have been healthy for the client to be able to explore other things. I think sometimes it got too much in to a ritualistic sort of pattern and behaviour.

This tension is similar to the dignity of risk versus duty of care dilemma, that of balancing respect for client choices and preferences versus developing a client’s repertoire of skills and functional independence.

In my own personal experience, I recognized and experienced conflict between therapeutic recreation ideology and self determination ideology of both the disability rights movement and contemporary leisure theories. On one side, my training and purpose was to use " treatment, education, and recreation to help people with illnesses, disabilities, and other conditions to develop and use their leisure in ways that enhance their health, functional abilities, and quality of life" (National Therapeutic Recreation Society, 2000). This is emblematic of a medical model approach, stemming from rational recreation approaches. That is, that a morality could be imposed on people through controlling their recreational choices, that there was a "right" way to use leisure. The logic of this approach infers that individuals who did not engage in leisure in the "right" way must not have known how to do so and therefore needed education.

On the other side is the self determination movement, which espouses that people with disabilities can make their own choices and those choices should be respected. This ideology is complimented by contemporary leisure theory that proposes an individual’s leisure is construed largely by the meaning an individual makes of the leisure experience, that there is no overriding definition or universal characteristics applicable to all people regarding how they perceive leisure (Samdahl, 1988). This takes a global view rather than the Eurocentric view which has been leveled at traditional definitions of leisure as being free time, freedom of choice, and pleasure. (Samdahl, 1988).
In this dilemma, the duty to educate and develop skills in clients is akin to the duty of care ethic. It espouses educating and developing skills in clients is in their best interest. Learning more skills, and having a wider repertoire of interests, will result in clients being able to live more independently and reap the health benefits of an active, diverse leisure lifestyle.

The self determinist ethic of respecting a client’s choices is akin to the dignity of risk. A client should not be pressured to make different choices when they have stated their preference. Respect of the individual’s choices is respect for the individual.

This may not be a conflict if the client has indicated he/she wishes to learn new skills and welcomes forays into learning new activities, or being exposed to new experiences. But what of the client content to remain with the same repertoire of skills and interest, even if such repertoire limits the client in his/her ability to function independently? There are additional complexities brought on by the sequella of brain injury, where symptoms such as lack of motivation, fatigue, impaired problem solving, overstimulation, and memory issues have a biological facet, and impair the processes of learning, self development, and independent (both physical and cognitive) functioning.

There is a strong drive in therapeutic professions to adapt the functioning definition of independence and for programming to sometimes be geared towards what is viewed as the best practice of increasing functional independence in the client. Violets’ narrative reveals her valuing of therapeutic definitions of independence, which influenced her approach towards the client.

One of the guys I worked with was in a similar, kept doing ten pin, and, I mean, he’s still doing ten pin. He hasn’t moved on from that, but, and it’s been tried to give him new ideas, things like that, but he’s been happy with the outcome of that, so I guess what’s been done in that situation is increase his, the amount of people who go with him, and have a variety of individuals go in with the hope that, the more different people, the more input they’ll have, and the more he’ll be swayed to do other things with those people. So I
guess it was taking a back, I guess another avenue in looking at changing, you know, what he wanted to do, and I think, that was again coming down to that’s what he felt comfortable with.

In this story, Violet balances what the client likes to do with an agenda to influence his activity choices through deliberate strategies to increase his social circle. Her reaction to the client "still doing ten pin" suggests a value disagreement with the client’s choice of activities.

Independence/Client Autonomy Summary

Independence is recognized in the literature as meaning both functional skills that can be performed without assistance (dressing oneself) and making autonomous decisions (choosing which movie to go see). However, decision making itself requires functional cognitive skills, and some clients with ABI demonstrate being unable to autonomously make their own decisions. The interview participants in this research rely on strategies, such as framing or limiting specific options to better facilitate client decisions, and create as many opportunities for the client to make his/her own choices. Some staff recognize a tension between client autonomy and staff authority, which may affect the strategy they chose to achieve their ethic of practice.

Viewing the Client as “Other”

In chapter two, the concept of otherness as related to disability was introduced. Otherness assumes that people with impairments are somehow qualitatively different from people without impairment and therefore should be regarded and approached differently, focusing on the differences between people rather than commonalities (Priestley, 1999; Wolfensberger, 1992).

Otherness is established by a dominant group determining the experiential and cultural norms. “Where this occurs the normalcy of the dominant group’s perspective leads alternate perspectives to be judged as deviant; to be characterised as ‘other’” (Priestley, 1999, pg. 28). Dominant groups establishing their perspective as the norm is also an interpretation of power in society (Lukes, 1972). As explored in the
contextual literature, the medical model of treatment and control is the dominant discourse of helping professions, legitimated by the high status accorded medical and helping professions in Western society. As medical model discourse and practices are taken to be the norm, so is viewing people with disabilities as ‘others’.

Several remarks across various narratives illustrate the pervading concept of otherness:

Just to treat (the clients) as a human being. Treat as normal as....I treat people the way I like to be treated myself if I was in their position, basically. That’s my philosophy. If I had a brain injury similar to theirs, I’d want to be treated in a humane way, encouraged to do as much as I can for myself. - Gregory

To be able to just, help them to be able to do the things they basically would like to do, you know, just as a normal person would like to be able to do, and to be there as an assistant to them in doing that. - Jeff

Usually the public is pretty good at saying, "no", you know, "back off" sort of thing, but a lot of the time, because the person has a disability, they seem to put up with a lot more behaviour than what they would from a normal person. - Melanie

The three remarks, from three different interview participants, each suggest the clients the staff work with are not normal, thus the reason why the client should be treated "as normal", meaning as if the client has the potential for normalcy but does not possess it. Other remarks suggested the related culture of tragedy (Priestley, 1999):

I think that’s probably a big reason why we keep things very joking and mucking around, because it helps you not to have to think about what they’ve really lost in their lives. Because I think, when you really sit down and think, you know, of the potential that they had, and you know, everything that they’ve lost for the rest of their lives, and not just them, but what their families have lost, and it’s a really sad, really heavy thing. And I find if I really sit and think about that sometimes, it gets to me. - Tess

Letting them be happy with themselves, because some of their lives are shit. Absolute crap. Nothing to live for, honestly, I think if they could do something about it, they would...... Often they’re very depressed. Most of them are on anti-depressants, but if they had the means, they’d do away with themselves, a lot of them would. Their life’s...we have people that can’t go to
the toilet, can’t eat, can’t speak, what are you there for? And I find that’s really...I don’t even really like working with those people because it just seems so futile. Why are they there? - Loretta

I mean, even though they’ve lost so much in their life, they still have got the ability to laugh and to be happy, and I think that is wonderful. I don’t know if I could be if I lost, you know, so much in my life and ended up with a disability. You know, I wonder if I’d end up in depression, suicidal, you know, and these guys are happier than most people I know... I don’t know how they do it. I don’t know how the carers do it, because I’d be the same, and as much as I , you know, don’t necessarily like abortion and things like that, and genetic engineering, and all that sort of stuff. If I had a child that , you know, wasn’t, it was still in that abortion stage and I knew that it had this disability, it would be a really hard decision not to abort, only because I see the..what happens. You know, you’ve got a whole lifetime....And it’s not just you, it’s your family, your friends, and the child....and as I said, it’s not just that I’m not into abortion, it really...that really makes me think twice. - Melanie

To these three participants, what has happened to the client is unimaginable, and ABI is responsible for devaluing some clients’ lives and worth.

While the comments may be regarded as off-handed or unintentional by interview participants, their presence supports the notion that ultimate power is the ability to prevent alternate options and ideas from being considered. The concept of otherness for some staff is at an unconscious level, having entered into their language and perspective as a conventional and appropriate way to regard clients. Some of the these staff have been socialized into the dominant discourse of helping professions, in which disability is embodied in the client, rendering the client ‘abnormal’ from the rest of the population and requiring intervention from staff to attain ‘normalcy’ (Wolfensberger, 1992). This in turn may have implications for the strategies selected in the ethic of practice if a participant views his/her purpose as helping to ‘normalize’ the client. This also raises the issue of what standard of normalcy is being used to redirect client behaviour.

I must admit to my own initial perspectives of clients as others and believing the culture of tragedy. Now, my own observations into my perceptions of otherness is my allowance and acceptance that fear of difference may be of “difference” itself,
regardless if difference is through impairment or disability. If I were born with an impairment and had known it all my life, would I be afraid of becoming “abled”? Or would I fear changes and difference in the life I had known? Moving beyond viewing clients as others, I have begun to see my role not as trying to help clients attain my subjective standard of ‘normalcy’, but rather as being receptive to what the client views as normal for his/herself, even if it is different from my view of normal.

The Client as “Other” Summary
Some of the participants used language and phrases that portray and reinforce the notion of clients as others, qualitatively different from themselves, and yet do not recognize that they make this differentiation or express awareness about the potential implications such a differentiation may have upon their ethic of practice. This is another example of the relevance of staff awareness to one’s work and relationships with clients. I observed that my own awareness of alternative discourses to “otherness”, and awareness of how my perceptions of the”otherness” of clients affected the way I approached my role as an outreach worker. This awareness of viewing clients as “others” was not present in at least half of the participants I interviewed, despite their stated beliefs of treating clients equally and being client centred in their work.

Staff Autonomy
Staff autonomy in ABI outreach environments is also a factor in the formation of a staff’s decision space. In the experiences of the interview participants, it seems as though the amount of freedom and direction staff have in their work affects the strategies they decide to use in their ethic of practice. Interview participants’ attitudes towards their own work autonomy level also seemed to factor into their decision space.

I was very interested in exploring the autonomous nature of the participants’ practice in outreach environments. Having greater autonomy in one’s work is usually regarded as desirable, and has surfaced in research as one of the elements contributing to staff satisfaction at work (Blegen, 1993; Knox and Irving, 1997). Yet,
there is an absence in both the general helping profession literature as well as the ABI specific literature of addressing the nature of autonomous work environments, the understandings staff have of such contexts, or the influence working autonomously has on a staff member’s decision space and practice strategies. I asked the interview participants in this research to speak about their autonomy, how they felt about it, and the freedoms and limits they had within it.

One on one front line work in a client’s home or on a community outing is the most autonomous of all outreach situations. Lois feels she has a fair amount of autonomy in deciding how she conducts her work with the client, using both formal guidelines from the agency to establish boundaries as well as setting informal boundaries in her relationship with the client. She feels free to consult her supervisors (seeking guidance) to make adjustments to the boundaries. She gave the example of allowing the client she works with to have her home phone number.

They know at the agency, I’ve told them, sometimes she just wants to ring me when she’s upset. She doesn’t keep me on the phone long, it’s not like it’s a big problem and encroaches on my personal life, so I’ve said that’s OK, and it doesn’t happen often anyway.

Lois gave the illustration of being able to make a personal choice in her work about how available she wishes to make herself to the client beyond the responsibilities of her job. Her story also speaks to being able to make a decision to engage in an action she feels is in the best interest of the client, even if that action is contrary to traditional policies in helping professions (rule bending), such as giving personal contact details to a client. Lois seeks guidance regarding the overarching boundaries of her duties specified to her by supervisors to give her a framework to work within, particularly as it relates to her own personal space and sense of comfort:

I know what I’m, what I have to do and what I don’t, and you know if your space is being threatened, you know you’ve got the right to say, "No", you know. "Really, it’s not working doing that," and I would say if her phone calls were encroaching on my personal life, I would say "well, look it’s just not...it’s in the guidelines", I would bring that up and say "Well, it’s not part of what I’ve got to do and I’ve got other commitments at home that don’t allow me the freedom to do that." But, yeah, I do know the guidelines, and I
feel that if we don’t follow them strictly we get around them the best way we can.

Lois demonstrated an understanding of agency policies as a tool she can use to justify her actions or decisions with clients. Referring to a policy as the reason for a decision can deflect potential emotional fallout if the decision is not popular with the client. Her statement about rule bending contrasts this understanding and touches on the theme of staff values and decisions conflicting with agency values and policies. In this instance, guidelines are signposts that can be observed or evaded. Lois is open with her supervisors about her preferred alternatives to the guidelines. The agency’s favorable response to Lois’s arrangement with the client suggests an open, flexible communication between Lois and her supervisors.

Violet did not view her position as having much autonomy when in the field with a client:

It was very much guided by the case worker as to what, I mean, you were out there in the community, you’re obviously doing the work, so, but it was very much, very specific as to what your goal was and what you were to achieve...I think sometimes it would have been healthy for the client to be able to explore other things. I think sometimes it got too much in to a ritualistic sort of pattern and behaviour.

Violet said she did not have any conflicts with the case manager over disagreements on goals for the client, but she also felt the issue was not open for discussion with the case manager. She expressed wanting to have had more input and freedom into the types of goals she would work on with clients, while acknowledging that there was freedom in terms of how to implement strategies with the client, strategies developed in consultation with the case worker.

Lynette, who runs a recreational group, presented a similar view in her narrative, though she did not demonstrate a conscious awareness of it. When asked about her autonomy and freedom in the types of decisions she makes in her work, Lynette first responded, "I think I’ve got absolute freedom". She explained that she had "no problem" confronting clients if they intruded on her personal space, or if she had to
take action to cease a particular client behaviour that upset her, such as one client predicting a negative future for Lynette. "I had no problem writing him a letter back saying I don’t want to know my future because it’s too upsetting for me", she reported.

Later in the interview, when asked if there were decisions she had to make but did not like to, her response was, "I’m not on that top rung. I’m not the boss, and I’m not a client. I just have to go with it, I don’t really get to make decisions... I just go along.” This response seems to indicate Lynette feels little freedom about the content of the activities she facilitates with the recreation group.

How a staff perceives their autonomy level in their work may depend on what level the staff feels they should be able to act autonomously. Lois reflected on her autonomy at the interaction level with the client while Violet reflects on her autonomy in goal setting with the client. Echoing Violet’s responses about job autonomy, the degree of freedom perceived by Lynette seemed to be related to the level at which she is evaluating her autonomy. Where interview participants may have felt limited in their parameters of autonomy, they may also have perceived limitation as to which strategies were available to them in their practice ethic.

Gregory is the coordinator of his recreation group as well as a direct facilitator of the activities he does with the clients. In regards to how much autonomy and freedom he held in his position, he replied, "Quite a lot. More then I’m probably allocated (laughs)". A series of managerial turnovers at his agency left Gregory without consistent supervision for several years. He grew more autonomous in his decision making by necessity. A recently installed manager had requested Gregory report to her prior to making decisions. He remarked, "I’m finding that a bit difficult at times, but she sort of backs me up when I do make decisions anyway". He elaborated that autonomy is necessary when working in isolated, or decentred contexts:

I quite like the autonomy, especially, it has to be that way because we are, we do run an out of hours service, and we are away from the centre quite a lot. We do have access to a bus and we tend to go out a lot so you tend to think
on your feet and make decisions as you go along.

Jennings and Wattam (1994) state that an advantage of decentralizing decision making powers from administrators to front line workers is "enabling decisions to be made much closer to the operational level of work, where questions of both information and implementation can best be addressed" (pg. 73). Gregory illustrated this point in his narrative:

Just an example, we’re only supposed to work eight hours on a Saturday and it would come down from management, who work out with business management degrees with no actually hands on contact working with people with disabilities, that our rate, our...the staff’s eight hour period was to be the whole group time as well, so that means that the clients were only getting a period of up to four hours for their group time instead of the eight hours when I first started, because we were picking them up before the group started and then doing drop offs in the afternoon after the group time, so the group were getting the full eight hours or near enough to the eight hours group time. Because management made this decision that we could only work eight hours on Saturday, we were having to do the pick ups within that eight hours, and the drop offs within that eight hours.

Gregory’s story points out that his managers did not factor in how long it took staff to collect and transport clients to and from activities, so direct activity time would be shortened by transportation time if staff were to strictly work for only eight hours. Gregory’s perspective and proximity to the clients allowed him to see how staff time was being spent with the client, whereas management was making a decision based on the number of hours a staff was working, and thus how much that staff was having to be paid for their time. The difference in policy decision between Gregory and management partially illustrates the difference in decision spaces each staff member has access to based on their position, perspective and autonomy within the organization. The difference in decision spaces resulted in different practice ethic strategies being favoured by each.

Loretta echoes Gregory’s assertion about management not being in the best position to decide how activities should be run with clients: "...sometimes the bosses aren’t that aware, they’re not the people who go out daily, or they don’t really know what those clients would really like..." Loretta works in a group home, where she is not
totally isolated physically from other staff. She recognized and appreciated the autonomy she has in her work context, in terms of being able to make autonomous judgements.

With in house people, if like today, I said, "well how ‘bout we go to the park and have a barbie", well, they all thought that was a great idea so off we went, and that’s great...... it’s good that you can do that, or....once you get to know the people, you get to know the sorts of things they like.

Autonomy in this situation does not mean Loretta holds all decision responsibility. She explained that decisions in the house are made using consultation strategies with the clients, drawing upon their input to decide what activities the group agrees upon. Loretta’s autonomy allows her to use suggestion, to decide the manner in which she facilitates activities and group decision processes, and if necessary, allows her to intervene (distract/redirect/negotiate) if the group seems to making a choice that is unfeasible. "Some of them are totally unrealistic, there is no wheelchair access, it can’t happen." Autonomy allows Loretta to be flexible and responsive to situations as they present.

Alexia and Jane also described their autonomy not as necessarily meaning they must make decisions in isolation, but rather they have the autonomy to consult with fellow staff (teamwork) to assist with decisions. As Jane explained:

I have a fair bit of autonomy, really because it’s a sole position, and, but having said that, as a team we discuss clients on a weekly basis, so anything that we’re uncertain about or that we have issues about, we bring to the team and chuck some ideas around and we do that informally during the week as well, over lunch and all sorts of things, so, yeah. I mean, I mean, the decisions I feel comfortable about have a lot of autonomy.

Alexia utilizes teamwork, seeking guidance, and uses both formal boundaries as well as personal boundaries in establishing decision space with her autonomy. She feels no one has ever interfered with how she does her job, but finds many people make suggestions, and she doesn’t "get offended" at her colleagues doing so. She feels her boundaries of responsibility are outlined pretty clearly. Alexia does not feel there is an air of things that she can and cannot do, but that some boundaries just seem
obvious. She also feels comfortable that responsibility in the agency is shared, and if she is not present, other co-workers can handle situations with clients that she may work with.

Jeff described taking ownership for his in-the-field decisions: "Ok, we’re out in the community, pretty well the decision has to be ours. What we do, and based on what it is the person wants to do." Jeff maintains a close communication with his supervisors regarding what types of decisions he can and cannot make when working with clients (seeking guidance, boundary setting). Anything he is not sure about, he may either call the agency from the field to seek advice from supervisors, or may defer the activity with the client until a later time, after permission is sought from key stakeholders. In particular, Jeff seems to seek guidance mostly on issues with clients that concern their personal safety, and tends to decide against personally facilitating activities outside his own personal boundaries.

I mean if they wanted there all of the sudden start rock climbing, but they’ve never done in their life before, well, obviously then, we would have to try and explain to them, "Ok, the decision is no, we’re not going, but we will talk about this later on. We will refer it back to the respite planner, and they will have a talk to you about it, and it may be something we then look at at a later date, or another arrangement." But, like a bit of cold turkey, you know, want to do a bit of rock climbing, then ok, perhaps a decision we’ve got to take then and there that it doesn’t happen, or you’re saying if anybody, you know, that was walking along the beach and all of the sudden decided that they wanted to go in swimming and they’re prepared to go in their underpants and you’re not prepared to go in yours, well then you may have to make the decision, "ok, look, we don’t go in swimming. We’re not going in swimming, we’re actually going to continue our walk. If we don’t, well then we go back, back to your home."

This is similar to Lynette’s assertion about her comfort with defining her personal boundaries with clients, and the freedom she is given in her role to do so. Some interview participants seemed to utilize deferring decisions or responsibility for decision outcomes to a higher authority, such as their supervisor or agency policies, particularly where the decision may be contentious or unpopular with the client. For Loretta, this reflects a concern about personal liability:
If I don’t go by their guidelines, if I’ve made up a rule of my own...so I won’t do that, and if it was really something tricky, well, I’d probably just ring back to the office and say, "Well, what do you reckon about this?" because I’m ...I just want to what work tells me to do. If I have a problem with the way, with their decision, well then I’ll talk to them about it, but I’m not about to change it without running it by them. To me, it’s too dangerous.

Lynette cited using agency rules and policy to establish a level of safety and equity among clients:

Some clients like to push themselves, we say, No, it’s against the rules, you can’t do that. Or some clients would be perfectly safe doing it, other clients would be quite risky doing it, so we have to try and keep that consistency, no one can do it.

She refers to a higher authority, her supervisor, for contentious issues or conflicts with clients. When asked about client grievances, Lynette says, "Usually, my supervisor would handle it".

Sometimes, deferring the decisional outcome to a higher authority is done in order to preserve the integrity of the therapeutic relationship between the staff and client. Having another staff with higher authority play ‘bad cop’ deflects potential negative feelings the client may have if the decision is unpopular with him/her. Kody reflected back on an incident where a client refused to shower while away on a summer camp. Kody said she would now handle the situation differently:

....to even move it away from me as being in that line of fire and maybe get...tell her that, "Well you have to go and talk to the camp organizer" and sort of like take that off me, that load, so then the camp organizer is the one that comes down the heavy and say, "And this what has to happen".....

Diverting the conflict to a higher authority, such as the camp director, would allow Kody to maintain a more positive relationship with the client. Even if the camp director upsets the client by imposing rules, his relationship with the client is temporary and not as substantial as the one Kody must maintain as a support worker for the client. The camp director may also be viewed by the client as having a different authority than Kody, and his directives may take on a different meaning for
In each of these narratives, autonomy is not used by everyone to make their own decisions about clients, but can also be the freedom to defer the decision making process, and responsibility to someone else.

Kody finds the policies of her agency very useful in forming her decision space regarding clients and families:

....she was ringing, and the carer was ringing and wanting me to make a referral to the mental health team, which I said I would do but I wouldn’t do it straight away, I couldn’t do it straight away, and that was one of the strategies that we put in place anyway, to not respond straight away to any crisis now, but to leave it for four days, because without fail, you put all this stuff in place and then in four days time, it would have passed and they don’t need it anymore....

I don’t want to just stop a service altogether. Like, I hate that. But, and we’ve had to do it with some of the nursing home consumers, because they’re not, they’re not in our funding guidelines anymore, so, I’ve had to stop services there. But because it been cut it’s been alright, like I can just say, "It’s not in our funding guidelines, we can’t do it"

If they want a particular support worker to come every week, but we say, "We’ve got a policy now that it has to be a rotation thing of all support workers so there’s no dependency issues", that’s a really important thing. Sometimes the families aren’t as happy about that, but you just think, well that’s how it is.

This seems to suggest a trust in agency policies to address potentially contentious or ethical issues with clients. The policies provide a clear line demarking limits in what could be ambiguous territory for a staff to wade through. For Kody, this, combined with her own experience, seems to give her more assurance and confidence in selecting practice strategies.

Gary expressed that he feels he has a lot of freedom in his work with clients, but was unable to offer any examples of his own autonomous decision making in client interactions. His responses were often contradictory, such as first responding that he had made an individual decision regarding a client’s safety. Then, when asked to elaborate, he replied:
Like, some clients want to do things like rock climbing, or something like that, and we might not have the right amount of staff available for one on one.

*(I ask: And so how is that resolved? Are you able to come to a conclusion?)*

They have, that place has trained staff and they’re able to help out with the clients.

Gary always referred to group decision making processes ("we", or "they") when offering examples. On several questions specific to decision making, Gary did not reply at all or only said "No", indicating either a lack of understanding of the question, an unwillingness to answer, an inability to articulate or lack of decision making autonomy in his work. I interpreted from these responses that Gary does not hold much, if any, individual decision making responsibility in his job role, based on other information he shared about his work environment and experience. He stated he never works one on one with any client, and that all decisions are made by senior staff or supervisors. He says his job duties are regimented for him, which he prefers as it makes his job easier. Gary is content with this arrangement, as it lifts direct responsibility away from him. He seems to view his work as uncomplicated. For Gary, decision space is largely defined for him, as are which strategies he should select in his practice ethic.

In contrast to the positives of staff autonomy, Felicity expressed frustration over the disadvantages of too much autonomy and freedom in her case management work, namely increasing workloads due to undefined role boundaries.

I can see the need and I think somebody needs to fill that but there’s no boundary that says "ok, well, this is where our service stops and this is where somebody needs, somebody else needs to be called in to assist"..... I don’t mind doing the work, there’s times where you can see you’re doing more than what you should be, or ought to be, or maybe that other people are doing, but that’s, pardon me, at this stage, a very personal decision that actually rests with the individual case managers of our unit, which probably does create extra stress for some people......then I look at that too, and I say, "but if I didn’t do that, I’d lie awake at night thinking I wonder whether they’re ok".

Here, the lack of definable boundaries overwhelm the staff member with too many options and strategies to select from. Shiloh, Koren, and Zakay (2001) note from the
literature that:

decisions with more alternatives and attributes were evaluated by decision makers as more difficult (Timmermans & Vlek, 1992), and contributed to physiologocal and self-reported measures of stress (Paterson & Neufeld, 1995)(pg. 700).

Jane expressed the same frustration and recognition that too many variables and situational factors preclude being able to determine definitive decisional boundaries:

Sometimes I’d like a policy and procedure that says, "In this situation you do that, and in this situation-" but we can’t, there’s not, you know, you just can’t have that for every situation. Every person is different. Yeah, I mean, sometimes it would be really use, really useful to have a checklist, yes, yes, yes, yes, no, no, yes...but the fact of the matter is, you’re not going to have one of those for every body, you know.

Kody’s autonomy is related to her position being one that was created from scratch, rather than adhering to a previously established mid management role. While creating a new job role in a new agency allows her freedom to decide her boundaries, she expressed similar difficulties with that freedom as did Felicity:

I can see that there are big gaps where this family will pull you in all the time, to try and do stuff for them, and you can find yourself getting caught up in things that aren’t even to do with respite..... So I guess there are decisions there where, for me it was making a decision not to get caught up in that....I’ve learned to put some pretty clear boundaries up, which I’ve had to do. See otherwise you get swallowed up.

Both Kody’s and Felicity’s concerns about being "swallowed up" by their work touches on the theme of how staff care for themselves in their jobs, which is of relevant consideration, as emotionally or psychologically stressed staff can be more damaging than helpful to clients in helping professions (Corey, Corey, & Callanan, 1998).

As seeking guidance and using formal established boundaries seemed to be common strategy selections used by the participants to help define their decision space, it is important to consider how supervisors may supervise autonomous decisions made by
front line workers in the field. Melanie states she has a lot of faith in her employees, having been a front line worker once herself and understanding the inherent responsibility in the job. Each of the mid managers interviewed cited client and staff feedback (seeking information/consultation/debriefing/teamwork) as important to monitoring the work the front line staff member is performing. Karen described the process:

I’m constantly checking with consumers, family members, and the person, and the support worker to see what’s happening. How are goals being reached, because in most cases, the workers are put in to undertake a specific activity or a specific role with that person, so I do check with the consumer, "How’s it going, you know? Do you feel that the support worker’s interacting appropriately with you? Is there anything you don’t like about the worker or the activity?" That sort of thing. We also have yearly reviews from a service perspective where, we ask all consumers that have a support worker to complete appraisal forms on their workers, where we ask questions like, you know, does the worker turn up on time? Do they speak appropriately with you? What happens when you make a decision? Who makes the decisions while they’re out? All that sort of thing. And we check informally with the family continually as well.

Another part of Karen’s supervisory role is helping staff become aware of how they are performing autonomously.

I have seen instances where people, with a negative attitude towards someone, struggle, I guess, to keep an objective.....With support workers, if it’s someone who I’m supervising, most definitely, I will bring it up, you know. It might be, "Look, I’ve noticed that this has happened when you’ve worked with this person. Is it an issue for you? Let’s look at what the situation was?" Talk about strategies in dealing with it, maybe it’s the worker that’s actually struggled with ideas on how to work with that person, and give the support worker the option, and the consumer, the option, of finding a new worker.

Felicity holds different views on how generalist front line workers may handle autonomy. She has experienced a tendency for some front line workers to depend on the guidance and authority of professionals or case managers, and in turn, letting the higher positions staff take responsibility for what occur at the front lines, as was discussed previously as deferring decisions to a higher authority:

I think that...because they haven’t got a therapy or a discipline, that they are perceiving themselves ...how would you put it?...underneath us in the pecking
order for want of a better way of putting it. Right, so, in a hierarchy, underneath, and therefore they don’t have any responsibilities, or they have fewer responsibilities, and they’re quite happy to shove things back up the line, and I think from our point of view...that hasn’t been particularly helpful...They see a problem, "ah, I’m not going to deal with that, that’s your responsibility"......I don’t think they handle the autonomy of the job (laughs)

This reflects an interpretation that autonomy should be regarding as taking responsibility for forming one’s own decision space and strategies used in practice.

I had a fair amount of autonomy in my work, though I was supervised by an administrator responsible for overseeing the various services provided by the agency. The autonomy and freedom were desirable for the ability it offered to let me make decisions I felt were in the best interests of the clients and programs I was responsible for. However, I also struggled with the issue of job boundaries and defining what was my responsibility in my position and what was not. It was the type of the job that could explode into total involvement in every aspect of the client’s life if one let it.

I felt I was also in a unique situation not faced by other specialized professionals in that my field was recreation and leisure, concepts that mean many different things to different people. Part of the difficulty in defining limits to my work content was related to the difficulty in defining the meaning of leisure and recreation in general. If the symbolic interactions approach is embraced in regard to leisure and recreation, which partially contends that leisure is whatever the person pursuing it deems it to be, then it was feasible that almost any human endeavour could be considered in my domain of responsibility towards clients.

Staff Autonomy Summary
Given the socially sanctioned power position staff hold, how staff implement practice strategies in autonomous environments needs to be investigated to monitor staff/client power dynamics in ABI outreach. The narratives illustrate that autonomy is viewed differently across the interview participants. How a participant sees their freedom of autonomy in their work seems to have a relation to the level of responsibility at which they consider their autonomy. Concern for how to balance autonomy and boundaries
seems to be a challenging issue where autonomy is interpreted as meaning taking responsibility for one’s decision space and selection of practice strategies. Even in positions of relative freedom, agency policies and established boundaries have been used to form decision space and select practice strategies. Perceived limits to autonomy may also contribute to perceived limits to strategies available for participants to use in their ethic of practice.

**Valency- Staff needs versus Client needs**

Gregory stated, “We are all individuals and we’re not robots.” We are as complex and varied as the clients we support. This includes staff having their own needs. Despite any efforts to leave one’s personal life at the door, as Tess remarked, it is unlikely that it is possible for anyone working in the helping professions to abandon their personality when entering the workplace and interacting with clients. Corey, Corey, and Callanan (1998) support this notion in their discussion on personal values and needs of helpers in helping professions. "A counselor’s beliefs, personal attributes, and ways of living inevitably influences the way he or she functions as a professional“ (pg. 34). "Counselor" can be interpreted in the wide context of any therapeutic relationship where a helper and client engage with each other in order to promote the client’s interests and support the client’s needs.

Why someone chooses a particular line of work is termed valency. Bion (1961, cited in Roberts, 1994) wrote of the concept of valency as it related to underlying psychological dispositions that explained an individual’s attraction and reactions to particular group behaviours. The concept has been widened to include valency as an understanding of the latent psychological needs in an individual which draw them towards a particular occupation (Roberts, 1994). This sense of valency is heightened in helping professions where psychological defenses and projections are engaged by both the client and the staff member. As Roberts states:

> To understand, and therefore to be able to help another person requires a capacity for empathy: to stand momentarily in the other’s shoes and experience their pain, using what one has learned as a guide as to how best to respond. ..... It is therefore of the greatest importance for helping professionals to have some insight into their reasons for choosing the
particular kind of work or setting in which they find themselves, and awareness of their specific blind spots: their valency for certain kinds of defenses and their vulnerability to particular kinds of projective identification (1994, pg 117-118).

Corey, Corey & Callanan concur, emphasizing the critical impact valency may have on the power position of staff:

When therapists are not sufficiently aware of their own needs, they may abuse the power they have in the therapeutic situation. Some counselors gain a sense of power by assuming the role of directing others toward solutions instead of encouraging them to seek alternatives for themselves. A solution oriented approach to counseling may also spring from the therapist’s need to feel a sense of achievement and accomplishment (1998, pg. 35).

There was one interview participant who described a few scenarios which seemed to illustrate tension between his own needs as staff and that of the clients, with implications for how practice strategies were selected.

Jeff recognized there is an element of power to his role, though he sees it more attributed to client passivity than staff status.

Because they all have different personalities, as same as, well anybody has a personality, and some are just so easy to get on with, you know, you could just suggest anything to them, and they’d be quite happy, you know, to turn around and do them. Some are a little headstrong, and want to virtually do things their way, or not your way, the case may be.

The client’s "way" versus the staff’s "way" came up specifically when Jeff spoke to one of the negotiation situation he encounters with clients.

Sometimes people don’t like to go to bed (laughs) at a reasonable hour, and they’re still stuck out. I mean, we start work at a certain time and we do a sleep over, but you’re not paid for the whole time that you’re there, so obviously you, just any person, don’t want to be up, you know, all hours of the night when you can be, you know, having a bit of a rest, but you don’t want to be getting there and you know, after three hours later, a person decides that they’re not gonna go to bed because the next morning they can have the sleep in but you’ve got to be up to knock off the shift, or to at least be up if there’s other people in to get their breakfast and everything, ready and everything, and, that can be a bit unpopular sometimes when you try and talk people, "Ok, look. Time to lock up".
This scenario illustrates one of the complexities of supporting clients in a residential or respite service, which was discussed in the literature review as the ambiguity of mixing work contexts and home environments in outreach. For the clients, the environment is their home. In our own homes, an issue such as what time we decide to go to bed is a self determined behaviour and something most people would probably argue is our right to decide. However, for staff, the house is a place of work, and in Jeff’s narrative, his responsibilities towards shift duties and concern with paid compensation for his work override the client’s self chosen bedtime. Jeff is exercising his staff status in using redirection, enforcing a bedtime for the client, legitimized by his role. Clients socialized into the norm of doing what staff tells them do not question this practice, and it seems neither does Jeff, who expresses no concern about impinging on client autonomy. This is not a failing of character on Jeff’s part, but rather a symptom of both the medical model approach to helping professions, as well as the decision space limitations imposed by juggling limited resources and multiple responsibilities. Because staff are viewed as having authority by clients and by society at large, that authority becomes genuine, and is used.

Lynette described a situation where she felt one client’s privately hired paid attendant may be abusing her status as a carer to meet her own needs over the client’s by forcing the client to go on community outings with the recreation group:

And I think in some cases, they’ve got carers at home that come, like live in paid carers, that will come to their home, and in one case in particular, I think, our client is pushed to go so that that person gets time off for the day or whatever...but, they’re a paid carer so that’s their job to be at home. So I think it’s really hard, it’s hard for this one person. But other clients pick and choose their outing. He sorta gets pushed in a bit.

It is possible the staff’s desire for respite overrides the client being able to determine his own leisure pursuits. While Lynette expresses concern about this contingency, she does not explore it further due to her uncertainty if a client’s grievances are legitimate or due to personality/brain injury factors. “I never know when it’s because of their brain injury or when it’s because of their personality, and I don’t try and separate it,” she says.
In asking interview participants what personal satisfaction they got from their work, several said the client contact and camaraderie was the most satisfying aspect of their jobs, others said it was “seeing people do something they never thought they would do”, or “thinking you may have helped someone”. For Karen, it is a combination of both:

Most satisfying aspect....probably the enjoyment I get out of just the personal contact with people. Working with people, and personally, I get a real buzz when people achieve something that they wanted to do. Like I said, it might not be the end goal, but they’re feeling a sense of value and a sense of achievement, that what they’ve done is worthwhile. Yeah, that’s probably my biggest motivation, is to see that.

Personal needs to achieve these satisfiers could play a role in how the participants choose strategies. In a seemingly unrewarding situation, where progress or goal attainment is not apparent, Lois attempts to fill her own need to feel useful in her work by seeking opportunities to provide help where she can and to see where her input has "made a difference".

It makes it more rewarding, the job’s a bit more rewarding because I think I’m making a difference somewhere, yet I haven’t got a lot of influence over the things they really need, you know, like the health and that, but for their living conditions, I guess...yeah, her husband might go through the budget of what he can afford and what he can’t, and I’ll say, well what about, do you really need that this week, and you could get that, you know, and sort of help them out.

Nicole pointed out the frustration of not being able to know conclusively if her involvement with the client has made any difference:

...Because so many things change over time, their, their parents might separate or they might have changed schools, or they might have changed teachers, or you know, so many thing, it’s often hard to, because there’s so many different factors to know how successful, and to know whether, what you’ve been responsible for, like I just went out and saw one child and he made *beautiful* improvements but it’s because they changed his medication. It had nothing to do with me (laughs). I’d like to, I’d like to have said, "I did that.".... it’s so hard to know whether they’ve improved because developmentally they’ve improved and they would have done that anyway, or if it’s something that, it’s because you’ve educated the teacher about brain
injury, and they’ve changed their teaching strategies, or you’ve talked to the parent about ways of prompting and they’ve changed their, how they, you know, prompt them in the mornings to get ready.

I sometimes wondered if a staff may have need for approval from clients or families, which in turn may have affected his/her practice strategies, such as occasionally rule bending to gain a favorable response.

That’s the thing that was so good in my job right? We were constantly given this great feedback, because the service was new, and they’re getting respite, it was like they were all so appreciative of it. It was like, it’s lovely feedback all the time. So that was really good...... I find that really good, like especially going out, maybe doing a review and the families are so happy to see you, and...I just love all of that. - Kody

Valency/Staff Needs Summary
Valency is the presumption that we are drawn to particular occupations by our psychological needs, often unbeknown to ourselves. We may not readily recognise that we feel a need to have approval, to control a situation or other people, or to take care of others. These are needs which may be met by our work in helping professions, but to be unaware of our own needs may improperly influence the ethic of practice with clients. This may range from trying to please the client in a conflict, to exercising our staff authority over a client’s autonomy to control a situation so that it satisfies our preferences over those of the client’s. This is a key point in recognizing the role awareness may play in negotiating these various needs and values. Strategies selected based on staff needs over client needs are manifestations of greater value being placed on the staff’s valency. It illustrates the use of staff power in the therapeutic relationship to achieve the staff’s desired end, and suggest that self awareness of one’s valency or predilection for particular outcomes may affect decision space formation.

Emotional involvement - Staff/Client boundaries
Another theme that clouds decisional clarity and may contribute to value conflicts is emotional involvement with clients. Ponsford (1995) in her description of attendant carers states: “Above all, an attendant carer may become an important friend to the TBI individual, actively assisting them to reestablished previous activities or social
contacts, or establish new ones” (pg. 202).

Ponsford’s use of the word “friend” is consistent with McClusky’s (2000) use of the term to describe one of the roles a staff may fulfill in his/her relationship with the client. Yet, the role of friend may be illusory, since any friendship qualities of the staff-client relationship are not naturally formed, nor based on mutual attraction and reciprocity, as typical true friendships are (Duck, 1977; Rubin, 1985). It is important to remember that staff are paid to fulfill their roles, whereas we do not pay our friends to be our friends. It is in this consideration that I interpret the term as being used by Ponsford and McCluskey euphemistically to connote a relationship with friendship-like features, but not necessarily to indicate true friendships between staff and clients. This distinction is significant to remember when exploring the interview participants’ emotional involvement with clients, and the ideology of maintaining a professional distance when working with clients. This easily is one of the most blurred areas of personal boundaries in helping profession work, since staff/client interactions can emulate friendship interactions (Corey, Corey, & Callanan, 1998; Wegener, 1996). Awareness of one’s feelings for a client and how it impacts their decision space is another relevant point in examining the significance of staff awareness in ABI outreach contexts.

It is very difficult to work day in and day out with the same people, often participating in recreational, vocational, domestic, and educational activities together, and not develop some form of feelings for the other person. Maslach (1978) observed that “providers of human services are usually required to work intensely and intimately with people on a large scale, continuous basis” (pg. 112), which is part of the reason for high stress in helping professions. Wegener (1996) writes of these close relationships, “These emotional connections and this affectively charged interaction provide a unique context for the development of ethical dilemmas,” (pg. 5).

Traditionally, staff in helping professions have been socialized into maintaining definitive boundaries between themselves and clients. This has been seen as
necessary to protect both the client and staff from unethical transgressions in the therapeutic relationship (Corey, Corey & Callanan, 1998; Freud and Krug, 2002a&b). Usually, such boundary setting has been explicitly addressed towards issues such as prohibiting dual relationships or sexual involvements with clients. These limitations are intended to avoid or minimize clients being taken advantage of, to prevent creating emotionally combustive and damaging relationships between the client and staff, and prevent rupturing the therapeutic trust central to helping relationships (Corey, Corey & Callanan, 1998; Freud and Krug, 2002a&b).

I asked the interview participants how these interpersonal feelings for clients affected their decision making, and if there was a place for these feelings in their work. Most of the interview participants expressed that emotional involvement with clients, either negative in terms of being angry or frustrated with a client, or positive in terms of having "favourites" can affect decision space and selection of strategies while working with clients. Some interview participants, like Gregory, referred to using the concept of professional distance to achieve balance in how they interact with clients:

I just put on a real professional persona. I tend to treat him and everybody else as equal as I can. Yeah, I do have my favourites as well, so you try to, you treat everybody as equally as you can. You try to give as much time to each individual. When we split up into groups, little groups, I tend to rotate myself around and not be with the same people all the time. Yeah, pull people in line equally. Don’t pick on one person. Yeah, it’s just a real balancing act.

Sometimes, the agency puts policies in place to encourage professional distance, such as rotating workers. Jeff spoke of his awareness of the risks of emotional involvement with clients and the policies of the agency put in place to reduce them.

There are friendships that can be set up. I think in the early piece with the agency, we were working a lot of one on one, and we started changing that then, or, I say we, the coordinator and the respite planners started changing that then and bringing other service workers in with the particular consumers so that one, it gave the community service worker a break from work constantly with the one person. It introduced the consumer who in some cases, if they were housebound, it introduces them to another person in their life and also makes it that, ok, one of the service workers is ill, there’s always somebody to step in and do the, do the particular shift, and we found out that there where some cases where in the early days, where when a service worker
actually left our service, might have got full time work somewhere else, that the person they had been working with, they felt that there was a, something had just dropped out of their life, because they’d had this person, they were a friend close to them, then all of the sudden, they’re not there. They’ve gone. Some of them probably realized that sometime or other, you know, that support worker is going to be gone, because some of our workers we have are only young people, who are, they’re looking for full time employment, and will eventually get full time employment. So they’re not going to be there all the time with them. Some of them can’t probably accept that whereas others can. So with having the number of people working with one consumer seems to have covered that to a degree.

Jeff touched on the complications that deep emotional involvements can have in a working relationship between the staff and client. The agency may have complications getting an appropriately trained staff to work with a particular client if only one staff member has developed the knowledge and skills needed to meet the needs of that client, and then becomes unavailable. Staff may burn out working constantly with the same client. There may also be emotional damage to the client if a reliance and dependency is built up on one staff member, and then that staff member leaves the relationship. With high staff turnovers an ongoing feature of helping professions, it is not unlikely for a client with ABI to be supported by numerous staff throughout his/her lifetime.

Jeff attested to his own experience of closely bonding with a client and then feeling a sense of loss when the working relationship ended. He is uncertain if the client felt the same, because, "in some cases, because of their brain injury, they may not even remember you, you know, five minutes down the track". He admitted it is not easy to be professionally distant.

Yeah, so I suppose there is a bit of a danger, you know, you gotta be careful you don’t get drawn in too close. You can go where they lay out the bounds of the consumer and worker type of a concept... We’re actually being told, you know, make sure that we don’t get too close to a person, which is not always easy to do.

Loretta, who works in the same agency as Jeff, spoke to the stresses of emotional involvements with clients.

We’re encouraged not to get attached to our clients. They rotate workers so
we don’t get attached. Mainly so that if we left the service, that person
wouldn’t devastated, but you do, you do form an attachment with people, but I
do try to stay fairly professional, because brain injured people have such
limited amount of friends. Virtually non-existent, it’s too much hard work for
most people to keep up a friendship with a brain injured person. So naturally,
apart from their family, and the odd friend, you’re the next contact, so yeah,
and so you do have to keep fairly aware of not getting involved.

Several interview participants spoke to masking their true feelings towards a client in
trying to maintain a fair, professional stance.

I try and treat, take clients at face value as much as I can so what, you know,
I get to know a fair bit about their past. I try and think, well, I’m here to deal
with this current issue. I’m not here to make judgement about something that
might have gone on or not gone on in the past, but having said that, there are
still clients that you just...don’t hit it off with (laughs) and, yeah...Aw, look, I
hope it’s not obvious (laughs). I just, I mean I just try to put that to the side if
I can......, you have to do what you’ve gotta do, but it affects the relationship. - Jane

You do have the people you really like and you do have the ones that you
really don’t and for me.Yes I have one client who dresses badly, smells badly,
argues the toss about everything, every little sentence you say, and I really
don’t like him, and not many people do, and so I probably avoid him as much
as possible in a group situation....because he’s just so...he’s quite repulsive,
and...yes, and so it would, it certainly, it’s very hard to...you think that,
professionally, that no one else would know that’s how you felt, but who
knows how good you are at that? I mean, it’s human nature, it’s it? I would, I
would always hope that you’d be fair and if any decision making, you would
make that same decision for him as you would this bloke over here that
you’ve really got a lot of time for. - Loretta

She’s quite a difficult, selfish person, and when our concerns are primarily for
her child, it makes it quite hard to work with because the effect she has on her
child is so significant, and we’re trying to work with him, but our
effectiveness is so limited because of her, makes it very hard, but, I’m sure
she doesn’t know that I don’t like her. I’d like to think that she(grins), and I
suppose it’s just maintaining, just reminding myself that, you know, that most
of the people that we work with live in very difficult, ongoing difficult daily
situations, but, is very stressful and usually financially difficult and have
effects on relationships and all sorts of things, so just reminding myself that
it’s not an easy situation, and even if there are certain things that I feel like,
you know, perhaps a parent should be doing what the child, but they’re not,
then just trying to take a step back and see the big picture and trying to work
out what might work - Nicole
These responses about negative feelings for clients speak to the hope that "it doesn’t show", acknowledging it can be present but maintaining a professional impartial demeanor is a strategy used to hide it.

Tess described that over identification with clients may actually debilitate a staff member from being able to support clients effectively.

I think also, and this is probably a bit hard sometimes, but just the ability to cut off the seriousness of what’s happened to them, and I think that’s probably a big reason why we keep thing very joking and mucking around, because it helps you not to have to think about what they’ve really lost in their lives. Because I think, when you really sit down and think, you know, of the potential that they had, and you know, everything that they’ve lost for the rest of their lives, and not just them, but what their families have lost, and it’s a really sad, really heavy thing. And I find if I really sit and think about that sometimes, it gets to.... I think that if you, if we just felt like that all the time, then you couldn’t function, and I had a girlfriend who actually volunteered with the group for awhile, and she could not cut that off. She didn’t stay for very long, and she was fantastic with them, and they loved her and she liked them, but she said it was just taking way too much out of her because she said she just could not stop thinking about what they had lost, and you know, how bad everything that had happened to them was. So I think that’s something that you need to do, and I think that’s also something that catches up with you sometimes, and you know, you might have your time where you feel really bad for them all. You know, you just can’t sort of push that aside.

Tess described here acknowledgement of a deep emotional empathy for clients, which she feels she has to deflect through using humour, lest it prevent her from functioning in her support role. There is a general recognition of human frailty and morbidity in her empathy, which can also be interpreted as viewing the clients as ‘others’; that their injury has altered their humanity, and their current situation is a tragedy. While the perception of otherness has been regarded as disempowering for individuals with disabilities (Barnes, Mercer, & Shakespeare, 1999; Priestley, 1999), the context of Tess’s comments suggest that her empathy for the clients she supports influences the way she performs her job, and motivates her to offer a quality, enjoyable service to clients.

Karen spoke to the role self awareness plays in balancing her emotional involvement with clients, and in maintaining a professional fairness.
It can be a trap and it’s something that I’m very conscious of not trying to fall into. I guess, yeah, for the people who I do find really frustrating, or people who, maybe because of behavioural stuff, I find difficult to work with, I sometimes find that I tend to...try, not so much try harder, but I guess I’m conscious of, Ok, well, this person is more difficult, there’s more traps for me to fall into, to not wanting to do stuff. I’m going to make sure I do do it properly. I definitely find it more challenging to work with someone who.....who yeah, is a little difficult to work with, but I’m also very conscious that I’m here to do a job and I need to employ the same principles in working with this person as I need to when working with someone I really, really enjoy.

Despite awareness that emotional involvement with clients can impede staff effectiveness, there is little to no effort for staff to distance themselves from clients in Tess’ agency.

Lot of, I’ve seen, from what I’ve seen of other groups, it’s more like, you know, the workers are here (holds one hand up in air), the clients are here (holds other hand lower than the first). I haven’t seen so much of that, you know, friendly mucking around....as much as we can, we try to make it seem less that we’re the workers and they’re the disabled clients, and I think because we’ve, a lot of the clients have been really long term clients, so you know, we know each other quite well, you know. Like they’ve seen me go through two pregnancies, and you know, they’ve had grandkids born, you know, my supervisor’s had a baby born since he’s been here. Yeah, so just those sorts of things, things that are ok for workers to share with their clients. You know, it just seems more friendly, you know what I mean?

This narrative seems in contrast to the narratives that emphasised maintaining professional distance and staff not growing too emotionally close to clients. There is no rotation of workers policy in Tess’s agency, and she has known and worked regularly with the same clients for six years. In contrast, Loretta is very clear about limiting personal knowledge about herself with her clients:

I’ve been out with one girl, and she’ll run into someone she knows, and she would say, "This is my friend", and would say, "No, I’m actually the carer”, and just to make sure that’s the basis that person is thinking of me. Sometimes they’ll...they want to know all about your family and what you’re doing when you’re not working, and I try to just keep that out of it, and turn it back to well, "what did you do on the weekend?” That sort of thing.

Professional distance in this situation highlights another of the inherent inequalities of
staff-client relationships. Staff obtain and know a large amount of intimate detail about the life of the clients they support, as well as monitor the ongoing details of clients’ lives, yet to be professional and maintain appropriate boundaries, clients are not privy to same amount and quality of information about the staff member’s life. This also illustrates why most staff-client relationships cannot be regarded as true friendships, as friendship is built on reciprocity and equal sharing of one’s self (Rubin, 1985).

Lois offered examples of a contrasting strategy, engaging in a friend role and not avoiding emotional involvement. She easily referred to herself as fulfilling the need of ‘friend’ for her client, whereas others are wary of maintaining a professional distance.

I really can honestly say, I don’t think I’ve seen any progress in her. That’s why I’ve said, I feel my role is to give her company, to give her support and a sounding board, and somehow that seems to be her main problem with her husband. She needs to tell me all about what’s happened, and let it out…..That’s where I find, at least, she can...yeah, and I can go away feeling she’s had two hours of quality relationship with somebody.

This view of being a friend for the client gives Lois some sense of satisfaction in her job in the face of the client’s continual lack of motivation. As it is, Lois, the client, and the agency see no issues with the current staff-client match. It has continued for over eight years.

For myself, I was very aware of the fact that I was fond of certain clients and disliked others. While I tried to remain vigilant to provide the same quality of service and regard to all the clients, I was aware that I tended to be a bit nicer and friendlier to clients I favoured, and a bit more cold shouldered and curt to clients who annoyed me. I considered it professional to try and present myself as neutral to all clients, but I knew in my own mind that my own willingness to smile a bit more or less with a client, or to return a client’s phone call right away or wait a few days, was my private way of dealing with and expressing my emotional affectations for clients.

Emily Involvement Summary
Staff in helping professions are socialized into believing the importance of maintaining emotional boundaries between themselves and clients (Fox, 1995). These boundaries are in response to real issues that can emotionally damage both clients and staff. However, the structure of outreach supports place outreach staff in environments and situations in which close affective bonds will develop between staff and clients - namely ongoing, repeated contact, intimate involvement in the details of the client’s life, and mutual participation in life activities that may mirror the types of interactions in which true friends engage. This is further complicated by the tendency for clients with ABI to lose most of their friends post injury, as well as for the mixed messages of the interaction and for client cognitive deficits to potentially contribute to a client’s confusion over the nature of the relationship between him/herself and the staff member.

Affective feelings for clients may influence strategies used with that client, such as avoiding a disliked client, or bending rules for a favourite client. Awareness of one’s emotional involvement with a client relates to one’s awareness about how affective feelings for clients are forming staff decision space. The tension between professional distance and personal involvement is also an illustration of the tension between Fox’s (1995) care-as-surveillance versus care-as-gift conceptualization explained in the literature review. Using friendship as a therapeutic intervention subverts policies of professional distance, which are born of the medical model. However, staff unaware of how their emotional ties to client affect them may actually reduce their ability to implement their ethic of practice effectively, and eventually lead to burn out.

**Stress/Burnout**

Stress and burnout among staff in the helping professions is a well documented and heavily researched phenomena (Edelwich, 1980; Cordes and Dougherty, 1993). Therefore, it is not a surprise that the topic emerged in the narratives of the interview participants. Awareness of one’s stress level in ABI outreach work is relevant to a staff being able to assess their own efficiency and capacity to work with clients in a emotionally healthy manner. A staff preoccupied with their own emotional and
psychological issues, or overwhelmed emotionally and psychologically by the work are unlikely to be able to form a decision space or select strategies most conducive to their ethic of practice (MacLean and Gould, 1988; Maslach and Jackson, 1981).

Interview participants spoke to experiencing work stress in relation to client interactions, job expectations, limited resources, and emotional burden. Jeff spoke to the emotional toll support work could have in general.

Probably the least satisfying is probably going home, you feel a bit emotionally drained, and physically drained sometimes. Sometimes, you feel worn out, you feel tired and emotionally drained at the end of the day, and then what you do, physical drain, you may not have done a lot of physical work, but the person you have been working with has been a bit of an emotional strain, or because of the high needs of that they may have..... Sometimes you just are not able to do things you actually, backwards and forwards, you know, with some of these high need people, and they can also be demanding, as well as having the high needs, and, you can be backwards and forwards, you know. Just running around all day, so yeah, you have really good days, and then there are some days that just aren’t so good, but ...(shrugs)

Jeff shrugged his shoulders in a wearied acceptance that stress is just part of his job. Several interview participants expressed they each just accept (acceptance as a type of self talk/self reminder) what happens at work and continue on. Lynette suggested that difficulties at work are universal:

I mean, in every place you work, if it’s an office or anything, you’re going to have whingers and complainers and you just have to cop it sweet, don’t you? What do you do?

Both Lynette and Tess expressed frustration with sometimes feeling as if the clients expected them to wait on them like servants. Tess also commented on how stress at work can exacerbate whatever personal stress a staff member may be experiencing:

I found the job can be very demanding if our personal lives are going through a hard time, because you walk in here, because I’ve had a marriage break up in the time I’ve been here, plus two pregnancies. Whatever our feelings are, don’t matter. (Laughs). You know, we could be feeling totally depressed and miserable and really feeling like we could do with a bit of pampering, and you
know, and being waited on like the client, or supported like a clients,.and you walk in here and you just totally got to leave it at the door.

Tess refers to putting on a professional demeanor to deal with putting client demands and needs before her own. All of the interview participants shared scenarios where they had to deal with emotionally frustrating and challenging situations with clients. As Gregory remarked: "We are all individuals and we’re not robots." Staff are people with feelings and opinions, as clients are. Maslach (1978) writes, “It should be recognized that clients can dehumanize staff just as staff can dehumanize them” (pg.111). The intensity and frequency of interactions in staff-client relationships creates “severe emotional stresses” which staff may attempt to deal with through emotional detachments (emotional removal/emotional avoidance). However, little formal guidance or training is provided for staff in using emotional coping strategies. The socially legitimated, but unrealistic status placed upon staff as being “healers”, lengthy work exposure to clients without seeing much progress in improved functioning, and the negativity a client may displace upon a staff member may contribute to staff stress and burnout (Maslach, 1978).

Loretta’s mention of the difficulty staff face when having to bear the brunt of emotional outbursts from clients illustrates the effect of clients dehumanizing staff.

I really hate it when you cop the abuse from them, because it’s often an *instant* thing, you know, and, particularly this, this young fellow I’ve been working with for a couple of years, and he just loves me and we just get along so well, then since his mum’s been in hospital, absolute shouting in my face, pushing me, you know, all these horrible things, and he wasn’t doing it to anyone else, but the bosses, who’ve known him for a long, long time have said that’s because he’s familiar, and safe with me, a little bit like that thing you do with your family, and, but, ah, I find that hard to take, and I find that when they’re rude and abusive and, and there’s no, it’s not that you’ve made a decision that they don’t like, it’s just this out of the blue explosion, and you quite often wear that, and as tough as I try to be, that really hurts my feelings, but it is, I say that to them. You know, "Look, whatever’s going on here, you’ve really hurt my feelings. I don’t deserve to be spoken to like that", but that, that is the hard part, yeah.

Felicity suggested the current mode of her agency offering lifetime service to clients is unsustainable, given the emotional stress it places on staff.
Yeah, look, I think my approach is you need to get them to a point and then discharge them, because they, I believe that, the burn out rate, if you were to keep them for a life long thing, the burn out rate amongst the case managers, a fair percent involved would be huge, because, and I guess that’s analogous to the, to the studies of the caregiver burden, which has shown to be incredible. I'd be more of the opinion that you needed a team of a couple of people to deal with the case management, intervention and discharge in between, and they might come back with another goal a year later, but that’s ok. You’ve had a break from it and you can set off again. That’s not the model of service that our agency uses for a variety of reasons, but my gut feeling is that something like that would be useful.

There are two people in the therapeutic relationship - the staff member and the client. Felicity recognized a burnt out staff member is not conducive to the ethic of practice. Maslach and Jackson (1981) note that burned out staff working continuously in intense relationships with clients "may lead to a deterioration in the quality of the care provided" (Jenkins and Allen, 1998, pg 466). While it is recognized that some clients with ABI and their families require lifelong support, the current model of outreach may not be a sustainable one, as staff are stressed under the pressure of supporting clients for long periods of time. Whereas the client can focus on responsibility for his/her self and perhaps family members, staff often face multiple responsibilities towards several clients at once. Lois and her lone client in rural outreach was the notable exception to this situation in this sample.

Several of the interview participants expressed frustrations with the structure of their responsibilities, particularly in terms of funding limitations and service guidelines as set by third party payers. These limitations can also be seen as contributors and influences towards the formation of decision space. Jane sees the cost cutting mechanics of insurance agencies as detrimental to the potential clients could reach, given the time:

I don’t like having to work to a time frame. I really, I don’t like the insurance type systems that, that are driven, you know, by financial things, whereas sometimes you just think, you know, this person, three more months, which would, in the scheme of things, not cost a lot of money, would make a lot of difference to this person for the rest of their life, and so that, I get a bit frustrated with that, with the insurance system, and the whole paperwork system that goes with that.
The imposed time frame places an external pressure on Jane’s decision space, foreclosing particular strategy options she has no choice over. Additionally, frustration regarding this limiting of options contributes to stress which will also feed into the decision space, perhaps in the form of time management pressures, or pressures to produce outcomes for third party payers. These pressure points can affect which strategy is used to meet the pressure demands.

Karen shares Jane’s frustrations, and sees part of the problem being that ABI support is an undervalued, misunderstood service.

I guess, when you’re talking about insurance companies, a lot of insurance companies don’t actually consider what this service does of value. We’re not a "therapy" (makes quotes sign with fingers), so sometimes, yeah, it can be difficult to convince an insurance company that what we are actually doing is, you know, not just going out and playing ten pin bowling, but there is actually some underlying skills here. That can be frustrating, I guess. It’s a process, once again, of trying to educate the manager, the case manager, whoever it is at the insurance company as to what we actually do, and quite often we’ll offer the services of our community education team to try and educate people, to get them to understand a little more, but yeah, sometimes dealing with government agencies is probably the most frustrating, or people who don’t understand the subtleties of brain injury, and you’re trying to explain and they’re not actually listening. That’s probably the most frustrating. Where you can see they’re just thinking (dismissively) "oh", you know.

Karen is describing a funding system for her agency that is based upon on medical model constructions of patient support, in that funding bodies expect definitive treatments, outcomes, and discharge from care. This overall ideology is an external limitation placed on staff decision space and strategy options. It is also an example of the conflict between medical model structures and self deterministic ideologies creating staff stress which has detrimental implications for client services. Gregory worries that these misconceptions will lead to cost cutting measures which will actually be further detrimental to particular services clients with ABI require:

I really get annoyed that there’s so much need out there and there’s not enough money to accommodate it....I’ve heard rumors that they were trying to integrate all disability services back together and not segment them as they
have done like with intellectual disabilities, physical disabilities, and acquired brain injury and mental health. They’re trying to reintegrate all the services back into one mass...because of lack of funds and stuff like that, and I just think people with acquired brain injury, because they were un...didn’t have a disability before their injuries, are quite a different client group, and find it very frustrating to be integrated with people with intellectual disabilities or people with physical disabilities, because of that..... They’re individuals, and yeah. I think should be treated that way, and more funding. (Laughs) Any funding.

Probably the ultimate way to cope with the stress of the work is to leave the job, which Maslach (1978) noted as a common response to burnout. Violet attested to this:

Very honestly. I guess I did resign from the position, but, and that was as a case worker, and that’s because it was too stressful. Too many cases, and I guess, yeah, not the ability to, you know, the time that you have, the ability to allocate, because I love the field as such but, I mean I love those individuals, I mean the individuals, the clients, but I guess it’s that, yeah, the organization’s in which you work, if there’s not time to actually allocate to each client.

Feeling overworked and underappreciated drove Violet out of ABI support work. I left my position for the similar reasons. The interview participants still in the field attest to the ongoing struggles of seeing the need and stretching what few resources they have to try and meet it. It seems lack of resources (such as financial, temporal, and human) is one of the key sources of stress and decision space/strategy limitations in the ABI outreach field among the research participants, as well as in my own experience.

Stress/Burnout Summary
Stress seems an inevitable part of helping professions and in ABI support. Concern about the quality of client services being provided when a staff member is burned out or highly stressed by client interactions relates this theme to staff self-awareness in staff-client relationships, as a staff not in tune with their own personal emotional state, or aware they are emotionally or psychologically stressed may affect the ethic of practice. How staff cope with work stress, or self care strategies, as described by the interview participants, were categorized in chapter five. Self care strategies seem to be used by the participant in response to stress, so they may clear their decision
space to focus on direct client strategies.

Chapter Summary
This chapter has examined themes that emerged from the participant interviews that relate to the formation of staff decision spaces in the field. The way interview participants defined client independence and autonomy for themselves seemed to bear relation to the formation of decision space and strategies selected to pursue the practice ethic, based on how the staff viewed best interests for the client. Staff autonomy shows to have a huge role in the way staff formulate their decision space, and yet is one of the least documented and least researched aspects to the ABI outreach environment. Valency, the undercurrent of staff needs in their work, seemed to also affect decision space, especially when participants did not contemplate if the strategy being selected was to meet a client need or their own need. Emotional involvement was cited by numerous staff as a threat to clouding decision space, but was also shown as a strategy in itself where the ethic of practice was to provide companionship. Stress was another widely recognized detrimental influence to decision space by the participants, both from external pressures, such as service parameters set by third party payers, and internal emotional pressures, such as close emotional identification with clients. Self care strategies were named by many of the participants as ways to clear decision space to focus on client strategies.

This chapter has demonstrated that there is a relationship between how these particular ABI outreach staff members perform their ethic of practice (balancing client autonomy and beneficence) with a sampling of various decision space factors. These factors are not comprehensive, but rather, were named by the participants and interpreted from the data as being prominent issues in the context of ABI outreach. It has also been indicated throughout the chapter some of the ways awareness of this relationship by the participants may or may not further affect their ethic of practice.

The number of decision space factors that converge, the ways they converge and the way they are considered by the different participants in any given decisional situation with any given client are too numerous and unpredictable to create formulas for
specific strategies to be used in specific circumstances, as some participants attested to. Participants also attested they are not always able to control, predict or compensate for which decisional influences may affect a decisional situation. This begs the question of how then do these staff members manage to deliver a coherent, consistent ethic of practice with their clients in such an unpredictable, multi-variant context.

One variable a staff member can control is their own level of awareness. In the next chapter, staff awareness will be directly explored in terms of how awareness may permit these participants to reflect upon and monitor their own formation of decision space, strategy selection, and overall practice ethic in the ABI outreach environment.
Chapter Eight
Awareness: Monitoring the link between decision space and practice strategies

Chapter Abstract

This chapter examines awareness directly through the perspectives of the participants, and how they regard the role of awareness towards their ethic of practice. Participants who were able to self-reflect and spoke to awareness agreed awareness is a necessary element to enable them to make effective decisions in practice. Instances of participants who were not self-reflective in the interviews and did not speak to awareness are noted, and it is speculated this lack of awareness may have implication for practice. The disparity between interview participants recognizing the significance of awareness is potentially an indication there is disparity in the field of ABI outreach regarding recognizing the role of staff awareness.

Introduction

Analyzing the perspectives of a sample of ABI outreach staff members interviewed for this research, it was revealed that the central ethic of their practice is balancing client autonomy with a duty of care. A catalogue of practice strategies were reviewed and then re-examined in consideration of decision space factors the participants felt or described as influencing the way they made decisions. The role of awareness within the interplay between decision space and strategies has been highlighted along the way.

In this thesis, awareness is theorized to be the mitigating factor between the power position staff hold over clients and the practice ethic staff try to implement. From the symbolic interactionist view, we do not simply react to the environment, as followers of behaviorism may advocate. Rather we act upon the contextual environment as we understand it, that is, in respect to the meanings we have assigned to the symbols and events we come to know in our experience. These meanings may be explicit or implicit to us, that is, we may be aware of how we make meanings of our world, or we may just act upon it without particular reflection (Foucault, 1990). The tension between the medical and social models has been used as an explanation for what contributes to the
ambiguity of the ABI outreach environment. It is acknowledged the way the interview participants act within the ABI outreach environment is contingent on this context. In this chapter, the participants’ perspectives on their own awareness and its role in the ethic of practice is explored.

**Awareness of the Influence of Values**

Values, both personal and professional (ethics), are central to the decision making process. Jane spoke directly to the role of recognizing her own personal values and the awareness of dynamics that occur in therapeutic relationships.

*I have to always be aware of things like transference and countertransference, with, especially with client’s parents, if there, are the parents involved or a partner’s involved. So I’ve always got to be aware of that. I think I’ve become pretty good at that, about trying to work out what’s a value that I, that’s my value and is that actually affecting the decisions that I might make about that person?... I think when you first graduate, you think, I won’t do that. You know, I won’t let my values get in the way, and that’s why supervision’s really important, because you get someone more experienced who can actually challenge you and say, you know "Well, what are your values around that and how’s that influencing your decisions."

Karen also reported being self aware of her values and their role in forming her decision space:

*I’m very conscious of my own, not putting my own values on the person. I guess just questioning myself, you know. Is this something that I personally wouldn’t do so is that why I’m having a problem with it? I’m very aware of, of what my beliefs are and what my values are, so I guess therefore it makes it a bit clearer to me if it’s one of those reasons that I’m feeling uncomfortable... It’s also, we’re also the type of service where we do tend to bounce ideas off each other, so staff meetings or even informal meetings with the service coordinator or the other co-workers, if we’re not sure about something, you know, it might be, "Look, I’m not sure about this, how do you see it? Am I a bit too close here?" Look from an independent view, you know.

Jane and Karen both spoke to personal self-awareness, maintaining the importance they feel in being in touch with their own beliefs and motivations in relation to how it may impact the decisions they make regarding clients. Nicole spoke to her professional code of ethics as being important to guiding her values and practice. After awhile, she feels
personal values and professional values merge.

You tend to internalize those over the time. I certainly don’t go to work and, you know, recite off my code of ethics, my OT code of ethics, because I probably couldn’t find them, but, yeah, you tend to internalize them and you’re aware of what’s the right thing to do and confidentiality, and all that sort of thing, just awareness of that, so some legal obligations in terms of things like confidentiality, but mostly just, moral/ethical sort of situations.

Beyond personal values, and values endorsed by professional ethics, Felicity recognized social and cultural values as well when working with a client, and determining appropriate behaviour.

Yeah, although there are certain levels of, certain standards of behaviour that are pretty, pretty set in concrete, you know. The whole groping sort of stuff, that’s way over the limit, and everyone knows that. You know exactly what and how to deal with that, but then, where does the "piss off’s" become to the really gross language, and where do you stop them? Where’s that line, because what you would consider to be inappropriate language really is a culturally and socially determined thing. What might be completely inappropriate for me maybe what, you know, this particular person uses all the time at home, so where do you, where do you draw that line? And I don’t know that I’ve got a good answer for that either.

These statements illustrate the strata of values that are intertwined in belief systems and influence decision making. Values are represented at social and cultural levels, at professional ethic levels, and at personal levels. This also illustrates the value-laden nature of helping profession work. The decision to intervene with a client, to "correct" them, even to formulate what a client’s best interests are or optimal potential goals are all shaped by values the society at large embraces, and the values the staff themselves hold to. Recognition that there is another set of values to consider, those of the clients, is a major step in staff self-awareness. Recognizing that a client’s values are as worthy of acknowledgement as those of the staff and society, even if such values are controversial or counter to mainstream social values, presents the complex continual negotiations between the client’s values (which inform behaviour), and socially condoned behaviours which represent the values of society. The staff is poised at the fulcrum of this balancing act.
Awareness of value differences

Balancing and weighing values may be facilitated by a value hierarchy. Panzarella (1980) writes, “The position a given value holds in a hierarchy of values determines the degree to which that value succumbs to or overrides other values when conflicts arise and decisions have to be made” (pg. 10). Finegan (1994) highlights that both organizations and individuals have value hierarchies, and that the two may sometimes differ in terms of where values are ranked. She writes, “When an individual is faced with an ethical dilemma, his or her value system will colour the perception of the ethical ramifications of the situation,” (pg. 747). In other words, individuals may refer to their own value hierarchy and the order of priority in which they personally rank values to decide what situations are worthy of more attention, and the manner in which they address such situations. This may or may not occur in agreement with the value hierarchy of the agency they work for. This is a key point in understanding the relevance of staff awareness regarding their own values and the values they use in a decision space, as levels of awareness factor into how decisions are formulated and made.

Loretta is aware that her own values may be in contest with client values, and that she may have to pick and choose her battles with clients over their choices. She discussed the example of clients with unhygienic grooming, and the tensions between her own awareness of her dressing standards and the choice of the client to dress as he/she wished.

Well, that’s, that’s very difficult, because I have very high personal standards, but I’ve had to...you know, I can’t be like that, and so, yes, there’s times when I take people out dressed really weirdly, but as long as their boobs or something aren’t hanging out...I have to just make that decision. If, if everything’s covered (laughs), even though it looks really weird, ....the way some of them are dressed is just a shocker, an absolute, and some of the clothes would stand up on their own, they’re so dirty. It’s just, and the smell, it’s just...but I have to, and I know that’s just my personal thing, and I, a lot of times, that you just don’t make an issue of that, because that’s just your standards. In the general public, it’s...well, you see people dressed all very differently.

Awareness in this example has been used by Loretta to monitor her own decision process with the client, and prioritize her goals in regards to interacting with the client.
She decided that client autonomy within a parameter of behaviour that will not create offense in public spaces is more important than infringing on a client’s choice of dress in an attempt to change their dressing standards to her own personal standard of grooming.

Loretta is aware that tension exists between the client’s personal choices and what society deems as acceptable. As a staff member, she sometimes feels a responsibility to assist the client with a prioritised value of being socially accepted than the value of individual choice if those choices may risk the client being further isolated socially.

I mean, basically the whole aim of the thing is that people fit into society in some way, and if you’re dressed really badly or, you know, holes and bits of your body hanging out, that’s not fitting into society really, and it’s just...their lack of insight. They don’t, either don’t see it or sometimes they just, they, they’re determined that that’s how they’re going to be. So yeah, so I ...I, I sort of have to turn a blind eye to that sometimes.

Kody reflected on a past experience where she struggled with a client over the client’s refusal to shower during a summer camp expedition. She recognizes now that her own values of what was right drove her determination to overpower the client’s choice at the time.

It’s been awhile ago, and I think I would handle it really differently now with this, having more experience behind me, because this was about three or four years ago. I took some guys on a camp, and there was one girl who would not shower, and it was really bad because she was smelly and...it was really quite offensive, and one of the things that we spoke about before she went was her having to work on personal hygiene and that sort of stuff. So I guess I was making decisions on her behalf there, saying that "No, you’ve got to have a shower", and I was sort of coming....it was a situation where we came to loggerheads a lot, and I think, she got really angry with me, and I got really angry with her. I think I would do that very differently now. It’s her decision....making, yeah, because I found I was just always frustrated with her, because she just wouldn’t do it, and then there was always a reason, like the water was too cold in the morning, and then at night, she just, there was just another reason why she wouldn’t, and she just refused to shower. It was really off. Yeah, that was one thing where I was trying to get her to do it. (Now) I think...yeah, I know that I wouldn’t let it get out of control like that, where I ...I would hope that it wouldn’t to that point where we were just angry. It would be more being able to sit down with her and have a chat and say, "Look, you know, do you realize it’s quite offensive that..." you know, and talk about it so that
...try and give her the feedback. And then, and maybe not be so...because I was getting so angry with her that she wasn’t coming, like she came away on a sports type camp, and yet didn’t want to participate in any of the sports. And that was frustrating me too, whereas now, I think I would let that go. She didn’t want to do it, that’s fine. That’s ok. So, yeah....and then as far as the personal hygiene, well, I mean, if she doesn’t shower, she doesn’t shower. Like we prefer her to but I can’t make her, so probably just not getting myself all so stressed and upset about it.

In recalling and reflecting on this situation, Kody demonstrated how her previous lack of awareness regarding what was motivating her to use the strategies she selected at the time of the situation resulted in a difficult conflict. Her self-reflection upon the situation now and her awareness of how her personal values influenced the decisions she made has influenced the way she forms decision space in current decisional situations. Having gained more experience working with people with brain injury, Kody’s values around how she should interact with clients has changed, and her raised level of awareness helps her to monitor her decision making to better understand what may be influencing her decisions.

Sometimes, there may be value conflicts between what Loretta feels is just and the policy of the agency. Her strategies of suggestion and skill challenging fall within the boundaries of agency policy and expectations, and may be used to confront the agency itself.

I’m well aware of what the companies want, and as I say, I’m real stickler for carrying that out to the letter, and generally, that decision is between the families and the agency, in the best interest of the client. So no, I don’t really have...I’m probably unpopular a lot of the time (grins) because you know, I will say that to the client, "well, I’m sorry, mate, but that’s what the boss wants, that’s what your family wants, you need to talk to them," and so that they’re not powerless, I say that. "If you wanna change that, if you’re not happy with that, you go back and talk to those people, then they’ll change it for me and then we can do what you want".

Loretta seemed to demonstrate two beliefs about her role in this statement. On one hand, she states that she is a rule follower and does not make decisions outside her authority. On the other, though, she shows there are ways to make changes in the
authority, and does so through encouraging clients to confront rules they do not agree with. In another situation, she expressed difficulty with an agency policy about different freedoms allotted clients in the same group.

Some of the people live independently, and they find it really hard to then get in a group situation, and basically be told what to do, and so, it’s often little rules made that, you know, Frank can break away from the group as long as he tells you where he’s going and when he’s coming back...another one can go and do something, and I have I have a real problem with that because the rest of the group has a problem with that. Why is Frank allowed to go? And, I just say that that’s something he’s discussed with the boss and she’s ok’ed it. Uhm, and if that person has a problem with, well, they need to go and talk to the boss about it.

Loretta again directs the client to the higher authority to complain about seeming inequities in the group arrangements. She does not directly confront the agency about the policy, but is aware she can use her influence to suggest to clients that they challenge the policies.

Value differences may also occur between client family members, and the staff. Loretta perceives some clients to be overprotected by family members, which she challenges by challenging the client to do more on his/her own.

I see a lot of people, the brain injured people, totally dependent on family, and yet, they’ll come into the respite house and they can do things, because we just expect of them, you know. "Gerry, can you get such and such", and I said to him a minute ago, "Gerry, can you wash those cups up?" and he said, "How do you wash up?" I said, "Mate! (Grins)You just put them in the water and whizz them around!" We’ll he thought that wonderful. He’d washed up, and he’s quite capable of washing up, but a lot family don’t ask anything of them.

Loretta negotiates the differing priorities between herself and the client’s family through making suggestions towards the client.

I know I’ve got a fellow at the moment that I keep saying to him...because he’s able to be home by himself, but his mum doesn’t let him, and I’ve said to him, "If you get a key cut, we can drop you off on the way home to save going all the way back to work and getting a cab," but that’s something that he has to take up with his mum, and the boss, but it’s just like too scary for him to make that
decision, so you just have to leave it and I just make that suggestion every now and again, that he could do something like that himself.

Both these stories indicate a level of tension between her and some family members regarding the client’s abilities and values around what is best for the clients. Loretta’s awareness of value differences helps her to be sensitive to them. She manages to follow her principle of encouraging independence for the clients without directly confronting family members who may be inadvertently acting as barriers to greater client autonomy.

Karen contends with negotiating between client values and the values of the client’s family.

I guess it’s trying to...trying to, I guess, to get both sides to see the other side. So getting the person with the disability to understand why the family has concerns, for instance, and also for the family, why this person wants to do the goal, what’s the motivation behind the goal, is it, you know, the need for more independence, is it the need for more ability to decision make, or is it that they just *really* want to do this activity. So, maybe, there’s a middle ground... I guess it’s kinda like mediator kind of role, because, I’m very conscious, as I said, of not get the family or significant people in the person’s life off side, because that only makes the rest of their life difficult *(laughs)*. So, I guess the role there is mainly as mediator..... Finding out why the person particularly wants to do that activity and working from there to see if both sides can come to some common ground.

Karen is aware both parties need to be respected, and the risk of alienating family members could lead to negative consequences for the client. Nicole is aware that operating to a differing hierarchy of values from that of the client or family, and not taking what the client and family consider important when articulating therapeutic goals will lead to failure.

If you go in asking them their opinions and respecting their observations and asking what they’ve noticed over time, things like that, I think that tends to lead towards a relationship that’s more open and respectful of both, that you don’t come in as a person and say,”You do this, you do that, you do this,” and you leave and everyone goes ”nyah nyah” *(puts thumb to nose, wiggles fingers and laughs)*, you know, like that. So I suppose I’ve been in a few situations as a less experienced therapist where you go in, and say, you know, ”You should do this and you should do that,” and then you realize afterwards that everything you’ve said has been totally ignored anyway, so there’s, it’s not a good approach.

Nicole spoke to the importance of building relationships to achieve goals, and that
knowledge is valuable from a variety of levels and experiences. The personal, experiential knowledge and values of family members and non-professionalized staff is just as important and relevant as the specialized training knowledge and values of professionals. To carry oneself as an expert runs the risk of alienating key-stake holders in the client’s support circle rather than garnering respect. In this scenario, the old adage of respect needing to be earned, not demanded seems to hold true.

**Awareness of Power Position**

The socially sanctioned dominant role that staff inhabit was stated as a key reason for pursuing this study. For staff working with clients with ABI, this power position is potentially exacerbated by the diminished capacity of most clients to make autonomous decisions. Developing awareness of this power imbalance in the staff/client relationship is how some participants monitor against inadvertently misusing or abusing this power position. Some participants recognized the power in their staff role, but none seemed to connect this power to medical model ideologies. Rather, participants tended to attribute their power to the diminished capacity and vulnerability of their clients.

Tess is aware of the power status in the staff role, and the responsibility she has to bear because of it. A client’s lack of insight can lead to situations where staff must use their authority to intervene if a client decision may cause harm.

"Sometimes we have to pull the plug, because some of our guys just don’t realize, you know, what they’re not capable of doing. You know, some of them are pretty good and they know their limitations, and I know that I can trust them, if I say to them, ‘can you do such and such?’ and then I know that if they say ‘yes’, then they should be safe. I’ll still be there to try and, you know, make sure everything goes well And if they say ‘no, I don’t think I can do that’, I’ll say ‘ok fine, I trust your judgement’.

Loretta is aware of the vulnerability of clients with ABI and the status of power in the staff role:

"I think the most important thing that I can do is to let them be as independent as possible. Sometimes it’s much harder. You could do everything for them and tell them what to do, and that. To me, it’s really important to give them the
independence.

Loretta guards against abusing her power as a staff by stating her values, and sees her strategies as maneuvering clients towards greater self-autonomy. She also stated, "I just think it’s in the client’s best interest that we all have the same, totally the same values as far as what’s acceptable, what’s not." The strategy of suggestion as a means of persuasion came up often in her narrative of how she works with clients.

She was a very big lady, couldn’t fit into her wheelchair, and...she was supposedly on a diet, and I used to, she wanted an ice cream, I’d say, "Well, look, I get the low fat one, it’s great." And usually she would say, "Great", but five minutes later she’d forget she’d had the ice cream and want another one, and things like that, or if we were going to have lunch, before she said anything, I’d say, "Oh I’m having a salad sandwich", so it wasn’t me telling her to have a salad sandwich, but often with people with a brain injury, if one has a meat pie, everyone has a meat pie, because it’s just that suggestion to them.

Loretta cited that the nature of brain injury enables the suggestions of staff to hold significant power in the staff-client relationship. In this instance, the value of helping the client lose weight overrides the value of the client choosing what and how much she wants to eat. Loretta is aware that her influence in the power position as a staff member means she can use suggestion and persuasion as strategies to assist the client to lose weight and lead a healthy lifestyle, which will have long term benefits for the health of the client.

Lois is also aware of her influence with her client and tries to utilize it towards facilitating positive outcomes with the client.

She’s very determined, like as far as her smoking goes, once again. (Laughs) I don’t think I have any influence in her decision to give up smoking. I don’t think, if she wants to do something, nothing I say is going to stop her, but I think she does respect my views on a lot of things, particularly with her husband, you know. If I say well look, look how wonderful, he’s doing the garden, you know, he’s got a wheelchair, and she said, Yeah he’s really good to me, and it turns her mindset around from being a selfish sort of mindset to saying well, really, yeah he is good and I’m lucky, but I mean I know he gets very cranky as well so .I try to give her a positive outlook because I know I’m going to leave and I want them to be happy. I mean, I’m only in there four hours a week, so I want to try and get things going in harmony so that it’s better for her when I’m not there.
Lois uses persuasion and suggestions to influence the client, but the power in her suggestions seems to be more from the mutual respect of the interpersonal relationship and less from her status as a staff.

Nicole is aware of the tension in the juxtaposition of a staff’s socially legitimated authority versus a client’s autonomy. She spoke to having to balance respecting a client’s interests with her own professional judgement over what goals the client should be working on.

... like there’s often things that you just think, "*awwww*, look at that, that really needs work!" *(Laughs)* " I’d love to do something about that!."... sometimes you just have to back off and, and realize that, you know, this child might have a real problem with handwriting, but the parents don’t care, the kid doesn’t care, the teacher thinks it’s normal and it’s like, well, Ok *(grins)*. And so sometimes it’s just accepting the fact that other people have different priorities to you and, I mean, sometimes it’s worthwhile saying, letting people know things that professionally that you’re aware of that they might not be aware of, such as, you know, if you don’t address handwriting before the age of 10, the likelihood that you’re gonna change it is, you know, and they might realize that, they might think we’ll leave that til next year and we’ll deal with that then, but the effect that you can have after, on that when you get to that age is, is small, so I suppose just providing them with the information that you’re basing your preferences on, and if they still don’t prefer it, then you can’t work on something that they don’t, they aren’t interested in working on, because there’s no point, because you don’t get follow through, and you don’t, the kid doesn’t care, and the aide doesn’t care, or whatever.

Nicole acknowledged there may be discrepancies between what she feels is in the best interest of the client and what the client and/ or family sees as important goals to work on. She is aware that unless the goal is a priority to the client and family, it is unlikely they will put any effort into achieving it or follow any directives she may write into the service plan.

Nicole also spoke to situations where the family and the client may be at odds over what goals to work towards, reflecting different values between the family and the client. She finds herself as a negotiator between the two parties.
I often try and take a middle road between the kids and the parents but sometimes, you need to sort of, see what the child wants to do and talk to the parent about that and sort of, I suppose you see yourself as a bit of an advocate for the older child or the young person with their parents. There’s an older 16 year old boy.... Mum and Dad don’t want him to catch the bus to go to the movies by himself, and all that sort of thing, so often there’s not, it’s just being there to be a bit of a devil’s advocate, suggest things that they mightn’t, they mightn’t be there at the time, but if you suggest it six months later, they might have moved on and be willing to, to think of it, that this might be something their child may do.

In this scenario, the client values and desires greater autonomy for himself while the parents place a higher value on protecting their son, and ensuring his safety. Nicole is sensitive to the emotional factors that play into family decisions and willingness to try new strategies and goals with the client. In this situation, Nicole is aware of utilizing her staff authority to influence the outcome of the situation, through seeking information, giving information, making suggestions, and negotiating. The process actively includes the client and family in the negotiation process with Nicole.

However, some clients and families defer unconditionally to the socially legitimated role of staff-as-authority, which Nicole saw as antithetical to her working approach.

Trying to help families to make goals and decide themselves, like there’s some families who want to, you know say "You just do what you want", and trying to involve those sort of families more, who, perhaps don’t have the skills or the ability to make decisions easily, so giving them the information that you would base your decisions on and helping them, you know, try and decide what they’d like to do for their child, or whatever.

Nicole also mentioned that for her: "being aware that if I stuffed up it would make a huge difference to this family in the long term, so feeling that responsibility", which in turn at times could make her feel "overwhelmed". Nicole is acutely aware of the influence and responsibility she has in the lives of her clients, and the potential impact the decisions she makes will have.

Melanie expressed that when she first started in the ABI field, she found the level of responsibility for clients, "A bit scary". She also was attracted to the autonomy of the job because, "you knew that you were responsible for yourself and I think, and you’re
responsible for another person." However, she is aware of the dominant power position staff hold over clients.

It gives you a bit of control, and a bit of authority, which sometimes I worry about that (laughs) with some people... not necessarily for me. But I think with some people, but... again, I think with all the support workers we have, with the interview process and the debriefing and the constant contact, none of them ever have abused that power... because I mean it is. You’re there, you’re supporting a person, and you’re encouraging independence, but still, you could have the power to say, "Naw, we’re gonna do this because this is what I want to do. We’re gonna eat here, we’re gonna go there," you know, "No, you’re not going to have that", you know, that sort of thing. But, we’ve been pretty lucky. As far as I know anyway. I haven’t had to deal with it.

However, Karen has.

I guess there’s only been one instance that I can think of where someone has blatantly gone against, not so much a policy, but a commonsense feedback to the co-worker. Where, yes, something that was very, very relevant and the worker knew it, didn’t get back to the co-worker, because the support worker didn’t agree with the way that it was being handled, but the support worker didn’t know the entire picture, so they made a judgement based on what they knew, but we really only give the workers information that they need to know to do their job, given confidentiality and issues. Quite often the support workers aren’t given all the information, it’s only the stuff that’s relevant to their position. So, yeah, this worker made a decision based on what she knew, which actually needed to come back to the co-worker, and we found out in a roundabout way that that had happened.

In this situation, what the staff felt was important and appropriate conflicted with the manner in which the agency was working with the client. The staff acted on her own autonomy to withhold information from the case manager. In this example, Karen regarded the autonomous decision the staff member made as presenting a problem to the client situation.

Yet Karen mentions that information is regularly withheld from staff. Here, the agency is ranking confidentiality higher than staff having access to information. This calls into question how this might affect a staff’s decision space. How much information about a client does a staff need to make autonomous decisions in regards to the client while in the field? It is possible, given the information that Karen’s staff worker had available to her, that the decision she made was, in the staff member’s perspective, the best decision
she could make in the best interest of the client. The irony of this speculation is that it infers even more invasive surveillance of clients (a medical model based practice) and dismantling of confidentiality regarding clients’ private lives may be needed to better inform staff decision space.

**Awareness of Communication Style**

Aside from being aware of one’s own values and how they influence one’s work with a client, awareness of how one communicates, particularly with body language and other non-verbal cues also play a role in the staff-client interaction. Nicole spoke to her awareness of body language and non-verbals in her interactions with clients:

> I mean, I think it’s, it really depends on the client’s age. I think, you know, it’s a lot more, in terms of, you know, you might be a lot physically closer with a young child, whereas when I’m seeing a 13 year old boy, obviously we’d keep it, more of a distance, and you know, try and interact with him on level that he can cope with, you know. Usually when I arrive, he’s got his head in his hands, hiding in the corner of the lounge, so I went up and sat right next to him and held his hand, he’s run a million miles, so I think it’s just being aware of, you know, non-verbal communication, and, and appropriate things for different ages, and different sexes and all that sort of, that sort of thing as well.

Nicole’s response highlights the notion of awareness in her interactions and decision making with clients. She knows she needs to read the client’s non-verbal communications, as well as be clear in the meanings of her own nonverbal messages. This affects how she interacts with her clients and which strategies she selects in her practice.

Combs and Gonzales (1994) write: "Helpers need to be aware of the nonverbal messages they convey, for these messages play an important part in the kinds of relationships helpers establish and affect success or failure in those interactions."

However, clients with acquired brain injury may have a "reduced sensitivity to nonverbal or situational cues" (Snow and Ponsford, 1995, pg. 137), increasing the potential for mis-communications and misunderstandings between staff and clients, and requiring staff to be extra attentive to the way they communicate nonverbally to clients with ABI.
Felicity presented a very unique and clear example in her narrative about the inherent inequality between staff and clients, the significance and meaning of non-verbal communication, and the difficulties individuals with cognitive deficits may have in comprehending the role and meaning of context in behavioural differences.

You’ve got the client who can’t read your body language and you might be getting really ticked off with them and giving them all these non-verbals, and they’re just not responding, and it’s like (laughing) "oh, bummer, I’m really going to have to spell this out"....In terms of physical contact, I mean, I’m touching people all the time in my profession as a physio, and, you know, sometimes I’ve actually got to be quite in close to people to try and control what their body is doing to teach them a new movement, sometimes I’m literally wrapped around a client, who might be sitting there, and I’ll think, ok now I do that, and a client comes a pats me on the shoulder and I take offense at that. You know? Where’s the justice in that? And that’s really difficult for a cognitively impaired client to understand what’s the difference between what I’m trying to teach them to do using bodily contact, and what they’ve just done to me, and that’s not easy, and that creates a problem too for that consistency amongst other therapists.....I’ll actually end up saying to the client, "Yes, Ok, I am sorry. I am touching you a lot, and that’s because de-da-de-da-de-da, and I’m doing that to try and help you to move in a better way, ok, and I felt that what you did to me was, or had another purpose or another meaning which I wasn’t sure I liked." So, I’ll try and come across it that way, but again, if you’ve got a client who’s got a difficulty reasoning, then you’ve got a lot of problems with getting that over. What’s differences between what I’ve done and what you have done? And that creates a lot of problems.

I experienced similar questions of "What’s differences between what I’ve done and what you have done?" in client-staff interactions. A vivid example was during a winter camping retreat with clients in Canada. Some of the staff and clients began to engage in a friendly snowball fight. One client, unable to judge the limits of what was an appropriate engagement in the play, scooped up an enormous, heavy amount of snow and dumped it directly on my head, knocking me violently down in the process. Instantly I was furious, and tempted to rage at the client, but reminded myself he had poor insight/judgement skills. I looked at the scenario as he might have and couldn’t think of a way to explain why the way everyone else was throwing snow was appropriate and the way he did was not. As a result, the entire playfulness had to be stopped. How do you explain such subtle differences that rely on social perception, social empathy, and self restraint when these cognitive abilities are impaired in a client? Is the solution to always reduce everything to the lowest common denominator, even if
it means taking away from others in a group who understand the contextual differences? After that, I was merely angry we couldn’t play anymore in the snow while this individual was present.

Both Felicity’s and my narrative demonstrate our awareness of our communication styles and awareness of some clients’ impairment to recognize or differentiate socially acceptable behaviour contingent on social context and social relations. Awareness allows monitoring ourselves for how we communicate with clients, verbally and non-verbally, adjusting our behaviour or changing strategies when we are aware our intentions or communications are not being understood by the client in the way we intend.

**Lack of Staff Awareness**

Some participants interviewed seemed to demonstrate an incongruity between statements about awareness, and descriptions of their strategies used in practice. This illustrates one of the difficulties of this type of research - to induce individuals to reflect upon their own decision making. What if the individual does not perceive where he/she has made decisions? Does this reflect on the way participants formulate their decision space, and select practice strategies? It is much more difficult to directly ask an interview participant about how his/her lack of awareness impacts his/her practice than to discuss the influence of awareness on practice with participants who freely brought up the topic in their narratives.

The application of a symbolic interactionist framework to the research process allowed me to interpret a participant’s general level of awareness or reflexivity about their ethic of practice from the depth of awareness they demonstrated in the interview process. While this research is not attempting to account for individual differences between the participants in terms of their levels of awareness, it is important to document that not all participants in the study were able to speak to themes of awareness, or that some demonstrated incongruities between their stated values and descriptions of their behaviour.
For example, Lynette stated, “I’m a controlling person”. This alone is a significant statement of self-awareness, particularly for someone who works in a socially sanctioned dominant power position over a client. However, Lynette did not indicate any awareness or belief that her staff role inherently holds any power over clients. She stated the opposite, that she does not have much, if any, power or influence over clients.

I don’t think I have much influence at all. I think that...yeah, I don’t think I have any influence really. They’re stuck with me, so they can come and go with the group as they please, but they’re stick with me because I’m going to be there, but I’ve never...the only thing that I can think of that would be like an influence would be if they didn’t like my personality or didn’t like the way I handled things, that would be the only time it would ever be a problem, and I , I don’t think that’s the case with any of them, but I don’t think I influence their lives at all. I don’t influence the outings we go on. I don’t influence what they do on their outings....I try to make sure they have a good time, so I guess that’s one way I influence them a bit or have an impact on them, is that this is their outing, their one outing a week, and if they’re not enjoying themselves, then so I try and help them to enjoy themselves, so I guess that would be an impact. I can’t think of any other impact I would have.

It is difficult to ascertain why Lynette has made these comments - has she interpreted the use of the term "influence" differently from the way I used it in the interview and the way other interview participants responded to it? Lynette’s answer seemed to indicate she regards the term negatively, as if influence in any form is undesirable. Is this a socially desirable answer she has given to appear that she supports client self determinism and does not impinge on their autonomy? Or does it demonstrate a lack of awareness and reflexivity regarding her practice, and if so, why is she still able to be reflective about her own valency for control? Similar interpretive questions arose with the incongruent responses in Gary’s interview, as documented in chapter seven under the discussion on staff autonomy. Jeff’s narrative in chapter seven under the discussion on staff valency also raised a question of staff awareness of personal needs in regards to making clients go to bed so he could get some sleep while on an overnight shift.

It is difficult to know why some narratives contained these incongruities. One possible explanation is they represent the ambiguity of the outreach context, and that participant incongruity in behavior and attitude may represent an intermingling of both medical and
social model ideologies and concepts in the way they view and perform their ethic of
practice. It is my position in this thesis, as justified by the literature and illustrated by
the interview data, that awareness about decision space factors can affect the quality of
practice in ABI outreach settings. Awareness of the source of some ethical dilemmas as
located within medical and social model tensions may be one way to decrease
attitudinal and behavioural incongruity for staff. The disparity between interview
participants recognizing the significance of awareness raises the possibility there is
disparity in the field of ABI outreach regarding recognizing the role of staff awareness
towards ethical practice.

Chapter Summary
This chapter has explored staff awareness through the comments interview participants
have made regarding how they harness awareness in forming decision space and
selecting practice strategies. Many interview participants recognize the centrality of
values in the decision process, and use awareness to sensitize themselves to value
differences and resolve value conflicts. Some participants spoke to the need for
awareness to guard against impinging on client autonomy or abusing their power status.
Some participants presented incongruities in their narratives, with contradictions
between statements of their values or roles and descriptions of strategies they used. This
may be seen as representative of the ambiguity in outreach due to the tensions in
medical and social model ideologies. Overall, awareness is shown to be useful for some
participants to assist with negotiating the ambiguous ABI outreach context, and to self
monitor their decision making in order to improve their ethic of practice.

From the symbolic interactionist perspective, the agency of the individual and the
structure of the environment continually affect each other in a dynamic ongoing
interaction. While the participants’ decision making and work behaviour is contingent
on the ABI outreach context, the action the participants put forth into that context will
also change what happens in that context. The medical/social models may be a source
of contextual ambiguity in ABI outreach, but staff have the capacity to be more than
passive recipients of this ambiguity. Becoming more aware of how oneself is interacting
with the ABI outreach context is a way one can have an effect upon that context through
one’s own agency.
Chapter Nine

Conclusion

Chapter Abstract

In this chapter, it is concluded that staff awareness does play a significant role in staff decision making specifically in the context of ABI outreach. The relevance of this finding is related back to the social and cultural contexts from which contemporary ABI outreach has stemmed, namely the medical and social models. This thesis contributes theoretically to the field of ABI outreach by emphasizing the role of staff awareness in ABI outreach. The practical use of this thesis, following on from the theoretical aspect, is recruitment and training of staff in ABI outreach needs to hold a stronger focus on developing staff awareness - both self awareness of how staff use values in decision making, as well as awareness of ideological tensions between medical model and self deterministic approaches to practice. With this awareness, staff can better monitor their use of power in the staff role, and make ethically sound decisions that best serve clients in their immediate practice. Over the long term, raising awareness in the field of ABI outreach about the medical/social model tension may contribute to the disability rights movements by enabling staff to think critically about their role in the lives of clients and potentially becoming advocates for systemic and social change.

Introduction

This thesis is an exploration of the significance of staff awareness in acquired brain injury outreach contexts. Using constructivist grounded theory, I have sought to move beyond prescriptive descriptions of outreach ideologies and document the manner in which the outreach context is conceptualized, understood, regarded and operated within by a sample of staff who actually work within it. Through their understandings and my interpretations based on symbolic interactionist theory, balancing the ethic of client autonomy with the ethic of beneficence emerged as the central ethic of practice the interview participants try to achieve through the range of practice strategies they discussed and described. Participants spoke to a selection of decision space factors as
being highly relevant to the ABI outreach context and how they form decision space. Numerous examples were presented of how the participants’ awareness acted as a monitoring system of the relation between decision space factors and practice strategies used, and sensitized them to some sources of potential ethical conflict.

**Decision Space Factors, the Medical Model and the Social Model**

It was argued and illustrated in the literature reviews that contemporary ABI outreach contexts are shaped by the conflicted blending of the ideologies of the medical model and the social model in the ABI outreach workplace. The existence of these tensions gave a basis for exploring meanings of this context at the micro level of the individual, through the experiences of a selection of people who worked within ABI outreach. In this section, the macro ideologies of the medical model and the social model are revisited to position the experiences of the interviewed staff within a particular social/cultural context.

Each of the decision space factors discussed in chapter seven (individual differences, resource access and availability, values of independence/client autonomy, staff autonomy, valency, emotional involvement, and stress/burnout) emerged from the individual perspectives and experiences of the interviewed participants as bearing particular significance to the way they pursued their ethic of practice - balancing their duty of care with the client’s dignity of risk. The tension between the duty of care and the dignity of risk is emblematic of the tension between the medical model and the social model. The social model champions self determination for clients, thus creating a new dilemma for ABI outreach workers that historically may not have been an issue. Prior to the social model, it was accepted that practitioners knew what was best and clients, socialized into a sick or patient role, may not have challenged this. (Barnes, Mercer, & Shakespeare, 1999; Priestley, 1999).

The medical model is a cultural ideology determining what is normal in our society. It is the major paradigm through which we still regard health and human activity (Borsay, 2002; Hugman, 1991). The social model has been useful in highlighting the disabling way the dominant medical model paradigm has resulted in negative attitudes and devaluing of individuals whose bodies and/or minds do not function in the social normative standard. In spite of this, social model advocates have reminded us we still have a long way to go to shift the paradigm. Hagner (2000) pointed out that while social
model ideas and language have been adopted under the guise of client centred services, in actuality, the ideas and language of the social model can easily be misapplied in practice in outreach contexts. Beckett and Wrighton (2000) go a step further to discredit client centered services as being inappropriate applications of marketplace economics in which "public assessors and service providers are free to enter into private arrangements and relationships both physically, through entry into the ‘home’ space, and conceptually, through stress on individual need" (pg. 992). Beckett and Wrighton argue that this does not liberate the individual from the medical model but rather harnesses the individual’s impairments as a vested interest for the industry of welfare, and continues to deny individuals with impairments equal respect and value in society as those without impairments.

Because the medical model is a dominant ideological paradigm in our society, our institutions and industries of welfare reflect this dominance. It is in this paradigm that socially accepted practices for helping people are structured, which in turn, affects how agencies are structured, what type of programs or services they offer, how they are funded, and how the staff who work within them are trained and educated. These many layers of influence filter down to how people engage in social interactions - such as the staff and client interaction in ABI outreach contexts. It is through this filtering of the dominant ideology through the layers of society (in government policy and funding, organizational structure and culture, and social expectations) that it can be seen how the influence of the medical model contributes to the way many decision space factors are perceived. Likewise, the social model has entered this arena of influence, not only as a challenge to dominant ideas, but also as an instrument of disruption to the status quo. For practitioners in helping professions trying to implement social model ideas while maintaining medical model structures of service organization, policy, staff training and funding, the result is an ambiguous, challenging environment. This is exacerbated in the ABI outreach context due to uncertainties about a client’s cognitive capacity to decision make, and the increased responsibility on staff to facilitate client decision making or make decisions on behalf of clients.

An illustration of ideological influences revolves around the differences in values among the interviewed staff concerning client independence and autonomy. This decision space factor can be viewed as a manifestation of differences in medical model values and social model values. Independence defined as functional activity stems from
medical model assumptions about normal human functioning and Westernized ideals about independence as self-reliance. Social model beliefs advocate for self-determination and valuing an individual’s right to make their own decisions, even if functionally dependent on others to attain a satisfactory quality of life.

Another illustration concerns the juggling of resources. Resources were acknowledged as tangible factors that enable or constrain certain decision options over others. The impact of the medical/social model tensions is most obviously manifested in the organization and funding structures of ABI outreach agencies. Often, ABI agencies are funded along the same principles as acute or short term care may be funded, with emphasis on outcomes and cost effective services. Yet, ABI is a lifelong impairment, requiring lifelong supports for a client to attain a satisfactory quality of life in the community. It has been easy for organizations to adopt social model mantras and claim they are being client centered, but the funding structures and procedural pathways in organization are often unrealistically matched to support stated aims (Hancock and Moore, 1999). The social model stands as a challenge to the devalued status of people with disabilities, and the way the medical model institutionalises this cultural devaluing through industries of welfare.

The autonomous conditions of many ABI outreach environments can be viewed as arising from meeting the social model demand to support clients in their homes and community. This has decentralized the traditional medical model care environment, and placed workers outside of structured, controllable environments into unpredictable, natural settings. Workers trained in a medical model ideology may have difficulty with the chaos of the natural environment or may attempt to impose order on it or the client.

Decision space factors such as valency, emotional involvement, and stress/burnout relate to how the worker is caring for him/herself in the ABI outreach work environment. It has to be considered that the medical/social model tensions, manifested as ambiguity or ethical dilemmas in the work environment, have an impact on the stress level of staff. Staff may become overwhelmed by decisional responsibilities and too many decision options (Shiloh, Koren, & Zakay, 2001). The discussion of emotional involvement illustrates the tension between the medical and social models in the tension between the expectation that staff keep a professional distance from clients (medical)
and the ‘care-as-gift’ exchange based on a relationship of equality between practitioner and client (social) (Fox, 1995). A person’s valency to work in a helping profession, or with people with ABI in particular, may be partially influenced by which ideology that person subscribes to or accepts as the appropriate way to structure relationships between staff and clients.

**Would the medical model change if staff were more aware?**

The social model of disability is about changing the status of disable people from a devalued segment of society to a valued segment. (Beckett and Wrighton, 2000). To this end, it has been used as a political advocacy tool to bring attention to the ways in which social/cultural, economic, and environmental factors have disabled people with impairments, or people whose bodies or minds operate in a manner atypical of the mainstream population. Social model theorists have pointedly challenged the medical model, citing it as a source of oppression for disabled people.

Several authors (Illich, 1975; Hugman, 1991; Priestley, 1999; Marks, 1999) have cited the medical model’s dominance as stemming from its status as an unchallenged cultural paradigm; that people accept the medical model because it is what they have known. One potential way to alter this view is to educate people to think about the medical model as a particular ideology, and introduce other ideologies for consideration, such as the social model. Sumsion and Smyth (2000) surveyed occupational therapists to understand what creates barriers to client-centered practice. The top four responses given by OT’s in the survey as the greatest barriers to client-centered practice included "The therapist and client have different goals (#1), the therapist’s values and beliefs prevent them from accepting the client’s goals" and "the therapist is uncomfortable letting the client choose their own goals (both at #2), the intervention is dominated by the medical model (#3), and the therapist has difficulty taking risks in order to support client goals (#4)” (2000, pg. 19). While OT’s rated the medical model as a barrier to client centered practice as the third most important overall barrier, the barriers related to different goals, values and beliefs, discomfort with client self-determination and taking risks can be related to a medical model paradigm forming expectations about practitioner-client relationships. If a practitioner has been trained and is socialized to be in control of the staff-client relationship, the staff may find changing to a new paradigm of staff-client relations challenging and difficult. Stewart and Reutter (2001) note these potential difficulties for practitioners having to adapt to a new paradigm and ways of
practice, and acknowledge that "role modification and preparation," (pg. 99) is required of the practitioner to adjust to changes driven by the agenda for social change. Hagner (2000) suggests a change mentor, working with organizations to guide them through paradigmatic change, would help with this process more so than merely educating practitioners about new ideological models.

People cannot advocate for change if they are not aware a change can or should take place. Tying to dismantle the medical model power structure in outreach settings in helping professions by only changing the structure of the environment or context has been unsuccessful partially because staff still react to the power dominance of the staff role they have been socialised into. (Brown & Ringma, 1998; Cohen, 1998; Vaughn & Stamp, 2003) Raising awareness in staff who work in ABI outreach contexts about the tensions in the medical and social model may enable staff to better understand the source of ambiguity and some ethical dilemmas in their practice. Raising awareness about self awareness may enable staff to better monitor their own reactions and decisions, engaging in self reflective practice that will enhance their practice-wisdom, and permit staff to actively apply social model principles to their practice, rather than passively accept medical model principles as the norm.

Raising staff awareness may be a small start, but it is a start. Syme (1998) notes the irony between advocating for sweeping paradigmatic social reform and targeting reform strategies at individuals. He argues, "However, rigid insistence only on fundamental, revolutionary social change may doom us to wait for an event that will require years, even generations, to accomplish...Changing the world may require a more modest, practical beginning" (pg. 503).

**Theoretical implications**

The medical model and social/self deterministic models stand in tension in outreach environments, creating ambiguity in decision space for staff. While staff experience tensions and ethical dilemmas most commonly as a debate between their duty of care versus the client’s dignity of risk, the source of this dilemma as a manifestation of the medical model versus social/self-deterministic models does not seem apparent to some workers in the field of ABI outreach.
An important theoretical finding of this research is the notion that staff awareness is a critical contribution to the quality of client services in ABI outreach. This conclusion is supported by anecdotal evidence from a sample of diverse staff working in ABI outreach - and while not generalisable - the perspectives and issues they bring to light are triangulated both by related helping profession literature and personal experiences of the researcher who has also worked in ABI outreach environments. This suggests an area for greater research into staff perspectives in the wider field of ABI. This research also highlights the possibility that there are staff in ABI outreach without a functional recognition of the role of their own awareness in decision making. This issue is of concern because of their inherent power over clients, and the autonomous environments they work in, implying staff not aware of their power to exercise values through their decisions may inadvertently impinge on client values and rights to self determination.

Whilst technical skills and knowledge can be taught to ABI outreach staff, staff awareness is a much neglected aspect of the already inconsistent training being implemented in the field. As this research has demonstrated, the variance and number of factors that influence staff decision space precludes any attempt to formulate a consistent staff decision making strategy for workers in the ABI field. However, each staff can potentially take responsibility for their own level of awareness regarding their decision space formation and decision making processes with clients. Awareness in turn can contribute to staff better monitoring their decisional behaviour in the field for more ethical and effective decisions that most benefit clients. Overall, elevating awareness of staff in the ABI field can potentially lead to a greater number of staff critically reflecting on medical model practices and the applications of social model principles in staff-client relationships in ABI outreach.

New theoretical models for ABI service supports, working towards resolving the tensions between the medical model and the social/self-deterministic models, and taking into consideration the central role staff awareness plays in the delivery of client supports, need to be forged to create a more flexible, appropriate approach to ABI client support. Emphasizing self reflective practice (Drew, 1997; Healy, 2003; Schon, 1983) or contextual practice (Fook, 2002) over situation-specific, impairment specific, or skill areas of speciality may be of promise. Self reflective or contextual practice models take into account that the situational environment and the people within in them are dynamic, unpredictable, and ever-changing. Rather than attempting to apply particular
knowledge bases to particular situations, impairments, or clients, the practitioner critically engages with the context, and is flexible, and responsive towards the situation as it unfolds and changes. In ABI outreach, such an approach would enable staff working at any level with any client to move fluidly from situation to situation, positioning and adjusting themselves as necessary to meet with the demand of the situation.

New theoretical models also need to be based upon research conducted specifically in the context of ABI outreach supports, and not literature and research from related disability populations, as the unique aspects of ABI outreach support, as demonstrated in this thesis, are marginalised or absent in other disability outreach contexts. This research has used literature from other fields where ABI specific literature was deficient to forge a new synthesis of knowledge specific to ABI outreach contexts, and then empirically corroborated this knowledge synthesis with research conducted with ABI outreach staff members.

**Practical implication**

The immediate practical applications of this research can be related to staff training and recruiting methods. A shift in emphasizing staff awareness, both awareness of professional values and ideologies, as well as self-awareness of personal values and the ways these values impact formation of decision space, should come to the fore of staff training for ABI outreach work. In recruiting individuals to work in ABI outreach environments, personal characteristics such as an ability to be self-reflective should be a consideration to employers when hiring staff.

Fussey and Giles observed the following in 1988:

> Brain injury rehabilitation is a highly specialized area, and yet there is little formal education into its intricacies. It is, for most professionals in this area, something they acquire in the course of their daily work. A fuller education structure is necessary..... Brain injury rehabilitation techniques are powerful tools in the hands of therapy staff and, like effective medical treatments, are capable of misuse. More harm than good can be done-by well meaning, though misconceived, treatment methods. (Pg. 197)

Linking the idea that a staff member’s raised awareness of their decision space and decision making processes can enhance the way they make decisions and select practice
strategies, I would propose that the emphasis in staff training should be less about the injury of the client and more about the staff’s own awareness of how they interact with the client. This is also consistent with self-reflexive or contextual practice models. In my experience and those of the interview participants, learning skills in self-reflexivity is a deficient area in the training and education of ABI outreach staff.

This position is supported by several scholars in related literature. Klein and Bloom (1995) acknowledge that practice is less clearly defined than dominant practice models would indicate, and they advocate for practitioners working with clients to engage in a conscious development of their own intuitive knowledge to work in tandem with their technical knowledge. Drew (1997) in her research on nurses exploring their own meaningful experiences in practice, concluded that:

> Self awareness enhances congruence between one’s practice and one’s deeply held personal values, thus increasing chances of fulfillment in a profession that frequently produces more alienation than satisfaction for its practitioners. Awareness of self and satisfaction with one’s work foster development of holistic practitioners who have the ability to evaluate the impact of their actions and behaviors. Such holistic caregivers act as advocates and empathic facilitators of patients’ efforts to regain and/or maintain their sense of autonomy and significantly mitigate the depersonalization associated with contemporary health care (Pg. 422-423).

Healy (2003), in her study of ethical decision making by social workers supporting elderly individuals with cognitive impairments, recognized the duty of care versus the dignity of risk balance, which she termed client autonomy versus beneficence. She advocates:

> A major implication for practice is the need to increase awareness of how clinical and ethical aspects of decisions are interwoven. The findings suggest that practitioners must carefully and consistently evaluate the ethical dimensions of clinical decisions...we must clearly articulate our position, state our rationale for holding that position, and be open to the interpretation and values of others. Such a dialogue may help ensure a balanced care plan in which narrow adherence to the principle of autonomy does not result in neglect or abandonment and rigid adherence to beneficence does not result in paternalism that leave clients with little control over decision making (pg. 302).

Specifically, in training and ongoing staff development, higher emphasis should be placed on guiding staff through values clarification exercises, interpersonal
communication techniques, an understanding of transference and countertransference, and techniques for monitoring how they formulate their own decision space, such as keeping a journal. Ducharme and Spencer (2001) found that "performance based training strategies, such as modelling and role playing" (pg. 345) were effective in increasing staff skills in client teaching techniques and general interaction skills to enhance the staff-client relationship in ABI contexts. Schaefer (2002) found that nursing students assigned to write about and reflect upon caring narratives from their own experience could enhance their ways of knowing and caring practice with clients.

**Areas for further research**
An obvious area to conduct further research is in regards to the suggested methods for modifying training and staff development curriculum. Field testing of new staff training/development protocols and ideas should occur to see how raising staff awareness impacts the delivery of ABI support services to client. Due to the specific, limited nature of this research (conducted with 15 participants from New South Wales, Australia, between June and October 2002), replication studies of the research should be conducted in other geographic areas to account for differences that may be culturally or locality based. More narratives from a diversity of ABI outreach staff with differing experiences, perspectives, and histories will contribute to a growing body of knowledge on the ABI outreach environment.

The line of inquiry begun in this research of looking at medical/social model tensions and how they are experienced at the individual level could also be expanded in other social layers that surround and influence the staff-client interaction in ABI outreach. Areas of investigation should include the organizational structure, culture, and climate a staff works within, client family dynamics as they relate to the role of the staff in the life of the client and client’s family, the wider community values, as well as historical and cultural paradigms, such as comparing Westernized medical model paradigms with Eastern cultural philosophies of healing, and differences in how each may filter down to practitioner-client interactions. It is also important to look closer at the relation of staff to the medical model in terms of what the medical model does for staff role definition, identity, confidence and mastery at work, and what effects changing the paradigm has on staff and their ability to engage efficiently with clients in a changing service environment.
Conclusion

I came to this research wanting to better understand the discrepancies in approaches to staff-client interactions I felt and experienced between myself and other staff, as well as between staff I observed in my previous ABI outreach work contexts. I have emerged from this research with a strong body of evidence that supports the notion that a staff’s level of awareness plays a role in how they deliver support to clients, and the way they make decisions. My research has enabled me to use my own self-reflexivity, which guided me as a practitioner, and has allowed me to become a reflexive researcher in the process.

Conducting this research also permitted me to learn about the social model of disability, which I had not previously known about, even though I could personally sense the tensions in my practice that I would come to identify in this research as medical/social model tensions. There are many levels in which disability services are in need of reform or enhancement to reflect contemporary advocacy and ideologies. Social model advocates particularly note the social, cultural, and legislative changes that need to occur to further dismantle the medical model apparatuses that remain embedded in client centered/self deterministic services. My position is that while I agree that further change needs to continue to occur at all levels of disability services to enable a truly client centered model, at the same time, I echo Syme’s (1998) reasoning that we need to address what currently occurs at the front line level between staff and clients, and do what we can, with the resources and structures do we have in place. I have located the source of most ABI outreach ambiguity and ethical dilemmas as stemming from medical/social model tensions, and have acknowledged that staff decisions are contingent on this context. However, I do not believe contextual influences and contingencies abdicate personal responsibility. Staff working in ABI outreach should take personal responsibility to engage in critical thinking practices and raise their own level of awareness. Educators and administrators in ABI outreach can give staff the tools to do this through enhanced training and staff development which focuses on staff awareness as a critical instrument in the delivery of client services.

Balancing the emphasis between both the role clients and staff play in the staff client interaction, and training staff to take responsibility for raising their personal level of awareness (becoming a more self-reflexive practitioner in the process), we can effect an immediate change in effectiveness and ethical practice of ABI support to clients. Over
time, these small changes at the practice level can multiply into greater advocacy for
systemic change to the social/cultural beliefs and social/cultural institutions
(specifically helping professions) that maintain the devaluing of people with disabilities
through medical model ideologies and practices. The current challenge is making staff
aware that they need to raise their awareness. Speaking to these issues and conducting
research such as this signals the importance of this issue and gets the discussion rolling,
both in the academy and the field of ABI outreach.
Appendix A

Method Procedures
**Method Procedures**

Altheide & Johnson (1994), and Taylor & Bogdan (1998) call for the qualitative research process to be transparent and accountable, in order for the trustworthiness of the thesis to be evaluated by the readers of the text. Here I present an account of how I proceeded with the research, and my reasons for my procedural decisions.

**Assumptions**

Methodical assumptions here refer to assumptions I make about the research process, rather than the assumptions I made about the nature of decision making in ABI outreach support. The assumptions represent the conditions which I trust have occurred for me to conduct the research in a rigorous and truthful manner.

1. All interview participants have volunteered to participate and were not coerced into participating by myself or other parties, such as fellow staff or employers.
2. All interview participants have field experience in direct outreach support work with clients with acquired brain injury.
3. All interview participants engaged in an honest conversation with me during the interview and were not willfully or deliberately fraudulent in their responses.

**Limitations**

Limitations are variables in the research that I had no control over and also contribute to the trustworthiness and application of the research.

1. This research cannot be generalized with certainty to the wider staff population in ABI outreach support or helping professions in general. These narratives are personal accounts of subjective experiences a select number of outreach staff have. The research has value in highlighting potential issues, challenges, and situations that may occur in other ABI outreach contexts, but the conclusions of this research cannot be regarded as definitive. Rather, conclusions are to be regarded as possibilities.
2. This research cannot determine causality or correlations. The intent is not to ascertain which antecedents cause which outcomes in ABI outreach, nor to predict staff behaviour. In the symbolic interactionist view, “What the actor
takes into account and how he or she constructs his or her activity in concert with real or imaginary others can never be predicted but is always subject to change or the possibility of change” (Lal, 1995, pg. 425.) This research indicates how a specific group of staff encounter and act in their perceived worlds of ABI outreach, and it is the richness of this information and the themes it suggests that give this research its value.

**Delimitations**

Delimitations are the limits I placed on the scope and size of the research in order to focus the investigation, and also in line with the realistic temporal and financial limitations of a study conducted within the constraints of a Ph.D. thesis.

1. Only individuals who worked as staff in front line outreach with clients with ABI were included in the study. This is elaborated on under sampling and inclusion criteria in the next sections.

2. Data was only collected in New South Wales, Australia. The selected ABI agencies within New South Wales were comprised of staff within roles that met the criterion for inclusion in this study and are typical of ABI agencies and outreach staff found throughout Westernized, English-speaking regions with ABI populations. Staff from agencies in metropolitan, regional, and rural areas throughout New South Wales were included in this research. However, criterion for inclusion in the study was relevant to ABI outreach context, regardless of the geographic location in which they are located.

3. Data collection began in June of 2002. Data collection was open to continue until no further volunteers came forward to participate. The last interview for the research was in October of 2002. Deliberate seeking of additional volunteers to participate in interviews continued, but was formally ended in January 2003 when no additional volunteers could be located.

**Sampling and inclusion criteria**

The sampling in this research was purposive, and criterion based (Miles & Huberman, 1994). The central research concern was the subjective experiences of staff working in
ABI outreach. Since the working environment and nature of staff-client interactions defined the types of individuals to be interviewed, an inclusion criteria was designed to recruit interview participants who would have experiences in ABI outreach.

First wave recruiting was targeted towards only staff in front line, direct daily client contact capacities. Recruitment was then expanded to include other staff who impact the front line outreach context, even if they themselves are not in daily contact, or front line positions in relation to the client. This was to gain a multiplicity of perspectives and theoretically saturate the themes emerging in the study. High level managers and supervisors who perform in a largely administrative roles were excluded from the study, due to their position’s lack of client contact. While I acknowledge top management does affect the outreach context, indirectly through its influence on organizational climate and culture, and directly through policies, procedure, and supervisor-subordinate relations, staff at such positions would not be able to speak to interpersonal staff-client interactions. This research is concerned with the significance of a staff member’s awareness within the staff-client relationship, of which regular, repeated contact and direct involvement with clients is a criteria for interview participants to speak to such experiences and interactions. This study is not about exploring and documenting the entire organizational structures of agencies, along with the multiplicity of hierarchal relationships between staff within them, to extrapolate its role in influencing the outreach setting. It is simply beyond the scope of this study. However, I do acknowledge there is more to the total picture of ABI outreach supports than what has been examined within this thesis.

In first wave recruitment, participants were sought who were over 18 (a standard hiring age, and also legal age to be able to consent to participation in research), and who had specific experiences working with clients with ABI that would enable them to speak to making decisions on their own with the client in relation to functional, daily mundane choices. (See Appendix B for the recruitment information letter and criterion).

Only paid staff were sought for interviews, not individuals who volunteered their time.
with people with ABI, due to the complications and contradictions remuneration can present within a therapeutic relationship that bears many similarities in form and emotional content to a friendship. Exploring the contradiction of “paid friendships” between staff and clients could not be conducted with unpaid volunteers motivated to enter into helping relationships with people with ABI.

Criteria was based around staff who would most likely have very specific experience in an exact setting - having to make decisions on their own regarding functional, mundane daily choices for and with clients, choices that have immediate impact in the client’s life. Mundane, routine decision making about everyday occurrences, both in the general population, and specifically within ABI contexts, (where decision making is both the crux of a staff’s role with a client with ABI, and the very function that is impaired to some degree in the client) is a taken-for-granted exercise by most people. It is the subtlety of mundane, functional choices, the frequency with which such choices present themselves to people in everyday life, and the lack of attention given to or awareness about such decision opportunities, that makes this study unique and significant. It is the preciseness of this decision making context that defines the subject population being recruited for this study, and the exactness of this context that contains all the ideological issues outlined in the previous chapters of this thesis. Staff in related contexts may have similar issues, or even a few of the same issues. However, only staff in this context will have to potentially deal with the unique challenges of applying a self deterministic decision making ideology towards a client population with potential decision making deficits, within a helping profession structure that retains a medical model dominance which is in tension with a philosophy of client autonomy and self determination.

**Recruitment - Gaining access**

I gained access to potential volunteers for the study through direct contact with agencies that supported clients with ABI in community settings. New South Wales has one of the largest population of clients with acquired brain injury in Australia, partially due to New South Wales being the most populated state in Australia, resulting in higher demographics (Fortune & Wen, 1999). Newcastle has a well integrated network of ABI
support agencies, which are representative of typical ABI outreach services in Westernized nations and was the initial recruitment catchment. The criteria for participant recruitment focused on the structure of the staff’s work conditions, duties, and environment, and not the geographic location of the agency. This study could have been conducted anywhere that a staff member met the criteria as outlined above. Recruitment was expanded to the Upper Hunter, Central Coast, and Sydney, to include participants from various outreach environments, including rural and metropolitan areas.

I located potential agencies through a variety of methods, including phone book listings, Internet searches, support group literature, and word of mouth recommendations once contacts were established within the ABI network. I called each agency and inquired about the nature of their services and the types of employee positions they had, so as to ascertain if their staff met the participation criteria. Agencies that had employees that fit the criteria for interview were then sent a cover letter, and copies of the information letter for potential volunteers via a contact person (usually the manager/CEO of the agency). I followed up within two weeks with a call to the contact person, and requested permission to enter the agency and recruit staff to participate in the study. (See appendix B for cover letter and appendix C for recruitment letter).

If the agency agreed to allow me to enter the agency, I established when a staff meeting would be occurring in the agency and then attended as a guest to inform staff personally about the study and distribute information letters and consent forms. Staff were then on their own volition and initiative to directly contact me to express interest in the study. I offered an email address, a phone number, and pre-stamped pre-addressed return envelopes as contact methods, enabling interested staff to express interest without compromising their right to confidentiality. The employing agency was no longer in the recruitment loop once I was allowed to speak with staff.

In agencies that agreed to allow recruitment but could not or would not allow me to attend a staff meeting, I sent informational flyers, letters, and consent forms to the contact person to distribute on my behalf at staff meetings or through staff public areas,
like lunch break rooms and bulletin boards. While this method of the recruitment prevented me from supervising how the research recruitment material was disseminated, it at least allowed information about the project to enter the agency. It was important that the project was viewed and understood to be conducted as a study separate from the workplace environment and that employers had no input to the study. This distinction was necessary to build trust between myself and the interview participants, as well as to assure them of their confidential participation. I emphasized this distinction to the contact person and documented in the information letter, but I could not directly monitor for confidentiality measures to be properly observed where I was not able to disseminate recruitment information myself.

I wanted to recruit as many potential volunteers as I could, anticipating that I could gain more variety and greater theoretical saturation the more narratives I had to draw from. However, there were not a lot of ABI specific agencies to recruit from, and not all contacted agencies consented to assist with recruitment. Getting the recruitment information into the agencies I could not personally enter increased recruitment potential, and trust was held that recruitment information would be properly represented by the contact person. After two months of recruitment targeted exclusively at ABI agencies, low response numbers of interested participants caused the decision to expand recruitment from community agencies that solely supported clients with ABI, to community agencies that supported multi disability populations in which ABI would be one of the populations served. Multi-disability agencies were contacted by phone to confirm they did have clients with ABI. I emphasized to potential staff in the information letter and in recruitment sessions (when I was allowed to personally enter the agency) that the staff must have contact with clients with ABI in their work experience in order to be able to participate in the study.

A total of 12 agencies that had staff who fit the criteria for study participation were contacted for potential recruiting. Four agreed to collaborate. After four months recruitment in the Newcastle area (April - July 2002), I expanded the geographical area from which recruitment would take place in effort to increase the volunteer pool. An
additional fifteen agencies with appropriate subject populations from the Upper Hunter, Central Coast, and Sydney suburbs were contacted. Second and third wave recruiting efforts occurred from July to October of 2002. Of the fifteen agencies, six agreed to allow recruitment. Overall, of the ten total agencies that permitted access, either through allowing me to enter the agency or by distributing information letters on my behalf, nine yielded participants. Only one interview participant came from an agency that distributed literature on my behalf, one came via a recommendation from a mutual contact, and the other interview participants came from agencies I personally visited.

Confidentiality/ethics
Ethics approval to conduct the study was sought from and granted by the Human Research Ethics Committee at the University of Newcastle in April of 2002 for a period of three years.

Employers were not informed of which staff members from their agency participated. No personally identifying information, such as interview participant names, agency names, or client names were used in the transcriptions. Quotes are identified through pseudonyms only. My supervisors, myself, and the interview participants were the only ones with access to the data. Participants had a right to access only the data related to their own interview to review, edit or erase their contributions if they requested to do so. Parties not involved in the direct research did not have access to any of the research data, such as the audiotapes and the dialogue transcripts. Agencies and clients also remained in confidence in the reporting of the results, either through not being directly mentioned or use of pseudonyms.

Interview process - Semi Structured, interview guide
Once an interested staff member contacted me to participate, I set up a meeting time and location as per the staff member’s convenience. Most interviews were conducted one on one either in volunteers’ homes, or in a public location such as a café. A few were conducted in private rooms at a staff’s work location. While I requested interviews not be conducted on work grounds out of concern for staff confidentiality (the risk of them
being seen with the researcher), interview participants in these situations expressed that it was the only place they could be available for interview. I accommodated their choice. I tape recorded all interviews, except for one, in which the staff member expressed her desire not to be recorded. Extensive notes were taken and a summary of the notes was submitted to the participant for her approval.

Interviews followed an open question format. An interview guide was used to semi-structure the interview, but the interaction was flexible and I had the freedom to allow the interview to take its own course of discussion. An open ended interview guide allowed interviews to flow organically, where I could follow up on topics of interest and relevance as the interview participant told his/her story (Kvale, 1996). Interview questions were used as points to launch discussions and not as strict survey type items. (See interview guide in Appendix E.)

After a series of interviews had been completed, I began to use information given in previous interviews to explore if similar experiences or perceptions were present in other interview participants. For example, if a participant spoke to the difficulty she had in knowing when to intervene to assist a client, this legitimated asking other participants in separate interviews if they had a similar difficulty in their experience. This gave some indication to the commonality of particular issues and experiences among the participants, as well as revealing differing discourses and negative cases. This dynamic process allowed for the complex weaving of a tapestry of experiences particular to these staff who work in ABI outreach support.

**Data Coding- Emergent Themes**

**Data Analysis**

The research project took a constructivist grounded theory/framework analysis approach with a symbolic interactionist focus. Grounded theory investigates the personal and social meanings people give to experiences by using the narratives of participants to construct an interpretation of a social phenomenon (Charmaz, 2000). I consider myself a participant, by using my own personal narrative of experiences as a front line worker.
supporting clients with ABI to interpret and understand the narratives of the subjects in the study. Adopting a constructivist grounded theory/framework analysis method for the data interpretation allowed for this inclusion of my personal experience to contribute to a priori assumptions about the experiences of other participants within the same context (Charmaz, 2000; Lacey & Luff, 2001).

I transcribed all the interviews, which acted as an initial data analysis. Transcribing myself allowed me to attune to themes in the interview that I may have missed at the time I was conducting the interview. Transcribing as each interview was completed and listening to myself interview also helped me to become a better interviewer as I conducted more interviews. I certainly think the last few interviews I conducted were a lot better than the first few, and this confidence is evident in the transcripts as I grew more willing to depart the interview guide, and had stronger recall of the topic areas in my head. The most important thing I learned was just to shut up and let the participant talk. Even if she sidetracked a bit or was not answering the questions in the way I would have liked for her to, the manner of her responses still gave me information into how she viewed and gave meaning to her experiences.

Once the interview collecting and transcriptions were complete, I adopted a three step framework analysis method to focus themes from the data. Framework analysis allows emergent theory as well as incorporating a priori assumptions about the topic area (Lacey & Luff, 2001). This way, I could search for themes based upon evidence in the literature and my own personal experience, as well as be sensitive to novel or unexpected themes provided by the participants through the telling of their individual narratives.

Step one - Transcription annotation. I read through each transcript multiple times, and made both descriptive and interpretive notes in the margins. Descriptive notes were short phrases to summarize the essence of what a participant was saying in any particular passage. Interpretive notes were short phrases or single words to describe behaviour either reported by the participant in their narrative or exhibited by the
participant in the interview, and the meaning I ascribed to that behavior.

Step two - Open Coding. Using a coding scheme suggested by Potter and Wetherell (1987), I went back over each transcription and reduced the notations further into one, two or three word codes to label the dominant theme expressed in each annotation. When possible, the code was elicited from the interview text, such as if the participant had chosen a particular word to describe a behavior. 290 codes were generated.

Step Three - Grouping/Axial Coding. The 290 codes were looked at independent of the transcripts and grouped by dominant shared characteristics or themes. Five overall thematic categories were formed, with sub-categories in four - Duties at work (descriptions of what staff do), antecedents (descriptions of background information, ideologies, values, decision structures), strategies (formal and informal ways of decision making with clients, formal and informal ways of coping with the stress of the job), conflicts (interpersonal and internal/within oneself), and knowing.

Narrative reconstruction - The interview transcripts were reviewed again from a narrative approach. I was unhappy with my coding analysis as it felt too removed from the discourse encountered in the interview, too dry and mechanistic, and not true to the heart of the data I was trying to understand and relate. Interview transcripts were re-written as narrative stories as told by each interview participant, and intersected with a narrative I wrote about my own experiences in ABI outreach. This was a critical step, as I was still encumbered with my own negative feelings about my outreach experiences and aware that these negative feelings were affecting my appraisal and interpretation of the data. Writing my own narrative was a cathartic process and allowed me to step back and see where my own perspective was overshadowing those of my interview participants. Re-writing the interview transcriptions as stories, conceptualizing the interview participants responses to my questions as tales about a journey through a world of ABI outreach, allowed me to group thematic concepts contextually. Themes extrapolated from narrative writings could be compared and contrasted with themes emerging from coding methods, creating a multi-method and varied approach to
examining the data and theoretically saturating concepts. This was an organic, intuitive process I embarked upon, but have found it is not inconsistent with Richardson’s (1994) encouragement for researchers to experiment with creative writing, to seek out different forms of representation and violate prescribed conventions. It was through this narrative writing that the significance of self awareness emerged as the central theme to the thesis.

Appendix B

Initial Contact Information Letter
Dear XXXX,

My name is Suzanne Snead, and I am postgraduate student at the University of Newcastle. I am writing to you to request your assistance with a study I am conducting for my thesis research. This study is being conducted as meeting requirements for Research Higher Degree in the

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**Project Title:** The Nature of Decision Making Used By Staff Who Work With Clients With Acquired Brain Injury

**Chief investigators:**

- **Dr. Kevin Lyons** (Project Supervisor) 4921-8989
  Lecturer, School of Social Science

- **Dr. Wendy Gunthorpe** (Project Supervisor) 4921-7364
  Lecturer, School of Social Science

**Student Researcher:**

Suzanne Leigh Snead (PhD candidate) 4921-5552
suzanne.snead@studentmail.newcastle.edu.au

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Appendices pg. 258
School of Social Science, Faculty of Arts and Education, University of Newcastle.

I am currently interviewing support workers who work with clients with acquired brain injuries in one on one community outreach situations. I am interested in learning about how support workers experience decision making while on shift and what factors influence the way they make decisions. I believe this type of research will be of great value to better understanding staff effectiveness with clients and how we can construct better rehabilitation and support modules for clients with acquired brain injury.

I’d like very much for the support workers in your agency to know about this research and invite them to participate as interviewees if they are interested. I am available to you to visit your agency, preferably during a support worker staff meeting, so I may explain the research to potential volunteers and leave information for individuals to decide if they would like to be part of the research. Enclosed is a copy of the information letter and consent form for interested support workers to read.

The actual interview will be coordinated between myself and the volunteer upon the volunteer contacting me. Interviews will take place during the support workers non-work time and in a location away from the agency. The agency will have no involvement in the research beyond permitting me to make initial contact with your employees. A final copy of the thesis, however, will be available for the agency to review after completion of the study.

I will be phoning your office within a week to follow up with this request and clarify any questions you may have. Please do not hesitate to call me before then if you wish or email me at suzanne.snead@studentmail.newcastle.edu.au

I look forward to speaking with you.

Suzanne Leigh Snead, M.S., CTRS
Student Researcher

Kevin Lyons, Ph.D.
Project Supervisor

Wendy Gunthorpe, Ph.D
Project Supervisor

Appendix C

Participant Recruitment Letter
Project Title: The Nature of Decision Making Used By Staff Who Work With Clients With Acquired Brain Injury

Chief investigators:

Dr. Kevin Lyons (Project Supervisor) 4921-8989  
Lecturer, School of Social Science

Dr. Wendy Gunthorpe (Project Supervisor) 4921-7364  
Lecturer, School of Social Science

Student Researcher:

Suzanne Leigh Snead (PhD candidate) 4921-5552  
suzanne.snead@studentmail.newcastle.edu.au

Hello!

My name is Suzanne Snead, and I am a postgraduate student at the University of Newcastle. I am conducting a study to meet requirements for a Research Higher Degree in the School of Social Science, Faculty of Arts and Education.

What it is about:

As someone with experience in working with clients with acquired brain injury, I am interested in learning about how you make daily decisions in your work with clients, and how
you assist clients with their decision making. It is my intention to describe these processes so that we can better understand our professional behavior and ethical values, which will enable us to provide stronger supportive staff-client relationships.

**What it involves:**

What I would like from you is approximately an hour of your time to take part in a personal interview. Interviews will be audiotaped, from which a written transcript will be made. The written transcript will then become the main source for me to analyse and understand the content of the discussion. You will not be expected to be further involved after the interview occurs, however you are invited to continue to make contributions to the research as much as you wish (i.e., be available for a follow up interview or correspondence).

**Eligibility**

To participate in this research, you must meet the following criteria:

1. Must Be over 18 years of age
2. Have experience working with adults with acquired brain injury.
3. Work in the capacity of a front line worker with direct daily client contact.
4. Must work with the client in the client’s home or in community settings, such as recreational outings, shopping, or job coaching in a vocational environment.
5. Shift duties should include working on functional skills with client or following program plans.
6. Must have work experiences where you are the only staff present on shift with the client
7. Must not be in a mid-management position where your primary role is to work on program plans or major life decisions with the client.

If you are unsure about your eligibility to participate, please do not hesitate to ask me!

**Confidentiality**

A pseudonym will be used for you in the transcription so that you personally are not identified. Those who volunteer will not be personally identified to your employer. Parties not involved in the direct research will not have access to any of the research data, such as the audiotapes and the dialogue transcripts. You, as a participant in the study, have the right to access the recorded tapes and/or the written transcript of the focus group you participate in to review, edit or erase your contribution to the discussion. Myself and my supervisors, Dr. Kevin Lyons and Dr. Wendy Gunthorpe, will be the only other parties with access to the data.

In conducting qualitative research such as this project, it may be necessary to directly quote someone in the dissertation as a way to illustrate a point brought about in the results. In such cases, quotes will be identified only through pseudonyms, maintaining confidentiality. Agencies and clients will also remain in confidence in the reporting of the results, either through not being directly mentioned or use of pseudonyms.

**Where will it take place:**

The interview will be conducted in a location and at a time that suits you. Arrangements for where and when we meet will be decided by you when we make contact to schedule the interview. I request that interviews not be held on agency/work sites so as to further ensure neutrality and confidentiality of the interview.
What are the risks:

It is anticipated that the interview will be fun and insightful, with no foreseeable risks to you. However, the University Human Research Ethics Committee requires I inform you of potential risks and resolutions for such risks. In the unlikely event that our discussion during the interview turns to subject matter that you may find distressing, you may ask to change the topic or even end the interview for your comfort. The phone number for a counseling service will be available to you in the event that you find the discussion continues to disturb you after the interview has ended.

Please note your participation in this study is completely voluntary. Your employer has no involvement in the design and direction of the research. You may withdraw from the study at any point, without penalty or harm.

What am I going to do with this stuff?

Data (audiotapes, transcripts) will be stored in a locked filing cabinet in the postgraduate room of the division of Leisure and Tourism Studies, University of Newcastle, Callaghan campus during the duration of the research. Only the investigator, Suzanne Leigh Snead, and project supervisors, Dr. Kevin Lyons and Dr. Wendy Gunthorpe, will have access to the data. Upon conclusion of the study, all written data will be stored in a locked cabinet in the resource room of the department of Leisure and Tourism Studies for a period of five years, and then destroyed.

I have attempted to give you as much information as possible about my research as I can in a straightforward manner. However, please do not hesitate to call me with any questions you may have. At the university, I can be contacted via the postgraduate room phone - 4921-5552. The most efficient way to reach me is via email - suzanne.snead@studentmail.newcastle.edu.au

Complaints

The University requires that all participants are informed that if they have any complaint concerning the manner in which a research project is conducted, it may be given to the researcher or if an independent person is preferred, to:

The University of Newcastle Human Research Ethics Officer
Research Branch
The Chancellery
University of Newcastle
Callaghan NSW 2308
Phone 4921-6333

Thank you for taking the time to read this letter and considering participating in the study.

Sincerely,
Appendix D

Consent Form
Project Title: The Nature of Decision Making Used By Staff Who Work With Clients With Acquired Brain Injury

Chief investigators:

Dr. Kevin Lyons (Project Supervisor) 4921- 8989
Lecturer, School of Social Science

Dr. Wendy Gunthorpe (Project Supervisor) 4921- 7364
Lecturer, School of Social Science

Student Researcher:

Suzanne Leigh Snead (PhD candidate) 4921-5552
suzanne.snead@studentmail.newcastle.edu.au

Consent Form

I, the undersigned, agree to participate the research project titled “The nature of decision making used by staff who work with clients with acquired brain injury” and give my consent freely. I understand that the study will be carried out as described in the information letter that has been given to me and which I have retained. I realise that my decision to participate or not will not in any way affect my relations with my employer or the University of Newcastle. I also realise I can withdraw from the study at anytime without having to give reason, and that I cannot be penalized for withdrawing. I have had all questions answered to my satisfaction.

Signature:_____________________________________ Date:___________________

Please retain this consent form and accompanying information sheet for future reference. :

Participant Copy

Consent Form

I, the undersigned, agree to participate the research project titled “The nature of decision making used by staff who work with clients with acquired brain injury” and give my consent freely. I understand that the study will be carried out as described in the information letter that has been given to me and which I have retained. I realise that my decision to participate or not will not in any way affect my relations with my employer or the University of Newcastle. I also realise I can withdraw from the study at anytime without having to give reason, and that I cannot be penalized for withdrawing. I have had all questions answered to my
satisfaction.

Signature:_____________________________________ Date:_____________________

The participant has retained a copy of this consent form and has possession of an information sheet about the project.

Researcher Copy

Appendix E

Interview Guide
**Ice Breaker Questions** -

1. How did you come to work with clients with acquired brain injury? What led you to choose this profession?

2. What is the most important service you can provide for your clients while you work with them?

3. What sort of education or training have you undergone related to your work?

**Main Questions** -

4. Think back to a recent shift in the field - a situation where you were working one on one, alone with the client, in the client’s residence or out in the community. Can you tell me about that shift?

4b. Think about the decision that were made by you or the client. What types of decisions were made on that shift?

5. Did you make any decisions for the client? Are there any situations or types of choices that the client could make the decision but the staff made that decision instead? Can you share some examples?

6. (Using an example given by the client from either question 4 or 5 or both) What factors influence those decisions?

7. Do you make decisions on shift that you would consider routine, or automatic, which don’t require much thought? Could you give me an example? How do those decisions compare with more thoughtful or involved decisions? Could you give an example of a decision that required more concentration and effort to make?

8. Can you think of an example of a decision you found difficult to make while working with a client? What made it difficult? Was it resolved? If so, how?

9. Are there any types of decisions related to your work with clients that you do not like to make? Could describe an example?

10. Do you make decisions that are or may be unpopular? Decisions that other interested parties such as the client, family members, or the agency potentially may not agree with? (If yes:) Could you give an example? When does that situation occur?
How do you resolve the decision?

11. Is there a standard or principle you try to follow? Do you sometimes have to go against that principle? How come? Can you describe an example? How does that make you feel?

12. How do you feel when you have made an effective decision?

Segue

So far we have spoken about your decision making. I want to ask a bit about your client’s decision making and your role in it.

13. Is teaching decision making to your client part of your work? How do you teach decision making to your client? How do you know when the client has made an effective decision?

Closing questions-

14. What is the least satisfying aspect of your work?

15. What is the most satisfying aspect of your work?
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