Holding Centres or Agents for Social Transformation? An Exploration of Australian Community Access Services

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Dedications

Edward (Ted) William Evans (1936-2013)
Dad, adventurous spirit, protector, great love.

Dr. Gary Crilley (1953-2010)
Mentor, supervisor, colleague, inspiration, friend for 30 years.

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Abstract

This research explored processes and approaches that may contribute to a transformation of Australian Community Access Services (CAS) from models that are driven by professional experts to models that stress co-production of services with professionals and consumers actively involved in developing innovative programs with high quality outcomes for individuals. Although CAS, which are often referred to as, 'day activity services', or even, 'holding centres', may have contributed to social, psychological, health, wellbeing and professional opportunities for people with disability, little research about CAS internationally or nationally has been conducted.

A Constructivist Grounded Theory approach was adopted and involved six data collection methods: memoing; observation; focus groups; face-to-face interviews; a questionnaire; and a critical discourse analysis of extant texts. International and national literature was reviewed throughout the research. Five focus groups and eight face-to-face interviews were conducted in metropolitan and regional South Australia with people with disability, family members/informal primary carers and CAS providers. Additionally, a questionnaire gathered responses from people with disability and family members/informal primary carers accessing CAS. A critical discourse analysis of Australian publically available CAS policies (n=42) and written evidence also occurred. An analysis of the data sources was conducted using Nvivo 8 and 10 data analysis software.

A theory of, "Social Transformation', emerged during the current research as processes and approaches of CAS were explored. Seven concept areas were identified that may be useful to inform the development of high quality services that are consistent with contemporary disability philosophy and values. These were:

1. Eligibility and equity,
2. Individualised service options,
3. Locally accessible services,
4. Positive agency culture and values,
5. Innovative opportunities,

6. A progressive approach to community inclusion, and
7. The involvement of people with disability as active and equal partners in CAS design, implementation and evaluation.

The findings of this study identified a need for Social Transformation from competition and disempowerment to citizen-centric approaches; approaches that are built on relationships rather than power struggles, and evolve through a co-production, between the producer and clients who want to be transformed by the service. In Australia, barriers to social inclusion opportunities and community participation through CAS were identified, including the lack of planning prior to leaving secondary education, conflicting demands from policy makers and CAS providers and, particularly, misinformation regarding eligibility and equity of funding for CAS participation.

Processes and approaches to overcome these barriers were identified for both the individual and through policy and practice transformation aimed at addressing the inequity experienced by people with disability who, for decades, have faced unemployment, underemployment and limited further education opportunities because of assumed lack of potential. Evident in this current research was the inequity of power relationships including inconsistent eligibility criteria and assessment processes, limited and misleading policy and unfair treatment of people with disability who were participating in CAS.

It is argued that the transformation of CAS with, and for people with disability, strengthens community inclusion, contributes to CAS policy development and professional practice, and adds to academic research in this underexplored area.

Declaration

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

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Ted Evans

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Evans, T. (2014). Creating Quality Services Together. *Quality Australia. 25*(4), p. 6.

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Glossary of Terms

Acquired Brain Injury (ABI)

The term Acquired Brain Injury (ABI) encompasses all forms of brain injury and is the consequence of a neurological injury sustained after birth (Rushworth, 2008). Damage to the brain can be caused by an accident or trauma, by a stroke, or a brain infection, by alcohol or other drug abuse or by disease (Grimshaw, 2007).

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorders (ASDs) are neurodevelopmental disorders that cause substantial impairments in social interaction and communication and are associated with unusual behaviours and interests. For a diagnosis of autistic disorder a child must meet a specified number of 12 criteria covering impairment in social interactions, impairment in communication and repetitive behaviours and stereotyped behaviour patterns (O'Reilly & Smith, 2008).

Block Funding

Block funding has been described as a contractual arrangement with services to offer developmentally focussed activities for up to five days per week, generally occurring Monday to Friday (excluding Public Holidays) during the day, 9am to 5pm approximately and up to 48 weeks per year (Department for Families and Communities, 2014). Funding is paid by the funding body directly to the CAS provider.

Community Access Service (CAS)

Services designed to provide opportunities for people with disability to gain and use their abilities to enjoy their full potential for social independence (Australian Institute of Health and Welfare, 2016, p. 8).

Constructivist Grounded Theory (Grounded Theory)

A constructivist approach places priority on the study's phenomena and sees both data and analysis as created from shared experiences and relationships with participants and other sources of data (Charmaz, 2014, p. 239).

Co-production

The term co-production has been developed to describe the possible relationship between, ‘regular’, producers and, ‘clients who want to be transformed by the service’ (Fledderus, Brandsen, & Honingh, 2014, p. 426). Co-production is characterised by the transformation of, ‘the perception of people from passive recipients of services and burdens on the system into one where they are equal partners in designing and delivering services’ (Boyle, Slay & Stephens, 2010, p. 23).

Disability

Disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives (Productivity Commission, 2012, p. 494). Disability is a human characteristic that includes medical, functional and social perspectives (McDermott &Turk, 2011, p. 1).

Individualised Funding

The term individualised funding has been described as simply giving control of funding to the person so that they can purchase the services they require (Laragy, 2002).

Innovation (Public Sector)

The process of creating new ideas and turning them into value for society (Bason, 2010, p. 34).

Intellectual Disability

Intellectual disability has been defined as a person having an intelligence quotient (IQ) of 70 or less, experiencing difficulties in living and working in their community including difficulties in social skills, communication, safety and self-care and limitations in intelligence before the person is 18 years of age (Dyke, Leonard & Bourke, 2007 p. 4).

Learning Disability

Learning disability is the label given to disturbance in mental cognition and functions that results from a diverse range of underlying and pathological processes. The term is used differently around the world with the name given to this group of conditions including terms such as, ‘mental retardation’, ‘mental handicap’, and ‘intellectual disability’. (Dyke, Leonard & Bourke, 2007, p. 4). Throughout this thesis the term **intellectual disability** is used in reference to people with a learning disability.

Policy (Government)

Policy is a course of action by government designed to attain certain results (Althaus, Bridgman and Davis, 2007, p. 8).

Service Quality

As a conceptualisation service quality involves comparing a customer's evaluation of the perceived performance of specific attributes of a service to their prior expectations (Howat, Crilley & McGrath, 2008).

Transformation

A change or alteration, especially a radical one (Collins, 2009).

Chapter 1
Introduction

1.1 Introduction to the research

> ‘People with disabilities want to bring about a transformation of their lives’ (National People with Disabilities and Carer Council, 2009, p. 9).

This research was conducted between 2008 and 2016, a time of policy and practice upheaval in Australia as the National Disability Insurance Scheme (NDIS) and accompanying *National Disability Insurance Scheme Act 2013* (Cth) were introduced. Described as Australia’s greatest social reform in the 21^{st} century (Swinburne, 2015) the NDIS, when fully implemented in 2019, promises potential for increased sustainable funding and dramatic operational service changes. This represents an exciting time to commence exploratory research.

Prior to the introduction of the NDIS, the need for strategic disability policy changes were identified through learnings from a range of research investigations including the National Disability Strategy Consultation Report, 2009 (referred to as the *SHUT OUT: Report*). Involving consultations with over 2,500 people with disability and their families in Australia, the report described the disability service system in frank and honest terms. Disability services across all service types including accommodation, employment, and Community Access Services, were seen to be operating in a dysfunctional manner. The service system was:

> ‘characterised as broken and broke, chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need. Services were unavailable or infrequent, unaffordable or of such poor quality as to be of little benefit’ (National People with Disabilities and Carer Council, 2009 p. 4).

Furthermore, over half of all people with disability who provided responses to the consultations (56 per cent) (National People with Disabilities and Carer Council, 2009) experienced difficulties with social participation, exclusion and negative social attitudes. They lived in communities but experienced being, ‘shut out’, from their communities.

The current research, therefore, commenced at a time of change. While social participation and community inclusion are fundamental human rights of people with disability, barriers to their participation clearly existed. For young people leaving school, it is anticipated by themselves and family members that they will be employed and a part of their local community. However for many people with disability, particularly people with intellectual disability, seeking and sustaining employment may be difficult. They may lack cognitive and/or organisational skills or the tasks with which they are presented are not sufficiently motivating for them. As a result 88 per cent of people with an intellectual disability in Australia do not have full-time employment (Australian Bureau of Statistics, 2012). In Australia, Community Access Services (CAS) are often seen as providing more suitable alternatives for these people as they provide leisure, arts and recreational opportunities and other alternatives which may provide a regular and more fulfilling routine of daily activities. As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (2006), Australia has a commitment to participation by all, with Article 30, participation in cultural life, recreation, leisure and sport, stating:

> ‘People with disability have the same right to take part in cultural life as other people do…to make it possible for people with disability to develop and use their creative, artistic and intellectual abilities, not only for their own benefit but for the benefit of society’ (United Nations Convention on the Rights of Persons with Disabilities, 2006, Article 30)

Participation in leisure, arts and recreation is a fundamental component of CAS.

CAS are commonly referred to in the literature as, ‘day programs’, (Australian Institute of Health and Welfare, 2015), day options, day activity services, adult social care services or, less generously, as, ‘holding centres’ (Riches, 1996).

CAS are defined by the Australian Institute of Health and Welfare (AIHW) as:

> ‘Services designed to provide opportunities for people with disability to gain and use their abilities to enjoy their full potential for social independence’ (AIHW, 2016, p. 8).

In Australia, the demand for CAS has increased steadily over the past decade, with predominant users being people with intellectual disability whose eligibility assessment, based on their, ‘needs’, is moderate, high or very high although eligibility criteria across Australian jurisdictions is inconsistent. There were 44,166 people with disability participating in CAS in 2004-2005 (AIHW, 2011, p. 8) and this has increased to 57,493 people with disability participating in CAS in 2013-2014 (AIHW, 2015, p. 23). Expenditure on CAS has increased from $483.4m in 2004-2005 (AIHW, 2011, p. 12) to $738.2m in 2013-2014 (AIHW, 2015, p. 10). Under the National Disability Agreement (NDA), CAS are provided primarily through non-government support services.

1.2 Context of the research

Historically, CAS have been provided for people with intellectual and physical disability as day programs in institutions, for the rehabilitation of war veterans, and for retirees in aged care facilities. Since the 1970s and the introduction of deinstitutionalisation policies, CAS have continued to be provided for people with disability in segregated settings and long entrenched problems with CAS have been identified. Wilson (1997), for example, questioned why public sector managers and government policy makers spend millions of dollars moving people with disability into a range of community accommodation settings only to return them to segregated day activity services. Stancliffe and Lakin (1999) further highlighted that unless transfer to the community is associated with a, ‘major change’, in the nature of people’s experiences of day programs, one of the most important benefits of deinstitutionalisation policies, that is meaningful community inclusion, remains unrealised.

The recognition of the associated problems of a segregated, ‘time occupation’, model of CAS which is driven by the services’ needs has continued throughout the 21st century. Despite an increasing demand for CAS and increasing funding requirements, there has been a notable absence of research in Australia and internationally on consumer perceptions of the benefits of these types of services.

In Australia, limited studies have focused on the participation of people with disability in CAS. However, the unique needs, goals, interests and preferences of people with Autism Spectrum Disorder (ASD) participating in CAS were explored by Burrows, Ford and Botroff (2001). Additionally, Bigby, Balandin, Fyffe, McCubbery and Gordon (2004) explicitly identified the need for studies of day programs to determine the extent to which the, ‘aims and program documentation,’ which CAS providers articulated, were realised and that these produced sought after outcomes. Internationally, there has also been limited research concerning CAS participation, particularly regarding people with a severe or profound level of intellectual disability who have little opportunity for employment or further educational opportunities (Hartnett, Gallagher, Kiernan, Poulsen, Gilligan & Reynolds, 2008). As a result, major gaps in information about current practice exist (Cole, Williams, Lloyd, Major, Mattingly, McIntosh, Swift & Townsley, 2007).

People with disability, family members, informal primary carers, academics, policy makers and advocates may question if a segregated approach should continue or if alternative opportunities to, ‘co-produce’, CAS with, and for, people with disability are possible in the 21st century, particularly as changes to policy, practice and legislation have commenced. Rather than segregation, CAS may provide an important role as agents in the facilitation of opportunities, with and for, people with disability in their actively chosen social pursuits. Participation in CAS within an innovative structure may provide a valuable socialisation option for people with disability compared to a lifetime of unemployment or underemployment, isolation, boredom and/or limited further education studies.

For example, when young people with disability complete their secondary education, CAS could contribute in the provision of a pathway for independence in adulthood by increasing opportunities to access community services in a supportive environment, while also providing vital respite for themselves and their families/informal primary carers**.**

The need to explore processes and approaches which contribute to quality outcomes for individuals and innovative co-production of public sector managed services, such as CAS, has gained increasing attention. According to Fledderus, Brandsen and Honingh (2014, p. 426), the term co-production was originally developed by Ostrom and colleagues in the 1970s to describe, ‘the possible relationship that exists between the regular producer and clients who want to be transformed by the service’. Researchers have highlighted the importance of a fundamental shift from an underlying public sector tradition of expert-driven creation and delivery to that of increased co-production of services enabling the leveraging of people’s own resources and engagement to enhance public service delivery (Hartley, 2005). This contributes to a paradigm shift from people with disability being perceived as, 'passive recipients of services and burdens on the system, into one where they are equal partners in designing and delivering services' (Boyle, Slay & Stephens, 2010, p. 23). It is also a strategic move in services for policy makers and for CAS providers from being, 'holding centres', in which the primary purpose is perceived as being, 'time occupation', for people with little to contribute to society, into, 'active participants', in service design, delivery and evaluation and a process in which consumers of services have an important role as agents of social change.

A social justice paradigm, is sought in which the fundamental, 'power of decision-making', shifts to the person with disability and their families/informal primary carers and away from government departments, organisational hierarchies and funding bureaucracy. As researchers highlight, such a process of co-production may, 'promise productivity gains with no reduction in service experience, or most likely even an increase, since citizens tend to value something they take an active part in producing' (Bason, 2010, p. 160).

The identification of customer service quality processes and approaches may further contribute to the co-production process. Service quality as a conceptualisation involves comparing a customer's evaluation of the perceived performance of specific attributes of a service to their prior expectations (Howat, Crilley & McGrath, 2008). In the context of this research, service quality involves an exploration of a person with a disability's expectations and rights/needs of a service (their user requirements) and their experiences of the services received (what they actually received from the service). This experiential knowledge may contribute to informing the innovative co-production of CAS, with, and for people with disability.

This research topic has considerable interest for the researcher professionally, academically, and personally. Professionally, both the strategic and operational provision of CAS, with and for, people with disability in Australia is relevant in his current role of Chief Policy Officer, Policy and Community Development Division, Department for Communities and Social Inclusion, Government of South Australia. Academically, in order to contribute to the body of knowledge regarding the quality, innovation and co-production of CAS. Personally, as a father of two children with intellectual disability.

1.3 Research aim

The aim of this research is to explore processes and approaches that contribute to quality outcomes for participants of Australian CAS.

Outcomes of this study include:

- exploration of the expectations of people with disability about CAS and the process of transition planning, prior to participating in CAS in Australia,
- exploration and identification of the rights and needs of people with disability and their experiences of the service design and implementation of CAS once they have been involved with these services,
- identification of existing policies and practices, and opportunities for future individualised approaches, and
- identification of recommendations to contribute to service quality.

Policy and professional practice alternatives are presented which can be implemented **with** people with disability through the introduction of the NDIS, and how these might address historical barriers that have contributed to the segregation of people with disability from mainstream services. The NDIS reforms aim to ensure that services will be high quality, appropriate to each individual’s needs and efficiently run (Cortis, Meagher, Chan, Davidson & Fattore, 2013).

1.4 Synopsis of chapters

This thesis presents the following chapters:

Chapter 2 reviews the literature including the definitions and epidemiology of disability and implications for CAS service provision. The historical development of CAS, perceptions of benefits and criticisms of CAS, service quality, innovative strategies and individualised considerations are presented.

Chapter 3 provides an overview of the research approach, participant involvement, collection, recording and analysis of data and consideration of ethical issues.

Chapter 4 presents the results from observations and memoing by the researcher, and findings from focus groups, and interviews with people with disability, family members/informal primary carers in South Australia. For clarity of expression the term, ‘family members’, is used throughout the study. Also presented are the responses from representatives from CAS providers as well as results from a questionnaire for people with disability and family members. Finally, findings from a critical discourse analysis of Australian extant texts are presented. The texts reviewed include Australian publically available CAS policies and written evidence from CAS providers about CAS design, implementation and the evaluation tools used.

Chapter 5 provides a discussion of the previously mentioned results and introduces a substantive theory of, ‘Social Transformation’, and the seven concept areas identified during the research. Implications for policy development and professional practice and the strengths and limitations of the research are also presented. The Chapter concludes with implications for further academic study.

Chapter 6 revisits the aim and intended outcomes of this research, and concluding comments are presented.

Chapter 2
Literature Review

2.1 Introduction

This chapter reviews research regarding people with disability, Community Access Services (CAS), leisure, the arts and recreation, service quality and individualised funding. Disability definitions, epidemiology, anthropological evidence and legislation and policy which have implications for service provision are provided. In addition, a review of the historical development of CAS in Australia and internationally, participation of people with disability in CAS and leisure, arts and recreation, and perceived benefits and criticisms of CAS provision is presented. Furthermore, a review of service quality definitions, the development of service quality instruments and processes and approaches relevant to public sector managed CAS are provided. Finally, individualised funding of people with disability and CAS services are explored.

The literature review was conducted between 2008-2016 using six electronic data bases CINAHL (Nursing and Allied Health data base), Medline (Medical database), Informit (Australian database including Health, Medicine and Education) ProQuest, Scopus, Ulrichs and Google Scholar Advanced. An initial search of the literature was performed using the following key words: disability, day activity, day programs, community access service, recreation, leisure, art, sports, service quality. All data bases were searched for the following key terms; innovation, co-production, co-creation, co-design, disability policy, inclusion and respite were introduced during the current research to further explore barriers and opportunities for the social and community participation of people with disability.

Published books and peer reviewed journal articles were reviewed as well as; unpublished research articles written by people with disability, family members/informal primary carers, public sector managers, educators, rehabilitation providers, federal, state and local government policy makers.

These unpublished research articles were accessed via the Flinders University Disability collection, Autism SA, Down Syndrome Association of SA, Brain Injury Network of South Australia (BINSA), the Disability Information and Resource

Centre (DIRC) and the Department for Communities and Social Inclusion Disability SA library collections at Fullarton, Gilles Plains and Central sites.

2.2 People with disability

An impairment is a physical fact, but a disability is a social construction (Braddock & Parish, 2001, p. 12). In Australia, people with impairment continue to experience disabling conditions. As McDermott and Turk (2011) state, most scholars and public health professionals are inclined to select one of the medical, functional or social perspectives and use that perspective predominantly or even exclusively for their program development and research (McDermott &Turk, 2011, p. 1). However, for many centuries stigmatising definitions and words have been used to describe people with disability, which were often derived from a person's, 'physical appearance or functional inabilities in a very simplistic manner' (Donoghue, 2003, p. 200).

Historically, descriptive words have been used to label people in society including 'incurable', 'lunatic', 'mongol', 'spastic', 'vegetative', 'retard', 'infirm', 'birth defect', 'deformed', 'abnormal', 'impaired', 'imbecile', 'deaf and dumb', 'feeble minded', and 'moron'. Such words have been used to stigmatise and demonise fellow human beings as being, 'other than normal' (Linneman, 2001). The term, 'cripple' (from the Old English 'crypel', meaning, 'one who can only creep') (Department of Families, Youth and Community Care Queensland, 1995, p. 9) is still used even today. The term, 'invalid', is also used yet may be perceived as meaning that a person with a disability is in-valid; that is in a literal sense not a valid contributing member of society. The term, 'dummy', is also frequently heard today yet it appears to have originated in reference to, 'an old and mutilated man who could neither speak nor hear and who lived in abject poverty in a mud hut', whose name was dummy (Quarmby, 2011, p. 36).

Language describing service provision also reinforced a separation for those who were shunned from society as they were segregated into, 'Mad Houses', and, 'Asylums', which were governed by, 'Commissioners of Lunacy' (Arnold, 2008). Literature which emphasised a person's inability to participate in community due to the, 'abnormal nature', of disability (Goffman, 1963) illustrates a reinforcement of negative stereotypes and assumptions. Specific colloquial terms have been used in society such as a person being a, ‘Minda’, in reference to a person with an intellectual disability residing at an institution called Minda in South Australia. The true meaning of Minda, a Kaurna Aboriginal word for, ‘shelter’ (Tutti, 2013), is lost if the intention of the use of the word is to be derogatory towards another human being.

In Western society such descriptions have often been replaced with words like, ‘different’, and, ‘special’, or having, ‘challenging behaviours’, and this continues to identify and segregate people with disability from other, ‘normal’, or, ‘neurotypical’, people.

2.2.1 Medical model

The, ‘condition’, of disability has been referred to as including, ‘people who have a physical, intellectual, psychiatric, sensory, neurological disability and includes learning disabilities, physical disfigurement and the presence in the body of disease causing organisms’ (*Disability Discrimination Act 1992* (Cth)). The term **disability** has long been based on an, ‘individual model’ (Burchardt, 2004) or as commonly referred to a, ‘medical model’, that has focused on a person’s medical limitations (Gilson & Depoy, 2002). The medical model calls for medical or other treatment or intervention to, ‘correct the problem with the individual’ (World Health Organisation, 2002, p. 8). As a result, people with disability or those who have a, ‘biological malfunction’ (Best, 2007), were viewed as needing to be segregated from society in order to receive care (Oliver, 1983).

2.2.2 Social Model

However, with increasing advocacy for human rights, alternative viewpoints to the medical model have emerged. The, ‘social model’, of disability, for example, recognises that disability is a, ‘socially created’, problem rather than that of an individual. The social model in contrast to the medical model demands a political response, since the problem is created by a physical environment, which is unaccommodating for people with disability, ‘and has been brought about by attitudes and other features of the social environment’ (World Health Organisation, 2002, p. 9).

Disability from a, ‘social model’, perspective has been defined as:

> ‘the disadvantage or restriction of activity caused by a contemporary social organisation 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, p. 22).

Literature regarding the social model of disability distinguishes between the impairments people have, and the oppression they experience (Shakespeare & Watson, 2001) and has included the realisation of civil rights of people with disability (Burchardt, 2004). Researchers, when considering the social model, argue that society’s understanding of disability should be viewed as a product of history, culture and politics (Hughes & Paterson, 1997). As such, there is a fundamental matter of social justice with regard to the dismantling and elimination of barriers for people with disability as they participate in society (Oliver & Barnes, 1998). Such barriers, whether architectural, social, organisational or attitudinal have affected the ability of people with disability to access services and truly participate in society (Darcy & Pegg, 2011; Dewsbury, Clarke, Randall, Rouncefield & Somerville, 2004). The development of a social model approach has been described as being an, ‘emancipatory force in the lives of many disabled people’ (Tregaskis, 2002, p. 457), and as an approach that enables the person with disability to take full control of his or her own life (Race, Boxall & Carson, 2005, p. 519).

2.2.3 International classification of functioning, disability and health

A third consideration has been proposed by the World Health Organisation, which emphasises that neither the medical or social model of disability is adequate. Instead, both are partially valid as disability is a problem both at the level of a person’s body, and as a result of complex and primarily social phenomena. Disability is therefore viewed as an interaction between features of the person with a disability and the overall context in which they live (Brown, 2003; Rhodes, Nocon, Small & Wright, 2008). A more useful model of disability according to the World Health Organisation, is referred to as the International Classification of Functioning, Disability and Health (ICF). The ICF is widely used as a framework for conceptualising, classifying and measuring disability and recognises that the components of functioning and disability—body functions and structures, participation and activity—reflect an interaction between health conditions and the person’s environment (AIHW, 2007).

The ICF was developed and refined by means of a 10-year international process involving over 65 member states. This led to a broad-based consensus over the terminology and classification, which, following field testing for cross cultural compatibility, ‘makes the ICF an international standard for functioning and disability classification’ (Goggin & Newell, 2005 p. 57). Often referred to as the ‘Biopsychosocial model of disability’ (WHO, 2002), as it integrates both the, ‘medical’, and, ‘social’, models of disability, the ICF is an important conceptual framework which underpins much Australian data (AIHW, 2007, p. 154). In Australia the Australian Institute of Health and Welfare has been encouraging the use of the ICF Framework for improving policy and information on disability and human function (AIHW, 2007, p. 154).

The ICF framework, Biopsychological model of disability is presented in Figure 2.1.

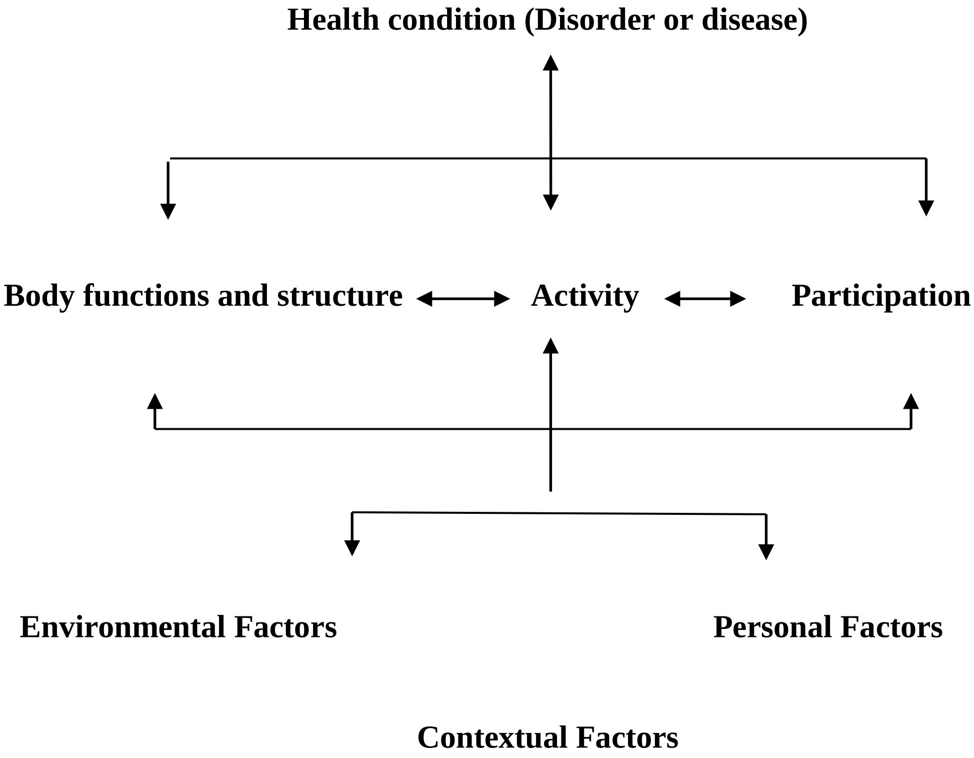

Figure 2.1 The biopsychological model of disability (World Health Organisation, 2002, p. 9)

Further definitions of disability have been proposed, for example, the United Nations Convention on the Rights of Persons with Disabilities, ratified by Australia on 17 July 2008, defines persons with disability as those who have long term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others (Productivity Commission, 2012).

The World Health Organisation has also defined disabilities as impairments, activity limitations and participation restrictions: an impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; and a participation restriction is a problem experienced by an individual in involvement in life situations. Disability, therefore, is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives (WHO, 2009 cited in Productivity Commission, 2012, p. 494).

Although the term, 'people with disability', which is commonly used in Australian literature, has been used throughout the current research, the researcher recognises that there is debate as to an alternative term, 'disabled people'. Cameron (2015), for example states that the term, 'disability', has come to denote the barriers disabled people face, rather than the impairments we live with (Cameron, 2015) and that disability is not something people, 'have', but is something done to people with impairments.

2.3 Epidemiology of people with disability

According to the International Centre for the Legal Protection of Human Rights, in 2004, 'one tenth of the world's population live with some kind of disability' (Goggin & Newell, 2005 p. 11). This equates to approximately 650 million people and has been described as the, 'world's largest minority', (World Health Organisation, Convention on the Rights of Persons with Disabilities, 2006). Approximately 80 per cent of the world's persons with disability live in low income countries with only two per cent of children with a disability in the developing world receiving any education or rehabilitation (Convention on the Rights of Persons with Disabilities, 2006). More recently the World Report on Disability (WHO, 2011) estimated that, 'based on 2010 population estimates (6.9 billion people) and 2004 disability prevalence estimates (World health survey and Global burden of disease) there were around 785 (15.6 per cent) to 975 (19.4 per cent) million persons 15 years and older living with a disability. Of these around 110 (2.2 per cent) to 190 (3.8 per cent) million experienced significant disability in functioning. Including children, over a billion people (or about 15 per cent) of the world's population) were estimated to be living with a disability' (WHO, 2011, p. 29).

In Australia, roughly one in five people (4.2 million people or 18.5 per cent of Australians) reported a disability in 2012 (Australian Bureau of Statistics, 2012). Of those with a reported disability in Australia, 88 per cent (3.7 million) had a specific limitation or restriction that meant they were limited in the core activities of self-care, mobility or communication, or restricted in schooling or employment (ABS, 2012). The Australian Institute of Health and Welfare (2007) have further highlighted that, of the total number of people in Australia with disability, some 2.6 million were aged under 65 years of age (15 per cent of the population). Indigenous people have significantly higher rates of profound or severe core activity limitation than non-Indigenous people in Australia with 10.3 per cent of Indigenous people aged 18 years and over reported to have a severe or core activity restriction in 2008, around twice the rate for non-Indigenous people (Productivity Commission, 2012, p. 501).

In Australia, people with a range of disability diagnoses have participated in CAS services, including people with intellectual disability, people with Autism Spectrum Disorder (ASD), and people with Acquired Brain Injury (ABI). A brief description of these disability diagnoses, an overview of their epidemiology in Australia and the potential implications for participation in CAS is provided in the following section.

2.3.1 People with intellectual disability

Intellectual disability is a major disability in the Australian population, especially among children and young adults. There are approximately 588,000 people with an intellectual disability in Australia (436,200 under 65 years of age), although the prevalence estimates of particular disability groups are more likely to be underestimated if only main conditions are considered, since people with multiple conditions are counted only once according to the main condition (AIHW, 2007, p. 159).

The statistical definition of intellectual disability occurs to present a comparison of an individual's performance to the performance of a standardised norm group. According to Dyke, Leonard and Bourke (2007) Intelligence Quotient (IQ) tests use the following classifications as displayed in Table 2.1:

Table 2.1 Classification of level of intellectual disability by IQ score

Classification	**IQ**
Mild Intellectual Disability	IQ 50-55 to approximately 70
Moderate Intellectual Disability	IQ 35-40 to 50-55
Severe Intellectual Disability	IQ 20-25 to 35-40
Profound Intellectual Disability	IQ below 20 or 25

Intellectual disability has been defined as a person having an intelligence quotient (IQ) of 70 or less, experiencing difficulties in living and working in their community including difficulties in social skills, communication, safety and self-care and limitations in intelligence first occurring before the person is 18 years of age (Dyke, Leonard & Bourke, 2007 p. 4).

In Australia 61 per cent of people with intellectual disability have a severe or profound limitation in, 'core', activities of daily living including self-care, mobility and communication (AIHW, 2008). People with intellectual disability are the major group of users of disability support services in Australia (AIHW, 2015). According to the Australian Institute of Health and Welfare report into Intellectual Disability (2008), service providers need to consider the level of support provided for people with intellectual disability in social areas especially making friends, interacting with others and maintaining relationships (AIHW, 2008). For people with intellectual disability, transition out of the labour force is common at ages 30-34 and onwards highlighting, 'difficulties for people with intellectual disability maintaining employment and a need for those who do leave a job to find alternative means of social participation' (AIHW, 2008 p. 3).

2.3.2 People with Autism Spectrum Disorder (ASD)

ASDs are neurodevelopmental disorders that cause substantial impairments in social interaction and communication and are associated with unusual behaviours and interests. For a diagnosis of autistic disorder a child must meet a specified number of criteria as identified in the American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders. DSM5* (Trochez, 2015) commonly known in practice as the, ‘DSM 5’.

The term autism was derived from the Greek word *autos* that means self. From as early as the 1960s autism was believed to have a psychological basis related to the mother’s inability to bond with her child, although this theory has been conclusively discredited (Baron-Cohen 2008; Firestone, 2008). In 1970, British psychiatrist and parent of a child with autism, Dr. Lorna Wing, and her colleague Dr. Judith Gould developed the concept of, ‘autism spectrum disorders’ (Wing, 1996). They characterised autism as a range of disorders based on difficulties with social interaction, communication and imagination (Firestone, 2008, p. 3). Just how these impairments and behaviours manifest themselves will vary from one child to the next (O’Reilly & Smith, 2008, p. 7). In the 1960s and 1970s, autism was considered a rare disorder and was estimated in the United States of America to affect four or five children per 10,000. These numbers stand in contrast to the recent estimates that one in every 150 children in the United States has ASD—a tenfold increase (Firestone, 2008, p. 2). In the UK the estimates are that about one in every 110 people have an ASD (Powell, 2006, p. 7) while the prevalence of ASD across Australia is estimated as 62.5 per 10,000 (1 in 160) for 6-12 year old children with a ratio of approximately one girl for every four boys and approximately 75 per cent have concomitant intellectual disability (MacDermott, Williams, Ridley, Glasson & Wray, 2006).

The implications for participation in society are significant. O’Reilly and Smith reviewed a range of individual case studies to provide a glimpse of the individual circumstances which affect both the very young in which diagnosis of ASD is very recent and those who have been living with ASD for many years (O’Reilly and Smith, 2008). For example, the following description is provided from the perspective of a mother caring for her son.

> ‘The medical profession and other health workers knew very little about autism in those days…When he was at home, I cared for a child who had no speech, was often significantly distressed with head banging, screaming and little sleep. He had ‘pica’ that is he ate everything in sight, like paper, soap, nuts and bolts, cigarette butts, his siblings’

> homework sheets and of course anything in the way of normal food at a phenomenal rate. He did things like emptying bins over the neighbour's fence, was not toilet trained at 16 years and would run away if anyone left the door un-padlocked. We had three younger children who learned the hard way to care for themselves and to live with dysfunction around them….To place him into a government facility was one of the hardest things I have ever done and I deeply respect that many other parents will choose differently. He will turn 50 this year and has been in 24 hour care since he was 16' (O'Reilly & Smith, 2008, pp. 213-215).

2.3.3 People with Acquired Brain Injury (ABI)

The term Acquired Brain Injury (ABI) encompasses all forms of brain injury and is the consequence of a neurological injury sustained after birth (Brain Injury Australia, 2010; Rushworth, 2008). ABI can be caused by accident/trauma, stroke, a brain infection, drug/alcohol abuse, or by a disease (Grimshaw, 2007). There are approximately 432,700 people in Australia who have a brain injury which equates to 1 in 45 individuals (O'Rance & Fortune, 2007). The leading cause of ABI is from a, 'stroke', where the blood supply to the brain is interrupted by bleeding or a clot. Strokes normally occur in older people, although around one in every five strokes occurs for people younger than 55 years of age. The next largest cause of ABI is by an accident or trauma and is referred to as a Traumatic Brain Injury (TBI) (O'Rance & Fortune, 2007). Males are twice as likely to experience TBI as are females. The highest incidence is among persons 15-24 years of age and 75 years and older. Alcohol is reported to be associated with half of all TBI, either in the person causing the injury or in the person with the injury (O'Rance & Fortune, 2007).

Social consequences of mild, moderate and severe TBI are many and serious including increased risk of suicidal ideation (Rice, 2003; Simpson & Tate, 2002; Teasdale & Enberg, 2001), psychosocial adjustment difficulties, physical disability and behavioural difficulties, relationship breakdown, substance abuse, economic hardship and social isolation (Ashley, Leal, Mehta, Ashley & Ashley, 2010; Bryan, Harrington & Elliot, 2010; Dawson & Chipman, 1995; Howard & Claiman, 1994; Kreutzer, Seel & Gourley, 2001; Kwan & Sulberger, 1994; McDonald, 2003; Moore, Indig & Haysom, 2014; Ponsford, Sloan & Snow, 2012; Sloan, Winkler & Callaway, 2004; Underhill, Lobello, Stroud, Terry et al., 2003.) These consequences are tragic to both individuals with a TBI and their families and place increased pressure on social service agencies, legal and police services as social networks are often fractured (Bellon, Gardner & Riley, 2008; Bellon, Crocker, Farnden, Gardner, Sando & Peterson, 2015; Godfrey & Shum, 2000; Lemair & Mallik, 2005; Nichols & Koscieulek, 2014; Rees, 1997).

Such disabilities occurring in young people in the prime of their life, can, 'have a catastrophic impact, not only on the life of the person who has sustained severe brain injury but also on that of their relatives, on whom they may have dependency for the rest of their lives' (Ponsford, Sloan & Snow, 1995, p. 27). As Helen Sage explained when describing her experiences with her daughter Jayne.

> 'Let's try something. See the alphabet here? Can you point to the letter A? I hold my breath. Jayne points to the A. It is clear and unambiguous. After four long months, we are on the brink of conversing. Today when I hold the board for Jayne, she spells out, 'C-a-n…I…g-i-v-e…y-o-u…a…h-u-g? I cradle her immobile body in my strong embrace, and wrap her arms, one limp and one flexed, around me; my tears fall silently' (Sage, 2013, p. 58).

2.3.4 Increased population of people with disability and demand for services

According to ACROD (2003, p. 11) the population of people with disability including intellectual disability, ASDs and ABIs continues to increase due to a range of factors including:

1. An increased life expectancy of children with severe disability and high support needs,
2. The improved survival rates for low birth weight babies linked to an increasing number of children with health issues and disability,
3. An increased number of children with significant disability surviving accidents, including an increasing proportion with brain injuries,
4. The increased number of children with a diagnosis of ASD,
5. The increasing service expectations among families, based on recognition of the value of early intervention and individual therapies in promoting children's development, and
6. The increased pressure on families, including level of family breakdown and reliance on formal services.

2.4 Disability: From a history of exclusion towards inclusion

Anthropological research and ancient religious texts provide records from pre-modern, renaissance, industrial revolution and modern eras of history. These show that there have been major changes in societal attitudes toward people with disability as well as the, 'lived experience', of individuals with disability. Examinations of concepts related to these changes may assist in understanding the transition that has occurred from the exclusion of people with disability toward their inclusion in society and the relevance and the potential strategic role and contribution of CAS in this process in the 21st century.

When exploring a history of people with disability, particularly in a Western world context historians have noted difficulties in relying solely on professionals' accounts, such as the public records from institutions, which have rarely represented the broad spectrum of disabilities including, mental, physical and sensory disability (Braddock & Parish, 2001, p. 12).

2.4.1 Scapegoats, cursed, stigmatised, freaks: Disability and community exclusion in a pre-modern world

References to people with disability, particularly in, 'Western society', are provided in a range of religious and anthropological historical texts. Scholars of Old Testament Hebrew Law, for example, illustrate paradoxes between disability perceived as punishment for wrongdoers while also acknowledging that followers were commanded not to curse people who were blind or deaf but rather to provide protection (Braddock & Parish, 2001). Indeed, it was suggested that widows, orphans, and the blind and deaf must not be wronged (Duignan, 2011). Unfortunately such protection has not always occurred. Ancient Greek and Roman history researchers highlight examples of brutality towards people with disability. Attitudes being attributed to the concept of the, 'body beautiful', in Greek and Roman culture separated those with, 'imperfections', and horrendous treatment was often inflicted on them. Children born with a congenital disability in ancient Greece were inspected as a legal requirement for citizenship and infanticide was frequently practiced (Mackelprang & Salsgiver, 1996). Any children who were inspected by elders and considered to be in any way, 'defective', were dropped into a chasm (Quarmby, 2011). Socrates determined that, 'defective offspring', will be quietly and secretly disposed of and Aristotle recommended that, 'with regard to the choice between abandoning a child or rearing it, let there be a law that no cripple child be reared' (Quarmby, 2011 p. 20). Those born with disability were often viewed as being, 'cursed', and unworthy of life because of some, 'sin', associated with them or even that their family had displeased their gods (Braddock & Parish, 2001).

Classical scholars highlight that, in times of hardship, a, 'scapegoat', was often sought. When a famine occurred, for example, they attributed this to the, 'most odious'; a cripple, a victim of nature, someone who was lame, and they would be sacrificed to be rid of the evil which the society was experiencing (Quarmby, 2011). The Greeks used the term, 'stigma', to refer to bodily signs which exposed the unusual; those who were, 'blemished', were, 'to be avoided in public places' (Goffman 1963). They were viewed as an abomination because of their deformed body. Such attitudes towards those who were stigmatised resulted in a separation between those who were human, and those who were excluded as they were believed to be, 'not quite human' (Goffman, 1963).

Roman history scholars also refer to examples of infanticide of children with disability. According to the Roman law of the 12 tables, deformed children should die after being shown to five neighbours (Heinemann, 1968). Those who were not killed were paraded in freak shows together with adults with disability. Ancient Roman spectacles occurred in which dwarfs, hunchbacks and, 'fools', were in high demand as entertainers. They were forced into combat to delight the Romans and were bought and sold in the, 'monster market' (Quarmby, 2011). The scholar Barton (1993) surmises that in the Roman culture part of the extended repertoire of pleasures included, 'the enjoyment of the available array of monsters, freaks, fools, exotic persons, animals and food' (Barton, 1993, p. 68). Brutal practices by the Romans continued as the empire expanded into Europe and England. For example, in the 1st century AD people with mental health conditions were treated using a primitive form of electric shock, using live eels, and a primitive form of neurosurgery known as trepanning, which involved drilling a hole in the patient's skull to let out the bad spirits (Arnold, 2008, p. 26, p. 29). In contrast, soldiers in Greek and Roman society injured in war received some compensation through pensions (Braddock & Parish, 2001). However, the overall legacy of Greek and Roman culture can be viewed as having a rich contempt for people with disability who should be, ‘banished from sight and segregated permanently’ (Quarmby, 2011, p. 26).

2.4.2 Possession and the supernatural in the medieval period

Historical records illustrate attempts to expel or kill people with disability as being, ‘possessed’, or as people having an illness which could be cured through an array of rituals. People with disability were linked to the supernatural, witchcraft and the demonic. As Arnold (2008) reports, though hospitals were being constructed in cities such as London as extensions of religious orders, those troubled in mind, ‘had to compete for beds with the lepers, the blind, the crippled, the toothless hags and the abandoned children scrabbling for scraps of bread and cheese, a jug of ale and a bed of straw’ (Arnold, 2008, p. 2). One of the most notorious Hospitals of this era was the Priory of St. Marys of Bethlehem (or Behlem), the first asylum for, ‘lunatics’, founded in 1247 in the east end of London caring initially for people with physical disability and then increasingly for people with mental illness (Braddock & Parish, 2001). Institutions for segregation of people with leprosy were also established from the 12th century throughout Europe as part of charitable work of religious orders (Braddock & Parish, 2001).

By the mid 16th century the Priory of Bethlehem had become better known as, ‘Bedlam’ (a byword referring to chaos and pandemonium) and this continued to operate into the 20th century as the longest continually operating mental hospital in Europe (Andrews, Briggs, Porter, Tucker & Waddington, 1997; Braddock & Parish, 2001; Hollingsheads, 2004). Though hospitals such as Bethlehem were initially established with good intentions for people with disability, societal beliefs continued to treat people with disability and their parents very differently.

In 1487, for example, a manual called *Malleus Maleficarum, (The Witches Hammer)* was written by two German friars Jacob Sprenger and Heinrich Kramer who stated that children with impairments were born to mothers who were involved in witchcraft and sorcery. Scholars believe that many thousands of witches were put to death across Europe between the 15th and 17th Centuries and many of those targeted were disabled (Quarmby, 2011 p. 32). Deafness, mental disorders, epilepsy and intellectual impairments were linked to the supernatural or demonological causes during the medieval period (Braddock & Parish, 2001).

Increasingly the targeting of people with disability occurred, through fear, hostility and as medical curiosities as institutionalisation continued to expand in order to separate the, ‘different’. Arnold (2008) reports that Bethlehem was listed in the 1690s as one of the sights of London, and though this public exhibition of people with disability and mental health issues appears to contemporary society to be demeaning, there was a charitable aspect to this. ‘Visitors may have come to mock but their entrance money contributed to the inmates’ welfare’ (Arnold, 2008, p. 103).

2.4.3 Industrial revolution: Asylums and institutionalisation

Asylums from the 17th century have been described as, ‘an early form of social welfare’ (Arnold, 2008, p. 5) as they were constructed across Europe and later the United States of America and Australia. As the industrial revolution gathered pace those who were labelled as, ‘feeble-minded’, were placed on the bottom of the labour market (Morris, 1969). The families of many were unable or unwilling to provide support (Braddock & Parish, 2001). Parish workhouses, private madhouses and local jails held people with disability, who were surplus to requirements. Confined together in asylums and institutions, people with intellectual disability and mental illness were kept from the streets.

Braddock and Parish (2001), also refer to the role of community following the passing of the, Poor Law by Queen Elizabeth in 1601. Since towns were responsible for people who were poor, ‘communities took steps to discourage vagabonds, beggars or idle persons from settling therein. People who were considered likely to become a public charge would be warned out of town, with public whipping—the penalty for not leaving’ (Braddock & Parish, 2001, p. 26). As a result people with disability were not welcome in towns because of their cost, were unable to be cared for by families and living in destitution. Incarceration and/or institutionalisation followed.

In 1828 in the UK attempts were made to change the, ‘degradation and inhumane treatment’, which had occurred by instituting a, *Madhouses Act* for better conditions in madhouses, including education and recreation (Quarmby, 2011 p. 45). In 1867 the London Metropolitan Asylums Board was established to bring relief for the infirm and build new asylums for, ‘lunatics’, and, ‘idiots’. By 1881 in the UK there were 30,000, ‘classified idiots’, in institutions, some of which had become a dumping ground for paupers, unwanted wives, orphans and lunatics. By 1890 there were some 66 county and borough asylums throughout the UK (Quarmby, 2011 p. 47). Institutional development was closely associated with the increasing role of charitable organisations during the 1800s such as the British and Foreign Blind Society (1868), National Society for the Employment of Epileptics (1892) and the National Association for Promoting the Welfare of the Feeble Minded (1896) (Quarmby, 2011). Not only were people with disability being housed in institutions, but also their segregation from society was being legitimised. For example, in the United States in the mid 19th century, ‘mendicant laws (dubbed the ugly laws)’, were instigated that banned the, ‘unsightly’, from streets, schools and restaurants (Schweik, 2009).

Australian colonial history also has a rich legacy of institutional segregation which contributed to the social exclusion of people with disability who were, ‘shut out from social and economic participation, not because of any perceived individual failings, but because of systems failures, the denial of citizenship rights to those most affected’ (Alston, 2010, p. 32). Following early English colonisation in Australia, people with disability who could not care for themselves or be cared for by family members had no option but to be placed in institutions. Prior to the first asylum being constructed, for example, in Castle Hill in New South Wales in 1811, people with, ‘mental imbecility’, were imprisoned in Parramatta gaol. In Fremantle in Western Australia, ‘lunatics’, were held in the hulk of a merchant ship in the harbour before being sent to a prison when it was constructed in 1831 (Cocks & Stehlik, 1966). In South Australia when the colony began in 1836 there was no provision made for people who at the time were referred to as, ‘lunatics’. Consequently they were kept in the Adelaide Gaol, ‘restrained and out of sight’.

By 1841 in South Australia about 2,000 destitute persons were on government support and a Board of Pauper Lunatics was set up to find an alternative to keeping people with mental illness in the Gaol (Disability Information and Resource Centre, 2007). By March 1852 the Adelaide Lunatic Asylum was opened as the, ‘Destitute Asylum’, in the west parklands which had provided relief for 187,‘outdoor cases’, had become inadequate (Geyer, 2008). However the Adelaide Lunatic Asylum also soon became overcrowded. The Parkside Lunatic Asylum, a purpose-built asylum for 700 patients, was constructed and opened in 1870.

The provision of further institutional supports for people with disability included the, ‘Home for Incurables’ (1878) as, ‘a haven for the incurably sick of all ages’ (Kerr, 1978, p. 3.), ‘Townsend House’ (1878) for children who were unable to speak, were blind, and/or deaf to provide a refuge, education and boarding facilities, ‘Estcourt House’ (1894), as a place to help people in need (including children from as young as four years of age and elderly impaired people) and the, ‘Minda Home’, (1897), ‘to provide care, education and special training so the children would have happy and useful lives’ (Disability Information and Resource Centre, 2007). The policy of constructing institutions to care for the, ‘feeble minded’, became common, such as the building of the Children’s Cottages at Kew in Melbourne in 1887.

As well as the construction of institutions, legislative changes were also introduced which affected the lives of people with disability in Australia. From as early as the 1890s the colony of New South Wales, for example, introduced an, ‘old-age pension’, for people over the age of 65, as well as an, ‘invalid pension’, for those aged 60-65 and those with a, ‘permanent disability’ (Tipping, 1992). In 1907 the New South Wales *Invalidity and Accident Pensions Act* extended the eligibility to include people 16 years and older who were permanently incapacitated for work but excluded people who could be supported by their relatives (Tipping, 1992). In 1916 an institutional pension was paid to pensioners in benevolent asylums (Disability Information and Resource Centre, 2007). Following World War One soldiers returning from war into the community were involved in vocational training.

This continued through the Great Depression of the 1930s and new legislation was introduced in 1941 to enable a vocational training scheme for invalid pensioners. While institutionalisation continued, alternative, ‘medical’, strategies were also emerging.

2.4.4 International eugenics movement and removal of the weak, unfit, unworthy

The late 1800s and 1900s, unfortunately will also be remembered not only for the institutionalising of people with disability but also their attempted annihilation. Charles Darwin’s theories of natural selection and evolution were embraced by eugenicists who believed that cleaning up the gene pool was vital to the safeguarding of the human race. During the early 1900s such views were espoused by members of the Eugenics Education Society and notable medical authorities of the era. For example, British consulting physician to University College Hospital, London, A. F. Tredgold argued that, ‘‘idiots’, were incapable of being employed … their care and support absorbs a large amount of time, energy and money of the normal population, … many are utterly helpless, repulsive in appearance and revolting in manners’, and that, ‘80,000 or more idiots and imbeciles in Britain should have their existence painlessly terminated’ (Arnold, 2008, p. 267). In the United States the sterilisation of disabled people who were, ‘feeble minded’, or, ‘unfit’, was permitted from 1907. The major argument for the benefits of legislated sterilisation was that it would be better for both society and the, ‘feeble minded individual’, in question if the latter had never been born.

American scientists such as Goddard further utilised the IQ test to divide the, ‘moron’, from the, ‘idiot’, and advocated for, ‘colonies’, where feeble minded could be, ‘hidden from view’. Claims were made that prostitution, unemployment, poverty and insanity were all linked to feeble-mindedness (Goddard, 1914). In Australia the Medical Journal of Australia in 1931 supported the sterilisation of, ‘mental defectives’ (Disability Information and Resource Centre, 2007).

During the 1930s the separation and systematic murder of thousands of disabled people occurred as the Nationalist Socialist Party in Germany attempted to create a pure Aryan nation. Historians note that in the early 1930s after the Nazis came to power films and posters stressed the financial, ‘cost of disability’. Asylums in Germany were opened up for tours with SS members stressing the necessity for eugenic measures (Burleigh, 2002). Further propaganda followed labelling people with disability as, ‘unworthy of life’, ‘useless eaters’, and a burden on society. The writings in *Mein Kampf* include statements that the lame and the defective are a scourge on humanity with a priority to get rid of, ‘cripples’, and, ‘cretins’. Disabled adults were murdered in six institutions in Germany from 1939 onward with Hitler granting permission for, ‘mercy deaths’. By the end of World War II it is estimated that some 200,000, ‘insane’, ‘retarded’, and, ‘disabled’, people were annihilated (Quarmby, 2011).

Despite the eugenics movement of the 20th century, institutional segregation of people with disability continued. In 1946 the newly established British National Health Service, ‘had inherited around 1,000 asylums with an average population of 1,000 patients each’ (Arnold, 2008, p. 267). The separation of children with disability from their families into institutional, ‘care’, continued to be advocated by, ‘experts’, such as Dr. Benjamin Spock. In *The Pocket Book of Baby and Child Care*, Dr. Spock stated regarding the, ‘seriously retarded’, child;

> ‘The child who is 1½ for instance, is unable to sit up, or satisfied to shake a rattle or look at fingers, shows little interest in people is a different problem. Being a helpless baby for an unusually long time, he will require much care over a long period and perhaps leave too little of his mother’s attention for older and younger children in the family. There is less chance that he will ever develop to the point where the family can enjoy him or he enjoy the family. It may be better all-round if he is cared for in a special home, boarding school or institution, beginning as soon as his defectiveness is recognised’ (Spock, 1946, p. 477)

Dr. Spock further provided advice regarding children with the condition of, ‘mongolism’, stating that it is usually recommended that the woman who has had a, ‘mongoloid’, baby, and has no other children, try to have another child before too long and that:

> ‘… if the family can afford to place the baby in a special home, it is usually recommended that this be done right after birth. Then parents will not become too wrapped up in a child who will never develop very far, and they will have more attention to give to their normal children who need it’ (Spock, 1946, p. 477).

Spock, in addition, stated that if a family has a child who is disabled and, ‘merely exists at a level that is hardly human’, it is better for the parents and other children for the child to be cared for elsewhere (Spock, 1946, p. 478). People with disability through state-sanctioned processes were described as being, ‘lives devoid of value’, (Kendrick, 2010, p. 1).

2.4.5 Human rights for people with disability

In 1946, following WWII, the United Nations constructed its Declaration of Human Rights. In Australia, the Commonwealth Rehabilitation Service continued to provide, ‘vocational education, training and employment programs for the disabled’, (Organisation for Economic Cooperation and Development, 2001, p. 286.). Under the *Social Services Act (Part VIII) 1947-1977* (Cth) rehabilitation could be provided free of charge to, ‘virtually any disabled person in the broad working age group who can benefit from such services including access to Day-Attendance Centres’ (Panckhurst & Panckhurst, 1982, p. 41). In Australia an Invalid Pension was paid to people undertaking vocational training or treatment from 1948. In 1967 the Australian Government passed the *Shelter (Assistance) Act 1967* (Cth) providing grants for non-profit organisations to equip sheltered employment and supported accommodation. A Sheltered Employment Allowance was also introduced by the Australian Government for people working in sheltered workshops (Disability Information and Resource Centre, 2007).

Legislation changes continued to occur in Australia, for example, in 1974 the *Handicapped Persons Assistance Act 1974* (Cth) was instituted which subsidised organisations providing approved programs of sheltered employment, activity therapy and training, associated accommodation facilities and ancillary rehabilitation and recreation programs (Panckhurst & Panckhurst, 1982). Though legislative changes contributed to supporting people with disability, institutions such as the Strathmont Centre in South Australia were being constructed to accommodate people with intellectual disability even during the 1970s.

This facility was promoted as a, ‘vibrant living village centre’, to accommodate up to 800 people with intellectual disability and separate them from the clients of the mental health service institution at Parkside. While this may have occurred because of good intentions, ‘under the guise of protecting them from the challenges of decision-making and living independently’ (Barriga, 2012, p. 51), the fundamental right of inclusion in society was affected.

2.4.6 ‘Normalisation’ and the welfare state

Internationally, changes began to occur during the 1960s and 1970s as families began to, ‘reject the advice given to them that their family member with a disability be sent to live out their lives in residential institutions’ (Kendrick, 2010, p. 2). People with disability, families/advocates, policy makers, academics and service providers became influenced by the increasing development of a concept referred to as, ‘normalisation’ (Bank-Mikkelsen, 1980). The theory of normalisation proposed that people who did not perform roles which were valued in society would be stigmatised and experience rejection. The theory of normalisation was developed by Neils Bank-Mikkelsen (1976) and Bengt Nirje (1969) and according to Nirje (1982), ‘the normalisation principle means making available to all mentally retarded people patterns of life of everyday living which are as close as possible to the regular circumstances and ways of life of society’ (Disability Information and Resource Centre, 2007).

Instead of experiences of stigmatisation, a reversal of the social processes was required so that the use of culturally normative even culturally valued means would enable socially devalued persons to achieve and maintain valued social roles (Wolfensberger & Thomas, 1983, p. 18). From a theory of normalisation, Wolfensberger developed Social Role Valorisation (SRV) principles, which advocated for the enablement, establishment and enhancement of valued social roles using, as much as possible, culturally valued means (Wolfensberger, 1983). In practice, to achieve normative outcomes the basic strategy is to defend a person’s role by helping them maximise their competencies and to support culturally valued images wherever possible (Walsh, 1995). In a transition experience from secondary education, this may involve identifying individual’s strengths and capabilities which are shared in an environment in which they are valued.

In 1976 the United Nations General Assembly proclaimed 1981 as the International Year of Disabled Persons. The theme of, ‘full participation and equality’, focused attention on disabled people’s rights and opportunities in order for full participation and integration in society (Disability Information and Resource Centre, 2007). From this growing call for reform, institutional care began to be replaced with supported cluster and individual accommodation options for people with disability. From the 1980s many governments in Western society adopted policy frameworks promoting the deinstitutionalisation of people with disability or mental illnesses. The development of policies aimed to enable people with disability to be supported in community-based settings rather than large congregate institutions. Steadily closing institutions which provided care for people with disability, therefore, became a promise of community inclusion and was one of the great social policy changes of the 20th century (National People with Disabilities and Carer Council, 2009, p. 9).

Legislative changes also recognised the need to support the rights of people with disability and their carers. In 1984 in South Australia, the *Equal Opportunity Act 1984* (SA) was introduced which aimed to promote equality of opportunity and to facilitate the participation of citizens in the social life of the community (Disability Information and Resource Centre, 2007). In Australia, the Spouse Carer Pension was introduced in 1985 which provided income support for carers providing constant and long term care to a spouse or near relative who was, ‘severely disabled’, and the *Disability Services Act 1986* (Cth) guided the funding and provision of Commonwealth support services for people with disability. Legislation such as the *Social Security Act 1991* (Cth) was implemented to determine the conditions for receiving a wide variety of social security payments including the Disability Support Pension (1991). The Invalid Pension was essentially unchanged from its introduction in 1910 until 1991 when the Disability Support Pension was introduced.

Eligibility for a Disability Support Pension required an applicant to have, ‘a physical, intellectual or psychiatric impairment, based on impairment tables in the *Social Security Act* (Disability Information and Resource Centre, 2007). In 1992 the *Disability Discrimination Act 1992* (Cth) was enacted to protect the equality of people with disability with other community members in Australia. In 1993 the United Nations adopted the Standard Rules on the Equalisation of Opportunities for Disabled Persons that have provided policy guidelines promoting the same opportunities to persons with disability as enjoyed by persons without disability. (United Nations Convention on the Rights of Persons with Disabilities, 2006). Legislative and policy developments to uphold equality of all community members have had important implications for people with disability not only in supporting, ‘normalised’, accommodation options rather than institutions but also, importantly, comparable changes in opportunities for employment, further education and volunteering as well as participation in, ‘mainstream’, recreation and leisure pursuits which also impact upon potential participation in CAS.

Being employed has been reported as increasing self-confidence and self-esteem as well as providing changes to the way in which people with disability perceived the way they were viewed by their peers and family, as well as encouraging feelings of making a contribution and being helpful to other people (McIntosh & Whittaker, 1998). Furthermore, employment has been identified as one of the major defining roles in the lives of people with disability as employment enables the generation of income and also provides structure to the week (Beyer, Grove, Schneider, Simons, Williams, Heyman, Swift & Krijnen-Kemp, 2004). Yet, despite employment being an important aspiration for many people with disability, low levels of employment, low wages and low hours of employment have been the norm (Watson, Williams & Wickham, 2005). Agencies assisting employment preparation through traditional services in Australia had not served people with disability well during the 1990s according to researchers such as Ford (1998). In 1994, for example, people with severe disability experienced 70 per cent unemployment in Australia, compared with the national unemployment rate, at that time, of 10.4 per cent for persons without disability (Ford, 1998).

Consequently, poverty is frequently associated with people with disability. Aspin (2002), stated that, ‘Handicapped and disabled people are often denied the opportunity to work, or depending upon the degree of handicap, employment options may be very limited. Many handicapped people must take part-time work, and therefore are more likely to suffer relative poverty’ (Aspin, 2002, p. 118). Furthermore, negative attitudes and misconceptions about disability means, ‘few employers—whether government, non-government or corporate—appear willing to employ anyone with a disability’ (National People with Disabilities and Carer Council 2009, p. 5). Alarmingly, people with disability are more likely to encounter discrimination because of employer’s uncertainty about productivity (Baume & Kay, 1995) despite legislation in Australia, which makes it unlawful to discriminate either directly or indirectly against a person on the basis of a disability (*Disability Discrimination Act 1992* (Cth)). Researchers also highlight that people with disability are more frequently working part-time compared to the non-disabled population and are employed in low wage positions in factories, as labourers or in domestic work (Emerson, Malam, Davies & Spencer, 2005).

In 2004 in Australia, people with disability aged 20-64 lagged badly in their relative income compared to that of non-disabled people. Researchers compared Australia’s relative incomes with 16 countries including Sweden, Germany, Netherlands, Switzerland, Austria, Denmark, Canada, Finland, Belgium, France, Italy, Norway, UK, Ireland and the United States and discovered that, while, ‘the 16-nation mean was to receive 80 per cent of the non-disabled income, in Australia the figure is only 44 per cent’ (Tiffen & Gittins, 2004, p. 153). In Australia changes to policy, for example the, ‘Welfare to Work’, package introduced in 2005 by the Australian Government, was largely focused on changing the behaviour of individual welfare recipients by subjecting them to mutual obligation requirements. The policy has been subject to criticism for, ‘…stigmatising the recipient of social benefits as an unworthy social condition’ (Humpage, 2007, p. 220).

Legislative and policy changes have also influenced opportunities for people with disability to participate in further vocational and tertiary education. As well as experiencing low rates of employment, people with disability continue to have limited further education and volunteering opportunities in comparison with, ‘able bodied persons’, in Australia (Taylor, McGilloway & Donnelly, 2004, p. 93). Similarly in the United States researchers state that, while young people with disability have not been enrolled in post secondary educational settings at rates equal to those of their non-disabled peers (Evers, 1996), dropping out of school prior to completing secondary education continues to lead to high unemployment rates and poor socioeconomic status (Lemaire, Mallik & Stoll, 2002).

According to Ball (2001), not only physical changes but also attitudinal barriers must be addressed so that equal participation in all aspects of community life can occur (Ball, 2001). Regarding participation in community leisure, arts and recreation pursuits, researchers have identified that people with disability are under-represented, compared to non-disabled people, in accessing local community-based recreation and leisure services (Dattilo, 2002; Edgecombe & Crilley 2002; Lockwood & Lockwood, 2007; McGrath, 2009). Facilities may have ramps but attitudes still appear to exclude people with disability from community recreation settings.

2.4.7 Social inclusion and social citizenship

> ‘Good intentions do not always make for good policy’ (Human Rights Watch, 2012, p. 52.)

Although changes have occurred for people with disability since the introduction of deinstitutionalisation policies, the need for further major changes were identified by research undertaken in the late 2000s by the National People with Disabilities and Carer Council. This research was conducted throughout Australia and over 2,500 people provided responses, including people with disability, family members, and primary carers.

The resulting, *SHUT OUT: The Experience of People with Disabilities and their Families in Australia,* National Disability Strategy Consultation Report (The *SHUT OUT: Report*) recommended that fundamental changes to policies and programs were required as, ‘people with disabilities want to bring about a transformation of their lives’, (National People with Disabilities and Carer Council, 2009, p. 9). While people with disability in Australia had been physically segregated in the past, many Australians with disability now reported finding themselves socially, culturally and politically isolated as negative attitudes towards people with disability continue in the community. This national study discovered that, ‘a clear picture emerged from the consultations and submissions. People with disability may be present in the community but most do not enjoy full participation in it. Furthermore, daily instances of being segregated, excluded, marginalised and ignored were reported’ (National People with Disabilities and Carer Council, 2009, pp. 2-3).

Changes to policy and legislation have undergone reforms since the 1990s. However, institutional practices of service delivery still remain and act as barriers to participation of people with disability (Darcy, 2001). An increasingly, ‘managerialist approach’, together with competitive tendering for service delivery has changed the arrangements between the government funding bodies and the providers of services such as CAS. In Australia, federal and state government funding of disability advocacy and rights groups, and other non-government organisations (NGOs), has resulted in constraints being placed on these organisations through their funding agreements. For example, the transfer of state resources to the community sector through faith-based organisations and secular NGOs places limits on their traditional role as advocates for the disadvantaged (Spoehr, 2009). Researchers argue that, ‘charities are hamstrung in their capacity to criticise the system and advocate reform and take up cudgels on behalf of their clients because they may very well lose their funding for doing so' (Goggin & Newell, 2005, p. 70). Australian local government authorities have also undergone major organisational and structural reforms including amalgamations, adherence to performance management measures and requirements to manage service provision using private sector models (Aulich, 1999; Dollery & Johnson, 2005; Kloot & Martin, 2000).

Researchers highlight that as public sector management has increasingly moved towards a business model which has a focus on, 'target markets', and, 'cost efficiency', the provision of services for all citizens may be adversely affected (Thibault, Kikulis & Frisby, 2004). The introduction of local government Disability Action Plans (DAP) as legislated to ensure equitable access to services for all community members has been a significant step forward particularly for physical access to services for people with disability. However, in an analysis of 29 local government authority DAPs in Australia, statements which dealt with constraints faced by people with disability such as social or organisational aspects were either briefly addressed or found to be non-existent (McGrath, 2008).

When investigating the experiences of people with disability and their families as identified in the *SHUT OUT: Report*, researchers concluded that the disability services system in Australia was unable to meet the current need for services such as CAS and has limited capacity to meet anticipated increases in demand (National People with Disabilities and Carer Council, 2009). With restrictions and limitation on the capacity of service providers to express concerns, the, 'voice', and perceptions of people with disability and family members/informal primary carers for future legislative and policy development is essential (Fisher & Robinson, 2010; Mactavish, Mahon & Lutfiyya, 2000; Thomas, 2013). Where service system deficits exist, reference to United Nations Conventions which are in place to facilitate and help protect rights of people with disability, such as The Convention on the Rights of Persons with Disabilities, (2006), require exploration.

In Australia the development of the National Disability Agreement (NDA) from 1st January 2009 provided a national framework for the provision of government support and services for people with a disability and replaced the previous Commonwealth State Territory Disability Agreement (CSTDA). The focus of the

NDA was on the provision of specialist disability services which are complemented by mainstream services and income support measures.

The NDA identified 10 priority areas which underpinned the future policy directions including: better measurement of need; population benchmarking for disability services; making older carers a priority; quality improvement systems, based on disability standards; service planning and strategies to simplify access; early intervention and prevention, lifelong planning and increasing independence and social participation strategies; increased workforce capacity; increased access for Indigenous Australians; access to aids and equipment; and improved access to disability care (Productivity Commission, Report on Government Services, 2012, p. 492). Under the NDA, state and territory governments are responsible for services such as CAS, including regulation, service quality, and assurance, assessment, policy development, service planning and workforce and sector development, ‘in a manner which most effectively meets the needs of people with a disability, their families and carers, consistent with local needs and priorities’ (Productivity Commission, Report on Government Services, 2012, p. 496). In 2010 the Australian Government commissioned an inquiry by the Productivity Commission into a long term disability care and support scheme. Over 1,000 submissions from people with disability and the disability sector were received during the consultation process. The Productivity Commission sought to address major considerations including how a scheme should be designed and funded, how to determine who is in, ‘most need’, costs, benefits, feasibility and funding options, how the scheme could interact with other systems such as health, aged care, informal care, income support and injury insurance systems, how the scheme should be introduced and governed and what protections and safeguards should be in place (Disability Care Australia, 2013).

In South Australia the *Strong Voices* report was released (Department of the Premier and Cabinet, South Australia, 2011). This report identified that the existing disability services system in South Australia is unsustainable in its approach, both to the delivery of services and supports as well as funding. The result, ‘has been for far too long, people with disability have been shut out from participating in the social and economic life of our society’ (Department of the Premier and Cabinet, South Australia, 2011, p. 1). The *Strong Voices* report produced a range of priorities relevant to CAS services co-produced with people with disability. These included, the need to develop a user group to ensure people with disability are heard and have input into disability issues including the facilitation of annual regional forums with people with disability, their families, carers, and stakeholders (Priority 2, p. 23); the need to harness digital technology inclusion including use of social media particularly for people with a disability who are isolated and in regional and remote areas (Priority 5, p. 31); an increase in flexibility and successful transition from school to adult life by expanding school transition plans between school sites and post school pathways (Priority 9, p. 36); assessment and resource allocation, driven by a person with disability’s needs and aspirations (Priority 10, p. 41); Better support for carers, recognition of needs of older carers and assistance for costs of caring (Priority 14, 15 and 16, p. 47); a free public transport system for all people with a disability and their carer (Priority 34, p. 82).

The involvement of people with disability and their families in the management of individualised funding from July 2012 (Priority Action 11, p. 44) is a key priority directly affecting the choice of CAS providers. In July 2012 an agreement was reached nationally through the Council of Australian Governments (COAG) to proceed with the launch of the National Disability Insurance Scheme (NDIS) and in March 2013 the NDIS legislation was passed and the *National Disability Insurance Scheme Act 2013* (Cth) was created. According to the Federal Minister for Disability Reform, the Honourable Jenny Macklin at the time, the NDIS would provide, ‘people with disability with reasonable and necessary supports for their needs over their lifetime’ (Linkonline, 2013).

Internationally, changes to legislation for people with disability which strengthen social inclusion and citizen choice policies and practice have also occurred. In the United States, for example, the civil rights movement during the 1960s enabled the commencement of strategic and philosophical changes for people with disability in society (Middleton, Rollins & Hartley, 1999) and the transition from a medical to social model of disability from the 1970s followed.

This resulted in changes to legislation such as the *Americans with Disabilities Act 1990* (US) which referred to an individual with a disability as a person who has a physical or mental impairment that substantially limits one or more major life activities rather than referring to people as, ‘the disabled’ (Ainsworth & Baker, 2004). Further changes to policy and practice have been required because of limited program and service opportunities according to Keogh, Bernheimer and Guthrie (2004) to address the social inclusion of people with disability in society. This is particularly important as little research has been conducted regarding social inclusion from the perspectives of people with intellectual disability (Abbott & McConkey, 2006). Without opportunities for support in order to enhance meaningful social roles (Lemay, 2006) and greater participation in community-based activities and a broader social network (Burchardt, LeGrand & Piachaud, 2002) to strengthen social inclusion, ‘the appropriateness of institutional options for some clients is once again being discussed’ (Wanna, Butcher & Freyens. 2010, p. 10).

While deinstitutionalisation and changes in accommodation, employment, further education, volunteering and leisure, the arts and recreation opportunities in the past 30 years have occurred, deeper social and economic segregation is still a significant challenge. According to Taylor-Goodby (2008) social citizenship encompasses the duties and rights associated with providing services and benefits to enhance capabilities and enhance social needs and the resources to finance them. Perspectives of disabled people have been singularly absent from contemporary debates on citizenship, not just in Britain but also in other Western democracies with the discourse often excluding people who have physical and/or sensory impairment, mental health problems or learning disabilities. As a result many people with disability continue to encounter difficulties in asserting their rights (Morris, 2005, p. 5).

The evidence of society’s exclusion of people with disability is extensive from an anthropological perspective however this review of the literature would not be complete if only limiting assumptions were reported. People with disability and family members/informal primary carers have actively contributed to changing services for people with disability and this has occurred in cooperation with organisations and staff who appear to be doing their best to promote positive service options.

2.5 Development of CAS

2.5.1 Historical development of CAS

‘Day Activities’, including supported recreation, arts and leisure services in institutions and asylums have been recognised as providing opportunities for creativity and positive stimulation for patients. Horrible, ‘old regimes of whips, gags, manacles, straitjackets, chains, straw beds and dark cells’, were being, ‘replaced with comfort, kindness and relaxation in all well conducted asylums’, during the 1800s. Activities including attending workshops, reading in the library, contributing to an in-house magazine, skittles, bowls, dancing in the ballroom, chess and draughts, embroidery and the provision of artist’s materials were reported (Arnold, 2008, p. 208). The use of shackles and shock treatments were being reviewed and often replaced with medications as well as artistic creative therapies. A review of the Bethlehem asylum highlighted that artist Richard Dadd (1817-1886) was given a large airy room and art materials at Bethlehem so that he could continue painting despite being categorised as an, ‘educated, refined criminal lunatic’ (Arnold, 2008) . Rather than the poor and incurable being swept out of sight only to be displayed in front of paying visitors (as in Bethlehem Hospital) the creative works of people with physical and psychological disabilities increasingly became publically acknowledged. The introduction of leisure, arts and recreation originated from, ‘humanitarian concerns’, as the philosophy, ‘was to give inpatients with disabilities and illnesses their human dignity’ (Snead, 2003, p. 500). Health care pioneers such as Florence Nightingale saw the potential of leisure, arts and recreation, ‘to alleviate boredom and inactivity among wounded soldiers, and actually contribute to their morale and recovery’ (Snead, 2003, p. 500).

Australian institutions also began to include activities during the day for people with disability. A review of the history of Minda, a South Australian residential facility for children with intellectual disability, illustrates a deliberate attempt to bring variety and skill development to the lives of children with disability. Many children at Minda who were under 14 years of age, when it was first established, had been moved from the Parkside Lunatic Asylum, ‘where they had nothing to do but spend the whole days looking at stone walls’ (Minda, 1948). Minda, in contrast, became a school and a place of learning gardening, growing food and acquiring skills. With a difference in focus of activities, a report of the first 100 years at the, ‘Home for

Incurables', in South Australia includes in 1953 a record that artists, 'painted landscapes and studies in still life which are represented in the Art Gallery of South Australia and in other galleries in Australia and overseas' (Kerr, 1978, p. 37). Handicraft and art work produced by people from the Home for Incurables in South Australia were exhibited in the Royal Adelaide Show. In 1965 not only did artists from the local community provide instruction for residents of the Home for Incurables but two young artists living at the Home established, 'The Arts Society for the Handicapped', in a separate facility, away from the Home's grounds where copper work, painting and pastels could be learnt (Disability Information and Resource Centre, 2007; Kerr, 1978, p. 48).

Charitable and non-government organisations also increasingly provided, 'sheltered', or supported workshops and activity therapy centres. In 1974, *Compensation and Rehabilitation in Australia, the Report of the National Committee of Inquiry*, was published (Woodhouse & Mears, 1974) which highlighted the need for coordination and planning for voluntary organisations providing support for people with disability. This report proposed objectives of services including the;

> 'provision of day training facilities for mentally handicapped school leavers not yet ready for open or sheltered employment but who need further training and the provision of day activity centres for the severely handicapped adults of working age and aged persons for whom open or sheltered employment may not be practicable' (Panckhurst & Panckhurst, 1982, p. 43)

With the introduction of the *Handicapped Persons Assistance Act 1974* (Cth) organisations were subsidised by the Australian Government for the provision of a range of services including activity therapy and training. The Red Cross in South Australia in 1978 provided, 'two well-equipped handcraft centres open five days per week with six instructors at the Home for Incurables' (Kerr, 1978, p. 55). In the financial year 1980-81 some 146 activity therapy centres existed in Australia (Panckhurst & Panckhurst, 1982, p. 38). These centres provided activities for large groups of people with intellectual disability. Activity Therapy Centres (ATCs) were defined in the early 1980s as being;

> ‘facilities which provide programs for the more severely disabled adolescents and adults who are currently unable to be meaningfully employed in the workforce or in sheltered workshops. Ideally, structured programs are provided in the areas of social education, work and recreation in order to promote the personal and social development of ATC clients’ (Meade, Guy, Roulston, Cope & Dyke, 1981 cited in Panckhurst & Panckhurst, 1982, p. 51).

Policies during the late 1980s to support people with intellectual disability and high support needs into post school options in their local community had been largely ineffective. Individuals with high support needs had experienced high unemployment levels. This meant fewer opportunities and this placed a heavy reliance on long term placements in sheltered employment or Activity Therapy Centres, with reduced movement to less restrictive options. People with intellectual disability and high support needs following completion of secondary education experienced problems with segregated environments, minimal options and opportunities, unchallenging, inappropriate work and lack of information and cooperation exchange between government departments and agencies. In South Australia over the past 40 years the question of, ‘day occupation’, received some attention in the, ‘grey’, literature. During the early 1980s changes to day activities commenced largely due to the ideas of disability reformers including Wolf Wolfensberger and Bengt Nirje. A, ‘rhythms of the day approach’, for example, was advocated by Nirje so that instead of long periods of time at home or in bed, people with disability would get up in the morning, get dressed, leave the home to work or participate in activities, return home with a different pattern for weekdays and weekends. The Intellectual Disability Service Council (IDSC) which was formed in South Australia in 1982 was funded by the Government of South Australia to broker services including the purchase of day activities for people with disability.

The focus at this time was to provide activities in community facilities for smaller groups of people in which activities would be focused on achieving individual goals. As institutions began to be closed, people with disability were moved to small accommodation placements. As these accommodation services were not staffed during the day, groups of people with disability were transported to CAS, often away from their local community, as part of their, ‘natural rhythm of the day’.

A review of post school options for people with disability in South Australia in 1994 discovered that there were some 4,380 people with intellectual disability, aged 15 plus who did not have any known day occupation, with over 1,000 people with intellectual disability aged 15-24 years. Alarmingly the researchers conducting the review discovered that;

> ‘These young people are not in employment, they are not in education and training, they do not have recreation and leisure activities and they do not have opportunities for socialising and friendships. They do not access TAFE vocational education and training programs, job search and labour market programs and employment services. In other words they do not have post school options. They are denied access to the opportunities to participate in, and contribute to South Australian community life. As a result, they are more likely to lead a life of poverty’ (Department of Health, Housing and Community Services, 1994, p. 1).

Furthermore, it was proposed that, ‘day activities’, were rapidly becoming a catchment area for all people who were denied access to vocational opportunities because of an, ‘assumed lack of potential’ (Department of Health, Housing and Community Services, 1994). In South Australia, as a result of the efforts of parents of some young people with intellectual disability a, ‘Moving On’, Day Activities Program commenced in 1997. The, ‘Moving On’, program was ‘specifically designed to help school leavers with intellectual disability to move on to the next phase of their lives and to have interesting and meaningful things to do during the day’ (Department for Families and Communities, 2008, p. 1).

Advocates for the, ‘Moving On’, program for day activities highlighted the difficulties young people with intellectual disability experienced when leaving secondary education and trying to obtain employment in a market where employment opportunities for them were limited.

It was argued by parents and carers that the government’s support through the, ‘Moving On’, program of daily activities enabled young people with disability to stay longer with their families, as the program provided valuable respite. As a result a more cost effective option was provided compared to the need for higher cost accommodation services. Support for the, ‘Moving On’, day activity program resulted in an increased number of eligible people with intellectual disability with moderate to very high support needs accessing funding from the Government of South Australia for CAS services leading to spiralling costs to fund these services. In the disability sector in South Australia, attempts to review financial structures of the day option program have occurred. In August 2003 parents, service providers, advocates and representatives from IDSC and the Government of South Australia Disability Service Office raised concerns regarding various aspects of the program including transition from school, assessment, eligibility, transport, funding and the quality and monitoring of day options services. Three working parties were formed and lobbying for increased funding occurred throughout 2003-2004. In 2004 benchmarks for funding were considered at a rate of $17,500 per person for very high support needs and $15,000 for high support needs. In June 2005 a, ‘Cost of Day Options in South Australia’, report was produced by the Government of South Australia Department for Families and Communities and IDSC. This identified the average annual cost per, ‘Equivalent Full-time Client’ (EFC), in day options as being $23,480 (ranging from $25,101 for very high support needs to $17,211 for minimal support needs) (Department for Families and Communities and IDSC, 2005, p. 5). This involved six hours of support per day, five days per week (30 hours per week) for 48 weeks per year.

The researchers also highlighted that funding benchmarking across other states in Australia would be beneficial, for example, highlighting that in Western Australia (Disability Services Commission) $20,500 was provided for participants accessing day options up to 25 hours per week with very high support needs while in Victoria (Department of Human Services) participants accessing day options in the category of, ‘special needs’, received funding of $25,696 per annum. Notably, attempts to review, ‘outcomes’, of day option programs in South Australia have also occurred. In May 2006, *Day Options—A way Forward for the delivery of Day Options Services within South Australia*, was produced as an attempt to, ‘set future directions for day options’ (Department for Families and Communities, Government of South Australia, 2006), and this was followed in August 2006 by a, ‘Better Pathways’, consultation paper on improving the pathways from school to further education, training, employment and day options for young people with a disability prepared by the Social Inclusion Unit (Department of the Premier and Cabinet, Government of South Australia, 2006). This report stated that there were 1,049 young people with intellectual disability and or ASD with very high to moderate support requirements in the day option system, ‘however people with an acquired brain injury and/or physical disability such as neuromuscular conditions are not eligible to receive day options services’ (Department of the Premier and Cabinet, Government of South Australia, 2006, p. 19). The report further indicated that, ‘many of this group are not eligible for employment with business services because their disability inhibits their participation yet conversely they are not included in the day options programs (in South Australia) as they are outside the support requirements criteria and funding has not been provided for this group’ (Department of the Premier and Cabinet, Government of South Australia, 2006, p. 19). Opportunities for positive outcomes for these people through participation in day options services were therefore unavailable.

In 2008 the Government of South Australia’s review into post school pathways identified that approximately 240 young people with disability aged 15-24 would prefer to participate in day activities but did not meet the criteria at that time (Department of the Premier and Cabinet, 2008, p. 15). Furthermore, the report highlighted that regarding specific disability diagnosis, ‘young people with Asperger’s Syndrome are not eligible for a day options service and may have behavioural issues making it difficult for them to gain employment even in a supportive environment including business services (sheltered workshops)’ (Department of the Premier and Cabinet, 2008, p. 18).

In August 2008, the Social Inclusion Unit of the Department of the Premier and Cabinet, Government of South Australia, further produced a report titled, *Post School Pathways: How it is and how it works for young people with disabilities*, which highlighted that, ‘Although the Day Options Program was highly valued by families … this service could be improved through community partnerships that broaden young people’s experience and strengthen personal learning plans for young people to develop their capabilities to live as independently as possible in the community’ (Department of the Premier and Cabinet, Government of South Australian, 2008, p. 57). The researchers concluded that, ‘Day options opportunities for the 15-24 year old age group are limited and do not currently place emphasis on development that will lead to vocational outcomes' (Department of the Premier and Cabinet, Government of South Australia, 2008, p. 57).

In June 2009 the Social Inclusion Unit of the Department of the Premier and Cabinet, Government of South Australia, further produced a report entitled *Choices and Connections: The Better Pathways Service Approach for Young People with Disabilities,* which recommended that Day Options staff should be adequately trained to, 'inspire young people to achieve and have the capacity to provide effective developmental approaches to skill development', and discovered that currently, 'Day Options staff have little or no formal learning experience to draw from', and that, 'staff in regional areas require more support than the distance learning program currently offered' (Department of the Premier and Cabinet, Government of South Australia, 2009, p. 21). The report further recommended a focus on development and progression so that:

> 'Day options placements for the 15-24 year old age group will be flexible with an orientation of 'flow through' to more developmental options to give increased incentive for progression to other vocational options (e.g. 3-5 years)' (Department of the Premier and Cabinet, Government of South Australia, 2009, p. 43).

The, 'Moving On', program was subsequently replaced in name with the, 'Day Activities Program', in 2010, and a target of an additional 400 people with disability for participation in CAS was specified in the Government of South Australia's, South Australian Strategic Plan. In 2012 the Department for Communities and Social Inclusion engaged independent evaluators Lumin Collaborative, to review CAS in South Australia at a cost of $10,500 (Department for Communities and Social Inclusion, 2013). The steering group for the review included government and CAS representatives and one family member. No people with disability were involved in the steering group for this review which was conducted between September 2012 and May 2013. The Day Activities Report was completed in May 2013. The Report has not been made publically available. For this current research formal permission was provided by the Department for Communities and Social Inclusion in December 2014 to include information pertaining to the history of CAS in South Australia and the research methodology used for collecting data. However the, research findings were not to be included (Department for Communities and

Social Inclusion, 2014) which may seem at odds with a Departmental vision of, ‘Communities for All’.

2.5.2 CAS governance

Data regarding the governance and participation of CAS has changed over the past 20 years. However, limited data were collected by the Australian Institute of Health and Welfare (AIHW) concerning CAS during the 1990s. According to the AIHW the term, ‘Community Access’, is used in the collections relating to disability support services and before 1994, no national data on disability support services were available (AIHW, 2015). Between 1995 to 2002 collection was undertaken annually; data were collected as a snapshot on one day of the year, usually in May or June. Community Access was the term used for the grouping of continuing education, independent living, adult training, post school options, social and community support, community access and day programs. In 2002, following a major redevelopment a new data collection system was implemented resulting in the collection of data on a full year basis rather than a single day, leading to a much more detailed picture of the context of these services. CAS provision is also changing as individual states and territories commence the introduction of individualised funding. In Victoria the implementation of individualised funding commenced in 2010 and this has affected the collection of data. Data from 2004 until 2010 is presented as providing a historical context prior to the introduction of individualised funding.

In the funding period 2009/2010, 92.8 per cent of CAS were managed by non-government charitable or not-for-profit organisations (AIHW, 2011, p. 69) and were based in community settings such as community centres.

In Australia, there were 2,795 CAS providers in Australia in the financial year 2009/2010 compared to 1,551 CAS providers in 2004/2005 (AIHW, 2011, p. 6). This comparison between 2004 and 2010 demonstrates the steady increase of CAS outlets in Australia as displayed in Figure 2.2 below.

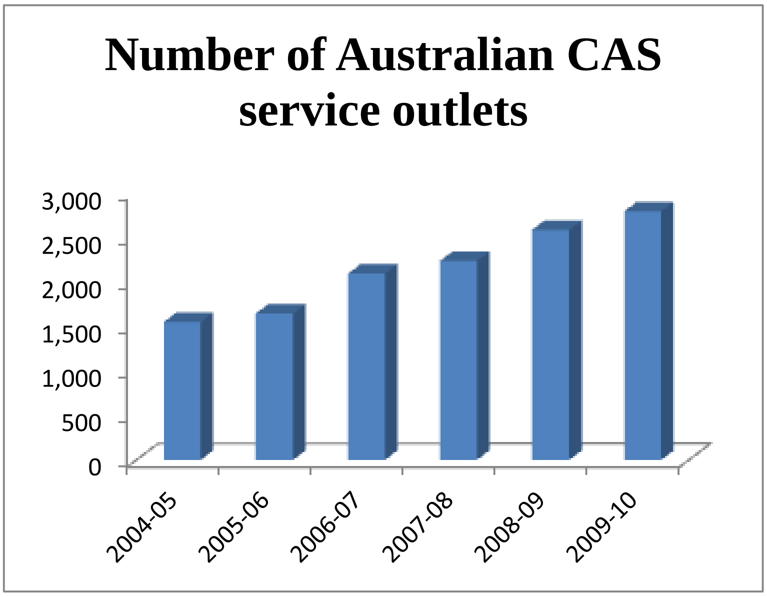

Figure 2.2 Number of Australian CAS outlets 2004-2010

2.5.3 Funding of CAS in Australia

In Australia in the financial year 2009-2010, the federal, state and territory governments provided $639.1 million towards CAS services, an increase of 32.2 per cent from 2004/2005 when $483.4 million was provided (AIHW, 2011, p. 12). The increase of funding provision is displayed in Figure 2.3.

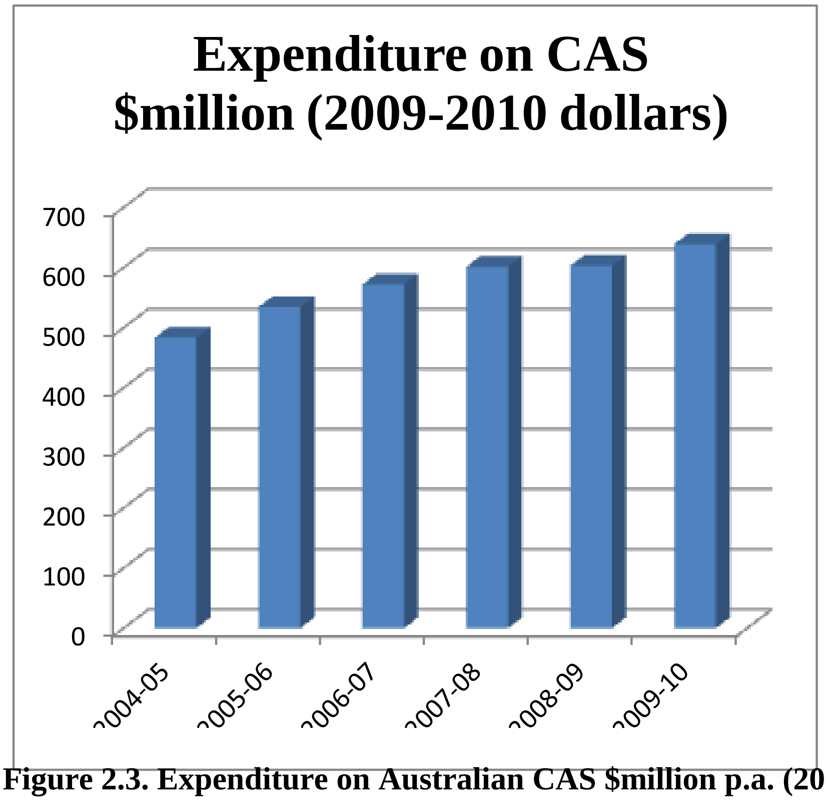

Figure 2.3. Expenditure on Australian CAS $million p.a. (2009-2010)

As demonstrated in the previous two figures, CAS in Australia has continued to expand in the number of service outlets and the amount of funding provided (the Australian Institute of Health and Welfare, 2011 pp. 5-6).

2.6 Participation of people with disability in CAS in Australia

2.6.1 Number of people with disability participating in CAS in Australia

There were 58,632 people with disability participating in CAS in Australia in the financial year 2009/2010, an increase of 32.8 per cent from 44,166 participants in 2004/2005 financial year (AIHW, 2011, p. 8) as illustrated in Figure 2.4.

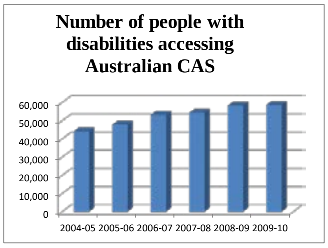

Figure 2.4 Number of people with disability accessing CAS in Australia

In Australia, in 2009/2010, 72.1 per cent of users of NDA-funded CAS needed help with Activities of Daily Living (ADLs) while 8.1 per cent required assistance with interpersonal interactions and relationships, learning, applying knowledge and general tasks and demands or education, community and civic life (but not with ADLs) (Productivity Commission, 2012, p. 515).

2.7 Participation of people with disability in CAS internationally

2.7.1 Participation in CAS internationally

Definitions of CAS, adult day activities, and adult social care programs vary internationally. CAS (day support services) in the United States for example include, ‘structured, comprehensive programs [which] provide a variety of health, social and other related support services in a protective setting during any part of a day, but less than 24 hours' (Fleming & Taylor, 2010, p. 1). The National Adult Day Services Association (nadsa) was formed in 1979 as a viable community-based care option for people with disability. Research by the Metlife Institute in 2010 reported that there were 4,601 day programs operating in the United States which was a 35 per cent increase from 2002 when 3,407 programs were operating. These services support more than 260,000 participants and family caregivers; an increase of over 100,000 people since 2002 (Metlife, 2010; National Adult Day Services Association, 2013).

Difficulties in determining the numbers of participants in CAS internationally has been reported in the literature as increasingly people are participating in a, 'portfolio of services', including sessional attendance, resulting in an, 'underestimation of the total provision of day services' (Simons & Watson, 1999, p. 14). Researchers, for example in the UK, discovered that between 1986 and 1990 the number of people without access to day services rose from 16 per cent to 23 per cent and that the proportion of people only partially involved also rose from 7 per cent to 14 per cent (Felce, Grant, Todd, Ramcharan, Beyer, McGrath, Perry, Shearn, Kilsby & Lowe, 1998). Further research in the UK in 2005, involving a national survey of people with disability, concluded that 39 per cent of all people with a disability were attending a day centre, with two-fifths attending five days per week (Emerson, Malam, Davies & Spencer, 2005). Furthermore, 20,000 people with disability in the UK had no form of support or provision at all for structured activities outside of the home during the day (Mencap, 2002). Researchers have concluded that demand for day activities is increasing despite many local authorities still struggling to move away from large congregate settings (Cole, Williams, Lloyd, Major, et al. 2007).

Researchers in Ireland discovered that 96.5 per cent (24,729) people with a mild, moderate, severe or profound intellectual disability who were registered on the national service planning database in 2007 were participating in day activity services (Hartnett, Gallagher, Kiernan, Poulsen, et al., 2008). The demand for day activity services in Ireland included an increase of 40 per cent from 1990 to 2003. However, researchers identified that the number of day activity centres was still inadequate, particularly in rural areas and in Dublin, and that a substantial increase in day centre facilities had been recommended from the then current national level of 1,480 to 3,080 (Ward, 2003, p. 528).

In other countries, such as the Netherlands, the Dutch Government has instituted policies and has called for greater options for stimulation and learning away from accommodation settings for people with profound intellectual and multiple disabilities (Vlaskamp, Hiemstra & Wiersma, 2007). The Dutch Government has increased the number of hours in CAS as more staff/client interactions can occur there than in accommodation settings (Vlaskamp, Hiemstra, Wiersma & Zijlstra, (2007, p. 158). Furthermore, researchers in Georgia have highlighted that formal day care which commenced in 2005 for people with disability has been a, 'critical first step towards their integration' (Makharadze, Kitiashvili, & Bricout, 2010) with 36 day centres functioning in the Republic of Georgia in 2009 (MoLSHA, 2009).

2.8 Participation of people with disability in leisure, arts and recreation

2.8.1 Leisure, arts and recreation

Discourse regarding the concept of leisure has experienced evolutionary changes. Leisure according to Rossman and Schlatter (2008) is not a set of identifiable activities, events or services, but rather:

> 'Leisure is an experience most likely to occur during freely chosen interactions characterised by a high degree of personal engagement that is motivated by the intrinsic satisfaction that is expected to result' (Rossman & Schlatter, 2008, p. 6).

Participation in leisure is a human right. The World Leisure and Recreation Association issued the Sao Paulo Declaration in 1998 declaring amongst other things, that: 'all persons have the right to leisure through economic, political and social policies that are equitable and sustainable', and that, 'all governments will enact and enforce laws and policies designed to provide leisure for all' (World Leisure and Recreation Association, 1998). Benefits of leisure as an important part of participants' lives are many, including; 'self-enrichment'; 'self-expression'; 'renewal of self'; 'feelings of accomplishment'; 'skill development'; 'social interaction and belongingness'; and 'quality of life' (Aitchison, 2003; Bittman, 1998; Csikszentmihalyi, 1991; Datillo, 2002; Ellison & White, 2016; Howard &

Claiman, 1994; Howat, Crilley, Rogers, Earle, Methven & Suter, 1991; Iso-Ahola, 1999; Miller, Schleien, Kraft, Bodo-Lehman, Frisoli, & Strack 2004; Stumbo & Pegg, 2004; Wehman, 1979). Leisure experiences and participation may result in numerous social, psychological and physical benefits similar to non-disabled peers (Patterson & Pegg, 2009; Stumbo, Wang & Pegg, 2011).

Intrinsic benefits through, 'serious leisure', have also been identified by researchers such as Stebbins, (1982) and Patterson (1997). Serious leisure, referred to by Stebbins (2006) as a, 'systematic pursuit of an amateur, hobbyist or volunteer activity', involves a seriousness which embodies qualities such as sincerity, carefulness, and importance. Stebbins (2006) has identified personal rewards from serious leisure such as; 'personal enrichment' (cherished experiences); 'self-actualisation' (developing skills, abilities, knowledge); 'self-expression' (expressing skills, knowledge, abilities already developed); 'self-image'; 'self-gratification'; and also social rewards including; 'social attraction'; 'group accomplishment'; and 'contribution to the maintenance and development of the group' (Stebbins, 2006, p. 453).

Recreation has been defined as leisure that is engaged in for the attainment of personal and social benefits. Recreation is not only good for individuals, it is also good for society (Rossman & Schlatter, 2008, p. 10). Community participation of people with disability in recreation activities which have beneficial outcomes have also received attention over the past 50 years (Carlson & Ginglend, 1968; Hunt, 1955). The emergence of the concept of, 'Therapeutic Recreation' (Gunn & Peterson, 1978; O'Morrow, 1976) has further contributed to the community participation of people with disability. Therapeutic recreation has been described as being:

> 'based on the idea that leisure is an essential component of healthy living, and that some individuals may have difficulties in reaching their full leisure potential. Usually such difficulties are caused by DISABILITY in the individual' (Snead, 2003, p. 499-500.)

In 1961 the Beatrice Hills private consulting organisation attempted to address the needs of people with disability in the community, and identified the lack of available services for them. According to Snead (2003), they first used the term, 'Therapeutic

Recreation'. Therapeutic recreation is based on the continual cycle of assessment, planning, implementation and evaluation, with the person with disability's needs and goals determining the type of service received (Snead, 2003). Central to therapeutic recreation has been a focus on individualised program planning as Recreation Therapists have been directly involved in client assessment, planning, implementation and evaluation (Robertson & Long, 2008; Stumbo & Wardlaw, 2011).

Leisure education, with and for people with disability, has also evolved over the past 40 years. According to Sivan (2006), researchers such as Brightbill and Mobley (1977) had proposed that leisure education included values, interest appreciations and skills essential for individuals to live a satisfying and meaningful life in leisure. Peterson and Gunn (1984), developed a four stage model of leisure education including; 1) awareness of leisure; 2) knowledge and use of leisure resources; 3) activity skills; and 4) leisure participation. In the 1990s Datillo and Murphy (1991) expanded the leisure education model into eight stages: 1) awareness of self in leisure; 2) appreciation of leisure; 3) ability to be self-determined; 4) decision-making skills; 5) knowledge of the use of leisure information and resources; 6) acquire social skills; 7) acquire activity skills; and 8) leisure participation (Snead, 2003).

A range of activities for leisure education have also been developed for leisure decision-making, skill development, self-awareness and social interaction (Dattilo, 2000; Stumbo and Thompson, 1988; Stumbo 1997; Stumbo, 2000). Models in therapeutic services included a range of aims according to Sivan (2006) such as increasing the individual's awareness of leisure, the meaning of leisure, leisure resources at home and in the community, strategies for increased leisure independence, leisure involvement and leisure skills (Sivan, 2006). Although discourse regarding leisure and people with disability will no doubt continue to evolve, what is of central importance, as Singleton and Darcy (2013) highlight, is giving a voice to people with disability to, 'negotiate a dignified, equitable and independent leisure life no matter what their choice of activity, role or model of engagement' (Singleton & Darcy, 2013, p. 187).

In Australia, a range of social, psychological and health and wellbeing benefits have been attributed to participation in leisure, arts and recreation pursuits. Historically leisure service provision for people with disability occurred in institutionalised settings with traditional pursuits including art, craft, reading and music (Andrews, Briggs, Porter, Tucker & Waddington, 1997; Geyer, 2008; Kerr, 1978; Tutti, 2013).

Participation by people with disability in arts has been recognised as contributing to a range of positive outcomes such as a sense of wellbeing and happiness (Kapetas, 2007; Matarasso;1997), a means of expressing to others how they were feeling (Lynch & Allan, 2007) and contributing to health outcomes (Clift, 2008). Furthermore, the benefits of participation in visual and performing arts for promoting inclusion and ensuring that people with disability have, ‘a voice’, has received increasing attention (Simons & Watson, 1999). In the UK, arts-based activities for people with disability which are purposely segregated have been developed in order to explore the experiences of having a disability through visual expression. Arts-based services are also being developed to nurture the ability of people with disability to manage and run their own activities (Price & Barron, 1999). In CAS a range of visual and performing arts are also implemented.

In Australia, researchers exploring post school options for young people with disability have described CAS or day activities (or day options) as, ‘meaningful activities which provide a range of psychological benefits including opportunities for improved confidence, self-reliance, community participation and self-image’ (de Zeeuw & McMahon 2005**,** p. 35). The role and importance of CAS as a contribution to the facilitation of social supports, friendship and individual choice, cannot be understated. In the transition process from secondary school to community options, for example, researchers have noted that friendships appear to be reduced once the supports of school are no longer present and, as such, it is primarily through day activities and employment that new social networks are formed (Devine & Dattilo, 2000; Duvdevany & Arar, 2004).

The improvement in a person’s ability to pursue recreation and leisure interests was considered in a study of 175 adults with moderate to severe brain injury who attended a follow-up interview two years post-injury. The results of this research concluded that only about 10 per cent were able to engage independently in all previous recreation and leisure interests and that support and transition into new or different recreation and leisure pursuits was required (Ponsford, Olver & Curran, 1995, p. 6). Whether or not return to work or study is possible, the participation in recreational interests assume a very important role in the life of a person who has sustained a brain injury (Ponsford, Sloan & Snow, 1995, p. 223).

In a further study in Australia of 25 people with ABI who commenced and maintained weekly participation in supported leisure activities over a six-month period, it was found that their leisure experience was, ‘having a positive effect on their sense of self and confidence, achievement, feelings of belonging and happiness and the experience of friendship. Participants further reported significant improvement in social integration and mental health, along with a reduction in the frequency of symptoms of depression’ (Douglas, Dyson & Foreman, 2006, p. 115). A range of benefits of supported recreation and leisure participation for adults with ABI have been identified including opportunities to improve in areas such as cognitive, physical and psychosocial adjustment, and the further development of independence (Miller & Briar, 1990).

Researchers Lundberg, Taniguchi, McCormick and Tibbs (2011) explored the outcomes and meanings of adaptive sport and recreation participation amongst 17 individuals with disability. The researchers discovered that individuals felt stereotyped and stigmatised however their participation in adaptive sport and recreation provided opportunities to build social networks, positively compare themselves with others with disability, experience success and freedom and feel a sense of normalcy. Also, Johnson, Douglas, Bigby, and Iacono (2010) observed an individual with a severe intellectual disability to explore her social networks and social support. The researchers identified and then interviewed 14 of her social network members. The researchers concluded that although social interactions with people with severe intellectual disability have challenges; personal satisfaction, enjoyment and a love of these interactions was experienced.

American researchers Thorn, Pittman, Myers and Slaughter (2009), have identified that simply living in a community-based environment does not automatically equate to success. Individuals, ‘without adequate functional skills who are thrust into a community living setting may become more isolated and segregated and can be relegated to living on the fringes of community' (Thorn, Pittman, Myers & Slaughter, 2009, p. 898). CAS may contribute to the development of social support networks for people with disability and the opportunity to improve social image through participation in mentoring and supported recreation and leisure activities (Fresher-Samways, Roush, Choi, Desrosiers & Steel, 2003; Gaylor-Ross & Haring, 1987; Lockwood & Lockwood, 1999). Researchers have identified that for individuals with disability, participation in recreation and leisure activities has contributed to psychological benefits including the exploration of their own capacities, talents and potential (Csikszentmihalyi & Kleiber, 1991). Furthermore experiences of reduced boredom and increased life satisfaction have been reported (Coleman & Iso-Ahola, 1993). In a rehabilitation context recreation and leisure participation has been associated with improved limb function and range of movement (Yoder, Nelson & Smith, 1989). Recreation and leisure participation may also contribute to opportunities for integration into a community and development of friendships (Crilley, 1999; Srivastrava, 2001) and for improving a person's quality of life (Muloin, 1997). Through recreation and leisure participation, it has been identified that people with disability have increased adaptive behaviour and reductions in problem behaviours (Sigafoos & Kerr, 1994).

By participating in freely chosen recreation and leisure activities, experiences of social benefits have also been reported by people with disability as they have the opportunity to meet and make friends with others and to expand their social network. Furthermore, these experiences are qualitatively different from those experienced with families/informal primary carers and other people with whom they may share accommodation and appear to have a greater social value (Stancliffe & Lakin, 1999). Having social contact with other peers with disability can also provide a sharp contrast with experiences in community settings. Researchers have discovered that, 'the discrimination, abuse and rejection they [people with disability] suffer at the hands of the community has led some people to seek safe spaces and networks where new forms of normality and inclusion can be shaped' (Hall, 2004, p. 304).

For example, in the UK researchers have noted that some recreation and leisure activities are deliberately segregated from the community in order to increase positive outcomes for individuals with disability. These activities, such as dances and discos, are seen to, 'honour', entertainment provided by people with disability (Price & Barron, 1999). In Ireland in a study including client's views of, and satisfaction with the service received, 156 clients from 13 CAS (day activity centres) participated in an interviewer initiated original questionnaire. While acquired disease or accidents were the cause of disability for 75 per cent of clients, 25 per cent of clients had a congenital disability. The clients had been attending the centres for a considerable length of time (up to 26 years) with the mean duration of 6.5 years attendance. The outcome of participation at these day centres was in the majority of cases (92.9 per cent) a positive one. The best aspect of attendance for over 75 per cent of participants in the CAS was the social and companionship element (Ward, 2003, p. 530).

In the Netherlands research concerning the participation of 33 participants with profound intellectual and severe or profound motor disabilities from seven CAS centres was conducted to determine the extent, duration and content of day services activities. The research conducted by Vlaskamp, Hiemstra, Wiersma and Zijlstra, (2007) involved recording the type and time spent in participation in a range of activities including physically oriented activities, task-oriented activities, artistic activities, play and games, micro technology, spiritual activities, visits and outings, nature-related activities and audiovisual activities.

Average attendance of 14.2 hours per participant per week occurred. The researchers concluded that having suitable day activities, 'makes a significant contribution to the quality of life of people with profound intellectual disabilities' (Vlaskamp, et al., 2007). According to Vlaskamp, et al., (2007), the contribution of CAS to people with intellectual disability is further highlighted by researchers Felce, Jones, Lowe and Perry, (2003); Perry and Felce, (2003); Petry, Maes and Vlaskamp, (2005); and Singh, Lancioni, Winton, Wahler, Singh and Sage (2004).

In the Republic of Georgia, researchers, Makharadze, Kitiashvili, and Bricout (2010) identified the development of adult CAS as contributing towards social integration for people with disability; the main aims of which being the improvement of 'social-adaptive skills', and, 'supporting social inclusion', (Makharadze, et al. 2010, p. 291). In their research, 80 adults with mild intellectual disability from the same region in Georgia were recruited, 40 who were users of community-based CAS and 40 who were unemployed, lived with their families and spent all of their time at home. The researchers stated that the role of community-based services has particular relevance for Georgian contexts, ‘because for the majority of people with intellectual disabilities in Georgia the day centres are the only place where they can go out and meet other people’ (Makharadze, et al., 2010, p. 298). Not surprisingly the researchers concluded that community-based CAS, ‘afforded users with opportunities to improve socio-adaptive skills, meet other people with intellectual disabilities and enlarge their social networks’ (Makharadze, et al., 2010, p. 300). However, while CAS provided positive contributions for participants and their families, the researchers identified that further multidimensional social marketing beyond the scope of CAS was required to influence broader societal attitudes, policies and practices towards people with disability in society.

2.9 Parent(s), siblings and informal primary carers’ indirect use of CAS

2.9.1 Introduction

Parent(s), siblings and informal carers have been described as the, ‘indirect’, participants in CAS. Parents have had a long history of active support for their child(ren) in community settings as advocates keen to ensure that the promises of deinstitutionalisation are realised.

2.9.2 Parental perspectives and pressures

> ‘In a large town in country NSW, three weeks before last Christmas, a mother is preparing breakfast for her severely intellectually disabled 22 year old son. The young man doesn’t know it, because he has a mental age of a toddler, but his mother is planning to drive him to his day activity centre after she has finished feeding him, and then abandon him there. Exhausted, severely depressed and suffering health problems, this woman has reached her personal breaking point’ (Mulconray, 2012, pp. 41-42).

Researchers have recognised increased pressures on parent(s), siblings, and informal primary carers of children with disability. In South Australia the Health Commission coordinated a review of services to determine the future of Disability Services in South Australia (Disability Directions Project, 1992) and conducted consultations with people with disability, their families/informal primary carers and service providers in regional and metropolitan South Australia. The researchers recommended changes to the, ‘fragmented and uncoordinated nature’, of disability services in order to ensure, ‘carers and members of informal networks of support are to be recognised, respected and supported in their provision of care and support to the person with a disability’ (Disability Directions Project, 1992, p. 4). An increased burden over many years of caring for their children at home (Baine, McDonald, Wilgosh, & Mellon, 1993; Cummins & Baxter, 1997) has been associated with feelings of depression and helplessness by family members (Freedman, Kraus & Seltzer, 1997; Gowen, Johnson-Martin, Goldman, & Applebaum, 1989).

South Australian reviews such as the Intellectual Disability Services Council (IDSC), *IDSC-Through the Nineties and Beyond* report stated that, ‘families at risk were getting too little help, too late’ (IDSC, 1995, p. 5), and that, ‘a focus on providing individual and family support was required increasing work with individuals and families from a non-English speaking or Aboriginal background’ (IDSC, 1995, p. 6). Researchers in New South Wales also recognised the pressures placed on families in the absence of support. The researchers highlighted that 834 people with intellectual disability, ‘have no activities during the day once they have left school. Consequently they lose skills acquired at school, become isolated, bored, lonely and often frustrated. Furthermore, their dependence on their family increases and this can increase family tensions and stress and impose restrictions on the lives of other family members’ (New South Wales Council for Intellectual Disability 1994, p. 34).

As such, difficulties have been highlighted by parent(s) when trying to maintain employment while, ‘nobody’, is providing the service (Brincat, 1990).

In Australia over the past 20 years, parents’ perspectives have been sought for a range of reviews and explorations including; *New Approaches to Community-based Services for Younger People with Disabilities: The Evaluation of the Individual Needs Analysis Pilot Projects* (Mitchell & Graham, 1994); the Parents with intellectual disability implementation project (IDSC, 1995), *Review of Family Support Services for the Intellectual Disability Services Council* (Peters, 1998), *Family resilience project: Report to the Intellectual Disability Services Council*

(Anstey, 2001) and *Administrative review of services for people with Autism Spectrum Disorder and their carers* (Watkins & Farinola, 2003).

Such research has highlighted the importance of support for families and young people with disability especially when people with disability are transferred from, ‘children’s services’, to, ‘adult services’. The pressures parent(s) with children who have disability experience, does not necessarily cease as they get older as many people with disability remain at home for a large proportion of their lives and continue to need support from their parent(s)/carers (Brown, 2003; Caldwell & Heller, 2007; Dixon & Reddacliff, 2001; Knox, 2000; Mactavish, MacKay, Iwasaki & Betteridge, 2007; Ramcharan & Grant, 2001; Social Policy Research Centre, 2002; Turnbull & Ruef, 1997; Wade, Mildon & Matthews, 2007).

Furthermore, parent(s) with a child with a disability were more likely to experience stress, feel weary or lacking in energy, have lower levels of marital satisfaction and poorer mental health than parents without a child with a disability (Australian Bureau of Statistics profile of carers, 2008; Gardner & Harmon, 2002; Llewellyn, Thompson, Whybrow, McConnell, Bratel, Coles & Wearing, 2003; Patterson, 2002). As a result parent(s) of people with disability are experiencing higher rates of relationship breakdown than parents without a child(ren) with disability. An Australian study involving 20 families of people with disability discovered that, because there was very little informal support from outside the family, families were heavily reliant on formal services (Schneider, Wedgewood, Llewellyn, & McConnell, 2006). Furthermore, these researchers discovered that the formal services were inadequate and sometimes non-existent. This was especially the case during adolescence and young adulthood, as the young people grew out of the age range of services for children. Families found that they were forced into new rounds of bargaining for funds and had to search anew for services on which they had previously relied. They also faced waiting lists and long delays, sometimes of years, and, when services did become available, families frequently expressed that these were then no longer appropriate for the person with a disability. Too often it was also impossible to plan because of the sporadic short term nature of funding and services. This was frequently the result of budget cuts, and programs were then changed or cancelled without notice or explanation (Schneider, Wedgewood, Llewellyn, & McConnell, 2006). Furthermore, economic and social marginalisation is not restricted to the individual with a disability but is a common problem for the families and informal primary carers. Apart from higher levels of stress and anxiety than their peers without a disabled child, 36 per cent of the parents with a child with a disability had turned down a job offer because of their child's disability, 17 per cent had turned down a promotion, 29 per cent had changed working hours, 36 per cent had reduced the hours they worked, 17 per cent had changed jobs and 17 per cent had quit altogether (Winn & Hay, 2009, p. 106).

Service users in remote or very remote regions were also reported to be more likely to have an informal primary carer than those in other areas closer to urban centres (Productivity Commission, 2012, p. 503). According to the Australian Institute of Health and Welfare there were 44 per cent of CAS participants (26,045 people with a disability) still living with their family and an additional 31.4 per cent (18,433 people with disabilities) who lived with others, for example, in supported accommodation (AIHW, 2011, p. 41).

CAS provide positive benefits for parent(s), siblings and informal primary carers because of opportunities for planned stability at a time when limited further educational opportunities and/or employment opportunities exist. Researchers have identified that for young adults with intellectual disability family involvement continues to be considered an essential component of the transition process after secondary education (Kohler & Field, 2003; Ludlow, Turnbull & Luckasson, 1998). According to findings in the Government of South Australia’s Department of Premier and Cabinet, *Better Pathways Consultation Paper* (2006), the transition process from secondary education to other post school options should be completed in a supported environment with communication focused on the young person’s voice as well as being inclusive of family and community stakeholders. The consultation paper highlights that, ‘the young person with a disability is part of a family and community and we should use the strengths and resilience of those relationships to support them to plan their future’ (Department of Premier and Cabinet, South Australian Government, 2006, p. 7). Unfortunately the transition from secondary education to adult life is also a time when young people, ‘can get lost between children's and adults services, finding their support cut off from one day to the next at their 18th birthday, and thrown back on their own unaided resources and those of their families' (McGrath & Yeowart, 2009, cited in Rajkovic, Thompson & Valentine, 2009, p. 125).

2.9.3 Policy implementation

> 'Policy needs to go beyond whether parents are involved; it needs to focus on how they are involved and what happens as a result' (Corter & Pelletier, 2004, p. 8).

Davies and Beamish (2009) discovered that although parents are portrayed as valued providers of information, in practice parents have been infrequent participants in transition research. Few studies have, 'sought the parent perspective on family experiences and outcomes following the transition of their young adult from school into adult life' (Davies & Beamish, 2009, p. 248).

In their research, Davies & Beamish (2009) discovered that over half of all participants in their research sample (n=110) of young school leavers participated in community-based day programs between 10 and 20 hours per week. Activities included community outings and life skills programs, physical activities and art programs. Positive benefits were identified by the research participants, however the research concluded that:

> 'there is an urgent need for change and change will only happen when there is committed action across government departments and community agencies. Both families and young adults with intellectual disability have a right to a normal life' (Davies & Beamish, 2009. p. 256).

Research concerning the perceptions and experiences of families in the transition process of their child from special education into post school options has also been conducted by Gillan and Coughlan (2010) in the southern region of Ireland. This study involved a small group of young people with mild intellectual disability and their parents. Using a Grounded Theory approach, researchers identified factors which contributed to barriers to post school participation. They discovered that although considerable gaps between policy and service provision exist throughout the transition process, the parents have a key role as facilitators. Parent(s) of people with disability as well as siblings can benefit from the provision of CAS. Researchers Arnold, Heller and Kramer (2012) identified that as parents age and are less able to provide support to their children with a disability, the involvement of siblings in the lives of their brothers and sisters becomes more necessary. A further study by Heller and Arnold, (2010) identified that most siblings anticipated taking on a greater role in the future, while Heller and Kramer (2009) reported that a major support need for siblings of brothers and sisters of people with disability was for information, especially on planning for the future (Heller & Kramer, 2009). While researchers have continued to examine parents' perspectives of services in community-based services for children and young people in order to provide a, 'family-centred approach' (Dunst, 2002; Epley, Summers & Turnbull, 2010; Tomasello, Manning & Dulmus, 2010) the wellbeing of families/informal primary carers with children and young people with disability requires further attention (Burton-Smith, McVilly, Yazbeck, Parmenter & Tsutsi, 2009; Hastings, 2002; Heller & Caldwell, 2006; Scheer, Kroll, Neri & Beatty, 2003).

As young people are no longer eligible for children's services, the associated stability for parent(s) in knowing that their son or daughter was in a school environment ceases. As parent(s) may enter a void of uncertainty for their child and also themselves, CAS may therefore have a valuable role ensuring that the skills learnt during the school years, such as in the visual and/or performing arts will not be wasted or diminished because of extensive periods of unemployment/ underemployment.

As such, following secondary education CAS services may be beneficial for parent(s), siblings and informal primary carers by contributing to a planned transition pathway for people with disability into adulthood. In addition to benefits for the individual with disability and their parent(s), siblings and informal primary carers, the development of supportive and inclusive CAS has a range of potential benefits for society as well as challenges which require addressing.

2.10 For society

'To be a part, not apart from society' Anon.

For community benefits to be realised for people with disability a variety of challenges have been identified as, 'Programs and services were built around organisational and system needs rather than the needs of clients' (National People with Disabilities and Carer Council, 2009 p. 4 and 5). Internationally, researchers have also identified the benefits of CAS for society. In the UK, for example, policy makers have reviewed the benefits of, 'restructured', day activities in their role, 'in promoting choice and empowerment and securing the social inclusion and human rights of people with disability', in society (Simpson, 2007, p. 235).

Despite the benefits for people with disability, parent(s), siblings, informal primary carers and society through community inclusion associated with the participation of people with disability in CAS, criticism of the traditional structure and delivery of these services exist, especially if these services continue to reinforce segregation of people with disability from, 'mainstream', community participation.

Researchers over the past 20 years have highlighted a range of consequences. For example, spending years in day centres may result in people with disability having low expectations of what can be achieved in their lives as a result of relying on a narrow range of support (Perrins & Tarr, 1998; Veck, 2002). Furthermore, few opportunities to meet people outside of the service may also occur (Pedlar, Haworth, Hutchinson, Taylor & Dunn, 1999). The traditional program of activities may be constrained by the building facilities and become, 'bricks-and-mortar-led', resulting in segregation of participants whereas a, 'successful centre may be largely empty during the day as people with disabilities are closely involved in activities in the local community' (Simons & Watson, 1999, p. 15).

A further criticism associated with a, 'traditional', centre-based day activity structure is the amount of time people with disability spend travelling to and from the central location and the proportion of the day service's budget absorbed by travel costs. Furthermore, by being transported away from a local service, fewer opportunities may exist to link with non-disabled members of their local community or accessing of, 'generic services' (Beyer, Grove, Schneider, Simons, et al., 2004). Although some services may move to smaller distributed centres in a local hall, to date there has been little evidence about the positive impact of these changes to a day centre model (McIntosh & Whittaker, 1998). Feelings of boredom have also been reported by people attending day centres (Ward, 2003), and it has been purported that attendance at a day centre can be stigmatising (Jahoda & Markova, 2004).

Alternatively, planning a more flexible approach to CAS may provide greater opportunities to participate in ordinary community settings, outside the traditional range of day centre opening hours or focused on organisational requirements. Facilities traditionally used as day centres may also become a more general community resource open to everybody including people with and without greater support needs (McIntosh & Whittaker, 1998). While CAS have been criticised for segregating participants with disability from the community, researchers have highlighted that participation, for example, in physical activity, can have positive effects where adequate personal support is provided but negative effects if this is not available (Temple & Walkley, 2007).

2.11 Service quality development

In order to further explore the issues related to the quality of CAS services and how they meet the rights and needs of people with disability and their support networks, a review of the formal processes of quality determination is provided. This includes service quality definitions, the historical development of the concept of service quality, the service quality instruments and service quality frameworks in use for services for people with disability, and research regarding the service quality of public sector managed CAS.

2.11.1 Historical development of service quality

The attainment of quality in products and services became a, ‘pivotal concern of the 1980s because quality in services, unlike tangible goods, were largely undefined and unresearched’ (Parasuraman, Ziethaml & Berry, 1985, p. 41). As consumers in the general community demanded higher quality in products, providers also sought to reduce manufacturing costs and improve productivity. Measures of quality were primarily considered in terms of numerical outcomes such as the number of incidences of a product failure both before leaving a factory, as well as after leaving the factory and having to be recalled. During the 1980s the need to develop service quality measures of, ‘human services’, and the process of service delivery and the outcome(s) of a service were identified (Parasuraman, Zeithaml & Berry, 1985; Zeithaml, 1981). During the 1990s an increasing demand for quality services occurred due to legislative, political, social, economic, technological and competitive forces (Zeithmal, Parasuraman & Berry, 1990; Frisby, 1995). A range of factors which affect the quality of services were identified including: the perceptions of people encountering a service (Oliver, 1993); customers' satisfaction and willingness to return to a service (Bitner & Hubbert 1994; Reicheld & Sasser, 1990); agency profitability (Rust & Zahorik, 1993); as well as the quality of services provided relative to customer expectations (Zeithaml & Bitner 1996). It was identified in the field of nursing research for example that, 'quality of care is frequently measured against professional standards and expectations only, overlooking consumer perceptions of, or satisfaction with, care' (Irurita, 1996). According to researchers Howat, Crilley and McGrath (2008), for over two decades research involving dimensions of service quality have been guided by two different approaches. The European (Nordic) approach (Gronroos, 2005; Lehtinen & Lehtinen, 1991) has been developed for when the technical quality of service production is sought and may be most useful when determining what the customer is left with when the service process is over (Howat, Crilley & McGrath, 2008; Gronroos, 2005).

Alternatively researchers have sought to discover the gap between service users' expectations of a service and their perceptions of the service that is actually provided (Parasuraman, Zeithaml & Berry, 1985). Through early exploratory work, researchers in the United States of America, using focus groups and interviews with executives in retail banking, credit card, securities brokerage and product repair developed a service quality model, referred to as SERVQUAL. Originally 10, 'determinants of service quality', were identified by Parasuraman, Zeithaml and Berry (1985) as displayed in Table 2.2 below.

Table 2.2 SERVQUAL: Ten determinants of service quality

Ten Determinants of Service Quality	**Application**
Access: approachability and ease and convenience of contact.	Accessibility of operations i.e. physical access, one stop shop.
Communication: informing users in language which they understand; listening.	Clarity of information. Listening skills, clear information e.g. Brochure, information leaflets.
Competence: the right skills and knowledge to perform the service.	Staff who, 'know their job'. Knowledge of relevant legislation, skills needed for assessment.
Courtesy: Politeness, respect, consideration of others, friendliness of staff.	All staff, 'treat users with regard, even difficult users'.
Credibility: trustworthiness, believability, honesty, having the users best interest at heart.	Integrity in work practice. Users have confidence in the independence of advice and undertakings that are given.
Reliability: consistent and dependable performance, accuracy.	The user's needs are properly assessed, whichever staff member undertakes the work.
Responsiveness: being willing and ready to provide services. Timeliness of service.	Response to requests in a timely manner.
Security: freedom from danger, risk or doubt. Physical safety, financial security and confidentiality.	Confidentiality of information including personal issues.
Tangibles: service environment, equipment used.	Physical equipment, layout, staff appearance.
Understanding/knowing the user: Attention to individual users specific needs.	Ability to build relationships.

A consolidation of the original 10 determinants of service quality occurred following the systematic analysis of service consumers' ratings from hundreds of interviews in several commercial service sectors and five core criteria that customers employ in evaluating a service were developed (Frisby, 1995, p. 26). An adaptation of the five SERVQUAL dimensions is displayed in the Table 2.3.

Table 2.3 Five SERVQUAL dimensions showing the corresponding original 10 dimensions for evaluating service quality

Tangibles	Appearance of physical facilities equipment, personnel and communication materials
Reliability	Ability to perform the promised service dependably and accurately
Responsiveness	Willingness to help service users and provide prompt service
Assurance including competence, courtesy, credibility and security	Knowledge and courtesy of employees and their ability to convey trust and confidence
Empathy including access, communication and understanding the service user	Caring, individualised attention provided by the organisation for its users

The findings of research involving the use of SERVQUAL were published during the 1990s and early 2000s in a range of research fields including sports and leisure services (Hill & Green, 2000; Howat, Murray & Crilley, 1999) tourism and leisure (Diaz-Martin, Iglesia, Vazquez & Ruiz, 2000; Juwaheer, 2004) and in a study of children as customers in a residential camping setting (Mikilewicz, 2000).

The service quality of activities involving participation of people with disability has also occurred. In a study of people with disability in the UK receiving care in their own homes the SERVQUAL tool was used because of the, ‘advantages of being concise, reliable, valid and applicable to a broad spectrum of services’ (Frisby, 1996, p. 16).

Using a SERVQUAL approach, the researchers discovered that, as far as service users were concerned, appearing neat and organised, being responsive, having empathy and bringing reassurance, and, in particular, being reliable are all important characteristics of members of a team providing services to people with disability (Frisby, 1996, p. 18).

In South Australia it is mandatory for all service providers for services for people with a disability to be participants within a service quality framework as a condition of their funding Master Agreement. A range of service quality frameworks is adopted by organisations providing services for people with disability. In South

Australia in 2013 over 80 per cent of organisations funded by the Government of South Australia Department for Communities and Social Inclusion were engaged with the Australian Service Excellence Standards (ASES). To achieve accreditation to the certificate or Award Level standard through ASES, organisation representatives register and attend training sessions prior to commencing a self-assessment. Following completion of self-assessment an external assessor is engaged to provide advice regarding readiness for assessment. On average it takes over 12 months for organisations to work through their self-assessment, undertake their external assessment and address outstanding requirements to achieve accreditation. Accreditation is then valid for three years (Department for Communities and Social Inclusion, 2013).

With an increasing, ‘managerialist’, approach during the 1990s and 2000s the development of key performance indicators have been used by funding bodies to, ‘measure’, the performance outcomes of services and funding has been allocated or withdrawn accordingly. While seeking to improve the efficiency and effectiveness of resource usage, funding bodies have attempted to provide a costing basis for services delivered. However, there is a real dilemma for service providers in this process.

For example, Women with Disabilities Australia (WWDA) which is the peak body for over 2 million women with all types of disabilities in Australia, stated in their submission to the National Human Rights Consultation (2009), ‘…organisations like WWDA (funded by the Australian Government on an annual basis) working to address the human rights violations of women with disabilities is hampered by narrow and prescriptive government funding contracts which require tangible outcomes that are related to government objectives rather than priorities identified by WWDA constituents’ (WWDA, 2009). So, while in Australia individual organisations have collected statistics on the number of people with disability participating in services for the past 10 years using both a service quality framework and the reporting requirements of the CSTDA the AIHW noted that:

> ‘while the objective of the CSTDA is to enhance the quality of life experienced by people with disability, there are currently no adequate measures of whether, or to what extent, the CSTDA is meeting its objective’ (AIHW, 2007, p. 192).

Organisations may participate in service quality frameworks to monitor their governance, and the government funding bodies may collect statistics regarding the number of participants but where is the voice of people with disability, parent(s), siblings and informal primary carers regarding their perception of the quality that has been experienced?

2.12 Service quality of CAS

2.12.1 Service quality

‘Service quality’, may be considered, as a conceptualisation, as involving a comparison of the evaluation of the perceived performance of specific attributes of a service (such as CAS) to prior expectations (Howat, Crilley & McGrath, 2008).

In Australia the service quality of CAS has received limited attention in the literature. In 1994 an examination of post school options, ‘day programs’, for young people with a disability was conducted in New South Wales, Queensland and Western Australia (The Moreland Group, 1994). This research sought to identify elements that comprise best practice in successful CAS programs particularly as people with disability transition out of secondary school settings. Using individual program data, discussion with stakeholders and an examination of literature including government reports, the researchers discovered that while there was a focus on employment, a valuing of alternatives to employment, where this was seen as appropriate, is important. Day programs frequently provided meaningful activities for people with high support needs who were unlikely to leave the program unless they moved to a new district (The Moreland Group, 1994).

The Moreland Group researchers further identified 10 important factors for the provision of CAS including:

1. The effective assessment of needs together with acceptance of goals set in the individual transition plan,
2. The development of a plan of action to ensure the client has a varied program which assists them to gain new skills and competencies,
3. A range of community experiences on a one to one or small group basis,
4. A varied program, based on individual needs and interests,

5. Well-trained staff who are able to manage challenging behaviours in community settings,
6. Regular monitoring of individual outcomes to ensure needs are being met and possibilities for progressing to employment and greater independence are canvassed,
7. Appropriate transport arrangements for access to the community,
8. Integration in community settings (friendships),
9. Skills development, and
10. The flexibility to move to employment programs if and as skills improve.

Source: The Moreland Group (1994, pp. 50-51).

During the 1990s, further Australian research also considered the transition planning process for people with disability from secondary education to post school options including CAS and recommended that both vocational and CAS options, ‘should not merely be holding centres but offer relevant and pertinent training’ (Riches, 1996, p. 85). In 2000 and 2001 in South Australia the post school outcomes of 28 young people with ASD participating in CAS (day option programs) were explored. While acknowledging the role CAS has in providing some structures to the lives of people with ASD, Burrows, Ford and Botroff (2001) concluded that there is an urgent need to focus on the long term learning and lifestyle outcomes of those who participate in day option programs. The researchers recommended an examination of the effectiveness of these programs to respond to the, ‘unique needs, goals, interests and preferences of young people with Autism Spectrum Disorder’ (Burrows, Ford & Botroff, 2001, p. 45).

In 2004 the findings of an Australian national survey of day services used by older people with disability were also published by Bigby, Balandin, Fyffe, McCubbery and Gordon (2004). In this research a survey was developed consisting of open and closed questions to explore the use of support and leisure day programs by older people with a disability. The researchers distributed the postal survey to 596 day programs for people with a disability in Australia with a 28 per cent response rate. Some 19 per cent of service users were aged over 55. The majority of respondents were between the ages of 40 and 60. The largest group of participants were people with intellectual disability (81 per cent). Three challenges identified by the researchers when providing day support for older people were, 'lack of financial resources, knowledge and expertise amongst staff, and difficulties interfacing with other service systems' (Bigby, Balandin, Fyffe, McCubbery & Gordon, 2004, p. 240).

2.12.2 Transition planning

Any processes to assist young people with disability, families/advocates in making future adult life choices requires considerable attention as:

> 'facilitating their ability to successfully navigate the years immediately following secondary school is critical both for them and for our society at large' (Wells, Sandefur & Hogan, 2003, p. 805).

Therefore, transition planning prior to leaving secondary education needs to comprehensively consider the expectations of people with disability. This would then ensure that major areas of adult functioning are addressed, such as daily living, health, community participation, recreation, arts and leisure, continuing education, employment, self-determination and place and nature of residence.

Little emphasis has been placed on what people with disability consider important, particularly aspects such as social life, friendships and leisure. For example, in a study of 250 young people with intellectual disability 40 per cent had little involvement with the transition process (Heslop, Mallet, Simons & Ward, 2002). For people with disability who also may have limited speech, service assumptions may be made (Dee & Byers, 2003) which in the modern age of technology and alternative augmentive communication should not be accepted (Simeonsson, 2003).

Concerning transition planning, research by Ward, Mallet, Heslop and Simons (2003) involving 283 families of young people with intellectual disability (aged between 13 and 25) in the UK, discovered that a third of the young people who had completed secondary education did not have a transition plan. Of concern, almost half of the participants in the research had little or no involvement for planning for their future and only two thirds of participants had a transition plan prior to leaving school, though all students are mandated to have a transition plan. In addition, the topics focused on for transition planning differed from what families and youth considered significantly important, and there was a lack of easily accessible information for young people with intellectual disability and families about future options and possibilities.

When considering the expectations of people with disability and their transition planning into post school options, a community-referenced approach to assessment that specifically asks students about their future aspirations is vital (Wehman, 2006, p. 517).

Transition planning is important for young people with disability ‘as they often have to overcome multiple social, academic and environmental constraints that may present roadblocks to meeting society’s expectations’ (Lehman, Clark, Bullis, Rinkin et al. 2002, p. 128). A recent example of a transition program in the UK includes the appointment of a facilitator who starts working with each young person two years before they are due to leave school, helping them to think about their options (McGrath & Yeowart, 2009). The facilitator coordinates regular meetings between people involved with the young person’s transition, including professionals such as teachers and social workers, as well as family and friends. This approach takes into account what is important to the person for whom the planning is being done and actively consults the people close to the young person making the transition (McGrath & Yeowart, 2009). In the UK recent research has identified five principles underlying a Transition Support Program. These principles included: comprehensive multi-agency engagement; full participation of young people and their families; provision of high quality information; effective transition planning; and an array of opportunities for living life (Merriman, 2009). A range of positive strategies which may assist effective post school transition planning has been identified in the literature and some examples are summarised in Table 2.4.

Table 2.4 Strategies for transition planning

Strategies for transition planning	Author
Opportunities which consider the effects of the severity of disability	Eisenman, (2003); Kendrick (2011)
Holistic, outcome oriented approach	Nuehring & Sitlington, (2003) Dyke, Leonard & Bourke, (2007) Rosenbaum & Stewart, (2007)
Consideration of safety and security of participants	Taylor, McGilloway & Donnelly, (2004)
Strategies which facilitate the use of suitable technologies	Modell & Valdez, (2002)
Identification of opportunities to overcome barriers	Wells, Sandefur & Hogan, (2003), Broadhurst, Yates & Mullen (2012)
Commitment and support at the central policy and funding level	Gillan & Coughlan, (2010); Riches, (1996); Winn & Hay, (2009)
Development and implementation of individual transition planning, involving students, parents/caregivers, advocates, and significant others such as teachers and community agency personnel responsible for providing services	Carnaby, Lewis, Martin, Naylor & Stewart (2003); Davies & Beamish (2009); King, Baldwin, Currie & Evans, (2005); Luft, Rumrill, Snyder & Hennessey, (2001)
The provision of relevant and appropriate school curricula and instruction	Carter, Lane, Pierson & Glaeser, (2006); Riches, (1996)
Community involvement and local planning	Fabian, Lent & Willis, (1998); Riches, (1996); Zigmond (2006)
Interagency cooperation and collaboration at all levels	Katsiyannis, deFur & Conderman, (1998); Riches, (1996)
Liaison and linkage of students to post school options prior to leaving school	Koch, (2000); Riches, (1996); Stumbo, Wilder, Zahl. DeVries, Pegg, Greenwood & Ross, (2015)

The challenges of addressing service expectations for people with disability such as their transition planning prior to leaving secondary education are evident. A collaborative approach to policy, practice and research on the issues of transition for youth with disability and their families/informal primary carers is clearly important in order to produce improved life outcomes (Dyke, Leonard & Bourke, 2007). Supportive and flexible approaches are also important for people with acquired disability transitioning from rehabilitation services into future community participation options including CAS.

The increasing focus on person-centred planning may also contribute to positive transition planning processes for people with disability and their families. The term person-centred planning can refer to approaches which place the persons with disability at the centre of decision-making (Broady, 2009). This approach supports the idea that people with disability should not have to, ‘fit’, into existing services which are controlled by, ‘expert professionals’, (Nelson, Lord & Ochocka, 2001). As a result, people with disability are seen to have an enhanced control of an array of services, such as CAS, which can address their aspirations and needs (Arksey & Kemp, 2008). This partnership between people with disability, their families/carers and others relevant to such services is central to contemporary thinking in the disability field. As Kendrick (2011) explains, moving away from, ‘group-based’, fixed models of services such as traditional, ‘day programs’, is required, otherwise organisations and service providers have, ‘relabelled’, themselves as personalised but are largely still operating as traditional, group models of services. Service providers may devote efforts to formalise person-centred planning, ‘but lack the precise and dependable means for implementing aims such planning generates’ (Kendrick, 2011, p. 1).

In a CAS context the adoption of person-centred planning may include the following characteristics according to Kendrick, (2011) as presented in Table 2.5.

Table 2.5 Characteristics of person-centred planned CAS

Characteristics of a person-centred planned CAS
The organisation would have in itself the capacity to routinely create individualised options with a person, ‘from scratch’.
The organisation could convert existing group-based models to individualised ones as requested.
The organisation could not only create but also sustain and evolve these options.
The organisation could generate an individualised option for all people with disability, including people [for whom it is] allegedly difficult to provide services. Otherwise individualisation would only be feasible for some rather than all.
The organisation could sustain individualised options identified through person-centred planning across multiple time periods and jurisdictions with varying economic, political and leadership climates.
The organisation would have the capacity to deliver individualised arrangements at a cost which is competitive with aggregate group-based costs of service delivery.
That, as a result of the person-centred planning, individualised options are created. which assure comparable security for people with disability using, ‘intentional safeguards’.

Person-centred planning is characterised by having a focus on sustainable flexible, economically viable and secure individual choices and opportunities for people with disability. This concept is at the core of contemporary academic thinking in disability studies, as well as professed disability practice as reported later in this thesis.

2.12.3 Service quality rights/needs: Implementation

> ‘In the name of doing things for people, traditional and hierarchical organisations end up doing things to people’ (Leadbeater, 2009, p. 1).

The service needs/rights of people with disability are central to the provision of CAS and the exploration of service In the context of the implementation of the NDIS In the context of the implementation of the NDIS quality. In Australia the needs/rights of people with disability of older age (over 55 years) has received some attention in the literature with researchers highlighting that those participating in day programs have valued them highly and have also expressed a desire for increased activity (Bigby, 1997).

Researchers in the Netherlands endeavoured to consider the day activity needs of people with profound intellectual and multiple disabilities (PIMD) as relatively little attention has been paid to the quality and appropriateness of such services

(Vlaskamp, Hiemstra & Wiersma, 2007, p. 102). The researchers proposed a simple questionnaire for use by staff so they could have a good overview of the special attention that is needed when offering day activities. Their findings highlighted that the needs which pertain to the adequacy of day services included the provision of age appropriate service planning, degree of community inclusion and the extent to which activities fit into the individual educational or activity plan for the person involved (Vlaskamp, Hiemstra & Wiersma, 2007).

Researchers from the UK also explored the needs of people with disability and identified themes and issues to inform best practice for future CAS service delivery (Cole, Williams, Lloyd, Major et al. 2007). The following, 'key ingredients', for achieving successful community-based CAS provision were identified. Firstly the development of partnerships with people with disability who use the services directly as well as their families/informal primary carers who are the indirect users of CAS services is important. These partnerships may involve inclusion in CAS service design, development and planning, based on people's individual (person-centred) plans. People with disability and their families/informal primary carers may be involved in the organisation of CAS through participation in steering groups and/or on Boards of Management as well as involvement more broadly across state and national policy development. In doing so the researchers emphasised a transition away from constraints of power and decision-making resting with service authorities only. This meant that cultural changes are needed in CAS and people need to be exposed to alternative models of service so that, 'integrated opportunities and community connections', can exist. The researchers also highlighted that planning with, and for, people with disability was recommended and can be linked with individualised funding and direct payments (Cole, Williams, Lloyd, Major et al. 2007).

In addition, 'smart commissioning', including overseeing transitions from centre-based activities, reconfiguring resources and responding to individuals' unmet needs were also highlighted as important ingredients. In practice, this often meant people with disability moved to a mixture of CAS and vocational services rather than relying solely on one service (five days per week) although it is purported that people with high levels of support needs do not have such diverse opportunities

(Cole, Williams, Lloyd, Major et al. 2007). Importantly, CAS providers need to provide ongoing staff development to increase person-centred practices (Cole, Williams, Lloyd, Major et al. 2007). The researchers also highlighted that developing people's independence and skills are vital rather than doing an activity in a community setting and considering this to be social inclusion (Cole, Williams, Lloyd, Major et al. 2007). Increasing community infrastructure and capacity building which welcomes people with disability is also needed to reduce reliance on transportation and for building sustainable relationships. Clear information which assists people to make choices is also required from the service providers. Finally the researchers recommended the development of supports for people who may develop difficulties if unoccupied during the day, providing political will and support to the process, ensuring skilled team management and strong partnerships between government, local funding bodies, and policy makers as well as, of course, CAS providers.

2.12.4 Service quality: experiences (evaluation)

Evaluations relevant to community-based services for people with disability have been conducted over the past 30 years which recommend the active involvement of people with disability and their parent(s). In 1994, Mitchell and Graham evaluated pilot projects using individual needs analysis in Queensland, the Australian Capital Territory, Victoria and South Australia. The evaluation focused on ways of developing a coordinated approach to service delivery. In their evaluation of assessment processes they recommended that assessment should:

a) be multidimensional and look at the whole person in the context of their community and the range of formal and informal supports required to maintain their lifestyle,

b) involve the individual, their family and significant others in the process of assessment and planning,

c) be seen to be independent from service delivery and as independent as possible from the source of funding so that it does not become service defining and restrictive,

d) be carried out by an accredited person with good local knowledge,

e) be flexible and responsive to meet changing needs,

f) have a strong values base, provide adequate safeguards and grievance procedures,

g) provide an individual plan which should consider both Disability Services funded services and other generic options in each individual's community, and

h) ensure that planning is centred around the aspirations of people of similar ages, cultural and economic backgrounds.

(Mitchell & Graham, 1994 pp. 1-2).

The experience of CAS participants is important to inform service quality yet the evaluation of services is a frequently under-considered issue (Reid, Parsons & Green, 2001). Researchers such as Fisher, Robinson and Strike (2012), have highlighted the necessity for participatory and inclusive approaches to disability program evaluation. The researchers have identified a range of benefits of the active involvement of people with disability throughout the evaluation process. They argue that people with disability have the right to be involved in finding out about services/programs which affect their lives and that this changes the way that people think about people with intellectual disability.

They further suggest that this proves to the community that people with disability can be involved in planning and evaluating their own services if they are given the opportunity. Fisher et al. acknowledge that people with disability have a different way of doing things and that evaluation of services needs to take this into account but the experience of the people for whom the service is developed is valuable and significant. Other important points raised are that people with disability in a program feel more comfortable talking to someone who has the same kind of experiences in their life and that you get better information from people when someone with intellectual disability asks them. People can then understand what they are being asked, and are more likely to get involved in research evaluation (Fisher, Robinson & Strike, 2012).

The perspectives of people with disability and their families including transition planning, implementation and evaluation processes and approaches are vital when considering the quality of CAS. These can be influenced by a range of factors including, ‘external economic, social and value forces, overall societal values, the political ideology of government, governmental funding, laws, and the culture of services have a significant impact on the nature and development of services’ (Makharadze, Kitiashvili, and Bricout, 2010, p. 290).

2.13 Individualised funding

The term individualised funding has been described as simply giving control of funding to the person so that they can purchase the services they require (Laragy, 2002). Providing funding directly to the person with a disability turns the user into the purchaser, which is a dramatic shift in terms of control and power (Laragy, 2010; Martlett, 2006; Williams, Simons, Gramlich, McBride, Snelham & Myers, 2003). Traditional group-based programs such as CAS tend consciously or unconsciously to disregard the contribution of people with disability and as a result people with disability are placed in a passive role as a care recipient, ‘unable to enjoy the freedom and responsibility that goes with participation and reciprocation’ (Williams, 2007, p. 12). By orchestrating their own arrangements, people with disability may have opportunities for both formal and informal partnerships for support.

Internationally, individualised funding approaches have been implemented in Canada (Martlett, 2006), the United States of America (Polivka & Salmon, 2001), England (Glasby & Duffy, 2007), Wales (Stainton & Boyce, 2002) and France, Germany and Austria (Polivka & Salmon, 2001). A range of practical components associated with individualised funding have been identified including; the availability of someone to facilitate the planning and brokerage of support (Martlett, 2006); opportunities for capacity building to manage their own arrangements (Stainton & Boyce, 2002) and investment in infrastructure and technical support by governments towards the sustainability of the non-government sector (Lord & Hutchinson, 2003).

Walsh (1995) in his study of service coordination in South Australia recognised that an individualised approach to design and funding at that time had been quite difficult to implement with the intensive resourcing required for many people with severe disability. Walsh proposed that the individualised model could efficiently be operationalised if relevant to individual’s needs, well integrated into the life of the individual and if the services fostered other community supports from informal and formal services by maintaining access to everyday social participation opportunities (Walsh, 1995, pp. 3-4). Furthermore, Walsh recognised that a focus on the individual should not replace the need for ongoing planning of unmet needs amidst people with disability and their carers (Walsh, 1995, p. 2). With increasing policy interest in individualised funding and its implementation, researchers have explored potential benefits and challenges.

In Australia Fisher and Purcal (2010) identified a range of strengths of individualised funding when compared to traditional, ‘block funding’, of organisations particularly the facilitation of, ‘control’, and, ‘choice’, in service provision. The researchers discovered that packages managed by the person with a disability, family or facilitators which can be spent in the, ‘open market’, ‘can generally be tailored more easily towards the client’s preferences than more restrictive packages or those that are spent through a single service provider’ (Fisher & Purcal, 2010, p. 2). Fisher and Purcal (2010) also identified opportunities for improvement including support for people with significant cognitive disability and for people whose funding packages are insufficient for all the disability support the person needs. If there is a funding shortfall, either the person with a disability or family members incur the additional costs or the person does not receive the support they need.

2.14 Chapter 2 summary

In this chapter the definitions and epidemiology of disability, implications for people with disability and literature regarding service quality and individualised funding were examined. It was clear from this review that the more individualised funding models that are developing world wide provide a context in which a transformation of service models is occurring. This transformation is from service-based, professionally-led models to individual-based models. It is also evident that for the benefits of individual funding of services to flow on to improved outcomes for people with disability and their families that the people themselves must be able to become more actively and meaningfully involved in the planning, implementation and evaluation of these services.

In the next chapter the rationale for the research using a Constructivist Grounded Theory approach is presented as well as participants’ involvement in the current research. The collection, recording and analysis of data, ethical considerations and reference to relevant appendices are also provided.

Chapter 3
Research Methodology

3.1 Introduction

> ‘Grounded Theory has generated innovative ideas since its earliest beginnings’ (Charmaz, 2014, p. 16).

In this chapter a Constructivist Grounded Theory approach and accompanying instruments, participant involvement, data collection, analysis of data and consideration of ethical issues are presented. Constructivist Grounded Theory acknowledges the researcher in the construction and interpretation of data (Charmaz, 2014). A review of international and national literature, memoing and observation of processes and approaches occurred throughout the current research. The Constructivist Grounded Theory approach involved six data collection methods: memoing; observation; focus groups; face-to-face interviews; a questionnaire; and a critical discourse analysis of extant texts. In order to explore the processes and approaches of Community Access Services (CAS) customer service quality, focus groups and face-to-face interviews were conducted in metropolitan and regional South Australia with people with disability, family members/informal primary carers and CAS provider representatives. In addition, a questionnaire was distributed to gather responses on the perceptions of people with disability and family members/informal primary carers accessing CAS. A critical discourse analysis of Australian publically available CAS policies and written evidence also occurred.

3.2 Research approach

> ‘Constructivist grounded theorists attend to the production, quality and use of data, research relationships, the research situation, and the subjectivity and social locations of the researcher. Constructivist grounded theorists aim for abstract understanding of studied life and view their analyses as located in time, place and the situation of inquiry’ (Charmaz, 2014, p. 342).

Grounded Theory methods ‘consist of systematic, yet flexible guidelines for collecting and analysing qualitative data to construct theories from the data themselves’ (Charmaz, 2014, p. 1). The Grounded Theory approach was formulated by sociologists Barney Glaser and Anselm Strauss from the University of California during the 1960s (Glaser & Strauss, 1967). Defining components of Grounded

Theory practice included the: 1) simultaneous involvement in data collection and analysis; 2) constructing analytic codes and categories from data not from preconceived logically deducted hypotheses; 3) using the constant comparison method which involves making comparisons during each stage of the research; 4) advancing theory development during each stage of data collection and analysis; 5) memo writing to elaborate categories, specify their properties, define relationships between categories and identify gaps; and 6) sampling aimed toward theory construction (theoretical sampling), not for population representativeness (Charmaz, 2014, pp. 7-8).

A Constructivist Grounded Theory approach (Charmaz, 2014) was adopted for this current research, in order to build theory regarding CAS service quality from the experiential knowledge of research participants. The Constructivist Grounded Theory approach has contributed to the investigation of, 'social pressures that are by their very nature, not amenable to enumeration or measurement' (Harry, Sturges & Klinger, 2005, p. 12). This research articulated strategies and advocated for developing theories from research grounded in data, rather than deducing testable hypotheses from existing theories (Annells, 1990; Charmaz, 2006; Creswell, 1998). In essence, instead of attempting to prove or disprove a hypothesis based on controlled variables, this research sought, 'to understand what individuals experience, how they interpret that experience, and how those experiences help to structure their world' (Caroloeo, 2002, p. 383). Researchers highlight that the approach may contribute to an exploration if a new point of view regarding a phenomenon is sought (Denzin & Lincoln, 1994; Strauss & Corbin, 1990) and the resultant theory may be applicable to other settings and populations (Morse, 1994). This research approach seems very relevant to determining future directions in the creation of quality CAS in many settings throughout the world and, as the literature review identified, this is a timely development.

A Grounded Theory approach has previously been used in a range of service settings with people with disability. In a study of factors impacting on the participation of people with disability in their activities of daily living, researchers Wee and Paterson (2009) sought to explore what people with disability themselves believed about activities and roles that were important to them. By understanding those factors that have a large influence in the participants' lives, the researchers sought to recommend opportunities that, 'may help those with impairments and those working with them to better implement steps necessary to optimise engagement in their chosen activities' (Wee & Paterson, 2009, pp. 165-166).

The Grounded Theory approach has also been used to explore the support needs of adult siblings of people with developmental disability. Researchers Arnold, Heller and Kramer (2012), discovered that siblings often become the next generation of care givers when parents are no longer able to fill this role. The researchers concluded that, 'they need to be supported to play an important role and become recognised partners in the solution of the long-term care crisis in the United States' (Arnold, Heller & Kramer, 2012, p. 380). More recently, researchers Lewer and Harding (2013) have also explored how the holistic provision of communication and speech therapy intervention for people with disability in CAS and residential homes may benefit from a focus on developing the skills of those who care for and support people with learning disability. The researchers discovered a range of key themes to improve outcomes for people with disability including; building relationships, attitudinal change, and joint ownership of the therapeutic goals (Lewer & Harding, 2013, p. 74). Further research using a Grounded Theory approach involving people with disability has been conducted by researchers including Smith and Sharp (2013), Thornton and Underwood (2013), Koening (2011), Johnson, Douglas, Bigby, and Iacono (2012), Claes, Van Hove, van Loon, Vandevelde and Schalock (2010), Hammel, Magasi, Heinemann, Whiteneck, Bogner and Rodriguez (2008).

The attraction of this research approach was to gain an understanding of the expectations, rights, needs and experiences of CAS by people with disability. Therefore, throughout the current research direct quotations from participants and documentary evidence have been presented to explore the, 'voice', and participation of people with disability.

3.2.1 Ontological position

> 'Ontological assumptions are concerned with what we believe constitutes social reality' (Blaikie, 2000, p. 8).

Concepts of leisure, the arts, recreation, community access services and disability have been constructed because of the personal experiences of the researcher who is a father of two children with disability who have participated in various creative leisure opportunities during their early years and have been faced with uncertainty during post school preparations. In addition, the researcher has had professional roles in policy development for the past 10 years and prior to that has been responsible for recreation and leisure services in rehabilitation programs for 20 years. Academic studies have also greatly contributed to the researcher's understanding of community participation and inclusion of people with disability. Such experiences and learnings have contributed to changing the researchers understanding of world views including social and civic engagement in which social equity, social capital and social justice are important (Robertson & Long, 2008).

3.2.2 Epistemological position

The current study has sought multiple perspectives from varying research participants in order to understand individuals' views and has been informed by the direct involvement between the researcher and those who experience a social phenomenon (Silverman, 2009). Other sources of information such as the language of written strategic and operational policies and potential associated power imbalances between people with disability and others have also informed the researcher's epistemological position.

3.2.3 Philosophical position

The researcher was interested in identifying what was occurring and opportunities for contribution. Both the initial reading of the literature regarding CAS and discussions with people with disability and their families indicated opportunities for improvement of the quality of the services provided. The current research has been inspired by potential individual transformation. Shortly after the commencement of the current research the *SHUT OUT: Report* was released in which the following vision was expressed.

> "Disability is characterised by desire for positive change and striving for emancipation and flourishing. It is active hope. We desire a place within the community! This place is not just somewhere to lay down our heads, but a place which brings comfort and support with daily living, friendship, meaningful work, exciting recreation, spiritual renewal, relationships in which we can be ourselves freely with others. And out of this great things may flourish.' (*SHUT OUT: Report*, 2009, viii).

Thus, theory development regarding people with disability and social and community participation in leisure, arts and recreation and CAS has arisen. The philosophical position of the researcher has consequently identified both challenges and opportunities. Through participation in national and international conferences the researcher has constantly been able to learn other perspectives from people with disability, their families, academics and practitioners which have contributed to exploring a diverse range of data throughout the study.

According to Charmaz (2014):

> ‘a constructivist approach theorises the interpretive work that research participants do, but also acknowledges that the resulting theory is an interpretation. The theory depends on the researcher’s view; it does not and cannot stand outside of it’ (Charmaz, 2014, p. 239).

As a researcher, views on this topic have been deeply influenced by learnings from primarily the people with disability who are exploring ways to be engaged in leisure, the arts and recreation and families who assist alongside in this process. The literature, collection and analysis of data, PhD candidature and current and previous roles have contributed to the researcher’s philosophical position supporting the human rights of people with disability. People with a disability deserve and demand opportunities for equal and fair participation.

3.3 Research instruments

3.3.1 Memoing

> ‘Memo writing constitutes a crucial method in grounded theory because it prompts you to analyse your data and codes early in the research process’ (Charmaz, 2014, p. 162).

A journal was kept by the researcher between 2008 and 2016 to record learnings and perceptions which also assisted the development of the substantive theory during the current research process. Journal entries were made to identify any apparent linkages during the process of analysis. As Charmaz (2014) states ‘memo writing provides a space to become actively engaged in your materials, to develop your ideas, to fine tune your subsequent gathering, and to engage in critical reflexivity’ (p.163). In this study this occurred from the early proposal stage as the researcher explored concepts of quality from the perspectives of people with disability and their families as well as from CAS providers. Constantly comparing data and frequent reviews of memos during the study contributed, for example, to the researchers progressive move from services managed by providers to the human rights perspectives of people with disability having equal power with decision making. As a result the memos provided a record of the study and of the researchers analytic progress (Charmaz, 2014, p. 191).

3.3.2 Observations

Memos were also used during the data collection process in order to record observations by the researcher. Interviews with CAS representatives for example were, at times, conducted at CAS facilities at which people with disability were observed participating in a range of leisure, arts and recreation. In this way the researcher gained a deeper understanding of barriers to the community participation and inclusion of people with disability through CAS, which could have been missed if relying on digital recording of data alone.

3.3.3 Focus groups

Focus group questions were developed based on the initial learnings from the literature review and participation in community forums and conferences in 2009. Following approval from the Flinders University Social and Behavioural Research Ethics Committee (Appendix One), focus groups were conducted in South Australia between 2010 and 2014 with an extension to 2015 (Appendix Two) and involved research participants including people with disability and parent(s), siblings, informal primary carers.

Focus group topics for the current research included (see Appendix Five):

1. transition planning and expectations,
2. participant rights/needs,
3. experiences of CAS, and
4. recommendations to contribute to service quality.

Focus groups were conducted to facilitate planned, focused discussion and involved small groups of participants. The focus groups were designed to obtain participant perceptions of the current research topic in a permissive, non-threatening environment and so that participants could consider, discuss and debate the topic, allowing participant interaction, interpretation of each other's responses and the facilitation of new data (Ward, 2009). The use of focus groups also enabled an exploration of conflicting data, theory development and enabled participants to explore issues, feelings and opinions more widely and deeply than is usually possible in a structured interview or formal public meeting. The focus groups were, with permission, recorded and transcribed for analysis and non-identifying participant statements have been reported from the data (Ward, 2009). Each focus group was conducted mindful of the importance of creating a relaxed, informal atmosphere.

The purpose of the focus group was clearly defined, the questions were open ended, focused, simple and comprehensible and conducted within an agreed time arrangement (usually no more than 90 minutes). The focus groups were also facilitated by the researcher to enable input from quieter people and to encourage divergent thought by giving individuals permission to have different views from the rest of the group. Focus groups involving people with disability also provided, 'opportunities for peer support and validation of common experiences' (Abbott & McConkey, 2006, p. 278). Transcripts from focus groups were analysed using Nvivo data analysis software. Focus groups have been previously used to good effect by researchers with people with disability to identify barriers and strategies affecting utilisation of primary preventative healthcare services (Kroll, Jones, Kehn & Neri, 2006) and to gain an insight into how people with intellectual disability who lived mainly in supported housing perceived the barriers to their social inclusion as well as ways in which barriers could be removed (Abbott & McConkey, 2006, p. 277).

Focus groups were conducted with people with disability and parent(s), siblings and informal primary carers living in South Australia. Information regarding the research for prospective participant recruitment was posted on the Disability Information and Resource Centre (DIRC) of South Australia website and forums were advertised and conducted at DIRC in 2010 and 2011. Additionally, information was promoted by Peak Disability bodies in South Australia including Dignity for Disability (SA), Autism Association of South Australia, Down Syndrome Association of South Australia, Brain Injury SA, Conductive Education Association of South Australia, Families 4 Families, Carers SA and the Disability Professionals Association (DPA) of SA. Selection criteria for people with disability included a diagnosed disability, over 18 years of age, had, or were currently participating in CAS and who were accessible and able to participate in the research. Families participated in the focus groups, often to support their son or daughter and confirm responses to questions as required. Researchers Porter, Daniels, Feiler, and Georgeson, (2013) have also involved parents when exploring the views of children with disability and family members, ‘were seen as integral to understanding the impact of an impairment or health condition and primacy was given to their reports’ (Porter et al., 2013, p. 429).

3.3.4 Face-to-face interviews

The development of face-to-face interview questions occurred as a result of learnings from the focus groups. Following approval from the Flinders University Social and Behavioural Research Ethics Committee (Appendix Three) with an extension (Appendix Four), face-to-face interviews were conducted in metropolitan and regional South Australia between 2010 and 2015 and involved people with disability and family members/informal primary carers using the same recruitment and selection criteria as focus groups.

Face-to-face interviews were also conducted with CAS provider representatives from metropolitan and regional South Australia. Participants who are members of the Disability Professionals Association (DPA) of SA, received correspondence regarding the face-to-face interviews and were invited to participate. Additionally, CAS providers listed on the Disability SA *Look Book* during 2010, 2011 and 2012 and also on the 2013 and 2014 Disability SA website were invited to participate.

For this current research, face-to-face interviews were conducted using semi structured open ended questions with participants in metropolitan Adelaide and regional South Australia. The interview topics, for people with disability, are included in Appendix Six. Interview questions for parent(s), siblings and informal primary carers are provided in Appendix Seven and the interview questions for CAS providers are included in Appendix Eight.

3.3.5 Questionnaires

A questionnaire was developed in two parts. Part A involved questions for people with disability and Part B questions for parent(s), siblings and informal primary carers involved with CAS (Appendix Seventeen). The findings of focus groups and face-to-face interviews contributed to the design of the questionnaire as did a review of recent national and state-wide questionnaires developed for participation with people with disability. These included questionnaires from the *SHUT OUT: Report* (National People with Disabilities and Carer Council, 2009), *Strong Voices: A Blueprint to Enhance Life and Claim the Rights of People with Disability in South Australia* (2012-2020) (Department of the Premier and Cabinet, South Australia, 2011), the, 'Quantities of Life Data from the Tellus Survey 2012' (Williams & Fidock, 2012,) and the 'Evaluation of Day Activities in South Australia' (Lumin Collaborative, 2013).

Following approval from the Flinders University Social and Behavioural Research Ethics Committee, (Appendix Three) the hard copy and electronic, 'Survey Monkey', questionnaire was distributed within South Australia to gain insights from research respondents between 2013 and 2015 through distribution by peak disability, advocacy organisations (Appendix Nineteen). Each organisation was invited to: a) advertise the questionnaire on their website and or in organisation newsletters; b) forward the individual and family/informal primary carer questionnaire invitation to people with disability (their clients) and families/informal primary carers on their agency contact lists; or c) distribute the questionnaire at relevant conferences/ seminars.

Participants were self-selected individuals with disability, and family members/informal primary carers providing support to a person with disability in South Australia. Criteria for participation included that the participant was over 18 and had sufficient capacity and literacy in English to complete a questionnaire.

People with disability and their parent(s), siblings and informal primary carers involved with CAS provided responses regarding their expectations, needs and experiences of CAS. The questionnaire responses were also analysed using Nvivo data analysis software. Responses from the questionnaire provided an opportunity to expand understanding of the experiences of people with disability and provide an opportunity for participants to provide suggestions and recommendations to contribute to service quality.

3.3.6 Critical Discourse Analysis

The use of language is essential when exploring CAS for people with disability. As Tichkosky and Michalko (2014) have emphasised, disability is lived in the midst of meanings given to it. The meaning of disability, therefore, is given whenever we speak of disability, act upon disability or even think about disability. Critical Discourse Analysis (Fairclough, 2010; Fairclough, 1995; Grue, 2009; Jager & Maier, 2009; Liasidou, 2008; Rogers, 2011) is identified as a valuable tool for researching processes of social and political context as disability policy shifts towards a focus on disability as a basic human rights issue (Pinto, 2011). Critical Discourse Analysis has been defined as being;

> ‘fundamentally interested in analysing opaque as well as transparent structural relationships of dominance, discrimination, power and control as manifested in language. In other words critical discourse analysis aims to investigate critically social inequality as it is expressed, constituted, legitimatised, and so on by language use (or in discourse)’ (Wodak & Meyer 2009, p. 10).

Using this approach, studies have identified the existence of referrals containing discourses of, ‘both the medical model of disability and of oppression’ (Nunkoosing & Haydon-Laurelut, 2011, p. 415) and while documentation of legitimate, medically certified disability provides, ‘access to certain rights and privileges...[it also may be] accompanied by a considerable loss of personal autonomy, as well as social stigma’ (Grue, 2011, p. 536).

All publicly available Australian CAS documents that were published in English and involved people with disability over 16 years of age were included in the critical discourse analysis. Key words for the collection of written evidence included, ‘Disability’, ‘Intellectual and Developmental Disabilities’, ‘Policy’, ‘Discourse’, ‘Community Access’, ‘Day Activities’ and ‘co-production’ and strategic searches were conducted between 2010-2014 using Australian state and territory government websites. Having completed the initial review of documents and identified potential suitable documents for analysis in South Australia, further collection of documents from each Australian state and territory occurred.

The time period of documents considered for this study (2010-2014) has represented a unique time in Australia’s history as people with disability have had opportunities to commence the adoption of individualised funding and as service providers transition away from traditional block funding arrangements.

The process of data collection and analysis was repeated throughout the years 2010 to 2014 to include new texts. The type of written documents (n=42) included CAS policies (both strategic and operational), funding guidelines, information booklets and discussion papers. For each document references are made to the government department in which the sample documents were gathered, state or territory of origin, year of document production, document description and website of the sample documents and is included (Appendix Eighteen).

As an example of how the process of Critical Discourse Analysis has been used previously, McGrath (2008) used a critical discourse analysis in his exploration of Australian local government provision of community recreation for people with disability. This research highlights that a critical discourse analysis framework provides the researcher with the ability to regulate and define a particular mode of analysis and aids in substantiating and validating resulting interpretations and explanations that are elicited from the texts. For this research a, ‘three dimensional’, critical discourse analysis framework was adopted (Fairclough, 1995). The framework was appropriate as it seeks to establish connections between properties of spoken or written language texts, features of discourse practice (processes of text production, distribution and consumption) and wider sociocultural practice (Fairclough, 1995, p. 87). Each document identified underwent a line by line analysis (Fairclough, 2003) to attempt to identify the presence or absence of the voice of individuals with disability and their parents/carers. Cross document analysis was also conducted to assist in identifying differences in eligibility criteria and sociocultural practice evident in the transition from block funding policies to individualised and flexible policy and funding arrangements.

3.4 Data collection, storage and access

Focus groups and face-to-face interviews conducted with participants in this current research were, with permission, recorded on a digital recording device and handwritten notes were taken. Participants were able to request that information could be used or omitted at any stage. All data collected from focus groups, face-to-face interviews and responses to questionnaires were stored in compliance with the Australian Freedom of Information (AFI) legislation and will remain secured for seven years within Flinders University, Department for Disability and Community Inclusion. Access to the research data and results will be restricted, however consideration will be made regarding enquiries that would further the field of CAS with, and for, people with disability.

3.5 Data analysis methods

3.5.1 Grounded Theory analysis

The original conception of Grounded Theory methodology according to Glaser and Strauss (1967) was framed in a process of, ‘constant comparison’, (Walker & Myrick, 2006) in which the researcher moves amongst the data advancing from coding to conceptual categories and to theory generation (Harry, Sturges & Klinger, 2005). The analysis of data from the data sources was carried out concurrently with data collection, a characteristic of the Grounded Theory approach, in order to generate a more comprehensive and developed theory at the end (Charmaz, 2006; Creswell 2007; Whitcher & Tse, 2004).

In Grounded Theory, data analysis occurred systematically (Dey, 1999; Patton, 2002) and is a central means by which raw data is converted to theory and involves comparing and asking questions (Patton, 2002). The current research approach used minimal mathematical techniques (Bastalich, 2004) and memo writing to elaborate categories, specify their properties, define relationships between categories and identify gaps (Charmaz, 2006). In a Grounded Theory approach to data analysis, professional and personal experience also contributed to the selection of initial categories (Mikilewicz, 2000).

The Constructivist Grounded Theory approach, as a constant comparison process as presented by Tweed and Charmaz, (2011) is displayed Figure 3.1.

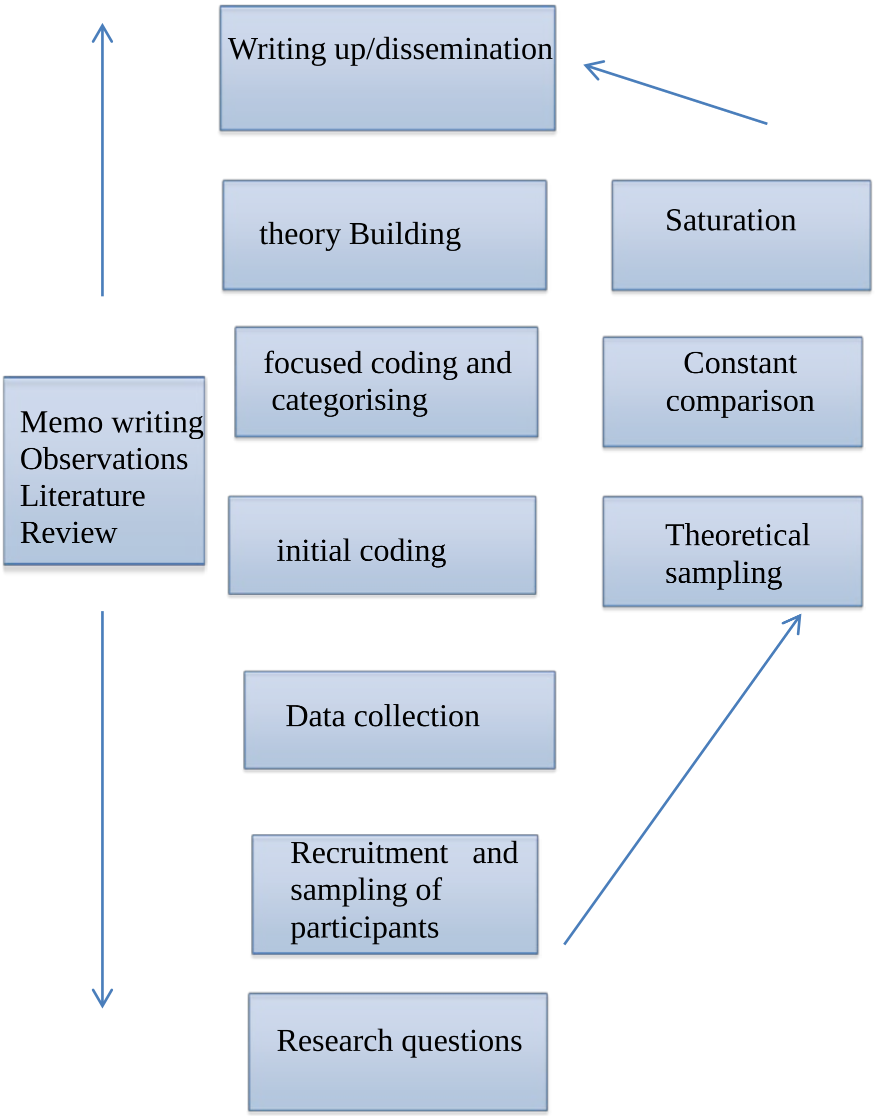

Figure 3.1 Constructivist Grounded Theory approach

3.5.2 Coding

Following the initial line by line coding, ‘focused coding’, occurred. Focused coding refers to using the most significant and/or earlier codes to sift through large amounts of data and, ‘requires decisions about which initial codes make the most analytic sense to categorise data incisively and completely’ (Charmaz, 2006, p. 58).

Using Nvivo data analysis software, data were coded into, ‘categories’, referred to as, ‘nodes’, and analysed for themes and repeated patterns. Research participants were assigned identification numbers and digitally recorded interviews were transcribed verbatim by the researcher. All focus groups and interview transcripts were completed by the researcher (rather than by a transcriber) as an opportunity to, ‘get immersed in the data’, as, ‘an experience that usually generates insights’ (Patton, 2002, p. 441).

3.5.3 Reflection, theorising and saturation

As participants were interviewed at a range of CAS settings, contextual information was also considered in the data analysis such as if the participant was accessing CAS in a regional or metropolitan location. The results of analysed data from the focus groups, face-to-face interviews, written evidence and questionnaires were aimed toward theory construction, not for population representativeness (Birks & Mills, 2011; Charmaz, 2006). Therefore, the results of data analysis should not be generalised for the whole population of people with disability, rather they are intended to contribute to the enhancement of the service quality of CAS with, and for, people with disability.

3.6 Ethical considerations

When preparing the design for the current research, ethical concerns including participant confidentiality, anonymity, data storage and retrieval were considered. Approval from the Flinders University Social and Behavioural Research Ethics Committee was provided prior to commencing the focus groups, face-to-face interviews and distribution of the questionnaire.

3.6.1 Participants’ information

A Letter of Introduction was prepared and distributed for focus group participants (Appendix Nine), interview participants (Appendix Ten) and hard copy questionnaire participants (Appendix Eleven). Research Participant Information sheets were developed for participants interested in participating in focus groups (Appendix Twelve), face-to-face interviews (Appendix Thirteen) or completion of the questionnaire (Appendix Fourteen). The participant information sheets included project description, participant’s role, alternatives to participation, research monitoring, counselling services, researcher’s contact details, privacy and confidentiality, participant right of withdrawal, funding of the research, financial declarations, reimbursement of costs for participation, the likelihood and form of dissemination of the research results and expected benefits to the wider community.

3.6.2 Participants' consent

The researcher also developed consent forms for participants relevant to focus groups (Appendix Fifteen) and face-to-face interviews (Appendix Sixteen). After consent was provided, confirmation of participation in a focus group or interview via a letter or email was forwarded to participants, depending on their preferences. Consent was provided by each peak disability organisation involved to the Flinders University Social and Behavioural Research Ethics Committee prior to distributing the questionnaire to members.

3.6.3 Participants' obligation and confidentiality

Participants in the focus groups or face-to-face interviews could withdraw from participation at any time as stated in the participant consent form. Participants did not have to finish a focus group or an interview and there were no effects on their current or future participation in CAS. All information which could potentially identify participants remained confidential and all participants' names were replaced with unique letter/numeric codes (e.g. A1, B1, C1) as stipulated in the Flinders University Social and Behavioural Research Ethics Committee Ethics approval letter.

Research participants completing the questionnaire were unable to be identified in accordance with approval provided by the Flinders University Social and Behavioural Research Ethics Committee. Peak disability organisations forwarded the questionnaires either by post (with a return envelope included) or electronically with no identifying markings, to ensure confidentiality of participants. The researcher did not at any time have contact details of research questionnaire participants. Participants were not pressured or even asked to complete a questionnaire, but only alerted that a questionnaire was available if they were interested. The questionnaire was completed and submitted completely anonymously. Confidentiality and anonymity assurances were provided to participants in the content of the questionnaire.

Before commencement of the current research, each participant was fully informed of the details of the research, including the aim, the purpose, what would be involved, how the data would be used, as well as being advised of the right to withdraw at any time. The completion of the questionnaire by participants was on a voluntary basis only. All information collected was treated in the strictest confidence, with the identity of all participants disguised. The method and use of data generated did not threaten or harm the participants' physical wellbeing or dignity. The anonymity and integrity of all participants was preserved.

3.6.4 Potential risks, safety precautions and participant payment

An identified risk of the current research for participants includes exposure to psychological stress, triggered by distressing issues arising from the focus group, face-to-face interview or questionnaire. All participants were provided with the contact details for Lifeline, a 24 hour telephone crisis support service, in the information sheets (see Appendix Twelve, Focus Groups; Appendix Thirteen, Face-to-Face Interviews; and Appendix Fourteen, Questionnaires). As the focus groups and interviews were conducted with participants in a range of metropolitan and regional settings a mobile phone was carried at all times to ensure communication options for participants were available. Participants were not paid or reimbursed and did not receive any other benefit as a result of their research participation in focus groups, face-to-face interviews or by completing the questionnaire as stated in the Flinders University Social and Behavioural Research Ethics Committee approvals.

3.7 Trustworthiness measures

Throughout the current research several trustworthiness measures were used including the use of multiple sources of data and multiple types of written evidence (Creswell, 2007; Maxwell, 2005). A written journal was maintained throughout the research in order to record thoughts and questions from the data (Charmaz, 2014) and the journal was also invaluable to record decisions regarding research design, data analysis and findings with Flinders University supervisors. Meetings with supervisors occurred monthly. An Annual Research Progress Report was provided to the Flinders University Faculty Higher Degree Committee with endorsement from the Dean of School and the Flinders University Social and Behavioural Research Ethics Committee. Following completion and approvals from the Flinders University Social and Behavioural Research Ethics Committee an Annual Progress Report was also provided and approved each year for focus groups, face-to-face interviews and the questionnaire prior to further data collection occurring.

To increase credibility, data was interpreted by the researcher and agreement was sought by two fellow PhD colleagues who were not involved in the study. They independently read five transcripts of focus groups and five transcripts of interviews which they independently selected. They then provided comments towards the coding and themes identified by the researcher. Following discussions regarding the coding themes and interpretations agreement was made. In addition discussion with Flinders University supervisors occurred regarding the framework for the critical discourse analysis. Findings from data collection and analysis were discussed at monthly meetings with Flinders University supervisors.

3.8 Chapter 3 summary

This chapter has provided detail on the Constructivist Grounded Theory research approach, research instruments, participant selection and recruitment, data collection, analysis and consideration of ethical issues.

In the following chapter the results from the content analysis of memos, observations, focus groups and face-to-face interview transcripts, critical discourse analysis of extant texts and questionnaire responses are presented.

Chapter 4
Results

4.1 Introduction

By adopting the Constructivist Grounded Theory approach this study has explored, questioned and theorised about the processes and approaches to Community Access Services (CAS) that were experienced by people with disability and whether barriers to social and community participation have existed. The voice of people with disability and parent(s), siblings and informal primary carers was sought throughout the current research.

In particular, the current study has explored:

a) their expectations of CAS and transition processes,

b) their rights, needs and experiences of service design and implementation,

c) identification of policies and practices and the opportunities for individualised approaches, and

d) identification of recommendations to contribute to service quality.

The results are presented in three sections; firstly perspectives of people with disability and parent(s), siblings and informal primary carers (referred to as families); secondly perspectives of CAS provider representatives, and thirdly analysis of policy discourse contributing to policy development and professional practice. A summary of the findings conclude the chapter.

4.2 Perspectives of people with disability and their families

In this first section the perspectives of people with disability (n=53) and families including parent(s) (n=61), siblings (n=2) and informal primary carers (n=3) are presented. While recognising that families may consist of a parent or parents, siblings and/or informal primary carers the terms, ‘families’, or, ‘family members’, have been adopted for the results section for ease of presentation. Table 4.1 provides a summary of data about research participants including the method of participation, number of people with disability, the nature of the disability and the number of family members. The table illustrates that the focus groups consisted of people with intellectual disability, Acquired Brain Injury (ABI), intellectual disability and ASD, and families.

Table 4.1 Summary of research participants: People with disability, parents, siblings and informal primary carers (family members)

Method of participation	**Number of people with disability**	**Disability**	**Number of family members**
Focus groups	4 (1 male and 3 females)	Intellectual disability	24 parents
	17 (11 males and 6 females)	ABI	5 parents
Face-to-face interviews	2 (2 males)	Intellectual disability	2 parents
	6 (4 females and 2 males)	Intellectual disability and ASD	8 parents and 2 siblings
Questionnaire responses	22 (13 males and 9 females)	Intellectual disability	21 parents, 2 informal primary carers
	2 (2 males)	ABI	1 informal primary carer and 1 parent

Results from focus groups, face-to-face interviews and questionnaires are presented sequentially in the order the current research was conducted.

4.2.1 Focus group participation

People with disability and their families participated in five focus groups which were conducted between 2010 and 2015. In total four people with intellectual disability, 17 people with ABI, and 29 family members participated in five focus groups (see Table 4.2).

Table 4.2 Focus group participation

Focus group and year	**Number of people with disability**	**Number of family members**
Focus Group 1 (F1) 2010	1 person with intellectual disability (female)	7 mothers
Focus Group 2 (F2) 2011	11 people with ABI (7 males and 4 females)	2 mothers
Focus Group 3 (F3) 2012	0	9 mothers and 2 fathers
Focus Group 4 (F4) 2013	3 people with intellectual disability (1 male and 2 females)	6 mothers
Focus Group 5 (F5) 2015	6 people with ABI (4 males and 2 females)	3 mothers

Four focus group topics (Appendix Five) were discussed relevant to the research aim and objectives. Topic one explored the perceptions of people with disability and their families, particularly regarding how individuals became involved in CAS and what were they expecting from CAS participation. Topic two explored participants' rights/needs from participation in CAS. Topic three explored participants' experiences of CAS. Finally topic four explored recommendations about services.

The four research topics and resultant emerging themes from the focus groups are summarised and presented in italics (see Table 4.3). Each theme is explored in further detail below.

Table 4.3 Focus group topics and themes

Focus group topics	**Themes**
Topic One: Expectations and transition processes	• *Transition aspirations and hopes* • *Eligibility* • *Congregate settings* • *Support of parents*
Topic Two: Rights and needs	• *Segregated and predetermined* • *Creative leisure, arts, recreation and sport, intellectual and physical stimulation* • *Safety*
Topic Three: Experiences	• *A community of friends* • *Understanding*
Topic Four: Recommendations	• *Positive culture*

4.2.2 Focus group topic one: Expectations and transition processes

The topic of, ‘expectations’, brought very emotional responses particularly for people with intellectual disability and their families. While expectations during the school years may have promised employment and further study opportunities, many of these promises did not come to fruition. Instead, focus group participants reported overwhelmingly that their transition processes from secondary education were characterised by a lack of planning and limited support for decision-making. People with disability and their families spoke of transitioning into CAS through various processes.

Three processes of transition included:

a) transition from school as an alternative if employment/further study were not available,

b) transition from school if ineligible for the State Transition Plan (STP), or

c) transition from a rehabilitation service.

4.2.2.1 Transition aspirations and hopes

Families and people with intellectual disability in Focus Groups 1, 3 and 4 who were transitioning from secondary school to a range of post school options emphasised how they had to learn along the way and that this affected the initial aspirations and hopes they had. This was in stark contrast to people with ABI and their families in Focus Groups 2 and 5 (F2 and F5) who reported supportive transition processes in which they were able to seek opportunities to further develop skills and knowledge as part of their ongoing rehabilitation process.

The literature regarding transition planning from secondary education repeatedly recommends the provision of accurate information, provided in a timely manner to allow people with disability and parent(s) resources to effectively consider choices when planning their future options. After 12 years of secondary education each individual’s aspirations and hopes for the future are acknowledged as important (Wehman, 2006; Wells, Sandefur & Hogan, 2003)

However, all research participants in Focus Groups 1, 3 and 4 (F1, F3 and F4) identified that the processes of transition from secondary school to, ‘post school options', was inadequate. As a mother of a daughter with an intellectual disability stated in Focus Group 1:

When you are planning to finish school it is misleading to me it seemed that what we talked about sounded fantastic but it wasn't the case.
(Mother of daughter with an intellectual disability, F1)

This was a common experience for people with disability and parents whose aspirations and hopes had focused on transitioning from secondary education to employment or further study and employment as preferred options in order to gain independence, to earn income and transition with other friends who they had known through the school years. Transitioning to, 'adulthood', was associated with, 'getting a job', and, like everyone else, using the knowledge and skills learnt at school. As a mother and father highlighted:

When our son left school the expectation was that he would go to [a sheltered workshop] and be registered for [an agency providing employment support]. Since then we have become aware of other options.|
(Parents of son, with an intellectual disability, F3)

People with intellectual disability and parents expected that they would leave school and be able to be employed or participate in further study. This expectation was reinforced during the final three years of school through their son or daughter's participation in, 'employment field placements'. Furthermore, in South Australia as part of a, *Blueprint for Disability Services,* an STP process had been introduced for, 'eligible', people with disability specifically to assist them in gaining, 'employability', skills before leaving school. Expectations, according to Focus Groups 1, 3 and 4 participants, were of a, 'smooth', transition process.

Instead the opposite was identified by focus group participants. Learning about other options after, rather than before leaving school appeared to be the main feature of their experience.

There aren't websites with all the information available at one site. We as parents need a website with different headings, perhaps the Disability Information and Resource Centre could be involved with that. Having this information through one site should then be available for parents/carers through schools and disability organisations like Down's Syndrome Association.
(Mother of daughter with an intellectual disability, F3)

What happened is we didn't know what was available and we were just as parents learning by accident.
(Mother of daughter with intellectual disability, F3)

The STP process did not enable all people with disability to gain employment. Parents in the focus groups reported that their hopes and aspirations had turned to **panic** even before their child left school.

Memo, 17/10/11: Having spoken about participants' fear of the future a father attending a conference presentation in 2011 described this time leading to the end of school as like, 'standing at the edge of cliff', and just hoping that something would be available.

There were also people with disability in the focus groups who had not been eligible for an STP. Being ineligible for STP was primarily based on the severity of the, 'diagnosis', of the person with disability and/or, 'additional behavioural support needs', often referred to as, 'challenging behaviours'. It appeared that young people with more severe disabilities or who had challenging behaviour were not eligible for an STP. This was confirmed by focus group participants.

The future during and after school often relates to the disability severity. Especially for people who are high functioning there are services. There are some setups for people with mild to moderate disabilities but ***not*** *for people with severe disabilities. The level of severity is definitely a key aspect when you are looking at what options are available.*
(Mother of daughter with an intellectual disability, F3)

Needs for therapeutic support around behaviour management is crucial.
(Mother of daughter with intellectual disability, F1)

Therefore, people who were not being employed, or studying post school or who had been diagnosed with a, ‘severe’, disability or had, ‘challenging behaviours’, may have been directed towards a CAS. Despite being directed towards CAS, no participants from Focus Groups 1, 3 or 4 reported having aspirations or hopes of participating in a CAS.

Preparations for transition from rehabilitation settings into community-based services for integration such as leisure, arts and recreation for people with ABI were explored in Focus Groups 2 and 5.

In stark contrast to the transition experiences reported for young people moving on from the school system, the process of transition for people with ABI was described as supportive in various ways

I had a home visit from a service coordinator. They talked about the community program and provided some information for us. They recommended I speak with the community program coordinators as this service was specifically for people with acquired brain injury.
(Mother and daughter with ABI, F5).

I had a referral from the rehabilitation service at Payneham before I left the service.
(Man with ABI in his 30s, F2)

Rehabilitation staff were described as using a proactive approach to consult directly with people with ABI and parents as part of a rehabilitation process and liaised with CAS staff to support the transition. This personalised approach which addressed options for community participation prior to being discharged from the rehabilitation service was not experienced by people with intellectual disability transitioning out of the school system. While difficulties with memory are associated with sustaining an ABI and participants were not always clear on their recollections, in Focus Groups 2 and 5 they emphasised their positive view of what CAS had to offer.

I remember it was very helpful because [he] found an area where he could extend his knowledge and use some of the background that he already had so that it’s been a very good area for him, socially and also intellectually.
(Mother of son with ABI, F5)

I don't remember much of that time at all, it's all a blur, it's more that I came along and, I guess, got a feel for it gradually over time and we certainly enjoy coming and being part of the group. When we were leaving the rehabilitation service we just wanted something to do.
(Man in his 40s with ABI, F5)

It is puzzling that there appears to be marked differences in the transition experiences of people depending on whether they are transitioning out of an education system versus a rehabilitation system.

4.2.2.2 Eligibility

The transition into CAS for people with intellectual disability required an 'eligibility' process. To be eligible to receive funding to participate in CAS, people, with intellectual disability and parent(s) experienced differing, 'eligibility processes', during the research between 2010 and 2015. Three different assessment tools, the, 'Vermont', the 'D Start' and the 'Vineland' (Appendix Twenty) were used by the same agency (Disability SA) staff with each requiring different training and reporting mechanisms. Each assessment relied on the person with a disability and family member demonstrating their need for CAS based on their physical, psychological and social requirements. As a mother of a son with an intellectual disability reported, there was inconsistency of assessment for eligibility at this crucial time of transition from school and this added to parental confusion about transition processes.

We were unsuccessful the first time. Then we appealed and had another assessment. This time we were funded.
(Mother of son with intellectual disability, F4)

4.2.2.3 Congregate settings

In the focus groups, single parents identified the need for CAS to be available during working hours. Being a single income earner is more common amongst parent(s) of people with disability when compared to parent(s) without children with disability (ABS, 2012). Parents reported the need for congregate CAS to maximise support received so that they could have as much support per week as possible. As one mother reported, group-based sessions were:

Generally five days per week for 48 weeks, however this varies amongst providers.
(Mother of daughter with intellectual disability, F1)

Just as schools have provided support each day, congregate settings provide longer hours of support than 1:1 support available for a person with a disability. Parents reported being exhausted from years of support for their child(ren) with a disability and were desperate to know that their son or daughter would be supported while they were working and as they got older. Fatigue, fear of the future and economic pressures were commonly reported.

It is particularly difficult for young people with severe and multiple disabilities. Parents are very tired especially as we are supporting our child who is now 21 or 22 and they are having their own problems.
(Mother of a son with an intellectual disability, F4)

What will they do when we are gone? Will they have things to do during the day? How will they get there if we are not taking them? Will they just look out of a window all day?
(Mother with a daughter with an intellectual disability, F3)

It is apparent that one aspect of interest to parents of young people with more severe disability is related to safe, ‘time occupation’. Parents have been able to engage in work and other activities during the day while their child was at school but, once they have left school, only congregate care options appear to meet this need because the funding available to support their young person buys less support time if this is used on individual support.

4.2.2.4 Support of parents

In Focus Group 4, in particular, the care for young people with heavy physical needs for lifting and providing care as well as their intellectual needs was discussed. As a result of many years of support through schools an expectation that these levels of service would continue post school was reported.

As people access better ways of caring for children at home they want and need more from support services.
(Mother with older teenage daughter with intellectual disability, F4).

Most special schools and units have written to [disability providers] whose funding ceases at 18 to have instead an interim stage until 24 years of age of more intensive services.
(Mother of son with an intellectual disability and high physical support needs, F4)

While exploration of potential CAS is occurring, the process of transition from secondary school to CAS is also impacted by a young person with disability's transition from, 'children's services' (under 18 years), to, 'adult services'. New disability service coordinators and the new adult service systems needed to be navigated at a time when school was about to finish. This seemed to have specific implications for parents whose children had physical and other therapy needs and there was clearly a view that parents felt they needed a voice.

We need to have a voice; we are not mums on our own. We need to have advocacy. There needs to be support for carers themselves, otherwise how are they being looked after?
(Mother of daughter with intellectual disability, F4)

4.2.3 Focus group topic two: Rights and needs

A congregate model of CAS may be viewed as being efficient because the hours of services available are extended if compared to 1:1 service provision. However focus group participants, particularly parents of people with intellectual disability in Focus Groups 1, 3 and 4 highlighted concerns with this model of service delivery.

4.2.3.1 Segregated and predetermined

The topic of rights and needs immediately led to discussions with parents who identified limited opportunities if CAS are only conducted in congregate settings with limited, 'choices', of segregated predetermined activities. As a result, people with disability and parents in the focus groups expressed strongly their anger and disapproval at the way in which services were, 'offered'. The power of decision-making regarding the model of CAS was held with CAS providers. This anger is expressed clearly by parents and was representative of the majority of parents regarding this topic from the Focus Groups 1, 3 and 4 with people with intellectual disability.

He doesn't want to go as an 18 year old to a retirement home. I want him to be intellectually and physically stimulated. If they go to a, 'retirement model' of day services they will still need far more from the parents who are exhausted. They need to be challenged.
(Mother of a son in his late teens with intellectual disability, F4)

I have been dissatisfied with what has been provided. I have been frustrated because the day options didn't fit his interests.
(Father of son with intellectual disability, F3)

There really is no choice. It's either an unsuitable service or an unsuitable service. They are not what my son needs.
(Mother of son with intellectual disability, F4)

However, these experiences of frustration, anger and dissatisfaction related to the transition from secondary school to segregated predetermined activities were not universally reported by focus group participants. There were other models which were described as having more creative approaches in which the voices of people with disability and parents, siblings and informal primary carers were heard. These involve more creative activities and projects that are reported on under the next theme from the focus group findings.

4.2.3.2 Creative leisure, arts, recreation and sport, intellectual and physical stimulation

The ability to participate in creative CAS was described by people with intellectual disability and with people with ABI who actively participated in CAS which specialised in creative leisure, performing art, visual art, recreation and/ or sport.

I have found the service good because I am always learning something new and different. I have been learning about life skills as well as specific skills as well, such as computing. I enjoy meeting people and socialising, which helps to train my brain. I have been meeting people through the drama rehabilitation group and we have produced a work which was filmed also. This has been good as I have been doing performances and have been trying to remember my lines.
(Man in his 30s with ABI, F2)

Memo and observation, 8/5/11: The participant in Focus Group 2 is making reference to the film titled *Walking through Walls*. People with ABI were active participants in the creation process through writing the drama script, practicing, and then the live performances which were observed by the researcher. Experiences of sustaining an ABI and creating together to tell stories of people who have ABI were portrayed through this film. Both community awareness raising and education for the wider community occurred. The creative process also had a focus on peer support.

What I know is that he is still learning and thinking all the time and that is why there are huge benefits from arts especially for people with mild to medium disabilities. *(Mother of son with an intellectual disability, F3)*

Creative opportunities were reported as leading to a broader range of options, when compared to, 'predetermined choices', which some participants had experienced.

What I like is to have options of recreation like disability arts and also sports activities.
(Man in his 20s with ABI, F2)

He wanted better control over his own health, and greater pursuit of his love of sport.
(Mother of son with ABI, F2)

It appeared that variety of choice and creative options resonated with many parents and young people with disability. This challenges the, 'time occupation', and, 'childminding', concepts which featured prominently in the thinking of some families, and demonstrates the diversity in needs both of people with disability, and their families, in the area of adult programs for people with disability.

A more stimulating environment, in a somewhat different sense, was the priority of one group of parents. The rights and needs for access to both intellectually and physically stimulating opportunities in CAS were expressed by those parents whose children had more intensive, 'active support', through programs such as, 'conductive education', during their children's school years. Although there is debate regarding the benefit for people with disability of these more intensive programs (Stiller, Marcoux & Olson, 2003; Tuersley-Dixon & Frederickson, 2010), in the words of one of these parents:

What Conductive Education (CE) has created is a monster. Both parents and participants expect more than what is offered when they finish school at say 18 years of age. As people access better ways of caring for children at home they want and need more from support services. Parents are often middle class and expect services for their kids.
(Mother of daughter with an intellectual disability, F1)

Memo, 12/9/10: Following this focus group, the researcher was invited to observe the provision of conductive education for participants with severe physical and intellectual disability in a community setting. The conductive education approach sought to increase the flexibility and range of movement of individuals and included the use of music and adaptive equipment. A high ratio of staff to people with disability was required to ensure this was conducted in a safe manner.

The safety of people with disability was also raised by parents during focus groups as a critical right and need, as explored in the following theme from the focus groups.

4.2.3.3 Safety

Safety is often a parental concern, and this was the case for parents involved in focus groups in the current research. Regarding the increasing complexity of needs of people with disability transitioning into CAS, a mother of a daughter with Autism Spectrum Disorder (ASD) and an intellectual disability stated:

The health risks are higher with an increasing percentage of people with autism and severe disabilities. As a result of increasing health needs, CAS staff require increased training and support. The needs for therapeutic support around behaviour management is also crucial, I recommend that for CAS two clients to one staff ratio is needed because of high health needs and there is an increasing need for qualified Developmental Educators[1] *especially regarding risk analysis.*
(Mother of daughter with ASD and an intellectual disability, F1)

Additionally, the relationship between CAS providers and accommodation providers is important to ensure that the individual is supported. If, for example, a person lives in a home that is closed during the day, and they become unwell while at CAS, safety strategies are required to ensure the person's health is cared for.

People with disabilities are transported away from their accommodation each day. People with disabilities living in some, 'cluster homes', are not allowed to stay between 10.00 to 3.00.
(Mother of daughter with intellectual disability, F4)

The safety of their children in a range of community settings was also an important issue for some parents who expressed the view that CAS facilities need to be safe.

It is important to consider the facilities and environment suitability. Church halls, for example, which are used for CAS without suitable equipment are not suitable. (F1)

4.2.4 Focus group topic three: Experiences of CAS

In response to questions about people's experiences of CAS, important themes emerged, including the need to be with friends in a non-judgmental environment.

4.2.4.1 A community of friends

Friendship is an important aspect of the human experience and so, not surprisingly, the issue of developing friendships was raised by focus group participants as an

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[1] Developmental Educators are graduates of a 4-year degree offered by Flinders University in South Australia. They receive extensive training, including lengthy practicum placements, in a range of disability issues including ABI, intellectual and multiple disabilities, development of life skills, advocacy, positive behaviour support, augmentative and alternative communication, and other specific and general disability issues and needs.

important aspect of a positive CAS experience. Participants made relevant comments such as:

I find the program is good. It is comforting to know that others with an Acquired Brain Injury are involved and I like the peer support as well.
(Young woman with ABI, F2)

I like being with my friends.
(Young man in his late teens with an intellectual disability, F4)

I enjoy being amongst a friendly, open, relaxed community of people, and certainly to be in a youthful, stimulating environment.
(Woman in her early 30s with ABI, F5)

I enjoy the different programs we partake in and the people and everything. The friendship and being part of a group. I come here for social interaction and group work. And the coffee. The coffee is a high priority. It's like I don't start ticking until I've had my caffeine fix (everyone laughs).
(Man in his mid 30s with ABI, F5)

This was in contrast to what had been experienced in work settings. One mother of a son with an intellectual disability stated that employment had been, 'isolating', for her son in comparison to his experiences of CAS.

We have found that mainstream employment can be socially isolating especially being the odd one out all the time and always feeling lonely.
(Mother of a son with an intellectual disability, F3)

So, getting a job, any job, is clearly not the only aspiration that young people with disability and their parents have, and working in the community does not necessarily lead to inclusion in the community.

This issue of isolation in mainstream employment settings also seemed pertinent to the next theme which relates to acceptance and inclusion.

4.2.4.2 Understanding

Most people have a strong desire to be accepted and included in whatever activity they are undertaking. Positive experiences of being with non-judgemental peers were reported with examples including:

You're around like-minded people because we've all had brain injuries. All of the people in the real world, they tend to judge you, [smile] at you and [not] very nice, you know. Here's it's cruisy; it's all good. No one judges anyone, not like the real world where you get judged a lot.
(Man in his mid 30s with ABI, F5)

It's an opportunity to be amongst people who understand the impact of ABI and are educated in the field and are youthful and innovative and they're very respectful and encouraging of participants. Generally, I think the activities are meaningful.
(Man in his 60s with ABI, F5)

4.2.5 Focus group topic four: Recommendations

Focus group participants recommended that a positive culture of services was important for supporting quality outcomes for people with disability accessing CAS.

4.2.5.1 Positive culture

Some examples of comments which reflect the importance of a positive culture for the individuals involved and for their families are provided.

I come along too because of the skilled leaders, that they seek to engage and encourage and enliven participants because part of the impacts of ABI can be that fatigue factor.
(Woman in her mid 40s with ABI, F2)

There's structure within the group but there's no constraint, an example of which, [is that] we come along on the Thursday and we have a drama facilitator and you ask her 'what are we doing today?' and she'll say, 'I thought of doing this and this but I'll throw it open to the floor. Any suggestions? What will we do?' so the structure is very, very fair.
(Man in his 50s with ABI, F5)

What I would love to see is a good balanced lifestyle so that they can have input into selecting what they want to do. That is different for every person.
(Mother of daughter with intellectual disability, F1)

4.2.6 Summary of results from the focus groups

For people with intellectual disability and their families, CAS may have been an alternative when leaving school, and for people with ABI as a community-based service to continue rehabilitation in a supportive environment with other people with ABI. In this transition, no focus group participants reported having aspirations or hopes of participating in a CAS and no participants reported receiving leisure education or having opportunities to explore field placements in leisure, arts or recreation in their local communities.

The rights and needs that were recommended included replacing segregated and predetermined CAS with opportunities for creative leisure, arts and recreation which had both intellectual and physical stimulation in a safe environment. The experiences of people with disability and their families included participation and being in a, ‘community of friends’, who are understanding and are non-judgemental. A recommendation of having a positive culture which contributes to quality outcomes for individuals was also explicitly made by many participants.

4.3 Results from face-to-face interviews with people with disability and their families

Face-to-face interviews were conducted between 2009 and 2015 with eight people with disability and their families. Interview questions for people with disability (Appendix Six) and for their family members (Appendix Seven) explored four topics including:

1) expectations and transition planning;
2) rights and needs from CAS participation;
3) experiences of CAS participation; and
4) recommendations to contribute to service quality.

The participants were all people with intellectual disability and their families (see Table 4.4) and the interview questions resulted in responses that fell under four categories that were the same as for the focus group findings (see Table 4.3) but with themes under each category that, while similar, had some interesting differences (cf. Tables 4.3 and 4.5).

Table 4.4 A summary of information about participants who were interviewed

Interview Month/Year	**Interviewees***	**Disability**	**Age**	**Years involved with CAS**
November, 2009	'Simon' and 'Marie' (mother)	Intellectual disability	mid 20s	0-5
May, 2010	'Lois', 'Paul' (father) and 'Renaee' (mother)	Intellectual disability and ASD	mid 30s	10-15
July, 2011	'Julie', 'Mary' (mother) and 'Jean' (sister)	Intellectual disability and ASD	late 30s	15-20
October, 2011	'David' and 'John' (father)	Intellectual disability	early 30s	5-10
October, 2013	'Merrilee', 'Ros' (mother) and 'Graeme' (brother)	Intellectual disability and ASD	early 20s	0-5
January, 2014	'Ralf 'and 'Sharon' (mother)	Intellectual disability and ASD	early 30s	10-15
March, 2015	'Jane' and 'Pauline' (mother)	Intellectual disability and ASD	early 20s	0-5
November, 2015	'Colin', 'Joan' (mother) and 'Michael' (father)	Intellectual disability and ASD	late teens	0-5

*pseudonyms have been used to identify each participant.

Table 4.5 The topics and themes that emerged from face-to-face interviews

Interview Topics	**Themes**
Topic One: Expectations and transition processes	• *Lack of planning* • *Confusing information* • *Transition to creative leisure, arts and recreation*
Topic Two: Rights and needs	• *Individualised support* • *Family involvement* • *Goal setting* • *Health and safety* • *Employment and CAS* • *Provider pressure and power relationships*
Topic Three: Experiences	• *Friendships* • *A deficit approach* • *Greater choices*
Topic Four: Recommendations	• *Empowerment* • *Positive communication and planning together*

4.3.1 Expectations and transition processes

Not surprisingly, there were strong similarities between information obtained from the focus groups and the individual interviews (cf. Tables 4.3 & 4.5). The interviews, of course, allowed for more detailed discussion of individual rights and needs and so more nuanced results emerged. Overall, this painted a negative picture of the transition process for young people with intellectual disability. The first issue related to planning.

4.3.1.1 Lack of planning

People with disability and parents strongly stated that the transition process was characterised by a lack of planning prior to leaving school and commencing in CAS. In fact, they were very critical of planning as illustrated in comments below.

What planning process? There wasn't any, absolutely none. It was horrible it was confusing especially because of your individual feelings for your child's future their hopes and dreams when they become limited and am unaware of what is available after school. We had been planning that Merrilee would be able to work as a library assistant. A self-initiated learning as we go process ended up occurring because there was none to work with. The school even said, 'I know I'm not being much help'.
(Ros)

This lack of transition planning was compounded by confusion over responsibility. As Jean, Julie's sister identified, the lack of planning started with the problems of responsibility which left family members feeling vulnerable and uncertain about important issues, as indicated by the following comment:

There is the question of whose responsibility day options are. For example, is the transition responsibility with Disability SA, with the individual schools or with the service providers?
(Jean)

School transition was also described as not meeting the needs of students and parents seemed surprised that educators were so unclear on future prospects and possibilities for individuals who they knew very well. The following comment spoke to that issue.

The school staff were not always sure what you can do especially when leaving school, and for the first six months Jane didn't really do a lot.
(Pauline)

It was not only that information was lacking but also that there was contradictory and confusing information provided as illustrated in the next theme.

4.3.1.2 Confusing information

It appeared puzzling to participants that information was not more easily available. Participants shared problems they had with the available information about CAS for people with disability and their families. The following comments highlight aspects of this theme.

When Julie was leaving school, there weren't a lot of options available. We have found that there is a lot of confusion about day options programs. Sometimes I have found that even with information sharing there is confusion for families as they may hear a story from one person and end up twice as confused if they talk with someone else.
(Mary)

I expected that I could be informed about options for Merrilee [daughter] about what she would be able to do after finishing at school but I wasn't informed at all. I had to do the research with Graeme, my son and Merrilee because I had no idea what was available. We really didn't know what would happen and I get quite angry about that. I didn't know what day options were until I saw the definition of what they were supposed to be.
(Ros)

I have been listening to what Mum had to say, and a lot of Merrilee's needs were overlooked by the school because they weren't able to tailor the services the way that Merrilee needs. The expectations were that her needs would be met, however with the school environment there was just the explanation that they really didn't know what Merrilee would do after school.
(Graeme)

While Colin was at school I remember us talking to his teacher about a sheltered workshop and I remember thinking that Colin would go to that place. We had limited knowledge about Colin's options and the organisation was just down the road. We thought Colin would be happy as he could work in the kitchen and he could be there five days per week. Never once did we know that there were other options for him and never did [his teacher] talk with us about any other options. I really felt we were on our own and we know that the school should really do more about educating and guiding people.
(Joan)

In addition, as had emerged in the focus group discussions, in the interviews under the second category of, 'Rights and needs', there was discussion of more creative leisure, arts and recreation options under the ‘Expectations and transition processes’ category.

4.3.1.3 Transition to creative leisure, arts and recreation

It was apparent in the interviews that the process of transition into creative leisure, arts and recreation has been an important part of participants’ lives. One parent reported that:

> *Through friends we were able to get to know [CAS organisation name]. I had thought when Colin was young that it would be great as he has got the talent in his art. We paid for everything ourselves and we had Colin at home for six months instead of at school until he got funding through Disability SA. [The CAS organisation] was incredibly supportive. They could work with Colin by finding out what he liked to do and what he was good at doing.*
> (Joan)

Furthermore, Joan stated that, *‘Colin has a fantastic week. Our friends are seeing what Colin is doing with his CAS including his art, leisure, his fitness and how he has such a rich aspect to life.’*

Transition to creative leisure, arts and recreation through CAS was also experienced by Lois who became interested in performing and visual arts while a secondary school student living in regional South Australia. Her parents, Paul and Renaee travelled the round trip over eight hours so that Lois could participate in performing and visual art workshops during school holidays, and this continued when she finished school and started participating in CAS. This was highlighted by the following statement from Lois:

> *I saw a dance performance of, ‘digiboy’, and I really engaged with the performance. I was invited to come to Adelaide to become involved in the workshops.*
> (Lois)

Lois and her family subsequently moved to Adelaide, South Australia, to reduce the travel and for part-time study opportunities, to participate in the CAS, and for Lois to try different options. Paul and Renaee were very keen for Lois to explore her creative interests through a range of services. Renaee also explained that the, ‘do it yourself', approach meant that some things were tried but did not really work. For example, Lois tried a sheltered workshop placement.

Renaee stated, *'Going to [name of organisation] was like that. We went there and they had worked out that Lois could be involved in caring for some birds in cages.'*

As Lois said, though, *'I didn't really want a job cleaning out bird cages so that one didn't work out.'*

As Renaee explained, *'Even though there has always been an uphill battle, it really was a matter of trying to find the right doors to open so that Lois could discover another experience. Lois has gained from [the CAS participation] an inner self respect.'*

As Lois stated, *'I have been involved in drama, dancing and filmed and have travelled to London and to Ireland'*.

Jane also became involved in CAS through creative activities:

We got into the singing group at [the CAS provider] by starting on Monday nights and then started to come along on Wednesday nights and they are great. It is something that we can do together and we have found it to be very enjoyable. Jane is a reasonable singer and that is one of her interests. Jane is also involved in a respite holiday group as well.
(Pauline)

4.3.2 Rights and needs

4.3.2.1 Individualised support

Transition to creative leisure, arts and recreation also occurred for Ralf. His mother, Sharon, advocated for his right to individualised support so that he could participate in services that met his needs:

I'm very selective about my son Ralf with our experience as he lives in an environment where he can't express himself verbally but he can be understood. There have been issues around mainstream disability services since he has left school. He has Aboriginal services now, which are much better. The information shared about services often has been patronising of his views. In fact there was

predetermined programs. Since he left school and was eligible after having a Vermont assessment for an adult 'day service' we tried three CAS programs but none of these met Ralf's needs.
(Sharon)

Sharon further explained that, '*As a result of these experiences we used his resources to train staff through a psychologist who was supportive and now he is in a very good accommodation service along with an Aboriginal service which Ralf enjoys. His arts and craft program at [the organisation] as well as physical activities is great because his mob have quite a different approach compared with the day programs. There are a whole lot of people who are bringing creativity to the service and so he is doing an appealing program. That's the difference. I get the fact that people who are running the programs think they are doing the best. Individual funding means that you can try and match people with Ralf who want to work with him.'*

4.3.2.2 Family involvement

In conjunction with individualised support, engagement with parents was identified as a right and need by participants. For instance, a number of parents, according to Mary, started up a day program which was arranged before Julie even left school.

She was able to continue with some of her friends who she had known over her eight years at school. The social contacts which were developed early on are still really important for people with disabilities and families also.
(Mary)

This occurred because, as Mary stated, '*There wasn't an extensive, 'smorgasbord', of day programs for people to choose from.*' As parents they got together and created the service for their children that they wanted. This proactive approach was further elaborated upon by Mary:

There is currently a real sense that, 'disability' is the government's problem and that new things can't occur without more money and that with more funding things will be better for people with disabilities in day options. What's needed though is a model for people to engage with others and to have a progression of their learning and their development. We would love to win the lottery and set up more services

with Julie and her friends.
(Mary)

Therefore, it seems that a model that includes having active family involvement may assist people with disability to advocate for their rights. As Paul explained, for his daughter, Lois, the arts, *'were such a good pathway into her community as she was finishing high school'.* Both he and Renaee have been, 'pathway finders', together with Lois as artistic opportunities emerged.

4.3.2.3 Goal setting

Setting goals with people with disability, in conjunction with their families, and CAS providers was also raised as a right and need.

Merrilee stated that, '*My goals are to learn to be more confident for the rest of the year. In this way I can learn some skills for perhaps being able to do a presentation with a few others and becoming more confident so that I could someday do a solo at my singing group.'*

While Merrilee had identified her goals, her mother, Ros, and brother, Graeme, had not been involved in the process. Subsequently Graeme highlighted that, *'As Mum said, I'm not sure if Merrilee's goals are being met because there have been meetings without even our knowledge of the meetings occurring. The other meeting only just happened so it's hard to know if Merrilee's goals are being met when we have only just had the meeting to talk about what her goals even are.*

Mary also confirmed that her daughter, Julie, had goal setting meetings. However, *'a lot of agencies aren't willing to release staff to attend goal planning with people with disabilities and families. As service providers tender for staff they can only pay rates for carers which are very low which restricts what they can do.'*

As a result, it appeared that people with disability may have less comprehensive, realistic and achievable goals developed.

4.3.2.4 Health and safety

An important right and need of people with disability is participation in a safe environment, including support for people with additional behaviour support needs.

In congregate CAS, for example, Jean stated that, *‘with some day options programs these days it’s more a case of dropping off and then an expectation that parents won’t stay around. They are not so welcome to be involved.’*

As a result, parents may not witness how the organisation’s staff are assisting people with disability, particularly people with additional behaviour support needs. If not supported, the person with a disability may be excluded from the program. Parents may provide valuable background information and insight that can assist staff from the outset and prevent escalation of challenging behaviours that may then lead to exclusion from a CAS.

As Jean noted, *‘to be involved again in the service the family has to organise psychological help and then this puts more pressure back on the families also.’*
The training for staff which contributes to the health and safety of people with disability accessing congregate CAS would also seem to require further exploration and development.

We have to address the more significant health and behaviour issues of people with disabilities as this is central to day option service provision. There needs to be intensive work done around skills development rather than if there are problems or issues telling people that they are not to come back. This is much about agencies not wanting to take risks.
(Jean)

4.3.2.5 Employment and CAS

Parents also found it restrictive that their child had to choose between employment and CAS instead of the possibility of doing both concurrently. The right to be employed and participate in CAS was raised by interview participants.

For example, Merrilee stated that, *‘I expected to get a job when I left school’*. However as Graeme, her brother, explained, *‘We were told that if you do some sort of employment you can’t do day options also. It was a confusing time for Mum and I.’*

David also wanted to do some work: *‘I did find a job part-time.’* But, David’s father John also emphasised that, *‘while being able to find part-time employment is an* *issue, there is also the complexity of being able to use public transport, especially when work locations change, unless they can transfer to each work site they lose their jobs. Again that's why keeping up social contacts and being in CAS has been good. After three to four years, though, we learnt that there is really not much work out there.'*

Lois had also been employed while involved in CAS, according to her father, Paul. As Paul commented, *'After two years in a pilot project they ran out of money. Some part-time tutoring has followed and so creative arts have also provided an income as well as being [Lois's] passion.'*

Simon also tried work for one week at a sheltered workshop, *'but it wasn't for me.'* Instead, Simon, *'started some part-time study which was really helpful.'*

4.3.2.6 Provider pressure and power relationships

While it is clearly a right for people with disability to be able to change CAS providers if they are not satisfied with a service; the pressure not to do so was apparent.

Graeme explained that, *'the thought of changing providers if we wanted to is a bit scary. It is like not knowing if another service would be better and what would happen if it wasn't, could you go back to the old provider? There has been pressure for Merrilee to stay in the program she is in.'*

Sharon described power relationships which were encountered concerning Ralf's rights and needs for services which were individualised.

> *The first service couldn't cope. He also didn't fit in with another program then he was transferred to an unfamiliar neighbourhood and he had four transfers within that service. I had to go in batting for him and I ended up taking him out of the service completely. Parents don't have any influence in day services.*
> (Sharon)

Paul, Lois's father, described the importance of the voice of families as advocates however he also noted that, '*Families also need to be empowered to be able to focus on their needs also otherwise they become overwhelmed.'*

4.3.3 Experiences

4.3.3.1 Friendships

It was noted that involvement in CAS contributed to the development of, and maintenance of, friendships for people with a disability that may otherwise only occur through coordination of already overburdened family members. Pauline discussed Jane's post school experiences stating that, '*Jane's biggest need since leaving school has been having friends. A lot of Jane's friends from school don't keep in touch. Or don't want to go out very much sometimes.'*

Mary stated that Julie had received funding for a four-day-a-week day options program which meant that on Fridays she did not attend a program. This became another opportunity to be with friends.

With a few clients who are friends they started to get together and began to go to someone's house and this became their social activity day. They would go to the beach, for a walk with friends and family. This was about creating and making the day enjoyable by being able to sleep in and having a leisurely catch-up without the sense of having to be somewhere by 9:00 and then lunch at 12:00 and back ready for a bus at 3:00. When you think about the services today for day options you get out of bed, then you get on a bus, then another bus, then you get changed, and then into a pool for maybe half an hour, and then you get changed then onto a bus and then another bus.
(Mary)

John, when reflecting on his experiences as a single father of David, highlighted that, *'Families are going through an ordeal trying to work out how their sons and daughters can go from school to work, study or day options and that's why being able to provide some support socially during this process is important. Especially when it comes to friendships people don't want to be with their families all the time. While they don't get on with everyone friendships are important.'*

4.3.3.2 A deficit approach

When reflecting on their experiences of transition from school, Michael described the deficit-focused assessment process that his son Colin, Joan and he went through to gain funding so that Colin could be involved in CAS.

With the Disability SA assessment they are assessed on what a person can't do; their deficits. They should be assessed on what they can do. This could be expanded even with the visual arts this could be sculpting and looking at other things also
(Michael).

After 12 years of learning skills during the school years, the transition process which was experienced appeared to focus upon Colin's deficits rather than his strengths.

Also alarmingly, Mary and Jean's experiences of the eligibility assessment process raised concern that Disability SA staff conducting assessments also had budgets to consider. An independent assessor may be preferable. As Jean stated, '*Much of this relates to eligibility of funding and while currently the Vermont scale is used alternatives may need to be explored. The whole process of looking at the services is required so that the bottom line is not the main driver*.

Marie and Simon summarised their experiences of difficulties which they experienced:

The interview was quite a rigmarole. In fact we were disgusted in the process. I felt frustrated by this process.
(Marie).

4.3.3.3 Greater choices

As well as the replacement of a deficit approach to eligibility assessment, participants also made the point that CAS should encourage opportunities for greater choices by people with disability and their families.

Day options have also been a bit of an insular process without seeing the big picture which is about each person's own quality of life and being able to actively give people what they want in terms of choices. The systems in which we operate are not actively giving people more choices and they are not readily set up when we need them.
(Mary)

Flexibility of service options is, therefore, required because the needs and interests of people with disability may change over time, as is the case for everyone in the community.

Furthermore, families also reported experiences of a distinct lack of information and guidance and direction regarding post school options which caused feelings of despair.

On reflection, to start with we could have at least been made aware of what was available. It is ridiculous that Mum, Merrilee and I had to do this and it was all up to us. If there was a family without Mum I think the kid would have no chance. God have mercy on someone who didn't have Mum.
(Graeme)

According to Pauline, in order to access greater choices for her daughter Jane, they had to be very proactive with organisations.

There isn't anyone who will do it for you. You have to really hunt out services and talk with others with similar experiences. You just have to be pushy and do it yourself and use all your resources and all your contacts.
(Pauline)

4.3.4 Recommendations

It was clear from participant responses, that empowerment of individuals and their families to make educated choices is a crucial component that needs to be fostered during post school transition and beyond.

4.3.4.1 Empowerment

For example, Julie needed to learn skills which would assist her to be empowered in her life.

Starting from school years eight onwards for example, we need to be able to ensure skills are developed so that the person can take a more active role and more aspects of life for themselves. The model for day options currently is still a, 'moving on', model of day options provided Monday to Friday five days per week. This is creating a cycle for people with disabilities and providers which needs to be replaced with a better system which works with the person to build self-

empowerment rather than being a service which relies on transporting people by bus to and from day options and being restricted by their programmed activities.
(Jean)

Furthermore, Mary emphasised that as a recommendation for future CAS an empowering approach is required. Otherwise through a monotonous and repetitive process a, 'deskilling', of individuals may occur.

I would love to see if there can be a model which can be developed that provides support without being a program that gradually deskills and dis-empowers people. I have seen how some people have learnt skills while at school but then these skills are not continued at the day option services. Everything becomes very time-focused.
(Mary)

Furthermore, Mary stated, *'We need programs which can build self-esteem and have variety. To show pride in their work and be innovative of what they are doing. This may then be more energising for everyone. I believe we need people who are in day options who want to make every day energising rather than routine. There needs to be ratios of carers and staff so that individually clients can do what they want to do. I believe that disability can be or feel very self-limiting. It seems like there is a, 'one model which tries to fit all approach' and it isn't really working.'*

As Mary concluded, *'There should be processes which are empowering of people so that actions which occur are what the individual really wants to be in.'*

Empowerment, according to Graeme, also comes through support and sharing experiences with other families so that they can be **leading change**, rather than being passive recipients.

It would be very helpful therefore if parents themselves could hear from other parents about services which are available after school. We read about services in the Look Book *and what they said they would do but a site is needed for families to be able to post what they say about the day option post school services. It would be helpful to know what is positive about different services and also what kind of people would really benefit from the way the services were provided.*
(Graeme)

Lois, summarised her experiences of being empowered through her participation in creative leisure, arts and recreation.

I have learned to keep going and never give up. There are plenty of opportunities. Everything may not be safe in the world but that doesn't mean you can't be involved.
(Lois)

4.3.4.2 Positive communication and planning together

A further recommendation from interview participants was to encourage positive communication between individuals with disability, their families, and CAS providers.

Some communication devices like COMPIC books are used with Julie for her to be understood while people are getting to know her. It is important that people are not only asked but also listened to.
(Mary)

Their responses need to be understood as people with disabilities have the same rights. People already have got the built in behaviours or gestures and it is a matter of confirming people's likes so that something can be picked up and understood rather than being disregarded.
(Mary)

Memo, 22/4/16: At the final PhD presentation in 2016, a Professor of Disability Studies stated that in a previous role, she had worked closely with a young person with a disability during his school years to enhance the person's use of communication through adaptive technologies.
When, years later, the Professor visited a CAS she was, 'in tears', to see the person they had been working with sitting in a corner, with no communication device to use to explain their preferences and to be generally understood by staff.

In contrast, Joan described positive communication experiences of her son, Colin, and his CAS which has a focus on visual and performing arts.

They are wonderful because of the way his mentors work with him. [His art mentors] take Colin for a walk if he is feeling stressed and ask him to concentrate on his breathing and helping him to relax. They don't ring me all the time. You dread the phone ringing.'
(Joan)

Positive communication strategies which have been developed with Colin, his mother Joan, and CAS staff have assisted in Colin's positive experiences as well as his family's wellbeing.

4.3.5 Summary of results from face-to-face interviews

In the eight face-to-face interviews a range of common themes emerged which supported findings from the focus groups. Lack of planning prior to transitioning from secondary education and confusing information had angered some families and this highlighted the apparent disconnect between people with disability and their families, and schools, CAS providers and Disability SA representatives. The rights and needs and experiences of participants included positive examples especially within creative opportunities through leisure, arts and recreation, individualised support, family involvement and experiences of friendships. These contrasted markedly with provider pressure, power relationships and experiences of deficit models of assessment. Recommendations of empowering individual opportunities, positive communication and being able to plan together concluded the results from the face-to-face interviews.

4.4 Questionnaires

Questionnaires were developed in two parts; Part A for people with disability and Part B for their family members (parents, siblings and informal primary carers). The distribution, collection and analysis of questionnaire responses occurred between 2013 and 2015. The following demographic data and results are provided.

4.4.1 Demographic data

Questionnaire responses were received from a total of 49 respondents. There were 34 responses received via hard copy questionnaires and 15 responses from electronic, 'SurveyMonkey', questionnaires. The majority of responses related to experiences of people with intellectual disability and their families (see Table 4.6).

Table 4.6 Participation of people with disability and their families

People with disability	Families
22 people with intellectual disability (13 males, 9 females)	21 parents, and 2 informal primary carers
2 males with ABI	1 parent, and 1 informal primary carer

Furthermore, the majority of the questionnaire responses were from people living in metropolitan South Australia (n=36) with the remainder from regional South Australia (n=13).

Topic One: Expectations and transition processes

4.4.2 Involvement of people with disability in CAS

A referral from school to a CAS provider was the most common means of initial involvement by people with disability as illustrated (see Table 4.7). Additionally, five people with disability identified, ‘other’, means of involvement in CAS which included; *Speaking with others and the* Look Book (Questionnaire Question 2 (Q2))*;* *Options Coordinator* (Q4); *Mum* (Q5); *Word of mouth* (Q7); and *Recommended by Autism SA* (Q16).

Almost 50 per cent of respondents with disability had been involved in CAS for more than five years with one person being involved in CAS for more than 15 years.

Table 4.7 Involvement of people with disability in CAS and length of involvement in CAS

Involvement in CAS: Source	Responses of people with disability n=(17)	Length of involvement	Responses of people with disability n=(17)
School referral	7 (41%)	< 1 year	3 (18%)
Rehabilitation referral	1 (6%)	1-5 years	6 (35%)
Attended a disability service information session/expo	1 (6%)	5-10 years	5 (29%)
I don’t remember	3 (18%)	10-15 years	2 (12%)
Other	5 (29%)	> 15 years	1 (6%)

4.4.3 Planning involvement

When responding to questions regarding planning involvement almost half of the people with disability and 30 per cent of family members were ***not*** involved in the planning process before going to a CAS (see Table 4.8). This must, surely, negatively affect the expectations and opportunities for decision-making by people with disability and their families, and be out of touch with disability policy that emphasises, choice and control.

Table 4.8. Involvement in the planning process before going to CAS

Planning involvement	**Responses of people with disability n=(18)**	**Responses of family members n=(20)**
No	8 (44%)	6 (30%)
Yes	10 (56%)	14 (70%)

Of participants who had responded, 'Yes', to involvement in a planning process, examples included:

The teachers kept us informed and then we met with Disability SA to discuss further.
(Q11, person with a disability)

Special education teacher at his high school sourced possible options. I liked her ideas and I did not know where to start.
(Q5, family member)

Visiting many Community Access Services.
(Q7, family member)

Attended four separate Day Options programs with my son.
(Q17, family member)

4.4.4 Expectations and goals

Responses to questions about their expectations and goals prior to starting in CAS by people with disability and their families were primarily to make friends, have fun and to learn new skills. One or more answers regarding expectations and goals prior to starting in CAS were reported (see Table 4.9).

Table 4.9 Expectations and goals

Expectations and goals	**Responses of people with disability n=(16)**	**Responses of family members n=(21)**
To continue to develop skills learnt at school	8	15
To continue to develop skills learnt at rehabilitation service	0	2
To learn new skills	12	19
To have fun	14	17
To make friends	15	18
Can’t remember	2	0

Additionally, 11, ‘Other’, responses were made by people with disability and family members. Some examples included:

To access information and meet with people who accept me as I am; trying to do my best with no support or advice.
(Q14, person with a disability)

Continue to develop and grow independence.
(Q16, person with a disability)

Activities to fill her days, not just home with mum.
(Q1, family member)

Physical health and fitness.
(Q2, family member)

4.4.5 Transition plan

Regarding transition planning, 35 per cent of people with disability and 80 per cent of family members (see Table 4.10) reported that their expectations and goals of participation in CAS were ***not*** recorded in a transition plan before starting. Without a record of expectations of, and goals in, CAS participation expressed by people with disability and their families, an opportunity for future reflection and improvement may certainly have been missed.

Table 4.10 Expectations and goals of participation in CAS recorded in a transition plan

Recorded in a transition plan	Responses of people with disability n=(17)	Responses of family members n=(20)
No	6 (35%)	16 (80%)
Yes	5 (30%)	4 (20%)
Don’t know	6 (35%)	0 (0%)

Additionally, one respondent emphasised the difficulties experienced for their daughter’s transition.

This has been a problem ever since my daughter started to go to kindergarten. If you have physical and medical problems everything is **too** *hard for them to organise, especially if gastrostomy feeds and medication are needed. You either have to be so disabled you need a one to one nurse with you or mild/intellectual disabilities to fit into* **their** *programs.*
(Q3, family member)

Topic Two: Rights and needs
Topic two, ‘Rights and needs’, commenced with the question, ‘Were any resources developed to assist your participation in Community Access Services?’

4.4.6 Resources

Almost all of the people with disability and their families reported that they ***did not*** have resources developed to assist with participation in CAS (see Table 4.11). As one parent stated:

They could have helped with communication devices.
(Q4, family member)

Where limited resource development had occurred one respondent stated that they had been supported with:

A very small communication device as day option not resourced otherwise.
(Q17, family member)

Table 4.11 Resources developed for participation in CAS

Resource development	People with disability n=(14)	Responses of family members n=(19)
No	14	16
Yes	0	3

As identified with responses to interview questions, the communication of people with disability to staff is integral to respectful relationships and their right to be heard and understood. Adaptive technologies are also fundamental to innovative opportunities for people with disability.

Memo, 12/11/15: A presentation at the Australasian Study of Intellectual Disabilities Conference illustrated the use of adaptive technologies with people with limited communication skills in adult social care programs in Wales. These low cost adaptive technologies were increasing the engagement and participation of people with severe intellectual disability in fun and enjoyable ways. In Melbourne, Australia, adaptive technologies to enhance leisure and sporting pursuits, are also being used with people with ABI.

4.4.7 Expectations and goals being met

People with disability and their families provided a range of responses to the question, ‘Are your Community Access expectations and goals currently being met?’

There were 15 responses that illustrated that respondent expectations and goals were ***not*** being met. Some examples are illustrated (see Table 4.12).

Table 4.12 Responses which illustrated that expectations and goals were not being met

Theme	**Number of responses**	**Examples of responses**
Limited resource development	4	*No. Evident that skills and resources are far less than received at school.* (Q17, family member)
Babysitting	3	*Boring. I want to laugh and learn.* (Q5, person with a disability) *[The service organisation] can be more like a babysitting service sometimes. I thought it would lead to work skills but that has not happened.* (Q8, family member) *She has several choices on activities each day but I do wonder what they do with the rest of their day as some activities only take one to two hours.* (Q13, family member)
Socialising	3	*He has friends, but not close friends.* (Q5, family member) *Kids are having fun, but aren't learning anything new. If anything they're picking up bad habits. I don't think the facilitator is correcting their social skills.* (Q21, family member)
Skill development	5	*There is a broad spectrum of activities that needs to be introduced to help people with living skills.* (Q10, family member)

It is heartening to see that there were 23 responses from people with disability and family members which illustrated that their expectations and goals were being met (see Table 4.13). People with disability reported that a range of skills were being developed through participation in cooking, shopping, fitness, gardening, team games, bowling and basketball. Having opportunities to make friends, socialise with, ‘like-minded people’, and opportunities to develop programs were also identified. Parents stated that participation in CAS has provided stimulation, social interaction, opportunities for meeting new friends, learning new skills, improved concentration and communication skills. The following table illustrates some of these examples:

Table 4.13 Responses that illustrated that expectations and goals were being met

Theme	Number of responses	Examples of responses
Leisure, arts and recreation	7	*Cooking, shopping skills and fitness.* (Q9, person with a disability) *I play team games, 10 pin bowling and basketball. I pick olives and plant seeds.* (Q16, person with a disability) *It has given her some amazing life experiences.* (Q1, family member)
Socialising	9	*Having fun with friend.* (Q5, person with a disability) *Opportunities to share and socialise with likeminded people.* (Q14, person with a disability) *[Name] has met new friends and is having fun too.* (Q2, family member)
Skill development	7	*I go on the bus without mum.* (Q16, person with a disability) *Learning and practicing new skills and improved fitness.* (Q9, family member) *My son's literacy skills have improved and concentration is improving, as well as verbal communication.* (Q24, family member)

4.4.8 Goal reviews

Goal reviews with people with disability, families and providers may contribute to identifying strengths in CAS and also especially opportunities for improvements. However, according to respondents, CAS goals were reviewed by 75 per cent of people with disability but only 55 per cent of family members (see Table 4.14.).

Table 4.14 CAS goals reviewed

CAS goals reviewed	Responses of people with disability n=(12)	Responses of family members n=(20)
No	3 (25%)	9 (45%)
Yes	9 (75%)	11 (55%)

The most common frequency of reported goal reviews occurred between 6-12 monthly (see Table 4.15.).

One family member made the statement that despite reviews occurring they were, *'Not sure if goal reviews are always followed up.'* (Q1)

Table 4.15 Frequency of goal reviews

Frequency of goal reviews	**Responses of people with disability (n=9)**	**Responses of family members (n=11)**
Every 3 months	0	2 (10%)
3-6 months	3 (25%)	2 (10%)
6-12 months	5 (42%)	6 (30%)
More than 12 months	1 (8%)	1 (5%)

4.4.9 People participating in goal reviews

Over half of the people with disability and 43 per cent of family members responded that they were ***not*** able to decide who participated in CAS goal reviews (see Table 4.16) despite disability policy encouraging the voice of people with disability and their families in decision-making. As one parent stated: *'[We] haven't had a goal review. Parents aren't involved. They set their own goals with the staff.'* (Q11)

Table 4.16 Goal review participants

Goal Review participation	**Responses of people with disability n=(13)**	**Responses of family members n=(16)**
No	7 (53%)	7 (43%)
Yes	6 (47%)	9 (57%)

As well as family members and informal primary carers, other participants who attended goal reviews were reported including; *brother, professional psychologist, occupational therapist, board member of the organisation* (Q4); *case worker and management of day options* (Q16); *coordinators* (Q18); *teachers* (Q24); and *organisation staff* (Q8).

Topic Three: Experiences

4.4.10 Experiences of CAS

People with disability and family members provided one or more answers regarding experiences of participation in CAS. Learning new skills, having fun and making new friends were the most common experiences reported by people with disability and family members (see Table 4.17). Additionally, one person with a disability stated that they had learnt to, '*build a social network'* (Q14); and a parent identified that their son or daughter had, *'learnt to be more independent'* (Q16).

Table 4.17 Experiences of CAS

Experiences of CAS	**Responses of people with disability**	**Responses of family members**
Continued to develop skills learnt at school	7	10
Continued to develop skills learnt at rehabilitation service	1	0
Learnt new skills	10	12
Had fun	13	15
Made friends	11	11

Additionally, people with disability and family members provided examples of positive and negative experiences of CAS participation.

Positive experiences of participation in CAS were reported by people with disability including; making friends and trying new things, gaining self-confidence, life skills, cooking healthy meals, leisure and recreation participation including, gym and fitness activities.

Family members also identified positive experiences including; making friends; life skill development; being more aware of the community; socialising; and leisure and recreation including increasing fitness, bowling and gardening.

Examples of positive experiences were reported by 21 people with disability and family members, with examples presented below (see Table 4.18).

Table 4.18 Positive experiences of CAS participation

Theme	**Number of responses**	**Examples of positive responses**
Leisure, arts and recreation	5	*Improve my fitness by walking in parks and going to the gym.* (Q9, person with a disability) *Made new friends, increased fitness and enjoys cooking.* (Q9, family member)
Socialising	3	*Done things I normally wouldn't do. I've made lovely friends.* (Q1, person with a disability) *Really helps to build skills reading, writing, communication and socialising.* (Q8, family member)
Community awareness	3	*Provides services to the Aboriginal community for children, youth and adults alongside recreation and the gym.* (Q4, family member) *He is much more aware of community now, loves to peruse the newspaper and points out to me things he has obviously talked about at the programs.* (Q12, family member)
Independence	4	*I have become more independent, I can do lots of things.* (Q16, person with a disability) *He has learnt to take turns at 10 pin bowling, to plant seeds and travel in day options bus without me.* (Q16, family member)
Skill development	6	*Learning to cook healthy meals that are gluten free for my dietary requirements.* (Q9, person with a disability) *She does help with some cooking and watering the gardening at her day options, so is adding some skills.* (Q13, family member)

Negative experiences were reported by 11 people with disability and family members, including descriptions of experiences such as conflicts, getting bullied, getting hurt and not being understood. The researcher sees these as incredibly concerning issues which appear to be compromising the safety, and outcomes experienced by people with disability. The researcher sees this form of abuse as completely unacceptable.

People with disability and their family members have a right to question, as paying customers, how such incidents have occurred in an environment which is supposed to be operating in a professional manner. Examples of negative experiences are presented (see Table 4.19).

Table 4.19 Negative experiences of CAS participation

Theme	**Number of responses**	**Examples of negative responses**
Disrespectful relationships	4	*I get upset when people lose the plot and yell and scream.* (Q1, person with a disability) *Conflicts with other people.* (Q10, person with a disability) *Sometimes other clients hurt me.* (Q16, person with a disability)
Lack of individualisation	2	*Large variation of clients' ages, abilities and level of support needed. Feels like sometimes the quieter, more physically abled people get ignored. On outings not encouraged to eat healthily.* (Q8, family member)
Boredom	3	*Some numeracy and literacy is boring.* (Q10, person with a disability) *Bored at a day options program by an unstimulating woman who was happy for everyone to just sit all day.* (Q5, family member)
Unsupported	2	*We all hoped and dreamed that [organisation] would somehow offer help and support for us and we as a community have been left to feel let down thinking why are there so many staff and what are they doing?* (Q24, family member)

4.4.11 Better support

Responses from 15 people with disability and family members were provided to the question, 'Could your participation in Community Access Services be better supported?'

Key themes identified by people with disability and family members included; increasing choices of opportunities for participation; improved staffing skills and knowledge; skill development opportunities of participants; and improved resources for regional programs. Examples of responses for better support for participation in CAS are provided in the following table (see Table 4.20).

Table 4.20 Better support for participation in CAS

Theme	**Number of responses**	**Examples of better support responses**
Choice	3	*More choice of activities.* (Q2, person with a disability) *Group meetings where the participants discuss new activities themselves.* (Q2, family member)
Staffing	6	*More workers to watch I don't get hurt and help when things are difficult.* (Q16, person with a disability) *Having the right person instructing on new skills. If she is not keen on the worker she is not interested in participating.* (Q13, family member) *It would help if more people involved in the program could learn to, 'sign', as this is his only means of communication.* (Q15, family member)
Skill development	3	*More encouragement on independence, physical activity, better nutrition.* (Q8, family member) *To continue age appropriate further education and life skills post school.* (Q17, family member)
Regional programs	3	*More services in the Mallee area would be great.... I currently travel 120km plus.* (Q23, family member) *Perhaps not available to mere country folk?* (Q24, family member)

Topic Four: Recommendations

4.4.12 Recommendations/suggestions for improved quality of CAS

People with disability and family members provided 18 responses to the question regarding recommendations for improved quality of CAS. Key themes included: being co-producers of CAS with people with disability and their families; ensuring that people have individual opportunities which recognise their intellectual and physical opportunities; improving communication between people with disability and their families, and CAS providers; and ensuring that developmental outcomes for people with disability occurs. Some examples which may contribute to quality of CAS are presented in Table 4.21.

Table 4.21 Quality of CAS

Theme	**No. responses**	**Examples which may contribute to quality of CAS**
Co-producers	5	*Being involved in what activities are included.* (Q2, person with a disability) *More individual time, more structured time to learn and better staff to client ratio.* (Q16, family member)
Mental and physical appropriateness	4	*I feel that the people are lumped into one group regardless of their mental age or physical disability. I fear that my son may pick up behaviours from others.* (Q8, family member)
Communication	6	*Communication between the organisation and parents could sometimes be better.* (Q1, family member) *More communication with parents. I do get a note in an envelope sometimes.* (Q13, family member)
Developmental outcomes	3	*Disability programs were unattractive and too prescriptive in their offers. There was no development. He had to fit into their way.* (Q4, family member) *Talking to other parents, Day Options for most seem to be just minding centres without anything constructive happening.* (Q5, family member)

4.4.13 Innovation

In response to the question regarding recommendations for new or innovative ways in which CAS can be provided, people with disability and family members provided 14 responses. Key themes included; being co-producers with CAS providers; having improved communication between people with disability and their families, and CAS providers; having developmental outcomes from participation; having peer support and also across-government funding (from local, state and federal government sources) were recommended. Some examples which may contribute to innovative opportunities in CAS are presented (see Table 4.22).

Table 4.22 Innovation of CAS

Theme	**No. responses**	**Examples of innovation of CAS responses**
Co-producers	4	*Yes; talk to parents, listen to parents and act on what is acceptable from parents who speak on behalf of their son and daughter. Be upright and honest in dealings.* (Q4, family member)
communication	3	*We are curious/concerned what effects the NDIS will have on this program.* (Q1, person with a disability) *More meetings should be organised between individuals family members and staff to address important issues.* (Q10, family member)
Developmental outcomes	2	*Incorporate specific health-related needs into the program e.g. if an individual has low muscle tone, then a specific program at the gym could be prepared, instead of just, 'hanging out', at the gym.* (Q2, family member)
Peer support	2	*Young teens should be brought together to socialise and support each other in small friendship teams.* (Q23, person with a disability)
Across-government funding	3	*The huge discrepancy between school funding and adult services is the reason why I cannot blame adult services for the standard of services. I disagree with Disability SA and some providers that it's all about fun in the way of entertainment (sightseeing, shopping etc). People can enjoy learning new skills, physical activities, education and topical events etc. The problem is the latter will cost more than entertainment.* (Q17, family member) *Perhaps the councils could get involved in using some of their respite money allocations in supporting groups in their community or sending people out to help if families are in crisis.* (Q23, family member)

4.4.14 Summary of topics and themes from questionnaire responses

A summary of the four topics and themes from the questionnaire responses from people with disability and family members are provided (see Table 4.23).

Table 4.23 Summary of four topics and themes from the questionnaire responses

Questionnaire Topics	**Themes from questionnaire responses**
Topic One: Expectations and transition processes	• Fun • Friendships • Continuing skills and learning new skills • Lack of transition planning
Topic Two: Rights and Needs	• Limited resource development • Babysitting • Leisure, arts and recreation • Socialising • Skill development • Goal review participation • Positive Culture
Topic Three: Experiences	• Leisure, arts and recreation • Community awareness • Socialising • Skill development • Lack of individualisation • Unsupported • Regional programs • Independence • Disrespectful relationships • Choices • Staffing
Topic Four: Recommendations	• Co-producers • Mental and physical appropriateness • Communication • Peer support • Developmental outcomes • Across-government funding

4.4.15 Summary: Perspectives of questionnaire responses from people with disability and family members

For the majority of people with disability and family members their expectations and goals of CAS were; that the services would be fun; that they would have friendships; and that there would be opportunities to continue to learn skills learnt during secondary education/rehabilitation while learning new skills at CAS. However, there was also a lack of transition planning reported by people with disability and their family members; with almost half of the people with disability and 30 per cent of the family members reporting not being involved in the planning process and 35 per cent of people with disability and 80 per cent of family members reporting not having expectations and goals of participation in CAS recorded in a transition plan.

People with disability and family members reported that, regarding their rights and needs, very limited resource development had occurred to assist participation in CAS. Furthermore, examples were provided of CAS not meeting some respondents' expectations and goals due to limited socialising and skill development opportunities and a, 'babysitting', approach to CAS (n=15). For other respondents (n=23), examples were provided of CAS supporting leisure, arts and recreation opportunities, socialising and skill development. Although people with disability and family members reported that some goal reviews had occurred, over half of the people with disability and 43 per cent of family respondents reported that they were not able to decide who participated in the CAS goal reviews.

Learning new skills, having fun and making new friends were the most common experiences reported by people with disability and family members. A range of positive experiences of CAS participation were provided, associated with; leisure; arts and recreation participation; socialising; awareness of community; independence and skill development. Negative experiences were also reported which reflected disturbing experiences from; disrespectful relationships; lack of individualisation; boredom; and experiences of being unsupported by CAS. From the reported experiences of people with disability and family members, key themes to better support participation of people with disability were suggested including; choice of opportunities; increased staffing; skill development opportunities for participants; and improved resources for regional programs.

Potential improvements to the quality of CAS were identified by respondents including; co-production with people with disability and their families; individualised opportunities; improving communication between people with disability and their families and CAS providers; and ensuring that developmental outcomes occur for people with disability. Innovative ways in which CAS could operate were also identified including; co-production; improved communication; peer support; and across-government funding initiatives.

4.5 Perspectives of CAS provider representatives

4.5.1 Introduction

Interviews were conducted between 2009 and 2014 with 19 representatives from CAS provider organisations including; Directors (n=3); Managers (n=10); and Coordinators (n=6) from metropolitan and regional South Australia. Both strategic and operational perspectives were reported on during the interviews. A list of the month and year of interview, organisation representative role, region(s) of service provision and range of numbers of people with disability accessing CAS is presented (see Table 4.24).

Table 4.24 Interviews with CAS provider representatives

Organisation number	Interview Month/Year	Organisation representative role	Metropolitan/ Regional	Numbers of people with disability
01	November 2009	Coordinator	Metropolitan and Regional	150-200
02	December 2009	Manager	Metropolitan and Regional	100-150
03	December 2009	Coordinator	Metropolitan and Regional	100-150
04	July 2010	Director	Metropolitan and Regional	200-250
05	July 2010	Manager	Metropolitan	0-50
06	July 2010	Coordinator	Metropolitan and Regional	200-250
07	September 2010	Manager	Regional	150-200
08	October 2010	Manager	Metropolitan	0-50
09	November 2010	Manager	Metropolitan and Regional	0-50
010	March 2011	Manager	Metropolitan and Regional	300-350
011	October 2011	Manager	Regional	100-150
012	February 2012	Manager	Metropolitan	0-50

Table 4.24 Interviews with CAS provider representatives (continued)

Organisation number	**Interview Month/Year**	**Organisation representative role**	**Metropolitan/ Regional**	**Numbers of people with disability**
013	April 2012	Manager	Metropolitan and Regional	300-350
014	June 2012	Manager	Metropolitan	200-250
015	June 2012	Coordinator	Regional	0-50
016	July 2012	Coordinator	Regional	0-50
017	August 2014	Coordinator	Metropolitan	0-50
018	November 2014	Director	Metropolitan	50-100
019	December 2014	Director	Metropolitan and Regional	200-250

A summary of the themes from the four interview topics is presented (see Table 4.25). Each will be examined in detail below.

Table 4.25 Summary of interview topics and themes

Interview Topics	**Perspectives of CAS provider representatives: Themes/categories**
Topic One: Expectations and transition processes	• Direct promotion • Eligibility criteria and assessment • Trial periods • Reduced fees and social justice • Individual transition planning and support tools • Transition to employment and CAS • Finishing school first
Topic Two: Rights and needs	• Resource planning • Transport • Health needs • Individual goal planning • Skills and knowledge development • Outward looking focus • Hidden needs
Topic Three: Experiences	• Positive organisational culture • Progressive approach to community inclusion • Funding implications
Topic Four: Recommendations	• Co-production as equal partners • Incentives

4.5.2 Expectations and transition processes

4.5.2.1 Direct promotion

CAS provider representatives described a variety of strategies used by organisations to assist people with disability and their families when considering CAS. These include direct promotion in schools, via organisational websites and through an annual expo conducted in Adelaide, South Australia.

A manager from a larger CAS referred to, *'organisation recruitment officers within the human resource department who are involved in going to schools and presentations at the schools and providing invitations for people with disabilities, teachers, family members to visit the services. Staff are also involved each year at the Disability Expo and this is another opportunity to provide information and discuss with families and people with disabilities about the day option services at [the organisation].'* (Organisation 2 (O2))

In comparison, a coordinator from a smaller regional CAS stated, *'The disability expo is also an example of advertising opportunity which has increased charges from $50 a few years ago to $2,000 plus additional costs for electricity, site size etc. Last year there were three to four day options providers and a lot more of a focus on aged care. The set up also made it difficult for visitors because day options providers weren't together but spread out throughout the hall.'* (O15)

Publically available information on organisational websites also directly promote CAS with descriptions including; 'South Australia's best day options programme'; 'We are very proud of our Day Options Centres and the vibrant atmosphere they offer'; and, 'Our hubs are permanent facilities based in the community offering a friendly and familiar home environment for clients'.

4.5.2.2 Eligibility criteria and assessment

The majority of CAS representatives raised the issue of Disability SA eligibility criteria and assessment process difficulties affecting the transition of people with disability from school to CAS. These difficulties included; limited knowledge of the Disability SA assessors indicating a lack of appropriate training; inaccuracy of assessment; and timeliness of funding following eligibility.

The assessment of what people can or can't do according to their Disability SA assessment is a challenge. The policy is in need of review, as sometimes what has been the assessment of moderate or very high needs is not always how people present when they are involved in our services.
(O8)

[The Vermont assessment process] is subject to an assessor and [the results] may be reassessed. There was an example of two clients being reassessed following concerns raised by a funded agency. They were reassessed and the same two clients were assessed as not having low support needs but rather they had high support needs. There are concerns that in, order to determine their care and support needs, a once-off assessment is insufficient. You almost have to not let the kids sleep or eat until it's over because the scale minimises their actual needs.
(O11)

There are also major concerns regarding the timeliness of Disability SA Vermont assessment of people with disabilities. We are still waiting in November to find out if people in early next year will be funded to access our services. This makes it very difficult as a provider because we try to keep the books open but there is still no confirmation and we can't do that forever.
(O10)

We have had to ask for a reassessment and we have had people on high support needs funding allocation who needed very high support.
(O13)

Furthermore, one CAS organisation representative also spoke of the frustration associated with the inconsistency of eligibility policy:

In terms of eligibility there are people with autism and they may not have an intellectual disability therefore being so called ineligible but ODACS know the importance for the individual and the family of day activities in the [regional setting] and so they can access the services
(O11).

This inconsistency supports an observation by a CAS representative that, *‘The eligibility criteria still means there are people falling between the cracks and so there is still a need to do more for them to be able to access some services.’* (O6)

4.5.2.3 Trial periods

To assist people with disability and their families, CAS representatives also referred to the introduction of trial periods for CAS.

> *We have a ‘come and try’ day, which is a full day to come and try the services and this helps to build a strong link with schools and helps to develop a relationship with parents and carers also. In the country regions one to one sessions are held for people with disabilities to come and try the services available.*
> (O2)

> *We don’t necessarily use a written transition plan instead I meet with people with [specific disability] and their families and discuss what the service involves in a more informal way and then after a four-week trial I can see what they want to do and they can decide if it’s the type of program they want to go to.*
> (O5)

A representative of a large CAS stated, *‘We have trial placements for 10 days, which are not funded. People can see what they think of the day options program. They can do this whilst still at school, like a fieldwork placement i.e. one day per week for 10 weeks.’* (O14)

However such trial periods do come at a cost for organisations. One example from a regional CAS representative stated, *‘We are involved with individuals but if they move, their funding, [which may be $15,000], moves with them and this can equate to a contractor(s) position. We recently spent five months assisting a young person with a disability for their transition but because they didn’t come to this service but rather to [another program] the time which we spent, was really for free, without us being able to gain funding from that time of involvement.’* (O7)

4.5.2.4 Reduced fees and social justice

Repeatedly, representatives highlighted that the costs associated with providing CAS were higher than the funding each person with a disability attracted. To support people with disability, reduced fees are sometimes provided.

In one CAS in metropolitan Adelaide, a manager stated, '*We also have a user pay system in place which is a little lower to try to help families and increase access for people with disabilities. People can be involved on a daily basis using the user pay system if they would like to.*' (O8)

Another manager in a CAS providing services in metropolitan and regional South Australia highlighted that, '*Some people with high support needs, though, may not be able to receive the services they need if it wasn't for the additional funds which [the organisation] gains through its many fundraising activities. In fact almost 30 per cent of funds are gained through fundraising activities. In some country regions like [name of towns] the ratio to clients and workers is very much reliant on group numbers so if some clients leave the service the service may not be able to operate.*' (O10)

A manager in a regional CAS described their three-tier fee structure:

We help people to access our services in three different ways. Firstly there is a self-funded sessional rate for clients. Secondly we have a service access through funding from Disability SA. We have thirdly a social justice approach which means that we do take some clients on board for free of charge, however the funders will use that on you and so we have to negotiate how that occurs and that is simply through funds generated from other services. Day options actually runs at a substantial loss because we want to have a quality service with the low staff to client numbers. We are providing a service for clients and families, therefore from a philosophical perspective, and this is a reflection of our values and social conscience.
(O11)

4.5.2.5 Individual transition planning and support tools

Although, as illustrated in the literature review, person-centred planning is a well-established approach, in practice difficulties with implementation were reported, For example, a director from a large CAS provider stated:

It would be important at some time to conduct a survey of teachers to see what they don't know about transition to target areas, especially their needs. A lot more work needs to be done on post school transition planning to prepare a proper planned system which involves all the key players being present. The whole person-centred planning process is not new but it is how the process is conducted which is important. There needs to be people around the table who actually know what they are doing and this needs to happen for transition planning while the individual is still at school.
(O4)

To assist transition planning, support tools have also been developed by some CAS providers.

A manager of a large metropolitan and regional CAS highlighted that, *'We use a range of tools to identify people's expectations such as a pictorial questionnaire and, 'some things you should know about me', including participants' interests and what they would like to try while involved at the service. This process is used across all of the [organisation's] day options sites. There is a handbook, which is very pictorial and this also is very helpful when discussing people's expectations and also provides an overview of [the organisation's] services expectations, guidelines for involvement with others'* (O2).

4.5.2.6 Transition to employment and CAS

People with disability may transition into employment services only to discover that they would like a combination of services. In a regional service setting, a CAS coordinator identified this as a common option.

A lot of people who are supported employees also have participation in day activities and this is negotiated. Some people also prefer a combination of working part-time and participating in day options. This means that whilst they must work a minimum of eight hours it may be only two four-hour days
(O16)

However some conflicting and confusing information arose, for example one manager stated that, *'Implementing changes so that everybody can have a choice of services is also important. For example, people used to be able to work and have* *day options and we have a handful of people in our service who do that but new people have to do one or the other rather than being able to do both. They have to choose either work or day options but what if the work doesn't work out? What is their choice and what are they able to do? Choice has really been taken.'* (O13)

4.2.5.7 Finishing school first

Despite direct promotion, trial periods and reduced fees, CAS provider representatives acknowledged additional factors can affect transition planning for families. As a manager of a CAS which operates in metropolitan and regional South Australia stated:

Not all people though who are planning to be involved in a day option program are planning early in fact some people don't even start preparing until they are 17 or 18 years of age. They are wanting to start thinking about life after school when they are able to feel like one door has closed and the next door has opened. Rather than trying to bring perhaps some confusion into the young person with [a specific disability's] life. For some people the transition to day options really is a last minute thing and unfortunately, because they haven't planned earlier they may not be able to get into a day option program.'
(O5)

This process puts additional pressure on CAS providers as a director of a large CAS organisation explained:

One of the most difficult aspects of transition planning is not knowing each year how many students with disabilities may be leaving school and going into day options. We don't know each year which regions they may live in either, so it is very difficult to do any forward planning and some families leave this to the very last moment.
(O19)

4.5.3 Rights and needs

4.5.3.1 Resource planning

Provision of CAS in traditional congregate models of service delivery requires constant resource planning as CAS representatives explained.

A manager of a large CAS stated, that, *‘Having resources can make or restrict our services. As you can see we have some very good facilities and we try to be involved with the community and other day option providers as much as possible. However due to funding resources we are always having groups of four to six participants and are on a daily basis needing to consider and plan the group dynamics, vehicles, staff to ensure that the services are best for the people involved in the services.’* (O2)

During the face-to-face interview visits, the researcher was invited to meet at CAS venues and observe sessions. The following memo and observation was recorded.

Memo and Observation, 2/12/09: The CAS operates from a section of a manufacturing plant with supported employees using part of the facility for packaging and assembly and part of the facility for CAS. People with disability were sitting in the workshop space with drawing paper and pencils. Little instruction or support was occurring at the time of the observation. Segregated CAS was being provided in a sheltered workshop environment.

Furthermore, *‘Services aren’t provided by [the organisation] for people with very high support needs. Only recently, vehicles have been provided which have access hoists to make transport easier. There are other agencies which work with people with very high support needs.’* (O2)

Other large CAS share resources, for example a manager of a metropolitan service stated that, ‘*We also share resources across our day activity outlets e.g. if there is a Karaoke session. Pottery, too, has become a very popular session across the day options program. Three of the programs are for young school leavers, others are for retired lifestyles quieter/older people and some also have a mixture of people with behaviours.’* (O14)

4.5.3.2 Transport

All CAS representatives, when reflecting on service needs and, in particular, resources, referred to issues associated with transport affecting access to services for people with disability and their families. The transport availability, choice, support for families and costs were common themes for CAS representatives from metropolitan and regional services.

Transport has a huge impact on the program and people with disabilities doing things in the community that they want to do. It affects their time and can be expensive.
(O1)

In addition, *'The amount of funding we receive from Disability SA doesn't cover the transport costs and so if we weren't a larger organisation I don't know how people would be able to access the services during the day, let alone for out of hours.'* (O10)

Issues of choice were also raised by the manager of a metropolitan CAS:

Also younger clients in accommodation services need to have some choices. For example, in a home with four young people, do they all have to go to the same day activity service because of transport convenience or can they have some say into the day activity service that they go to.
(O12)

For working parent(s) transport is an important consideration and has changed over time according to a CAS coordinator:

Day Option services are provided from this site from Monday to Friday. The service was originally set up 25 years ago and many of the parents were/are elderly and so the services were from 10am to 3.30pm so that they could be dropped off and picked up. In the last three years the service times have changed. While most participants are here from 10am to 3.30pm and are involved in a range of activities with younger parents who are working we have opened up the service to start from 8.30am so that participants can be involved in the service and the parents go to work.
(O3)

In a regional location, the manager of the CAS stated that, *'The other aspect, of course, is transport in a regional location which is so expensive. We have changed our arrangements now so that we have a bus driver who picks up and returns people on a 150km round trip per day. This is a new role and he is helping us again with stability so that we do not have different people on a roster.'* (O7)

Unique to some CAS in regional South Australia are transport restrictions because of the extreme fire danger.

As a Coordinator described: *'This fire policy has come about in the last couple of years. Transport times and costs are a real challenge. Families need to be realistic when it comes to pick up and drop offs. The true cost of transport in rural areas are not included as clients have to travel further and there are fewer clients.'* (O15)

When discussing rights and needs of people with disability and their families, supporting people's individual health needs was also a common discussion in interviews with CAS representatives.

4.5.3.3 Health needs

The challenges of working with accommodation services that close when people with disability are at CAS, were highlighted by a manager: *'A real challenge is in regards to older clients who are fatiguing and are stating that they really don't want to go to the day activities every day. One young client that we work with who has poor health has said that he needs greater choices and days off when needed but how we negotiate that is a challenge for sure. Even a few hours is enough for him so the challenge of real choices during the day is a concern currently.'* (O12)

> *However, as day option providers, sometimes clients have been sent to us because their accommodation is closed during the day, even when the client is obviously unwell and just needs to be resting at home.*
> (O18)

> *We, on occasion, have had to work with people who provide the supported accommodation for the best interests of the individuals so that if an individual isn't feeling well we may have to ensure they are able to be cared for while they should be at the day options program. We had a time last year when three people had swine flu and were taken to the day option program. We had to make sure they were cared for but also make sure that the other people in the day option including our workers didn't get sick. So even though the supported house was closed they had to make other arrangements.*
> (O5)

Having purpose-built facilities also supports health and safety for people with disability:

As you can see at these hubs they have been well modified and extended to ensure quiet rooms, library, community education, computing, literacy, cooking can all occur at the site and that activities in the community can then occur from these bases. At the purpose-built facility also makes sure that the safety and comfort of people is paramount also for staff who are providing the support.
(O10)

Memo and Observation, 8/3/11: Two facilities were visited with the CAS organisation representative. Both are located in metropolitan Adelaide but were distinctly different. The first location was a small modified house with room extensions and space for individuals to participate in passive activities including reading/literacy, board games, cooking/food preparation and computing. The facility looked like every other house on the street except for the vans parked along the side of the building. This facility is a base for people with disability to be transported to other community activities such as swimming, going to the gym and bowling. The second facility is purpose-built primarily for people with higher support needs with extensive space for use of transfer lifters, adaptive technology equipment and is located adjacent to a shopping precinct rather than in a local street so as to provide for increased parking access.

4.5.3.4 Individual goal planning

CAS representatives also explained that to support rights and needs of people with disability, individual goal planning is important. This occurs with them and their families, siblings and informal primary carers.

In a small metropolitan CAS the coordinator stated that, *'Goals are reviewed every day. They may learn differently and I can tell how much is learnt especially so that their self-esteem can be built up. I design the program so that there is progressive learning to build self-confidence.'* (O17)

According to the manager of a large CAS, goals are also reviewed formally:

Every year goals are reviewed with participants and people who are important in their lives. Every participant has a key worker and goals are recorded and progress of these goals are reviewed. We don't use a lot of writing only but also include photos to record people's experiences. Participants can take these home and this is great for the family/carers also.
(O2)

We involve families throughout the program development and we also use communication books to relay information to families. We take photos and create a scrap book as a reminder for the clients and families of events during the year and the range of activities they have been involved in.
(O6)

We have a recreation resource kit which is very helpful for both the person with a disability and also for family members. We produce recreation day option plans and personal support/care plans for clients. These are reviewed with the family and client every six months and we believe giving this feedback is important.
(O4)

In a multicultural community, CAS are also adapting as a manager explained:

The goals are recorded and actual folders are used with some people using tools such as COMPICs to assist them through pictures and for some people who don't speak English we also set goals with interpreters in place to assist.
(O13)

Regarding multicultural communities, workers also require support to understand the goal setting and service implementation processes.

As a manager of a metropolitan CAS stated, *'There are also challenges in regards to an increasing multicultural workforce and families have reported difficulties through language barriers with workers. I often hear that, 'I can't understand the worker', so the ongoing challenge relating to English as a second language is real for some families.'* (O12)

4.5.3.5 Skills and knowledge development

An important right for people with disability, according to CAS representatives, is the opportunity to continue to develop skills and knowledge.

We want to be working as a developmental model service and not a time occupier model of service provider.
(O4)

A coordinator stated that, ‘*We have seen that for many people in higher support programs their skills have been lost as many staff do things for them because of the workload. We try to encourage clients to do things particularly where we know they can.’* (O6)

The great part of this program also is the emphasis of skills which people can learn from the school years into employment. Some people are working part-time and then pay for this program so that their skills are continued and aren’t lost. Therefore students come as a transition from school directly into this program or while they are also working or involved in other day programs part-time elsewhere.
(O17)

We are a little different from most day options services. We employ people who are foremost successful artists, as this is an arts-focused service, and then we recommend that the artists attend a Certificate III in Disability Studies. The focus therefore is actually on the arts skills that they bring to the service and we do have a preference for people with the best arts skills to be involved with providing supports.
(O8)

This is why we work at a two-client-to-one-staff ratio, which I know is quite different from many of the other day option programs. I don’t want our programs to have lots of people sitting in a room watching TV all day. Our focus is on skill development and functional activities. Nowadays many people with disabilities aren’t able to find employment so we focus on continuing their skills.
(O18)

Skills and knowledge may also vary with people's age:

> *There is a challenge in terms of not being able to assist everyone with different age interests but this also provides an opportunity to create new programs as well as sustaining the programs which we have already developed*
> (O6)

Within a creative arts perspective, the continual development of skills and knowledge is also empowering.

4.5.3.6 Outward looking focus

The opportunity to have an innovative, outward looking focus is important according to CAS representatives as highlighted.

> *Visual artists exhibit their work in a public arena at least two to three times per year and have exhibited work overseas and there has also been an exhibition which toured nationally. The artists earn money for the sale of their work. I know that the sale of work is empowering, for example, a family member recently commented that she refers to her son/daughter as an artist who exhibits and sells their work not only to family and friends but also members of the public. Rather than saying their child has a disability which may be disempowering they are able to state that they are an artist.*
> (O8)

Using modern technology and networking to support individuals was also being used beyond attendance at CAS.

> *We have used our web page for clients to provide information and support people with disabilities and their families in this way with both the city and regional settings. We also have a Facebook group for [the organisation] participants in day options and also for families.*
> (O4)

4.5.3.7 Hidden needs

While CAS are able to support people in community settings, not all people who could participate are doing so. As two CAS representatives highlighted:

People with disabilities aren't leaving services, in fact the waiting lists are growing. We may even increase the number of people accessing services because of the increasing needs. There is almost a hidden group of disabled people who aren't involved but could be rather than being home all day.
(O2)

Some people have also been stuck in a big hole with their parents who are getting older caring for them but are needing a few days break per week. These are also often people without much money as many of the families are single parent families because of the pressures they have experienced looking after their kids with disabilities. We try to help them as much as possible
(O19)

4.5.4 Experiences

The experience of a CAS director regarding strategic policy and practice changes of CAS over the past 20 years was presented during one interview. This provided an illustration both in terms of the growth of larger organisations providing services and impact on choices of people with disability and their families of local services in local regions.

There have been limited changes to services for day options since the late 1990s and early 2000s. Over a period of about six years since the year 2000 there were no CPI increases so it was difficult to run day options programs. Over the past few years CPI has been reintroduced for day option service providers. This means that day option providers were expected to provide the same services over a number of years for less income. The addition of day centres accommodating larger number of clients in one centre, at [organisation names] have been supported by the state government. These centres had the effect of controlling prices for day option services. This makes it difficult for day option service providers that provide smaller more individualised community-based services to compete for new clients and demand drops. The effect will limit service choice and variety especially if Disability SA staff and families are trying to buy the most time for the individual. Currently service quality is not measured by Disability SA; cost per day is the major decider.
(O4)

Such changes have had an effect on the organisational culture including philosophy and values of services, quality and staff as described by some CAS representatives.

4.5.4.1 Positive organisational culture

The presence of positive organisational culture including staff knowledge, skills and passion for working with people with disability was also identified.

A manager in a regional setting stated that, *‘I know there is corporatising of NGOs and I have sat at meetings where larger providers have said we won’t even explore a service until we know how much money is available but we also in the regions need to be having the interests of clients at the forefront of our minds. What we need to be is respectful of families.’* (O11)

A Coordinator of a CAS for people with disability in metropolitan and regional South Australia explained that, *‘You* ***can*** *have a lot of money and still have a lousy service. The staff are vital for the program and how well it is run. The philosophy of the organisation being client-focused means that services are more likely to be beneficial for the client and regarding [the organisation] we want to make our service affordable whilst still meeting our expenses. There are services which charge less but have 20 people who sit around all day. The values of staff and the organisation all contribute to make the program.’* (O6)

Furthermore, a manager stated that, *‘We have a low ratio of staff to people with disabilities because we believe in quality. Competition in this industry means that with some services higher ratios means cheaper services are offered. This has an effect as this means there are quality plus financial considerations.’* (O13)

Also a manager of a metropolitan service added that, *‘Another consideration is that services need to continue to remain small. The need for a vibrant artistic organisation within a freedom from a much larger organisation has been very good. We, for example, in a smaller setting find it much easier to get volunteers than the recruitment that occurs in a much larger organisation. Having a small group gives you flexibility and being involved in community makes a big difference to any program.’* (O8)

A manager of a large CAS provider in metropolitan Adelaide highlighted that, *'I feel very privileged to be in an organisation like [organisation name] which actively fundraises and has such a strong commitment to disability services. I wouldn't be in this position if that wasn't the case. In fact ethically I believe that what we provide is what people need. We have excellent staff and I am always involved in the recruiting. I don't just look at their certificates but also their values, their skills and attitudes and so I like to have an eclectic mix of staff to provide support to the clients. I also believe in a culture where the expectation of all staff is to provide really good services.'* (O18)

To emphasise the importance of organisational culture, a manager stated that, *'Quality cannot be met when there are higher ratios. Day options is not a babysitting service but it has been hard. A lot of skills are lost when people are just sitting around and I have seen people go backwards if a challenge is not provided even for the most high care person.'* (O13)

4.5.4.2 Progressive approach to community inclusion

When reflecting on experiences of CAS provision, the topic of increasing community inclusion was highlighted by a manager of a, 'non-disability-specific', service organisation:

> *Regarding inclusion, we need a balance between segregated groups and a pathway for how people connect with their community. In a fitness and leisure environment people may connect by training in a gym, swimming at the pool, playing basketball and [this organisation] has the infrastructure, therefore, to assist people in their connection with the community. They are going to the [organisation] rather than a disability provider. A session like cooking involves going to the shopping centres, using their budgeting skills, buying the food and preparing in the leisure centre's kitchen. There are opportunities for socialising with other participants of the community facilities.*
> (O9)

Responses from other CAS representatives illustrated their commitment to a progressive approach to community inclusion:

We run day activities from Monday to Friday from 9:00 to 4:00 although we also have some evening programs. This includes the art groups and the [name of group] based in [geographical location]. This is a social group for people who might work during the day and need a social outlet in the evening. We also have half day outdoor adventure programs for people as a way of integration into day activities and may include a social activity in a park, for example, as going to a shopping centre may be too overwhelming.
(O6)

What makes something an institution? Complete and utter transparency or lack of transparency is important. You can't as easily just walk into [organisation's name] Day Centres. There appears to be no transparency of service provision, compared to our day option programs run in public community centres, where activities and venues are shared with other members of the local community.
(O4)

We do work in with other agencies and we recognise that interaction with the community is so important for the dignity of participants.
(O3)

Leisure, arts and recreation-focused services also assist the individuals' progressive community inclusion. An example was provided by a manager of a metropolitan CAS:

For the artist themselves, the art itself is a really good medium and vehicle for individuals' expression. We also want to have opportunities for people to sell their work or receiving a contribution through their performances. But also we know the bigger community benefits. I remember working with a gentleman who was very withdrawn and had some mental health issues. His artistic expression consisted of drawing grids, dark lines and in a way expressing a very dark mood. Page after page of these dark grids were produced. Over time and with support he began to communicate in bolder colours and with different patterns We could see a real freeing, and while we know sometimes it is hard to interpret changes, these were so obvious for him and he began to be so bright and this reflected his changing experience.
(O8)

4.5.4.3 Funding implications

Despite positive organisational cultures and a progressive approach to community inclusion, CAS representatives emphasised how opportunities for people with disability could be enhanced if funding implications were considered.

I want to passionately make the point that there is a severe case of underfunding of day options in South Australia. This means if we remain stagnant we will end up going backwards and this will mean reduced opportunities for clients for their holidays, for travel etc. While the competitive nature of service providers occurs there isn't necessarily a stance of more money equates to better services. But setting hourly rates for brokerage tenders simply means that there may end up being increased costs for clients so we have to be smarter than that. We don't want to rob Peter to pay Paul.
(O11)

Standards of service are affected by funding models which vary from state to state. In New South Wales the funding for people with disabilities, especially people with high support needs, is higher than in South Australia.
(O3)

Rather than trying to block people's opportunities for services i.e. what they can buy for the most time away which affects quality, instead funding needs to be related to what a person with disability wants to do so that the money can be matched to their needs rather than the funding body.
(O4)

All day option services cost different amounts of money and work with different classification of staff, with numbers of volunteers and ratios to people with disabilities. They can go to five different day options providers and get five different costings and this does reflect specialised skills, knowledge and quality of service.
(O5)

Another funding implication of CAS was presented by a director of a CAS. Citing one person's experience the director stated that they had been working with a person with a disability who had been accessing their service in a regional location at a fee of around $25,000 p.a. The organisation's staff knew the person well, and were very supportive. However the director highlighted that the economic benefits of CAS are rarely, if ever, considered, for example:

> *Regarding a person's additional behaviour support needs when this doesn't occur we have seen some dreadful things occur. An example was a young man who had the intellectual development of a two to three year old and when he came to [our service] he had violence and aggression needs. [At our CAS] we provided a lot of positive behaviour support and a lot of prevention measures were put in place to identify any triggers to the outbursts. For example talking with him occurred so that he was engaged and wanted to be involved rather speaking to him as a directive, which he didn't like. Unfortunately, such support wasn't provided with his accommodation and a violent incident occurred. As a result he is no longer supported at the CAS, and he is now having two to three staff costing over $300,000 per year.*
> (O19)

Another example highlighted that, *'I know that emergency respite is hugely costly and is in huge demand and so through recreation and holidays we are able, in a preventative sense, [to] continue to work with ODaCS [Office for Disability and Client Services], Families SA and the Commonwealth. We have shown that through recreation and holidays we provide three times as many hours as we are funded i.e. $50,000 for 7,000 hours which would, in reality, cost them over $150,000.'* (O7)

4.5.5 Recommendations

4.5.5.1 Co-production as equal partners

Recommendations by CAS representatives included the importance of working closely with people with disability and their families and having incentives to be innovative with CAS design, development and evaluation.

> *There is a dignity of risk that we need to consider, not just what the obstacles may be perceived to be and therefore, 'Oh no we couldn't do that.' We know that clients and families advocating for this quality is important also. We are not after militant parents but the ones that scream the loudest do seem to be the ones who get the services rather than them all standing together and being able to ensure they all get the service that is needed.*
> (O11)

In a regional setting, a manager of a CAS service reiterated that, *'Because we are a community regionally based program we have a real strength in being community rather than organisationally-driven. Our families' input is huge, as is our work with volunteers and so are our networks. So we do have an advantage in that regard which helps us to have a great quality service.'* (O7)

Another stated that, *'We talk with people individually and in groups so that they have opportunities to take responsibility for actions and we have found this to be a good process within the limited resources which we have available. If there are any concerns of parents we want to be able to provide written copies of the individual's goals rather than the exercise being about the family's goals only. We also have goal reviews filmed so that every three months artists are able to reflect back on all of the progress that has been made. We have found this to be a very interactive process and reflect the visual artists, which we are. We also have staff planning days in which reviews occur.'* (O8)

Being co-producers may assist people with disability, parents and providers to support each other. A director of a CAS expressed an example of pressures that isolated parents may experience when living in crisis and when the system has operated in, 'crisis':

> *The system has always been crisis-driven. Over the past 20 years our service has experienced people being dropped off at the service in the morning* ***and not being picked up****. We have been left to try and help them in this crisis because it was the only way to get a service that was needed. While this hasn't happened as often in recent times there are still issues.*
> (O19)

This crisis-driven system experience was also reflected in the literature and in Australia, particularly in the *SHUT OUT: Report,* leading to the introduction of the National Disability Insurance Scheme (NDIS) in Australia. The author of this current thesis asserts that the desperation of families to try to get support services has led to such drastic action.

4.5.5.2 Incentives

In addition to co-production strategies, one Director of a CAS recommended a review of incentives as have apparently previously occurred:

There is no incentive for [the organisation] to be innovative and to develop new programs. We have developed social programs for the weekends when there was some innovative funding but this hasn't continued. When there is no further funding allocated the service finished. There is also the new individualised funding trial being developed. However there is a lack of any sort of creative funding and there has been no new funding for years. There is an important need for quality services to help people's quality of life, for example, having services, which are age appropriate and are planned to take into account people's different cultures. [The organisation] is trying to continue to be a good service provider.
(O4)

4.5.6 Additional data from CAS providers

As the completion of each of the face-to-face interviews occurred, a request was made by the researcher for additional information from CAS providers such as written assessment, implementation and evaluation tools. Ten providers supplied information on the condition that information would be de-identified. Examples are provided including; Assessment of activities of daily living (Appendix Twenty One); Activity assessment using pictures and questions (Appendix Twenty Two); Client goal reviews (Appendix Twenty Three); Implementation choices (Appendix Twenty Four); Evaluation of CAS (Appendix Twenty Five); Evaluation survey (Appendix Twenty Six); and CAS member review (Appendix Twenty Seven).

Memo, 3/11/14: Each organisation has developed its own process of assessing, implementing and evaluating CAS. Today, during the interview regarding evaluation, the CAS survey had been designed by the organisation representative and, when asked, that person stated that it is used for developing further services, although people with disability and family members were not involved in the development, implementation or analysis of the evaluation process.

Additionally, having completed each interview, a review of publically available information about each CAS was sourced from the Disability SA *Look Book* including the organisation’s; **mission statement**; **service goals**; **program availability;** and **description of program’s individual needs**. CAS organisational websites were also reviewed, including information concerning leisure, arts and recreation opportunities and participant case studies, which were included on some organisation websites. One CAS provider states that they are the best in South Australia, however it may be difficult to ensure that people with disability and their families have an opportunity to compare that service with the other 22 in South Australia to make a reasonable decision. It may also contribute to confusion for people with disability and their families if there is not a process for determining, ‘the best’.

4.5.7 Summary of responses from face-to-face interviews with CAS provider representatives

For each of the four topic areas a range of key themes was discovered from the face-to-face interviews with CAS provider representatives.

Response to the questions regarding CAS transition processes, for example, once again identified difficulties experienced with the eligibility criteria and assessment processes. Similarly, the need for support for transition planning was raised. CAS provider representatives also indicated that trial periods had been provided, and for some families reduced fees had been made available, because of a desire for social justice.

The rights and needs of people with disability and their families were also raised. Responses from CAS provider representatives indicated that resource planning, transportation and the health needs of individuals were important. Additionally, CAS needed to provide individual goal planning in order to contribute to supporting each individual’s skill development. Having an outward looking focus and being innovative, for example with visual and performing arts opportunities was also raised by provider representatives. Hidden needs including an increasing need for CAS as parents are ageing, and the financial difficulties of families also emerged from the face-to-face interviews.

Concerning the experiences of CAS provider representatives having a positive organisational culture which supported increasing staff knowledge, skills and passion to work alongside people with disability was recognised. Having people with disability and their families, 'at the forefront of our minds', illustrated the commitment of working with people with disability, in a genuinely respectful manner. A progressive approach to community inclusion was also identified so that people with disabilities do not become, 'stuck', within a CAS but, rather, are connected to their local community. Finally, in this topic, issues of funding were also explored, including the issue of different standards in each state or territory in Australia.

Potential recommendations which may contribute to CAS included having a co-production approach for quality outcomes for people with disability and their families. Having incentives for CAS providers were also suggested.

4.6 Results from critical discourse analysis

4.6.1 Introduction

A critical discourse analysis of Australian, publically available CAS policies and written evidence (Evans, Bellon & Matthews, 2016), was adopted to explore the following questions:

a) Are the voices of people with intellectual disability or their families present in Australian CAS policy?

b) Do CAS policies influence practice with regard to community participation and community inclusion?

c) What can be learnt from CAS policy and practice across Australia?

The results and implications of this analysis are provided below.

4.6.2 The voices of people with intellectual disability or their families in Australian CAS policy

The engagement with people with disability or their families is evident in 16 of the 42 documents (Appendix Eighteen). For example, in South Australia discourse in the *Better Pathways Consultation Paper on Improving the Pathways from School to Further Education, Training, Employment and Day Options for Young People with Disabilities* (Department of the Premier and Cabinet, Government of South Australia, 2006) involved people with disability and parents having, 'direct input into the consultation process that could potentially have lasting benefits for young people with disabilities' (p. 3). In Victoria the *Evaluation of the Changing Days Initiative* (Department of Human Services, 2009) involved interviews with people with disability and their families to inform a range of practices by CAS providers thought to be effective in encouraging and embedding self-directed approaches. The discourse used in the evaluation referred to, 'high levels of choice', for people with disability and, 'a willingness to tailor supports around individuals' needs and aspirations' (p. 2).

The remaining documents did not directly acknowledge being informed by people with disability, their families, or informal primary carers. Although this does not necessarily preclude the possibility of a consultation process, it would be strange if such an approach had been taken and not mentioned. Also, while it could be argued that some documents have a more pragmatic purpose, such as directing how funds should be accessed and used, overlooking an explicit discussion of the implications for the people accessing these services does not seem to be consistent with contemporary views.

4.6.3 The influence of policies and practice on the community participation and inclusion of people with intellectual disability

Three key themes emerged from the analysis, which illustrated how policy and practice had influenced community participation and community inclusion: eligibility, design and implementation, and evaluation.

4.6.3.1 Eligibility

An analysis of the written language texts used in policies from the documents implied that people with disability would be able to participate in CAS. However, while this generic description was used, people with disability are not a homogenous group, and not everyone with a disability was, eligible, to participate. The discourse regarding eligibility criteria highlighted the power relationship between policy makers, and people with disability and their families. This varied between amongst Australian states and territories (see Table 4.26). It is noted that language varies and can be somewhat ambiguous, for example, 'age of compulsion', is used to determine eligibility in South Australia.

Table 4.26 Eligibility discourse

State/Territory	Eligibility discourse	Evidenced within documents
South Australia	People with intellectual disabilities over the age of compulsion whose support needs assessment is either moderate, high or very high are eligible. People with ASD and intellectual disability are eligible. People with ASD (without an intellectual disability) are not eligible. People with physical disability such as neuromuscular conditions are not eligible.	Department of the Premier & Cabinet, (2006, p. 19) Department for Families and Communities Day Option Program Guidelines, (2011, p. 1)
Victoria	People with a disability as defined by the *Disability Act 2006* (Vic) are eligible.	Department of Human Services, Individual Support Package Guidelines, (2010)
New South Wales	People with a disability who have an intellectual, psychiatric, physical, sensory disability or like impairment are eligible.	Department of Family and Community Services. Community Participation, Life Choices and Active Ageing Program Guidelines (2012)
Queensland	People with a disability who have an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment are eligible.	Department of Communities, Child Safety and Disability Services (2012)
Northern Territory	People with Disability as defined in the *Disability Services Act 2012* (NT) are eligible.	Department of Health, Aged and Disability. Aged and Disability Program (2014)
Western Australia	Any of the following primary disability diagnosis: profound intellectual, physical, sensory, cognitive or neurological are eligible.	Disability Services Commission (2010)

Table 4.26 Eligibility discourse (continued)

Tasmania	People who have disabilities as defined in the *Disability Services Act 2011* (Tas) are eligible.	Disability, Housing and Community Services), Tasmanian Government, (2010) Eligibility Guidelines for Access to Specialist Disability Services
Australian Capital Territory	People with a disability are eligible.	Disability ACT, Response to School Leavers with Disability Information Pack (2013)

The documents identified the impact of the eligibility discourse on community inclusion and community participation for both, ‘suitable’, people with disability and those who were outside support requirements criteria, who had, ‘no funding and no ongoing model, service or sector development to meet their needs’ (Department of the Premier and Cabinet, Government of South Australia, 2006, p. 20). An eligibility discourse has practical consequences. For example, historically, South Australian, ‘day option’, policies have defined eligibility by unique, ‘disability diagnoses’, such as ASD with intellectual disability. South Australia is the only Australian state to specifically exclude people with ASD without intellectual disability from CAS. In 2008, the Government of South Australia’s *Post-School Pathways Report* identified that approximately 240 young people with disability, aged 15 to 24 years old, would prefer to participate in day activities but, ‘did not meet the criteria’, at that time (Department of the Premier and Cabinet, 2008, p. 15). This report further highlighted that, regarding specific disability diagnosis, ‘young people with Asperger’s Syndrome are not eligible for a day options service and may have behavioural issues making it difficult for them to gain employment even in a supportive environment including Business Services (sheltered workshops)’ (p. 18.). People with disability are not a, ‘monolithic social group’ (Department of the Premier and Cabinet, South Australia, 2006) of people to be, ‘managed’, by policy makers. This segregation, based on, ‘level of disability’, reinforced a focus on discourse that was rooted within the, ‘medical model’, which promotes a, ‘welfare’, mentality and continues a cycle of unemployment, underemployment, and limited further education opportunities.

4.6.3.2 Design and implementation

Discourse in the documents illustrated the need to specify services design and implementation characteristics. Regarding age of participants, the *My Life, My Way Handbook*, (Department of Family and Community Services, New South Wales Government, 2011) highlighted three different types of day programs that used individual funding including: Community participation (for people up to 25 years); life choices (ages 25-54); and active ageing (ages 55-64). The changing needs of people were also considered in policy discourse. The *Disability Services: Day Services Guidelines* (Department of Human Services, Victorian Government, 2012) recognised that individuals may require additional support due to issues such as deterioration of a degenerative condition, an increase in behaviours of concern, or decreasing mobility. In practice, such guidelines assist both people displaying behaviours of concern and providers of services so that interventions, if required, can be supported. Rather than simply removing people with, ‘bad behaviour’, from services, strategies and processes to facilitate support were articulated in documents demonstrating a discourse focused on the individual (Department of Human Services, Victorian Government, 2012, pp. 9 & 13).

With the introduction of individualised funding, discourse supporting greater active involvement of participants in the design and implementation of CAS was identified; for example, ‘you become an active participant in the design and delivery of how you will meet your disability support needs’ (Department of Communities, Child Safety and Disability Services, Queensland Government, 2012, p. 3). Similarly, a document from Western Australia had a clear, individually focused discourse:

> ‘People with specialist disability funding are able to self-direct their supports and services, have flexibility in how their allocated funding is used, and have genuine choice and control over the design, planning and delivery of services they require’ (Disability Services Commission, Western Australian Government, 2013, p. 1).

In contrast, where policy discourse was, ‘ambiguous’, providers were able to operate in a vacuum of design or implementation direction. For example, the absence of directive discourse about optimal staff ratios for working with people with intellectual disability may mean that these people were not receiving an adequate service.

4.6.3.3 Evaluation

Discourse concerning evaluation approaches that result in active involvement of people with intellectual disability were identified, such as indicators that included, ‘regularly accessing information, participation in decision-making and providing feedback in their chosen program, model option, service provider and related activities’ (Department of Family and Community Services New South Wales Government, 2012, p. 40).

Fisher and Robinson (2010) recommended that people with disability be involved throughout the entire process of evaluation, including determining the evaluation methodology, conducting the evaluation, analysing results, and providing recommendations.

4.6.4 Learnings from CAS policy and practice in different state and territory jurisdictions

The exclusion of people with disability based on their disability diagnosis continues, despite their engagement in consultation processes. Each Australian state or territory has prioritised the funding for CAS differently, without consistent eligibility criteria or apparent equity for participation by people with disability. While discourse has promoted the concept that participation in CAS increases social independence, segregated services are still common. Furthermore block funding of services has had the potential to inflate the power and decision-making of service providers over the people using their services.

4.6.5 Summary from critical discourse analysis

Using a critical discourse analysis, this current study identified evidence of the voices of people with intellectual disability and their families or informal primary carers, in 16 out of 42 of the Australian CAS policy-related documents. The line-by-line analysis and comparison of documents discovered the presence of discourse that maintained inequity, as the language in these policies continued to define people with disability as a homogenous group to be managed. Individualised approaches with, and for, people with intellectual disability have contributed to redressing imbalanced power relationships, which may be further strengthened through the implementation of the NDIS. The introduction of Tier 2, now known as the Information, Linkages and Capacity Building (ILC) Framework, is an example of policy development and professional practice, co-produced through consultations with people with intellectual disability and family members. Policy development processes should explicitly address opportunities for people with disability and their families to contribute if the vision, ‘nothing about us, without us’, is to be genuinely addressed in the Australian community.

4.7 Chapter 4 summary

This chapter provided results from content analysis of data collected and analysed between 2009 and 2015. In a triangulation of data collected for this current research, responses from people with disability and family members; CAS provider representatives; memos; and observations and findings from a critical discourse analysis of extant texts relevant to CAS, were presented.

From this analysis of results, a range of themes was discovered which require further discussion. For example, the expectations of people with disability appear to be stifled because of processes and approaches when leaving secondary education which have resulted in confusion, anger and despair. Clearly, a strategic model of transition is required to empower people with disability and their families to make accurate and informed decisions during post school planning. An analysis of responses from CAS provider representatives and policy discourse confirmed the requirement of the eligibility process being transformed from a focus on the, ‘deficits’, of people with disability to that of a focus on each individual’s capabilities.

When exploring the rights and needs of people with disability and their families, the desire to move from a predetermined, ‘one size fits all’, segregated model of CAS was also conveyed by many who are seeking an alternative individualised approach. With the introduction of the NDIS, policy which supports this transformation is being implemented throughout Australia. The experiences of people with disability and family members also indicate the necessity for CAS to be involved in equal respectful partnerships with them. This was recommended as an innovative approach which may contribute to quality post school outcomes for individuals with a disability and their families.

The following chapter provides a discussion of the results and introduces a substantive theory of, ‘Social Transformation’, together with seven concept areas identified during the current research. Subsequently, implications for policy development and professional practice and strengths and limitations of the research, are also presented. The chapter concludes with implications for further academic study.

Chapter 5
Discussion of Results

5.1 Introduction

This chapter provides a discussion of the results of the current research and introduces a substantive theory of, ‘Social Transformation’, which was discovered by the researcher during the carrying out of the research, as processes and approaches of Community Access Services (CAS) were explored. A discussion of the following seven concept areas identified during the research are also presented as follows:

1. Eligibility and equity;
2. Individualised service options;
3. Locally accessible services;
4. Positive agency culture and values;
5. A progressive approach to community inclusion;
6. Innovative opportunities; and
7. Involvement of people with disability as active and equal partners in CAS design, implementation and evaluation.

This chapter also presents policy and practice implications for people with disability, parents, siblings and informal primary carers, CAS providers and policy makers. In addition, the potential application of the seven concept areas to the Information, Linkages and Capacity Building (ILC) Framework being developed through the National Disability Insurance Scheme (NDIS) in Australia are provided. Strengths and limitations of the current research are also presented and the chapter concludes with recommendations for further academic study.

5.2 A theory of ‘Social Transformation’

When commencing this current research with the initial exploration of national and international literature, CAS, ‘for’, people with disability had been provided, primarily in a group-based format. For over 40 years, CAS were delivered using segregating processes and approaches and there appeared, at that time, to be no indication of the likelihood of changes in these approaches.

However, with the introduction of the NDIS and accompanying legislation (2013), processes and approaches used to design, deliver and evaluate disability services have begun a transition towards individually focused programs. Not since the deinstitutionalisation and normalisation policies and approaches of the 1970s has such a potentially dramatic strategic and operational transformation been introduced. The progressive replacement of block funding, of services with the introduction of individualised funding opportunities for people with disability marks, the author asserts, a **once-in-a-lifetime** event in a shift of power and choice to eligible individuals with a disability.

Throughout the current research, the researcher has found it to be a privilege to listen to and speak with people with disability, to observe their pride and achievements with regard to participation in creative, social and community opportunities and to gain an understanding of services in which people with, and without, disability may participate together. As people with disability clearly want to transform their lives, support networks recognise the leadership of people with disability in roles such as directors, producers, board members, consultants, evaluators and participants. Witnessing the dedication of parent(s), siblings, informal primary carers, professionals and volunteers and their potential as co-producers to contribute to the community inclusion of all participants has been evident throughout the research.

From the very first community forums, focus groups and conference presentations relating to the current research in 2009 and 2010, people with disability and their families had described feelings of being overwhelmed by promises for the future only to be let down by limitations of opportunities. Not being, ‘disabled enough’, according to eligibility criteria, and being dissatisfied by what were felt by informants of the current research to be unsuitable services, were some of the frustrations observed and recorded by the researcher. Feelings of confusion, anger, disgust, helplessness and fatigue were also described by informants.

The data collected were constantly compared and findings presented at monthly meetings with Flinders University supervisors as well as with fellow students completing their postgraduate studies. The results were also presented through conference papers and posters at eight international conferences, seven national conferences and two state conferences to gather insights and learnings from people with disability, families, providers, policy makers and fellow academic research colleagues throughout the current research.

Initially, the necessity for change in disability services was identified because CAS were deemed to be a place for time occupation for people with disability who were eligible to attend, and unlikely to be employed or participate in further education on a full-time basis. An early conference presentations by the researcher (Evans, 2010) included the phraseology: ‘holding centres or agents for social change’. This reflected learnings from international and national literature reviews and initial data from focus groups and face-to-face interviews with people with disability, their families, and CAS provider representatives. The term, ‘holding centres’, reflected CAS as a place of safety and was accompanied by statements about CAS being supportive and a place for participation in segregated activities. Reference to CAS being, ‘agents for social change’, reflected the need for changes to CAS in a professionally-led, system-driven approach.

Upon the researcher’s constant reflection during the early years of the current research, it was evident that a stagnancy of CAS policy and professional practice had existed with, little incentive for innovation. An old service system was in place and people with disability had little power to bring about change and had to accept the, system. Furthermore, if people with disability were not involved in CAS what would happen to them in the future? Genuine concerns were expressed:

What will they do when we are gone? Will they have things to do during the day? How will they get there if we are not taking them? Will they just look out of a window all day?

As the journey of research candidature continued, though, throughout 2012-2015, greater understandings of the perceptions and experiences of CAS for people with disability clarified the need not just for change; but for radical change. It became more apparent to the researcher that radical change from service-driven segregation of CAS was required to ensure the voices of people with disability were heard and listened to. Otherwise, arguments which apportioned blame to agencies and state and federal funding bodies were simply circular in nature. Furthermore, it became apparent to the researcher that conflicting processes and approaches were developing and that, while the, ‘old’, CAS still predominated, newer models that did involve the voice of people with disability and their families were developing.

So, people with disability and their families required services when finishing secondary education and could blame the providers for not delivering the CAS they wanted. CAS providers could blame the government as increases in funding based on indexation had not kept up with the costs of providing CAS. However, in place of stagnancy, disability service policy makers and legislators were embarking on major changes as the NDIS was being developed and implemented during this research period. It was clear from the current research that many people with disability and their families wanted to bring about transformation of their lives and the attitudes of society towards them. The term, ‘transformation’, has been defined as, ‘a change or alteration especially a radical one’ (Collins, 2009), a, ‘marked change’ (Oxford, 2009). If the old systems of CAS prevailed in the NDIS then transformation would not have been a success. For, to transform CAS is, ‘to make better’, (Collins, 2009), ‘to change completely in form and function’ (Collins, 2009). A theory of change became a theory of Social Transformation.

5.3 Social Transformation practices in CAS

5.3.1 Introduction

Professor Kathy Charmaz (2014, p. 340) poses the question, ‘Should knowledge transform practice and social processes?’

The substantive theory described here as Social Transformation and seven concept areas which have emerged from this current research may inform the development of high quality services that are consistent with contemporary disability philosophy and values. These seven concept areas are:

1. Eligibility and equity;
2. Individualised service options;

3. Locally accessible services;
4. Positive agency culture and values;
5. A progressive approach to community inclusion;
6. Innovative opportunities; and
7. The involvement of people with disability as active and equal partners in CAS design, implementation and evaluation.

A theory of Social Transformation involves inclusion rather than exclusion and a shift from dominance of one party over another. It has been argued that people with disability, their families, **and** society benefit if there are opportunities, ‘to gain and use their abilities to enjoy their full potential for social independence’ (AIHW, 2016, p. 8). Clearly, society benefits when **all** people have opportunities to enjoy their full potential for social independence and this leads to a more inclusive society. The following table highlights this issue by illustrating the four research topics examined in this study, and provides a comparison between segregated, service-driven models of CAS and processes and approaches which may be characterised by transformation to contribute to quality outcomes for participants (see Table 5.1).

Table 5.1 Research question topics, examples of segregated, service-driven models and seven transformation concept areas for CAS

Research question topics	Examples of themes of segregated, service-driven models of CAS	Transformation processes and approaches. Seven concept areas for CAS
Topic One: Expectations and transition processes	Lack of transition planning, confusing information, inconsistency of eligibility, deficit approach	Eligibility and equity
Topic Two: Rights and needs	A, ‘menu’, of predetermined activities. Segregated and primarily group-based	Individualised service options
	Pattern of service provision based on service systems: transportation, limited resources	Local accessible services

Table 5.1 Research question topics, examples of segregated, service-driven models and seven transformation concept areas for CAS (continued)

Topic Three: Experiences	Maintaining CAS provider service's needs	Positive organisational culture and values
	No incentive for people with disability to leave CAS	A progressive approach to community inclusion
Topic Four: Recommendations	A focus on time occupation, 'minding'	Innovative opportunities
	Limited or no contribution to service planning. Completing a summative evaluation.	The involvement of people with disability as active and equal partners in CAS design, implementation and evaluation

People with disability are at the centre of a theory of Social Transformation and each of the seven concept areas emerging from the current research may contribute to quality outcomes. For example the participation in local accessible services may contribute to a person with disability's active engagement in a local community, and a reduction of the dependence on transportation to a segregated centre. Each of the seven concept areas is discussed in further detail below.

5.3.2 Eligibility and equity

Crilley (1995) argued that:

> '…integration in community recreation, implies activity taking part in a physical and social setting which is representative of community resources for that particular activity and usually includes individuals from the wider community as equals' (p. 7).

From research participants' expectations and transition processes, as well as from the critical discourse analysis of CAS policies, this current research has identified processes and approaches of CAS which were characterised by a lack of transition planning, confusing information, inconsistency of eligibility assessment and eligibility criteria and discourse which identified unequal power relationships between; CAS providers; policy makers; and people with disability and their families. CAS have predominantly provided leisure, art and recreation activities which were segregated and unequal.

According to Rossman and Schlatter (2008, p. 119) assessing the needs of a community in a leisure context:

> '…requires an assessment of the existing range of leisure options in a community, an understanding of the leisure service system, the role of each provider in the community and an understanding of the macro environment affecting the community'.

The concept of a community need is not simply the aggregation of individual needs, but also the needs created by a sense of community. Furthermore a, 'moral contract', exists for individuals who are part of the community and are held jointly responsible for the overall good of the community.

However, in this current research, the term, '**community'** access services, could be mistakenly thought of as the community into which people with disability are segregated. Not only have people with disability experienced a deinstitutionalisation process, but the very, 'community access services', which they have been a part of, may have continued to contribute to the segregation. The, 'moral contract', has become a handing of responsibility to a CAS provider rather than a community embracing **all** participants.

The first topic from the current research, 'Expectations and transition processes', examined the eligibility and equity issues that uphold this segregation and maintains barriers to community inclusion. Despite limited full-time employment opportunities, people with disability and family members reported aspirations and hopes of, 'open', employment associated with skills learnt through years of primary and secondary education, or perhaps, 'supported', employment in a, 'sheltered workshop'. But these aspirations of full-time employment were generally not realised. Instead, a process of transition into CAS for people with disability and their families commenced.

The discourse used in 42 policies from Australia analysed during the current research implied that people with disability would be able to participate in the development of CAS activities and programs. However, the researcher discovered this was not the case. The discourse regarding, 'eligibility criteria', identified that power relationships between policy makers, providers, and people with disability and their families may exist and that the, 'eligibility', discourse varied amongst state and territories in Australia. On a positive note, research participants with Acquired Brain Injury (ABI) and their families reported a highly personalised approach which addressed their options for community participation. However, the approaches reported from school leavers with intellectual disability did not appear to be based on their individual preferences and strengths. Furthermore, various assessment strategies were reported and these were all deficit-based, identifying whether each individual was, ‘disabled enough’, or, ‘too disabled’, for a particular type of service.

The issue of eligibility assessment is clearly a barrier to people receiving individualised support and clearly needs to be abandoned. The question of, ‘eligibility’, and, ‘ineligibility’, was raised at the researcher’s very first presentation related to this current research:

Memo, 26/9/08: The presentation for the thesis proposal went well, but one question needs to be followed up. What happens when people with disability are not eligible? The focus of the proposal had initially been on exploring the quality of services for people with disability. But what are the criteria and barriers to get into CAS in the first place?

Varying criteria continued to create barriers. In South Australia this had been recognised through a review into the transition of people with disability from secondary education into post school options; *Post School Pathways. How it is and how it works for young people*, identified that approximately 240 young people with disability aged 15-24 would prefer to participate in day activities but did not meet the criteria at that time (Department of the Premier and Cabinet, 2008, p. 15). The segregation based on, ‘level of disability’, was also discovered in the critical discourse analysis of CAS policies. Discourse maintained a focus on the, ‘medical model’, of disability services and a cycle of unemployment, underemployment and limited further education opportunities for those, ‘not disabled enough’. This maintains inequity for people with disability.

All persons have a right to leisure, arts and recreation (Rojek, Shaw & Veal, 2006), however, this current research has discovered that there are not equitable rights across CAS. In Australia, people with intellectual and developmental disabilities are the primary users of CAS. In 2012, there were an estimated 668,100 people with an intellectual and developmental disability of which 417,100 had a *profound or severe core activity limitation*, which meant they always, or sometimes needed help with mobility, self-care or communication (AIHW, 2012). Additionally, 344,100 people with an intellectual or developmental disability received assistance in activities of daily living from families and 221,000 people with an intellectual or developmental disability were not working (neither employed nor looking for work).

Only 12 per cent of people with intellectual and developmental disabilities were employed full-time (Australian Bureau of Statistics, 2012). Additionally, people with, 'other', disabilities are also eligible for CAS in some Australian states and territories.

Yet only 57,000, people with disability, participate in CAS in Australia (AIHW, 2015). Pinto (2011) highlights that the discourse used in policy may have resulted in services for a new and narrower category of people: the so called, 'deserving disabled', '... (which) risks leaving unprotected larger numbers of others whose levels of needs, although significant, may not be sufficient to qualify for special services and/or benefits' (Pinto, 2011, p. 2). With the progressive closure of institutional care from the 1970s, increased pressures on families and governments has resulted. It would seem that resources have been reserved for those who are deemed the highest priority and most desperate. In a repeat from observations of the 1860s in the UK, once again people with disability may miss out if they, 'were not poor enough to go on the parish (an early form of welfare) and not rich enough to afford private madhouses' (Arnold, 2008, p. 206). Policy discourse presents CAS as providing opportunities for, 'people with disability', to participate in the community. From a human rights perspective, transformation of policy and practice is required to address the assumption that only some people are, 'disabled enough', to receive individualised support in the community. There is obviously an absence of universal support.

When reflecting over the past seven years on the questions of eligibility and equity of CAS, and a constant comparison of the data (particularly with the introduction of the NDIS), the researcher in this current study identified the confusion people with disability and family members reported when having to make a choice between future post school pathways. This confusion was reported by people with disability and family members. For example, Merrilee stated that, ‘*I expected to get a job when I left school.’*

However as Graeme, her brother, explained, ‘*We were told that if you do some sort of employment you can’t do day options also. It was a confusing time for mum and I.’*

As a result, a choice of one, ‘transition pathway’, effectively stopped opportunities for other post school opportunities as displayed below (see Figure 5.1)

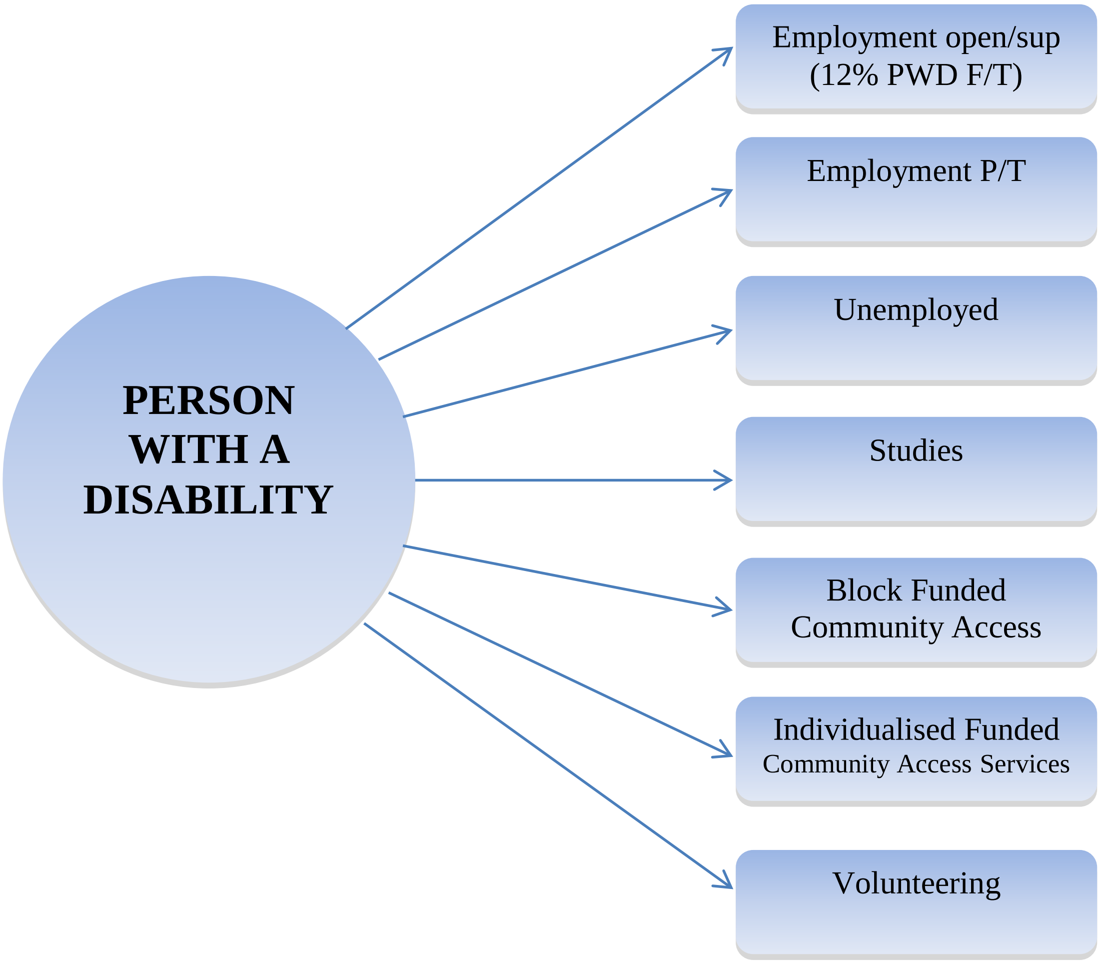

Figure 5.1 Transition pathways

As discovered in this current research, educators also seemed unclear about potential transition pathways:

While Colin was at school I remember us talking to his teacher about a sheltered workshop and I remember thinking that Colin would go to that place. …We thought Colin would be happy as he could work in the kitchen and he could be there five days per week. Never once did we know that there were other options for him and never did [his teacher] talk with us about any other options.
(Joan, mother)

However, instead of having to choose one pathway, underpinning this proposal is an acknowledgement of the strategic role of leisure, arts and recreation in individuals' lives being as important as employment. Harris (2005), states that a policy is more than just a document expressing an intention to act. Developing and implementing leisure policies involves analysis of a complex political and social context. It, 'requires the marshalling of knowledge and power in order to be implemented, often against the resistance, non-cooperation or sabotage of other groups' (Harris, 2005, p. 175). As a consequence of this current research it is proposed that transformative policy and professional practice to contribute to eligibility and equity may be characterised by; firstly, universal access to leisure education for people with disability; secondly, participation in local leisure, arts and recreation placements prior to leaving school; and thirdly, active participation in a, 'capability', framework which recognises individual interests, strengths, expectations, hopes and dreams for the future.

5.3.2.1 Universal access to leisure education

Firstly, CAS have been operating in Australia for over 40 years since the Activity Therapy Centres of the 1970s and yet the existence of limited information and referral processes has maintained ineffective service-driven models and limited planning processes as highlighted by the following comment:

'What planning process! There wasn't any, absolutely none. It was horrible, it was confusing especially because of your individual feelings for your child's future their hopes and dreams when they become limited and unaware of what is available after school.'
(Ros, mother of daughter Merrilee with Autism Spectrum Disorder (ASD) and intellectual disability)

Parents of children with disability who have received universal access to support when a child is first born with a disability or experiences an acquired disability are well aware of the benefits of early intervention and prevention at this time of support need.

The early years are an important life stage to support people with disability and their parent(s), siblings and informal primary carers. Yet at a crucial life stage, the transition of a person with disability from 12 years of school to post school, skill developments and familiar routines and supports ceases. An uncoordinated approach was reported by people with disability and their families in the current research.

The current research also discovered from participants that leisure education prior to leaving secondary education did not occur. Leisure education has been identified by Kleiber (2001) as a developmental process which aims at enhancing a person's quality of life. As Sivan (2006) states:

> '…through the process of leisure education, individuals increase their knowledge and understanding of the nature and significance of leisure in their lives, they develop their personal skills, and become more aware of their personal values and attitudes towards different dimensions of leisure' (Sivan, 2006, p. 435).

Leisure education and community development have been recognised as processes which are concerned with self-determination, empowerment and human rights and are related to the success of people with disability living in community environments (Grossman, 2000; Schleien, Meyer, Heyne and Brandt, 1995; Sivan, 2000). Instead of the, 'State Transition Plan', being focused primarily on employment as a transition pathway, it is proposed that universal access to leisure education, as an **equally valued component** of a State Transition Plan, is available to all people with disability. A deliberate combination of leisure education with recreation therapy practitioners may contribute to individuals learning the skills, attitudes and knowledge necessary for healthy and meaningful leisure involvement (Stumbo, Kim & Kim, 2011, p. 20).

Four components of leisure education, as depicted in the Stumbo and Peterson Leisure Education Content Model (2009), may contribute to community participation, including Leisure Awareness, Social Interaction Skills, Leisure Skills Development and Leisure Resources for people with disability (Stumbo & Peterson, 2009) (see Table 5.2).

Table 5.2 Leisure education content model

Leisure Awareness	**Social Interaction Skills**
• Knowledge of leisure • Self-awareness • Leisure and play attitudes • Related participatory and decision-making skills	• Communication skills • Relationship building skills • Self-presentation skills
Leisure Resources • Activity opportunities • Personal resources • Family and home resources • Community resources • State and national resources	**Leisure Activity Skills** • Traditional • Non-traditional

Participation in leisure education as a human right through leisure awareness, social interaction skills, leisure resources and leisure activity skills may contribute to the establishment of linkages and referrals to local accessible and supportive, leisure, arts and recreation participation. Universal access to leisure education may therefore contribute to a Social Transformation through inclusive, leisure, arts and recreation for individuals with, and without, disability, which is equitable, fair and just.

5.3.2.2 Local leisure, arts and recreation placement(s)

Transformative policy and practice which may contribute to eligibility and equity, may, additionally, involve the introduction of local leisure, arts and recreation placement(s). Participation in employment placements were reported by people with disability in this current research and encouraged through the Australian Government's National Disability Coordination Officer Program which focuses on transition to education, training and employment after the school years (Department of Education, Australian Government, 2015). However, people with disability in the current research did not report participation in inclusive local leisure, arts and recreation placements prior to leaving school. In Australia, over 1,000 community centres and neighbourhood houses provide a range of leisure, arts and recreation and, potentially, may provide placements for people with disability to experience participation in these local services before completing secondary education. Local government leisure, arts and recreation services may also be an alternative to placements in segregated CAS.

Person-centred planning with people with disability and their families; representatives from schools; funding bodies; local leisure arts and recreation service representatives; as well as local CAS, may assist the leisure, arts and recreation placement process. As with peers without disability, participation in a local community may then include leisure, arts and recreation and full/part-time employment, study, volunteering and hobbies. Such a combination of opportunities may also contribute to a reduction of isolation experienced by people with disability and their families at a time of great anxiety and uncertainty during transition from secondary school to post school life.

In the placements, local leisure mentors, with and without disability may assist people with disability with introductions to build social networks and to trial a range of leisure, arts and recreation pursuits. These mentors may link closely with local government Leisure, Arts and Recreation Officers, Social Planners, Community Development Officers and Visual and Performing Art Coordinators as well as CAS providers. The immense value to the individual of leisure, arts and recreation during these placements may provide a greater understanding of lifelong leisure if provided in empowering, supportive placement(s).

The National Disability Coordination Office (Australian Government) through the NDIS may also contribute to support the holistic approach to leisure, arts and recreation **as well as** the current focus on employment, training and further study.

5.3.2.3 A capability framework

Thirdly, to contribute to eligibility and equity transformative policy and practice, a process that recognises the capabilities, rather than deficits, of people with disability is proposed: as an integral part of assessment, implementation of a, 'Capability Framework' (Burchardt, 2004), would see independent practitioners together with people with disability and their families, seek to identify each individual's opportunities for leisure, the arts and recreation participation. This capability framework would then replace reliance on a deficit-based process in which a Disability SA representative conducted an, 'assessment', and determined a, 'needs-based', funding amount for the person as was reported during this current research.

With the Disability SA assessment they are assessed on what a person ***can't*** *do; their deficits. They should be assessed on what they* ***can*** *do. This could be expanded even with the visual arts; this could be sculpting and looking at other things also.* (Michael).

The introduction of a capability framework may contribute to the identification of opportunities in which people with disability may participate in their different endeavours with an emphasis on what they **can** do. As Burchardt emphasises:

> '…according to the capabilities framework, wellbeing should be assessed in terms of the capability set of the individual, understood as the substantive opportunities the person has to be, or to do, a range of things' (Burchardt, 2004, p. 738).

Instead of CAS providers pre-packaging CAS to fit allocated budgets based on, 'needs', of individuals, an essential element of a capability framework would be a focus on a sense of empowerment for the person with a disability and their family members to design, implement and evaluate a variety of local leisure, arts and recreation options in partnership (Schleien, Miller, Walton & Pruett, 2014). Capability frameworks are evident in contemporary disability practices. For example, focusing on individuals' strengths is central to the recently introduced strengths-based approaches for assessment and eligibility under the *Care Act 2014*, (UK). According to the Social Care Institute for Excellence (2015), in the *Care Act 2014* (UK) local authorities are required to:

> '…consider the person's own strengths and capabilities, and what support might be available from their wider support network or within the community'…Within a strengths-based approach it is fundamental that practitioners establish, and acknowledge the capacity, skills, knowledge, network, and potential of both the individual and the local community' (Social Care Institute for Excellence, 2015, pp. 1 & 3).

In Australia, and the transition to the NDIS, a Capability Framework, embedded in post school transition policy and practice, is crucial if young people with disability are to reach their true potential.

Although this current research has focused on people with disability in transition from secondary education or rehabilitation settings, a capability framework may also be beneficial for people with disability who are no longer able, or interested, in participation in full-time segregated or open employment or whose circumstances change during their life course. As their circumstances change, participation in leisure, arts and recreation of their choice which has therapeutic benefits, may be highly beneficial. For example, researchers Leahy and Singleton (2011) explored the experience of a person with Alzheimer's related dementia in Canada who was taking part in the therapeutic recreation services at an Adult Day Program (ADP) which, 'provide supports for the individual and the family to maintain the individual residing in the community' (Leahy & Singleton, 2011, p. 137). Following the therapeutic recreation assessment and treatment plan an effective intervention program (Nintendo Wii Bowling) was implemented. Progress and improvements in behaviour and skills were documented by the recreation therapist.

Implications from the Leahy & Singleton (2011) research included that:

> '…it does appear that leisure interests and associated participation skills can be enhanced through appropriate application of the therapeutic process. Furthermore, community-based ADPs appear to be an effective setting for delivering such interventions' (Leahy & Singleton, 2011, p. 143).

Transition from secondary education, rehabilitation services, or the transitions related to changing life circumstances for people with disability, may be improved through participation in leisure, arts and recreation as an equal and valued human right and part of individuals' lives (Stumbo, Wilder, Zahl, DeVries, Pegg, Greenwood & Ross, 2015).

5.3.2.4 Eligibility and equity summary

These three strategic initiatives:

1. Universal access to leisure education;
2. Local leisure, arts and recreation placements; and
3. The implementation of a capability framework to identify strengths and capabilities of individuals with disability

may support eligibility for participation and equitable leisure, arts and recreation opportunities that contribute to improved quality outcomes and increased community inclusion for people with disability.

Rather than uncertainty at a time of transition, the strengths-based process becomes one of exploring a positive hope for the future. The processes of leisure education, participation in local leisure, arts and recreation placements together with a capability framework may contribute to opportunities for empowerment and decision-making for people with disability and their families.

5.3.3 Individualised service options

> 'No greater challenge exists to the global community than to optimise opportunities for all people no matter what their race, gender, religion or disability state' (Pegg, 2003, p. 251).

Results from the current research indicated that CAS had been characterised by a, 'menu' of predetermined activities, segregation, and group-based activities in order to maximise allocated funding. The, block funding of services may have contributed to CAS providing limited staffing up to, in some instances, a one staff to seven people with disability (1:7) ratio (*Look Book*, 2013). As a result, limiting opportunities for individualised service options have been reported, as highlighted in the following comment:

He doesn't want to go as an 18 year old to a retirement home. I want him to be intellectually and physically stimulated. If they go to a, 'retirement model', of day services they will still need far more from the parents who are exhausted. They need to be challenged.
(Mother of a son in his late teens with intellectual disability, F4).

In contrast to segregated, service-led CAS, a transition to inclusion through individualised opportunities was reported by Sharon, mother of Ralf, a young man with ASD and intellectual disability: '*There have been issues around mainstream disability services since he has left school. He has Aboriginal services now which are much better. The information shared about services often has been patronising of his views in fact there was predetermined programs. Since he left school and was eligible after having a Vermont assessment for an adult, 'day service', we tried three CAS programs but none of these met Ralf's needs.'*

Sharon further explained that, '*As a result of these experiences we used his resources to train staff through a psychologist … His arts and craft program at [the organisation] as well as physical activities is great, because his mob have quite a different approach compared with the day programs. There are a whole lot of people who are bringing creativity to the service and so he is doing an appealing program. That's the difference. I get the fact that people who are running the programs think they are doing the best. Individual funding means that you can try and match people with Ralf who want to work with him.'*

This illustrates Ralf's right to participate in leisure, arts and recreation which were creative, enjoyable and satisfying to him. Three different CAS services were unable to support his individual skills and interests in their service structures however, thankfully, Sharon and Ralf were able to use individualised funding to transform his access to leisure, arts and recreation. This highlights that inclusion, in its true sense, 'seeks to assure everyone, regardless of their level of ability or disability, the right to experience an enjoyable and satisfying life' (Pegg, 2003, p. 251). Ralf's experience, ultimately, had powerful positive outcomes for him and his family. But, he had to, 'work through', three service models before reaching support that focused on his individual aspirations and strengths. Not all people with disability have the strength and support needed to battle through three services; this is why the transition process has to be transformed and become more streamlined.

With the introduction of individualised funding through the NDIS, the active engagement of people with disability and their families is of paramount importance. As identified in the discourse analysis in the current research the, Government of Western Australia Disability Services Commission Individualised Funding Policy (2013) states that:

> '…people with specialist disability funding are able to self-direct their supports and services, have flexibility in how their allocated funding is used, and have genuine choice and control over the design, planning and delivery of services they require. This is intended to lead to better outcomes for people with disability, their families and carers' (Disability Services Commission, 2013, p. 1).

As a result, people with disability and their families may align their service choices across one or more leisure, arts and recreation providers, using their individualised funding in order to create a wider variety of opportunities. In this way, the primary innovators become people with disability, their families, and professionals together (Duffy, 2012, 2010); a combination of contributors that ultimately empowers those with a disability to have greater control over their future. An example of this empowerment was recorded by the researcher when visiting and meeting with representatives from, 'In Control', in Birmingham in the UK.

Memo, 17/4/13: The priority of individualised funding within In Control is the active involvement of people with disability and their families. Such a strategic approach supports options for continuing to develop leisure, arts and recreational interests at flexible times which suit the individual, rather than being driven by organisational demands.

Instead of only Monday to Friday 9am to 3pm, 'day options', people with disability and their families may use the resources to access services at times that suit them, which then contributes to individuals' interests, skills and knowledge. This emphasis on individualised leisure, arts and recreation based on the interests, skills and knowledge of participants is different from having a carer who, 'does things', for a person with a disability. Individualised funding may contribute to Social

Transformation as people with disability do what they want to do and develop the inherent skills and talents that they want to develop; a right generally available to the rest of society.

As Joan (Colin's mother) stated in an interview: *'Colin has a fantastic week. Our friends are seeing what Colin is doing with his CAS including his art, leisure, his fitness and how he has such a rich aspect to life.'*

5.3.4 Locally accessible services

The current research identified patterns of service provision based on service systems, transportation issues, and limited resources. In contrast, at the heart of a desire for access to local leisure, arts and recreation services is a discourse about people with disability, 'belonging'. For example, the Department of Communities, Child Safety and Disability Services (Queensland Government) *Your life Your choice: self-directed support framework* (2012) defines community access as, 'support to participate and belong in the community', and, 'having more opportunities to connect and participate in the local community' (Queensland Government, 2012, pp. 4-5). Over the past 40 years, people with disability have transitioned into the community in segregated accommodation settings and continue to be segregated during the day in order to participate in segregated CAS. As a result, community inclusion (without the inclusion), often exists. The literature and results from the current research continually presented concerns that people with disability were unable to participate in their local communities and that segregation continued to occur, regardless of the deinstitutionalisation policies and practices of the last three or more decades.

This was illustrated during the current research by the following observation. During an interview, the suggestion by Mary (mother of Julie, a woman with ASD and an intellectual disability) to visit the Strathmont Centre car park had been made. The process was just as Mary had explained: each day 10 or more buses come, and then they go, and then they come again.

Observation and Memo, 11/2/15: It’s already a hot morning (forecast over 36 Celsius) and there is no shelter for people with disability to get in and out of the buses. But at least it’s not raining. People arrived from 8.25 in the morning from around a 20 kilometre radius to sit in the car park. It is the Strathmont Centre car park. The Centre was constructed in the 1970s and has been progressively closed ever since. The car park is a, ‘central point’, to drop off in the morning. People with disability who may have lived at Strathmont but now live in, ‘community’, accommodation with one of the disability services meet here. They sit in their buses and wait. As more buses arrive, exchanges occur. From a segregated accommodation service, to a segregated CAS service. It’s convenient for disability service providers. By 9.30 the buses have gone. In the afternoon, from around 3:00 pm when the CAS begin to close and the accommodation is reopened, the buses will once again arrive. The exercise is repeated Monday to Friday, 48 weeks per year, every year. People with disability leave a bus to get into another bus. From a segregated setting to another segregated setting.

The vision of Strathmont Centre in the 1970s had been a village for people with disability in which to reside as an alternative to living at the, ‘Lunatic Asylum’, at Parkside. Strathmont was to be one of two sites developed for people with disability within a community setting in which community members and people with disability could share resources such as the pool, the gymnasium, the oval. As a young primary school student, the author remembers playing football regularly on the oval as well as performing in the hall. People with disability lived in villas, surrounding these resources and accessed an art studio and multi-disciplinary team support. This was a progressive change from the Asylum with its 19th century architecture and limited resources for any leisure pursuits. The Strathmont Centre was completed but the second facility was never constructed. ‘Deinstitutionalisation’, commenced and the Strathmont Centre has been steadily closed as people were transitioned into, ‘homelike’, settings (Ford, Kirby, Wilson & Rillotta, 2011).

As Mary had explained in the interview that led the researcher to observe the, ‘Car Park Process’:

When you think about the services today for day options you get out of bed, then you get on a bus, then another bus, then you get changed, and then into a pool for maybe half an hour, and then you get changed then onto a bus and then another bus.
(Mary)

For people with disability, their participation in leisure, arts and recreation access is controlled by service processes and approaches. The experiences of people with disability are dominated by disability service systems which have been developed over the decades. Researchers have questioned why the experiences of people with disability at a CAS site may be segregating and why they may not be participating in mainstream activities with other non-disabled members of the community. A service-driven system maintains and controls the segregation. But, hopefully, this will change with the introduction of more individualised funding.

Rather than being transported to a segregated venue and transported back to segregated accommodation, people with disability participating in services such as CAS require opportunities to belong and be active contributors to the communities in which they live (Morris, 2011; Pegg & Compton, 2004). Participation in the community for people with disability is not only socially just, but also a human right (Convention on the Rights of Persons with Disabilities, 2006, Articles, 19, 23, 27 and 30). Yet, most respondents reported service provision based on accommodation services and CAS provider, ‘needs’, rather than being determined by processes and approaches which contribute to, ‘belonging’, to a local community. Policy and practice transformation requires consideration of the, ‘community’, of the individual, and not just the location of the CAS.

Researchers, Pedlar and Haworth (2006), define, ‘community’, as:

> ‘… including different aspects being nuclear (family or group); tribal (gender or social class); collaborative (special interest groups); geopolitical (political, educational, social or economic, contained by economic boundaries); and life communities which encompass the sum of families acquaintances, and other significant people recognising the modern community with increasing technology use’ (Pedlar & Haworth, 2006, pp. 518-519).

In a local community context, the participation of people with disability in leisure, arts and recreation may contribute to building stronger communities that are, '… set in a habitat that is genuinely open, inclusive, appreciative and encouraging of human flourishing' (Pedlar & Haworth, 2006, p. 530). In South Australia there were 23 CAS providers during the timeframe of this current research, which have developed centres for service provision (DCSI, 2014). In South Australia there are also 82 local Community and Neighbourhood Centres who are members of the Community Centres SA network. When reviewing the description of the services of each of the 82 Community and Neighbourhood Centres during this research, it was noted that leisure, arts and recreation opportunities were frequently promoted (Community Centres SA, 2015). These would seem to provide fertile ground for the development of individually-based services that are developed within a competency framework. In addition, discourse from Community Centres SA website states that:

> 'Community and neighbourhood centres work in a community development context in everything they do—they are **open to all** and aim to empower individuals and groups of people by helping them to develop the skills they need to drive change in their own communities' (Community Centres SA, 2015).

This availability and access is also a condition within service agreements for Community Centres who receive state government funding. In Australia there are over 1,000 Neighbourhood Centres, Community Houses, Learning Centres and Community Centres which are part of the Australian Neighbourhood Houses and Centres Association (ANHCA), according to Community Centres SA (2015).

As a practical example in metropolitan Adelaide, according to the *Look Book* (Department for Communities and Social Inclusion, 2012), there were five CAS service centres located in the Adelaide western region and 19 Community Centres and Neighbourhood Houses (Appendix Twenty Eight). Yet people with disability are transported away from their local region to access CAS each day.

Such local services must operate in accordance with Work Health and Safety regulations unlike CAS reported during the current research:

It is important to consider the facilities and environment suitability. Church halls, for example, which are used for CAS without suitable equipment are not suitable. (F1)

To assist with independence rather than relying on transportation by CAS (at an extra charge), the importance of leisure, arts and recreation requires recognition under policy and practice in Australia. Currently, people with disability are able to receive a mobility allowance from the Australian Government for travel to and from home, for paid work, voluntary work, study or training, or to look for work, but are **not** eligible for the same mobility allowance for access to participation in leisure, arts or recreation pursuits (Department of Human Services, Australian Government, 2015). This undervalues the contribution of leisure, arts and recreation and restricts access to services that are an integral part of a person’s life. Not being eligible for a, ‘mobility allowance’, particularly to use transport that may be required to access leisure, arts and recreation with other people with, and without, disability in evenings and/or on weekends, may also restrict flexible service provision. If participation in leisure is a human right, transport to the experience requires policy support, not barriers.

Transport issues in regional South Australia were also identified by participants in the current research:

More services in the Mallee area would be great.... I currently travel 120km+ (Parent, Questionnaire response, 23)

Also in a regional location, the manager of the CAS stated that, *‘The other aspect, of course, is transport in a regional location which is so expensive. We have changed our arrangements now so that we have a bus driver who picks up and returns people on a 150km round trip per day.’* (O7)

In regional South Australia, the introduction of, ‘place-based’, strategies is currently being implemented through the Department for Communities and Social Inclusion so that coordinated local services benefit from multiple funding sources within isolated regions. In South Australia, people living on Kangaroo Island were isolated with services predominantly being, ‘flown in and flown out’. The provision of coordinated multiple funding sources contributed to the establishment of a local community centre for all community members to access on the island (DCSI, 2015). The implementation of transformative policy and professional practice which support local service development and increases connections between federal, state and local government policy makers and funding sources are integral to the expansion of **local** leisure, arts and recreation opportunities with, and for, people with disability.

5.3.5 Positive agency culture and values

The current research identified a range of alarming experiences of people with disability and family members accessing CAS such as; goals not being met, limited involvement in goal reviews; and a range of negative experiences.

People with disability reported that at CAS; ‘*Sometimes I get bullied.’* (Q1); ‘*[There are] conflicts with other people.’* (Q10); ‘*Sometimes other clients hurt me*’. (Q16)

Additionally, ‘*Day options have also been a bit of an insular process without seeing the big picture which is about each person’s own quality of life and being able to actively give people what they want in terms of choices. The systems in which we operate are not actively giving people more choices and they are not readily set up when we need them.’* (Mary)

In contrast, it is anticipated that CAS organisational culture, values, staff skills and knowledge will continue to be transformed as individualised funding models are the stated future direction of the Australian Government under the NDIS (NDIS, 2016).

Memo, 22/4/16: At the final PhD presentation, a request was made to provide in the body of the current thesis a practical example of an organisation demonstrating positive organisational culture and inclusive practices. The following vignette is provided.

In South Australia, the Community Re-entry Program (CRP) provides a holistic rehabilitation program for up to 40 adults with ABI in South Australia. Established in 1992, the CRP mission is to enhance through education and supportive programs, the inclusion, participation and contribution of people with ABI in their community. The aim of CRP is to, ‘empower members’, to fully participate in the community. A variety of social, recreational and educational workshops are provided that incorporate writing and communication, movement and skill development. Along with a team of professionally qualified staff, the CRP recruits volunteer mentors and students from Flinders University to further support participants. Studies resulting from the CRP have been conducted including strengthening communities through a mentoring program for adults with ABI (Bellon, Gardner & Riley, 2008) and exploring the experiences and needs of families living with ABI in South Australia: Stage 1 Report (Bellon, Crocker, Farnden & Gardner, 2012). In light of the changes with the introduction of the *National Disability Insurance Scheme Act 2013* (Cth) from block to individualised funding, programs such as the CRP are actively engaged in exploring how opportunities can be provided to meet the individualised needs of members. The voice of individuals with ABI is central to the design, implementation and evaluation of CRP.

To contribute to policy and practice transformation, a positive organisational culture reflects a commitment to quality outcomes for participants (Schleien, Brake, Miller & Walton, 2013). This commitment was articulated by various CAS representatives as shown by the following comments:

A coordinator of a CAS for people with disability in metropolitan and regional South Australia stated that, *'There are services which charge less but have 20 people who sit around all day. The values of staff and the organisation all contribute to make the program.'* (O6)

Furthermore, a manager of a large metropolitan and regional CAS said, *'Quality cannot be met when there are higher ratios. Day options is not a babysitting service but it has been hard. A lot of skills are lost when people are just sitting around and I have seen people go backwards if a challenge is not provided even for the most high care person.'* (O13)

Additionally, a manager of a CAS provider in metropolitan Adelaide highlighted the commitment aspect of the newer models, which are developing:

> *I feel very privileged to be in an organisation like [organisation name] which actively fundraises and has such a strong commitment to disability services. I wouldn't be in this position if that wasn't the case. In fact, ethically I believe that*

what we provide is what people need.
(O18)

A positive agency culture and values also contributes to the quality of experiences for people with disability. In this current research, two quality conference presentations and a published journal article presented findings from the current research which may contribute to the development of quality outcomes for individuals participating in CAS. To complement a service quality framework which CAS providers may be engaged with, such as Australian Service Excellence Standards (ASES), a range of service quality attributes were identified during the current research (Evans, 2011; Evans, 2014).

Service quality attributes discovered during the current research are presented (see Table 5.3).

Table 5.3: Service quality attributes of CAS identified in this research

Service quality attribute	**Characterised by**
Transparency of information	Availability of CAS information and responses from people with disability, families/carers to inform client determination and choice for co-production with people with disability, families/carers, CAS providers prior to commencement of the service
Physical resources	Accessible physical location, appropriate transportation requirements, use of adaptive technologies.
Reliability and empathy	Staff competence, knowledge and expertise, staffing ratio reflective of individual need.
Inclusion	Innovative approaches to be inclusive of individuals including their culture, age and gender
Flexibility and responsiveness	Participatory evaluation, design, implementation and evaluation with people with disability, families/carers and CAS. Demonstration of goal review and goal setting

Regarding transparency of information, for example, an independent ranking website for people with disability and their families to access, and contribute to, may assist in clarifying expectations about CAS provided from organisation to organisation. The use of adaptive technologies for communication by people with disability to ensure their individual needs and choices are understood also contributes to quality outcomes. This also closely aligns with CAS staff competence, knowledge and expertise and the provision of staffing ratios and training which is reflective of individual need. Within the sample documents, the cultural appropriateness of CAS has also been identified. The New South Wales Department of Family and Community Services, *Community Participation, Life Choices and Active Ageing Program Guidelines* (2012), for example, identify the importance of providing, ‘accessible, equitable, responsive and respectful services for Aboriginal people with a disability’ (Department of Family and Community Services, New South Wales Government, 2012, p. 14). The guidelines further highlight that because people with disability from a non-English speaking background experience multiple layers of discrimination, ‘disability services must reflect accessible, equitable and respectful services that are responsive to cultural, linguistic and religious diversity’ (Department of Family and Community Services, New South Wales Government, 2012, p. 15).

Positive agency culture and values reflect a greater emphasis on; transparency; competency and relationships with organisation representatives and key workers; flexibility and responsiveness of service delivery; and dependability and reliability of providers to deliver what is promised with the knowledge that, if it is not, the funding can be transferred elsewhere.

5.3.6 A progressive approach to community inclusion

Twenty years ago, CAS were described as, ‘holding centres’, (Riches, 1996) with no incentives for people with disability to leave and this has clearly continued into the present. However, transformed policy and practice may seek to contribute to opportunities for transition into a range of community leisure, arts and recreation opportunities and this was becoming evident in this current research. Serious leisure pursuits such as volunteering, hobbies and amateur activities that are interesting and important to the individual (Stebbins, 2006, p. 448) may result if CAS supports a progressive approach to further community inclusion opportunities. As identified in the current research in an organisation embracing more inclusive activity models:

In a fitness and leisure environment people may connect by training in a gym, swimming at the pool, playing basketball and [this organisation] has the infrastructure, therefore, to assist people in their connection with the community. They are going to the [organisation] rather than a disability provider … There are

continually opportunities for socialising with other participants of the community facilities.
(Manager of Organisation 9 (O9))

Another, more innovative, provider stressed that leisure, arts and recreation-focused services also assist the individual's progressive community inclusion.

For the artist themselves the art itself is a really good medium and vehicle for individuals' expression. We also want to have opportunities for people to sell their work or receiving a contribution through their performances.
(Manager of Metropolitan CAS, O8)

Such, 'social scaffolding', seeks opportunities for people to have a variety of interests in step with the NDIS intention of greater choice and control. A recent example during the current research was provided through a group-based innovative approach of a major CAS service, which involved people with disability and siblings in Western Australia in 2014.

CAS provider, Rocky Bay, was provided with a Non-Government Centre Support (NGCS) grant to organise the *Let's Rock* program. The 4x10 week block was implemented in partnership with Music Rocks, another Not for Profit (NFP) group that has music groups and holds a concert in the community at the end of every term.

Let's Rock was set up to provide an extracurricular music group to assist the development of learning abilities (concentration, memory, following routines) and explored whether this would strengthen abilities to form relationships. Overarching outcomes were linked to Arts in Society areas (time, continuity and change, personal and social values, the value of learning and developing music skills). Pre-evaluations demonstrated that a major objective for parents was the promotion of social engagement. On evaluation, parents and a teacher reported that they felt children had developed in various learning abilities. There was a sense that children were participating more because they felt like, 'other kids in a cool group', thus promoting social engagement and feelings of being valued. The demands of performing and keeping time to the music were attributed to the slowing down of one band member's rate of speech and reports that he was having more successful interactions out of the group sessions. One individual’s dream to join a band was achieved and he found himself in the end being involved in two different bands. At the end of a 10 week series, the group joined in the community concert that was staged by Music Rocks, playing to a crowd of over 100 people. ‘This had been the highlight for parents to see their child’s ability playing a music instrument and singing. Not to mention bringing tears to their eyes’ (Rocky Bay, 2015).

For CAS participants, opportunities to develop peer support and/or a mentoring role may assist community inclusion. It is clear that progressively being more involved (rather than just being spectators) is critical and that, through socialising, building independence and the ability to participate in their chosen leisure, arts and recreation in community settings builds dignity and feelings of self-empowerment.

During the current research the desire to be actively involved in community was articulated by Lois and her mother Renaee.

As Renaee explained, *‘Even though there has always been an uphill battle, it really was a matter of trying to find the right doors to open so that Lois could discover another experience. Lois has gained from [the CAS participation] an inner self-respect.’*

Furthermore, Lois said that, *‘I have been involved in drama, dancing and film and have travelled to London and to Ireland.’*

5.3.7 Innovative opportunities

People with disability and family members stressed in the current research that they had experienced an overt emphasis upon, ‘time occupation’, in their experience of CAS participation, as illustrated by the following comment:

Talking to other parents, day options for most seem to be just minding centres without anything constructive happening.
(Family member response, Q5)

Innovative leisure, arts and recreation approaches seek to include people with, and without, disability as equals. Rather than, ‘time occupation’, in meaningless tasks, innovative creative leisure, arts and recreation opportunities are sought. A vignette of innovative opportunities is provided below.

Tutti (meaning ‘everyone together’), is an inclusive multi-arts centre, ‘with a focus on breaking down barriers, challenging preconceptions and boldly placing disabled visual and performing artists centre stage’ (Tutti, 2014, p. 2). Tutti commenced in 2004 with seven people with disability as a performing arts program, conducted three days per week. Tutti has continued to expand to include the production of works which are performed live, exhibited, recorded, distributed online, screened and occasionally toured locally and internationally.

Tutti currently has close to 50 participants attending visual, performing, film and media arts sessions across a five-days-per-week program as well as over 100 participants with, and without, disability in the choral program and 25 children and young people in Tutti Kids and Youth. Tutti’s vision is to, ‘Take our art to the world’.

Observations of people with, and without disability creating visual and performing arts, film, singing and music at seven sessions including, writing scripts, rehearsals, and, public performances, revealed to the researcher a creative environment in which the voice of all participants was respectfully valued and celebrated.

All staff are qualified and experienced artists who have engaged in further disability study, training and education. The culture of creating together extends interstate and internationally in partnership with creative organisations working with people with disability in Indonesia.

In a recent interview for the 20-year celebration of the *Disability Discrimination Act 1992* (Cth), members of, ‘Hot Tutti’ (now called ‘The Sisters of Invention’), shared their experiences. Rather than, ‘putting bolts in bags’, or some, ‘equally soul-destroying job like that’, Hot Tutti, a professional singing group, offers, ‘something the *Disability Discrimination Act* calls for’ (Human Rights, 2014).

Exploring innovative opportunities was also observed during the current research. The, Chicken Shed, in the UK has created innovative arts and recreation and leisure opportunities for people with, and without, disability. The organisation began with a few dedicated volunteers and has continued to expand throughout the UK and Europe. Drake music in London also incorporates creative technologies to explore the musical interests of people with, and without, disability. Animation technologies with people with, and without, disability are also utilised to engage with creative media.

Transformative policy and practice which seeks to include innovative opportunities for people with disability is proposed.

5.3.8 Involvement of people with disability as active and equal partners in CAS design, implementation and evaluation

> ‘Co-production is at the heart both of effective performance and of innovation in public services’ (Osborne, 2013).

The involvement of people with disability as active participants in CAS design, implementation and evaluation is important for quality outcomes to be realised. A critical discourse analysis of CAS policies identified that power relationships were present, which may reduce community participation opportunities. As reported in the current research by a manager of a regional CAS:

We know that clients and families advocating for this quality is important also. We are not after militant parents but the ones that scream the loudest do seem to be the ones who get the services rather than them all standing together and being able to ensure they all get the service that is needed.
(O11)

There may be an imbalance in perceived power between people with disability and their families and government funding bodies, policy makers and CAS providers, and, if so, this requires transformation (see Figure 5.2).

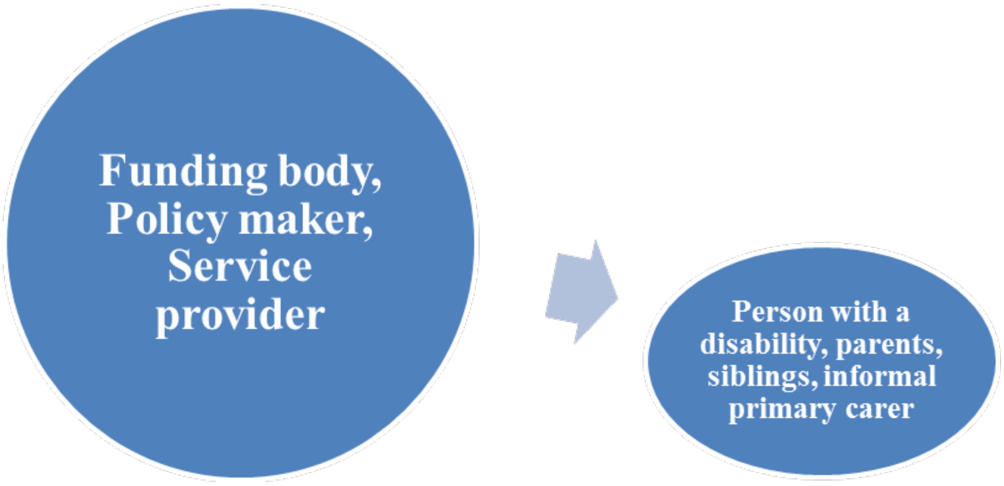

Figure 5.2 Imbalanced power relationships

CAS in Australia are primarily managed by public sector organisations. The concept of innovation has been described as a, ‘process of creating new ideas and turning them into value for society’ (Bason, 2010, p. 34). Rather than being observers of decision-making, public sector organisations are attempting to put citizens’ needs at the centre of their efforts (Brown & Osborne, 2012; Campana, 2012; Leadbeater, 2004; Parker & Heapy, 2006; Roberts, Greenhill, Talbot & Cuzak, 2011; Torjman & Makhoul, 2012).

The traditional block funding of organisations providing CAS may contribute to a perception of an unequal power relationship between people with disability and their families, and the decision-makers who control the CAS funding. In contrast, strategic and operational policies which support co-production of CAS provide opportunities for the establishment of a, ‘powerful partnership’, for people with disability and their families, and professionals (Cowen, Duffy & Murray, 2010). According to Ryan (2012):

> ‘co-production is an idea being discussed in the international public management literature but less so in New Zealand and Australia. Co-production rejects the idea of service delivery to passive users, proposing instead they be treated as active participants in the production of outcomes. Co-production requires providers to share power and negotiate the interaction’ (Ryan, 2012 pg. 314).

In this context people with disability and their families, and providers and policy makers may, ‘stand together’, for high quality services and outcomes for all participants. A sharing of skills, knowledge and expertise is promoted through a process of co-production as illustrated in the formula below (see Figure 5.3).

Figure 5.3 Suggested co-production formula that identifies important elements needed for co-production to occur with people with disability and their families, funding bodies, policy makers, and CAS providers

To contribute to transformative policy and practice, it is proposed that people with disability and their families be actively engaged throughout the process of service design, implementation and evaluation. Regarding the question of evaluation, Rossman and Schlatter (2008, p. 368) have highlighted that, ‘people use the results of evaluation and unless it addresses their concerns, it will go unused’. The involvement of people with disability who personally care about the evaluation and its findings (Patton, 1997, p. 44) is therefore crucial in a co-production process. Also importantly, being able to have the power to use the evaluation findings for decision-making is required so that people with disability and their families will not be repeatedly asked to participate in a summative evaluation, without seeing any benefit or contribution from their participation.

5.4 Information, Linkages and Capacity Building (ILC) Framework and outcomes

In July 2015, all governments around Australia agreed to a policy framework for an ILC Framework in the NDIS.

This current research may contribute to the ILC Framework in each of the five areas of activity: Information, linkages and referrals; Capacity building for mainstream services; Community awareness and capacity building; Individual capacity building; and Local area coordination (NDIS, 2016). The findings from this current research are timely, as a trial process of the ILC Framework will commence from July 2017 in the first jurisdiction of Australia, with full implementation of the ILC Framework planned to follow in 2018 (NDIS, 2016).

Throughout the current research, a model of processes and approaches to CAS has evolved as data was constantly compared and analysed. In a context of Social Transformation and the implementation of the NDIS, the approaches and processes for CAS which contribute to the ILC Framework and quality outcomes for people with disability are presented (see Figure 5.4).

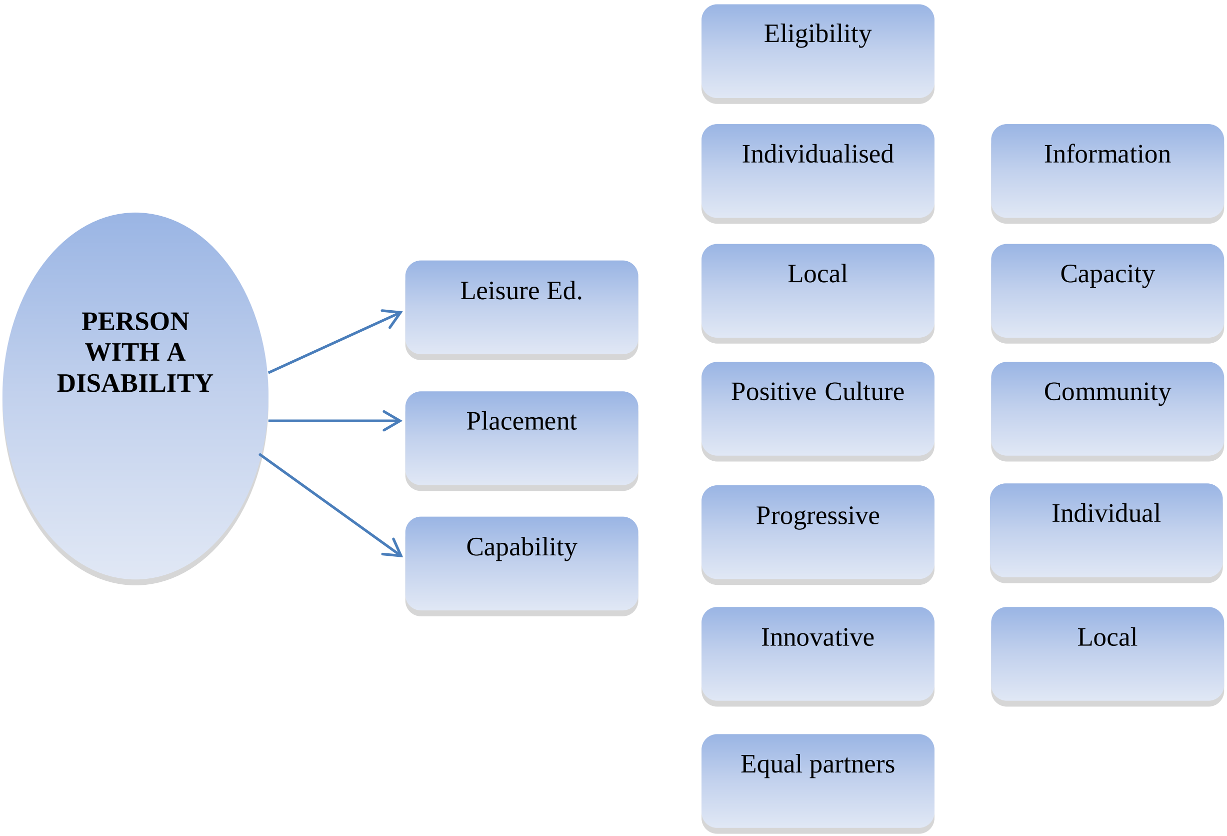

Figure 5.4. Approaches and processes for CAS which contribute to the ILC Framework and quality outcomes for people with disability

A discussion of the results of this current research, which may contribute to policy and practice development in each of the five areas of activity of the ILC Framework identified in the NDIS, is presented.

5.4.1 Information, linkages and referrals

5.4.1.1 Information

Participants in this current study indicated that information provided during the transition process from secondary school was confusing to people with disability and their families. Five examples are provided.

Firstly, people with disability were unsure if they could attend CAS activities and also be employed and, if so, for how many hours per week. Some people with disability were employed and were also accessing CAS but people with disability and family members also reported that they were told that they were not allowed to.

Secondly, CAS strategic policies in South Australia stated that a person with ASD could not access CAS unless they also had an intellectual disability. But in a regional setting according to a CAS provider, people with ASD, without intellectual disability had been approved to participate in CAS.

Thirdly, people with disability were assessed by Disability SA staff as eligible for, ‘low’, need funding ($17,500 p.a.) and on appeal by their families were reassessed by Disability SA staff and determined to fit a, ‘high’, need funding category ($25,000 p.a.).

Fourthly, information presented on CAS provider websites was ambiguous and provided little guidance for people with disability and their families.

Fifthly, each Australian state and territory had different CAS eligibility criteria.

In a national ILC Framework, the provision of consistent, factual information to address such concerns will contribute to assisting people with disability and their families in their decision-making.

5.4.1.2 Linkages

In order to contribute to the development of linkages to local services as supported in the ILC Framework, the provision of policies and practices which promote universal access by people with disability to leisure education and placements in the community prior to completing Year 11 at school is proposed.

5.4.1.3 Referrals

The implementation of the ILC Framework provides a strategic opportunity to replace a, ‘deficit’, approach based on a, ‘medical model’, of disability services with a, ‘capability framework’, which provides a, ‘strengths-based approach’, to assessment with, and for people with disability.

Providing referrals to local leisure, arts and recreation services which focus on interests and future aspirations of people with disability could replace assessment and information based on perceptions of what people **cannot** do or their perceived **needs**.

5.4.2 Capacity building for mainstream services

The results of this current research also contribute to the second ILC activity, capacity building for mainstream services. Transportation, location and availability issues were frequently referred to by research participants as barriers to community participation. Prior to the young person with disability leaving secondary education, the establishment of local networks for leisure, arts and recreation community participation is important. Three considerations are presented to contribute to capacity building for mainstream services.

Firstly, promote the role of local services, such as community centres as places of inclusion rather than venues for hall hire for groups of segregated people with disability. As Wolfensberger stated in 1983:

> ‘True generic services are those readily available to anyone wishing or needing to use them, and which are neither designed, operated, nor intended for only a specific person or group’ (Wolfensberger, 1983, p. 237).

Maintaining groups of people with disability segregated in community centres away from other community participants is not the intention of Social Role Valorisation nor of individualised service approaches.

Secondly, support mainstream services to have safe and suitable equipment and correctly trained staff who can assist mentors working with people with, and without disability. The very term mainstream may encourage an, ‘us and them’, approach rather than **all** people accessing services in a safe and supportive environment.

Thirdly, recognise that, historically, mainstream service facilitators may have developed services and expected that people with disability would participate, rather than people with disability and their families having active roles in program determination. Ensuring programmatic and physical access is crucial as a best practice for leisure, arts and recreation participation (Schleien, Miller & Shea, 2009).

The ILC capacity building of mainstream services may reduce barriers to community participation by people with disability as equal and positive opportunities to contribute to local services and mainstream service development arise.

5.4.3 Community awareness and capacity building

The current research identified opportunities to contribute to the ILC activity of community awareness and capacity building as people with, and without, disability were involved in creative leisure, arts and recreation projects together.

Specialist CAS, for example, which promote a variety of leadership roles for people with disability, such as directors, film makers and choreographers, may contribute to increasing awareness of the skills, talents and abilities of people with disability which are valued in society. The CAS organisational culture and values are integral to increasing positive community awareness raising as, together, people with disability participate in multimedia, exhibitions and performances. Additionally, within and beyond Australia, specialist CAS may contribute to partnership development with artists with, and without, disability from other developing or developed countries by promoting and actively sharing skills, knowledge and expertise.

5.4.4 Individual capacity building

To contribute to the ILC activity of individual capacity building, three strategies for transformation are presented to support inclusion and each individual's rights and needs.

Firstly, continue to promote opportunities for people with disability to receive individualised funding so that the inequitable ratios of people with disability to staff in CAS, which have arisen with traditional block funding arrangements, can be addressed.

Secondly, support strategies which contribute to specific challenges associated with regional and remote Australia such as the use of new technologies for leisure, arts and recreation services as well as social networking.

Thirdly, address issues associated with the group-based homogenous approach of CAS which has not considered the diversity, including cultural background, gender and age, of people with disability, and move towards having a focus on empowerment and individuals' equal access to community life (Shapiro, 1994).

5.4.5 Local area coordination

The fifth ILC activity identified in the ILC Framework is local area coordination. Opportunities for people with disability to access a range of leisure, arts and recreation in their local communities may benefit through strategic local area coordination. Local area coordination and a progressive approach to community inclusion may contribute to breaking a cycle of CAS being holding centres in which people commence at 18 years of age and retire at 65 years of age, segregated from the communities in which they live. Local area coordination may also contribute to social scaffolding for people with disability and their families as they transition into a range of community opportunities including employment opportunities, further education and volunteering while continuing CAS participation without a, ‘fear of failure’.

5.5 Recommendations for future academic research

5.5.1 Introduction

From the current research, seven implications have been identified for future academic research which may contribute to quality outcomes for people with disability and their families.

5.5.2 Quality from the perspective of people with disability and their families

In the context of the implementation of the NDIS and an emphasis on individualisation, further academic research which explores the service satisfaction and quality measures from the perspective of people with disability is recommended.

This current research discovered that the voice of people with disability in the determination of quality was limited. Information from CAS providers demonstrated differing approaches to human resource management (such as ratios of people with disability to staff), facilities and infrastructure.

5.5.3 Co-production from the perspective of people with disability and their families

Academic research in which people with disability are engaged in a co-creation of service development within a co-production process as active and equal partners and the outcomes for people with disability and their families, and the CAS is recommended.

5.5.4 Social and psychological impacts from the perspective of families of people with disability

Academic research which explores the social and psychological impacts from the perspective of families of people with disability who are accessing CAS is recommended.

5.5.5 CAS provider integration of leisure, arts and recreation

Future academic research for the implementation of inclusive leisure, arts and recreation prior to leaving secondary education is recommended.

5.5.6 CAS providers national network quality framework

Further academic research into the quality of CAS providers across state and territory regions through the NDIS implementation is also required.

National research which has occurred, such as an evaluation of 34 Australian integrated community recreation programs by Crilley in 1993, emphasised the need to maintain the developing culture amongst recreation professionals and a commitment to further applied research (Crilley, 1993). In the current research, participants identified limited knowledge of CAS provider practices across Australia due to competitive imperatives, reducing opportunities to share initiatives.

5.5.7 Economic benefit of CAS for people with disability, their families and society

The economic impacts of leisure participation according to Veal (2006) were first published in a study of the *Theory of the Leisure Class* by Thorstein Veblen in 1899 in order to consider the development of societies and a phenomenon of, ‘conspicuous consumption’. Principles such as, ‘cost-benefit’, ‘market place competition’, and, ‘welfare economics’, for government intervention are common place. However, the economic benefits of CAS provision have not been explored.

The current research has identified a range of instances of potential economic research which may benefit people with disability, their parents, siblings and informal primary carers, and society.

Firstly, economic studies which compare benefits of participation in CAS of people with disability as a preventative approach, instead of people with disability being left at CAS and forced into emergency respite.

Secondly, an exploration of the provision of funding for CAS for up to five days per week full-time compared to the expenditure required for people with disability being cared for in state or territory government facilities. Would additional CAS funding at critical transition times reduce parents being forced to leave their children or, ‘relinquish’ their child(ren) into 24-hour supported care?

Thirdly, economic benefits if parents were able to continue to be employed full-time compared to being unemployed or underemployed in order to provide care if the child(ren) do not access CAS. Daily CAS costing and transportation would vary on an individual basis.

Fourthly, the impact on people with disability, their families, and local economies particularly in regional settings as a result of the reduction of local CAS.

5.5.8 Social participation outcomes across three tiers of government and the non-government sector

The final recommendation for further academic research is an exploration of the role of the three tiers of government in Australia: federal, state and local government and the non-government sector’s support of people with disability and their families. Participation in leisure, arts and recreation may be enhanced by the strategic contribution of other departmental divisions such as the housing/accommodation sector, education, health and employment.

5.6 Strengths and limitations of the current research

> ‘A constructivist grounded theory approach places priority on the studies phenomenon and sees both data and analysis as created from shared experiences and relationships with participants and other sources of data’ (Charmaz, 2014, p. 239).

In order to explore processes and approaches that contribute to quality outcomes for participants of Australian CAS the researcher has used multiple sources of data with a constructivist approach. Multiple views and perspective of participants were recorded and analysed and additional sources of data from a critical discourse analysis of policies and texts have contributed to the construction of the Theory of Social Transformation.

Limitations to the study exist. Firstly, focus groups, face-to-face interviews, and questionnaire responses with people with disability and family members provided a small number (n=114) of responses which may be viewed as being unrepresentative of participants in CAS and, therefore, non generalisable (Charmaz, 2014).

Secondly, all respondents in the current research were from South Australia. This was discussed with supervisors throughout the current research given the resource requirements to travel interstate; this was accepted as a limitation because of financial and time restrictions but may be a topic for future research opportunities.

Thirdly, from the critical discourse analysis of the 42 documents all efforts were taken to source publically available documents using Australian state and territory government websites. Only documents that were published in English and involved people with disability over 16 years of age were included. Strategic searches were only conducted between 2010-2014 using Australian state and territory government websites. The process of data collection and analysis was repeated throughout the years 2010 to 2014 to include new texts, however there were documents identified that were no longer available or could not be sourced.

5.7 Chapter 5 summary

This chapter has presented and discussed a theory of Social Transformation and seven concept areas; eligibility and equity; individualised service options; locally accessible services; positive agency culture and values; innovative opportunities; a progressive approach to community inclusion; and the involvement of people with disability as active and equal partners in CAS design, implementation and evaluation.

Implications for policy and practice for people with disability, their parents, siblings and informal primary carers, CAS providers and policy makers were also presented. The potential application of these seven concept areas to the ILC Framework being developed through the NDIS in Australia was also provided to highlight important contemporary disability issues. Strengths and limitations of the current research were also presented followed by a summary which concluded the chapter.

In the final chapter the aim and outcomes of the current research are revisited and concluding comments to the current research are provided.

Chapter 6
Conclusions and Recommendations

6.1 Introduction

In this final chapter, the research aim and outcomes of the current research are revisited. Some concluding comments regarding the research findings are also presented.

6.2 Aim and outcomes of the research revisited

The aim of this current research was to explore processes and approaches that contribute to quality outcomes for participants of Australian Community Access Services (CAS).

At the commencement of the current research, responses from participants including people with disability, their families, and providers reported service processes and approaches which were segregating and led by professionals. Eligibility for CAS, for example, required people with disability and their families to demonstrate that they were, ‘disabled enough’, in order to receive funding. Alarmingly, people with disability, their families, and CAS providers reported instances of incorrect assessment and an analysis of Australian policy criteria demonstrated eligibility differences between jurisdictions (state and territory) throughout Australia.

If eligible for CAS, people with disability and family members commonly reported instances of feeling helpless in a system in which power relationships favoured professionals. CAS providers received funding directly through a, block funding model which restricted opportunities for the voice of people with disability and their families to influence decision-making. CAS providers also reported limited opportunities or incentives for innovation resulting in limited leisure, arts or recreation, choices. A culture of, ‘us and them’, was described by people with disability and family members with unequal power relationships being observed and reported.

This was reinforced if a person with a disability, perhaps because of additional behaviour support needs, did not, ‘fit into’, a group-based CAS model of service delivery. Additionally, people with disability and family members reported limited opportunities to contribute to CAS model planning or evaluation.

Through the application of a Constructivist Grounded Theory approach, seven processes and approaches were identified which may contribute to quality outcomes for participants of CAS. These were:

1. Eligibility and equity;
2. Individualised service options;
3. Locally accessible services;
4. Positive agency culture and values;
5. Innovative opportunities;
6. A progressive approach to community inclusion; and
7. The involvement of people with disability as active and equal partners in CAS design, implementation and evaluation.

People with disability and family members who participated in the current research and who had, however, been involved in creative leisure, arts and recreation, described being involved as equal partners as they worked together with professionals to achieve personal goals and desired outcomes. Observations of, for example, participation in visual and performing arts by people with disability illustrated a culture of creating together. Rather than segregation, people with disability were actively contributing to leisure, music, visual and performing arts and recreation together with their disabled and non-disabled peers as their human right (Darcy & Taylor, 2009). Together they were exploring their own ideas rather than being told what to think and do by professionals. Their ideas were listened to and opportunities for expression in mainstream visual and performing arts were explored.

Families were also active participants in co-production. Their support was often critical to the process and contributed to their sons' and daughters', brothers' and sisters' opportunities for independence, enjoyment and increased community participation while also contributing to their networks of support and participation as, 'indirect', participants.

The planned outcomes of this current study were to:

- explore the expectations of people with disability prior to participating in CAS in Australia and during processes of transition planning;
- explore and identify the rights and needs of people with disability and their experiences of service design and implementation of CAS;
- identify existing policies and practices, and opportunities for future individualised approaches; and
- identify recommendations to contribute to service quality.

Concluding comments about each of these outcomes is provided.

6.2.1 Exploration of the expectations of people with disability prior to participating in CAS and processes of transition planning

> ‘In spite of efforts during the past decade to improve transition outcomes, the educational system, functioning in the absence of a coordinated community system, has been relatively ineffective in providing support structures for youth that empower them to be full participants in mainstream society. The cycle of poverty and disenfranchisement appears to persist into adulthood and perhaps the next generation for many of these individuals’ (Lehman, Clark, Bullis, Rinkin & Castellanos, 2002, p. 130).

The above quotation expresses the disenchantment common in the literature about the challenges in the transition process from school to post school experiences for young people. The phrases; ‘absence of a coordinated community system’; ‘support structures for youth that empower them’; ‘cycle of poverty and disenfranchisement’; and ‘next generation’ inspired the researcher to want to make a contribution; to identify important issues and contribute through this process to making a difference in the lives of young people going through this experience in the future. This was at the heart of the passion for a constructivist approach; to both be immersed in the study and to contribute to Social Transformation.

The researcher could not imagine another generation with this, ‘negative cycle’, continuing. Throughout this current research the goodwill, determination and dedication of so many people engaged with CAS processes and approaches was observed. People with disability clearly wanted to be transformed and their families also wanted to see transformation of CAS. In listening to the voices of people with disability and their families, new insights for systemic change to processes and approaches were being revealed. This continually led to collecting data from more than one source through multiple data collection methods. Constant comparison of this data informed further exploration.

What has been discovered from the findings of this study is a need for Social Transformation from competition and disempowerment to citizen-centric approaches; approaches that are built on relationships rather than power struggles, and evolve through a co-production, ‘between the producer and clients who want to be transformed by the service’ (Fledderus, Brandsen and Honingh, 2014, p. 426). In Australia, barriers to social inclusion opportunities and community participation through CAS were identified, including the lack of planning prior to leaving secondary education, conflicting demands from policy makers and CAS providers and, particularly, misinformation regarding eligibility and equity of funding for CAS participation. Processes and approaches to overcome these barriers were identified for both the individual and through policy and practice transformation aimed at addressing the inequity experienced by people with disability who, for decades, have faced unemployment, underemployment and limited further education opportunities because of assumed lack of potential. Evident in this current research was the inequity of power relationships including inconsistent eligibility criteria and assessment processes, limited and misleading policy and unfair treatment of people with disability who were participating in CAS.

Families also described instances of great uncertainty and confusion at this traumatic time of transition. In the hurry to, ‘find’, opportunities for their son or daughter, families also reported confusing and limited information prior to commencing CAS. Most participants described their uncertainty about the responsibilities for eligibility assessment and funding provision by schools, CAS providers and funding body representatives.

For transformation to occur in the transition planning process, leisure education and facilitators are required in the key areas of leisure, the arts and recreation at the initial exploration stage of leaving secondary education. In community placements, local leisure mentors, with and without, disability may assist people with disability to build social networks and to trial a range of leisure, arts and recreation pursuits. Through the National Disability Insurance Scheme (NDIS), the National Disability Coordination Office (Australian Government) may also contribute to support an holistic approach to leisure, arts, recreation, employment, training and further education.

The aim for all young people, including those with disability, needs to be universal access to services that will promote growth, development and true community inclusion. Successful transition experiences contribute to individuals' meaningful social inclusion and, further, aids their future psychological, health and wellbeing. In short, their aspirations for the future are supported. Rather than continued segregation that excludes people with disability from full community participation (Schleien, Brake, Miller and Walton, 2013), inclusion, particularly in local accessible leisure, arts and recreation opportunities, strengthens both the individual and potential community capacity development. This is a key aspect of the Information, Linkages and Capacity Building (ILC) Framework through the NDIS. This also contributes to a transformation in the roles of local area coordinators, educators and policy makers who become members of the planning team in co-production with people with disability and their families.

6.2.2 Exploration and identification of the rights and needs of people with disability and their experiences of service design and implementation of CAS

People with disability and family members reported limited opportunities to address their rights and needs, especially during the initial stages of the current research prior to the introduction of opportunities for individualised funding. If eligible, opportunities for, 'choices', of leisure, art and recreation participation in a local community setting were minimal. Even when choices of activities were identified, a menu of these choices, determined by CAS providers, was the norm reported.

Rather than, 'community', 'access', 'services', people with disability were directed to access services, characterised as, 'babysitting', or, 'retirement models', which were considered unsuitable by most participants. Once engaged in CAS there was little incentive for a provider receiving funding directly from the funding body to assist a person with a disability to leave that provider's service and transition into mainstream community services. People with disability were scared or hesitant to leave a service and reported experiences of pressure not to do so.

The current research identified processes and approaches to contribute to transforming such rights and needs and experiences and address the imbalance of power between people with disability, CAS providers, and policy makers/funding bodies. Introducing individualised service options may contribute to increasing the rights of people with disability as their voices are heard and their needs explored more productively. As a contribution to a model of CAS provision, this supports individuals' control of their own budgets and choice of co-producers supporting their decisions. These leisure, arts and recreation opportunities may be conducted in locally accessible services, such as in local leisure, arts and recreation centres or community centres, reducing the need for additional transportation and increasing their engagement and belonging in their local community.

The rights, needs and experiences of people with disability were closely linked with the positive culture and values of the CAS provider(s). The recruitment of professionals with creative arts skills for example, demonstrated a commitment to the development of future creative pathways and professional opportunities for people with disability. Additionally, working together in creative leisure, arts and recreation, may contribute to society's recognition and understanding of creative abilities rather than just focusing on the impairments of people with disability. Having a progressive approach to community inclusion was also reported during the current research. A combination of leisure, arts, recreation, volunteering, study and employment activities may be a chosen lifestyle of people with disability in contrast to the full-time segregated experience of a, 'day activity model', or, 'sheltered workshop', employment model.

6.2.3 Identification of existing policies and practices, and opportunities for future individualised approaches

If people with disability and their families are not experiencing opportunities to, 'gain and use their abilities to enjoy their full potential for social independence' (AIHW, 2015, p. 6), then the CAS service is not meeting their individual outcomes. When commencing the current research, CAS organisations continued to provide CAS primarily in group-based programs.

However, over the years of the current research, participants provided insights into their commencement of individualised funding and the quality outcomes they had begun to experience. Furthermore, the critical discourse analysis of CAS strategic and operational policies in Australia discovered that the introduction of individualised funding models is supporting opportunities for future individualised approaches and is a strategic focus of the NDIS implementation.

6.2.4 Identification of recommendations contributing to service quality

The current research discovered that inequity existed both in strategic policies and operational practices. Promoting, ‘equal’, partnerships begins if all people are equal. The seven concepts that have emerged from the current research; eligibility and equity for people with disability; individualised service options; opportunities for locally accessible services; positive agency culture and values; active exploration of innovative CAS; a progressive approach to community inclusion; and the involvement of people with disability as active and equal partners in co-production of CAS design, implementation and evaluation, contribute to promoting equity through leisure, arts and recreation and strengthening the community inclusion of people with disability in society.

CAS, which are co-produced, are characterised by Social Transformation with, and for, people with disability as equal partners in designing, delivering and evaluating services.

6. 4 Concluding comments

The current research, which has had a focus on human rights and empowerment of people with disability, has provided a critical opportunity to reveal the anger, hopelessness and despair which had been reported, particularly during the early data collection and analysis of the current research.

It is the, ‘voice’, of people with disability as equal partners which will ultimately determine the outcomes from the implementation of the NDIS in Australia. Their lived experiences of CAS have informed the researcher’s theory of Social Transformation as developed in this current research and the seven research findings which contribute to future policy development, professional practice and future academic research.

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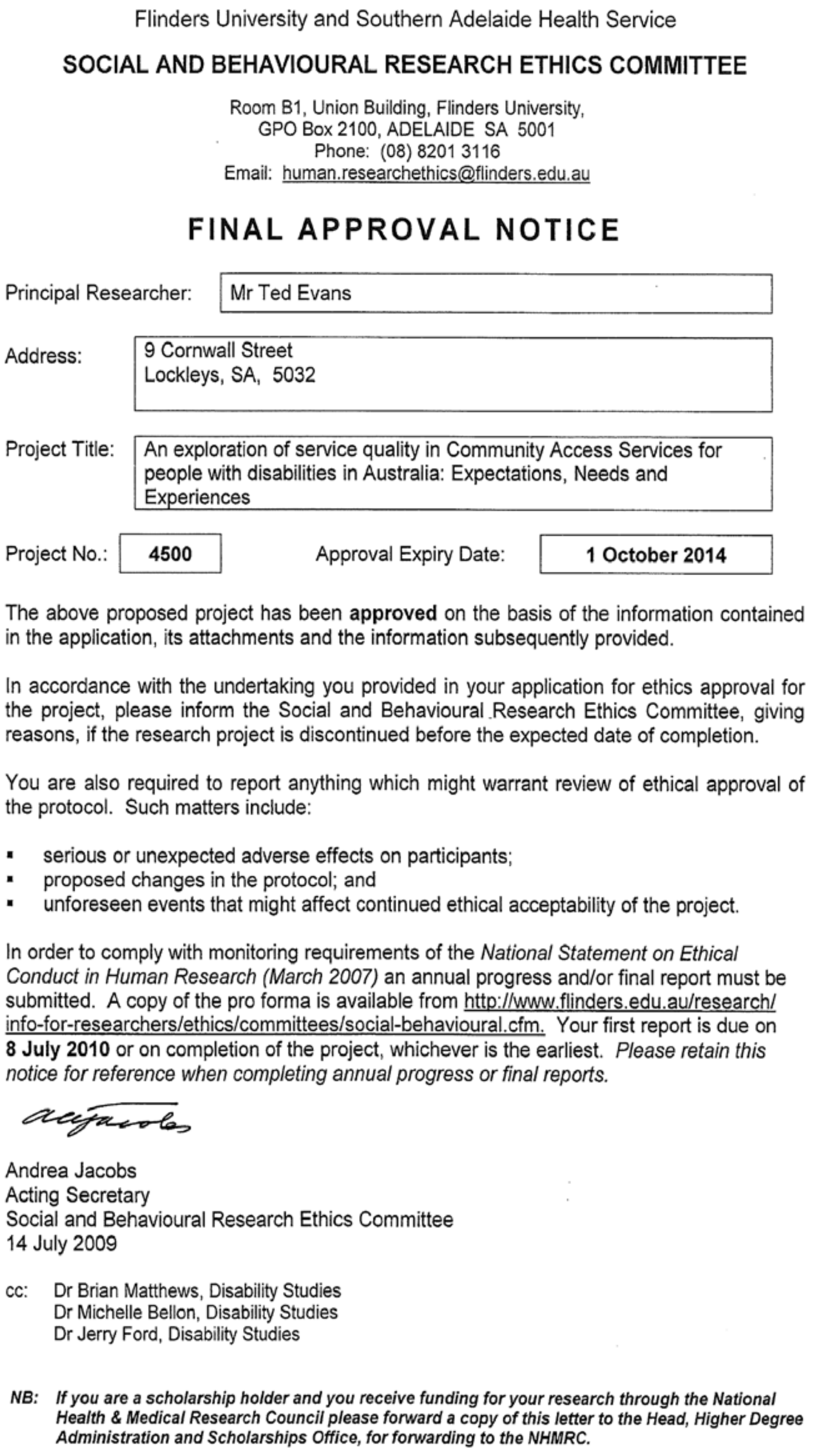
Appendix One



Flinders University and Southern Adelaide Health Service

SOCIAL AND BEHAVIOURAL RESEARCH ETHICS COMMITTEE

Room B1, Union Building, Flinders University,
GPO Box 2100, ADELAIDE SA 5001
Phone: (08) 8201 3116
Email: human.researchethics@flinders.edu.au

FINAL APPROVAL NOTICE

Principal Researcher: Mr Ted Evans

Address: 9 Cornwall Street
Lockleys, SA, 5032

Project Title: An exploration of service quality in Community Access Services for people with disabilities in Australia: Expectations, Needs and Experiences

Project No.: **4500** Approval Expiry Date: **1 October 2014**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

In accordance with the undertaking you provided in your application for ethics approval for the project, please inform the Social and Behavioural Research Ethics Committee, giving reasons, if the research project is discontinued before the expected date of completion.

You are also required to report anything which might warrant review of ethical approval of the protocol. Such matters include:

- serious or unexpected adverse effects on participants;
- proposed changes in the protocol; and
- unforeseen events that might affect continued ethical acceptability of the project.

In order to comply with monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress and/or final report must be submitted. A copy of the pro forma is available from http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-behavioural.cfm. Your first report is due on **8 July 2010** or on completion of the project, whichever is the earliest. *Please retain this notice for reference when completing annual progress or final reports.*

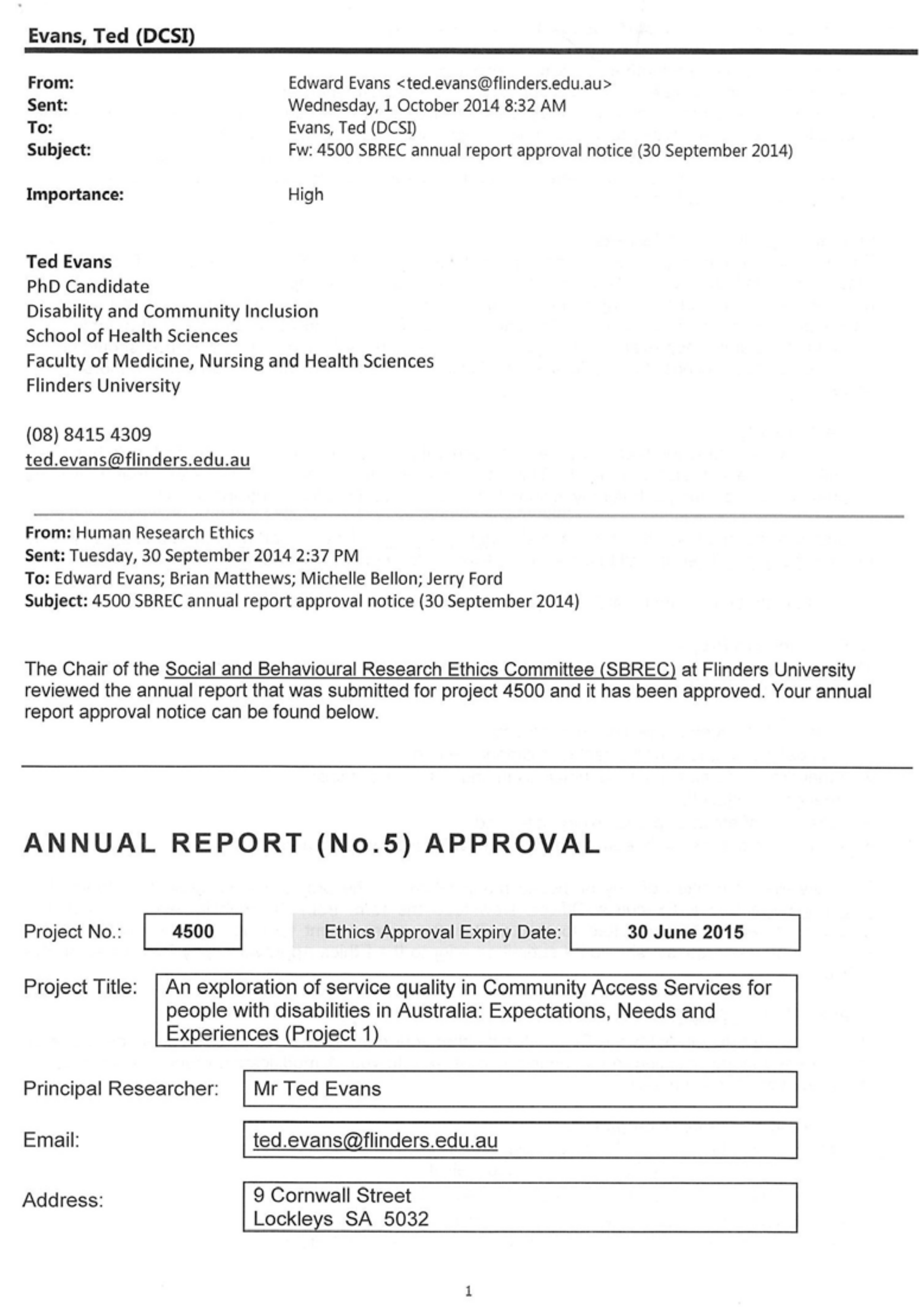
Andrea Jacobs
Acting Secretary
Social and Behavioural Research Ethics Committee
14 July 2009

cc: Dr Brian Matthews, Disability Studies
Dr Michelle Bellon, Disability Studies
Dr Jerry Ford, Disability Studies

NB:* *If you are a scholarship holder and you receive funding for your research through the National Health & Medical Research Council please forward a copy of this letter to the Head, Higher Degree Administration and Scholarships Office, for forwarding to the NHMRC.

Appendix Two

Extension to Project no. 4500



Evans, Ted (DCSI)

From: Edward Evans <ted.evans@flinders.edu.au>
Sent: Wednesday, 1 October 2014 8:32 AM
To: Evans, Ted (DCSI)
Subject: Fw: 4500 SBREC annual report approval notice (30 September 2014)

Importance: High

Ted Evans
PhD Candidate
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University

(08) 8415 4309
ted.evans@flinders.edu.au

From: Human Research Ethics
Sent: Tuesday, 30 September 2014 2:37 PM
To: Edward Evans; Brian Matthews; Michelle Bellon; Jerry Ford
Subject: 4500 SBREC annual report approval notice (30 September 2014)

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University reviewed the annual report that was submitted for project 4500 and it has been approved. Your annual report approval notice can be found below.

ANNUAL REPORT (No.5) APPROVAL

Project No.: **4500** Ethics Approval Expiry Date: **30 June 2015**

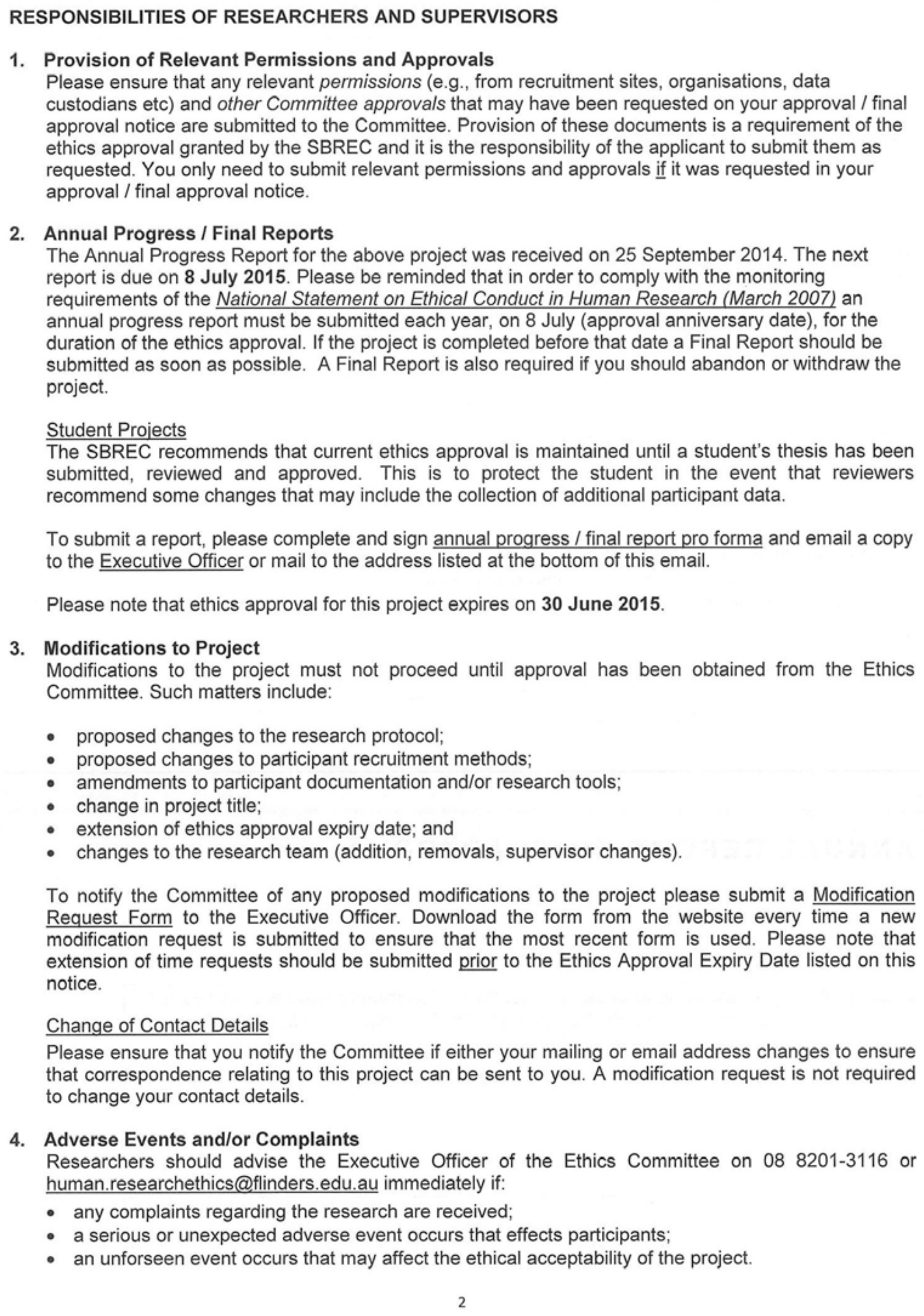
Project Title: An exploration of service quality in Community Access Services for people with disabilities in Australia: Expectations, Needs and Experiences (Project 1)

Principal Researcher: Mr Ted Evans

Email: ted.evans@flinders.edu.au

Address: 9 Cornwall Street
Lockleys SA 5032

1



RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Provision of Relevant Permissions and Approvals**
   Please ensure that any relevant *permissions* (e.g., from recruitment sites, organisations, data custodians etc) and *other Committee approvals* that may have been requested on your approval / final approval notice are submitted to the Committee. Provision of these documents is a requirement of the ethics approval granted by the SBREC and it is the responsibility of the applicant to submit them as requested. You only need to submit relevant permissions and approvals if it was requested in your approval / final approval notice.

2. **Annual Progress / Final Reports**
   The Annual Progress Report for the above project was received on 25 September 2014. The next report is due on **8 July 2015**. Please be reminded that in order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year, on 8 July (approval anniversary date), for the duration of the ethics approval. If the project is completed before that date a Final Report should be submitted as soon as possible. A Final Report is also required if you should abandon or withdraw the project.

   Student Projects
   The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

   To submit a report, please complete and sign annual progress / final report pro forma and email a copy to the Executive Officer or mail to the address listed at the bottom of this email.

   Please note that ethics approval for this project expires on **30 June 2015**.

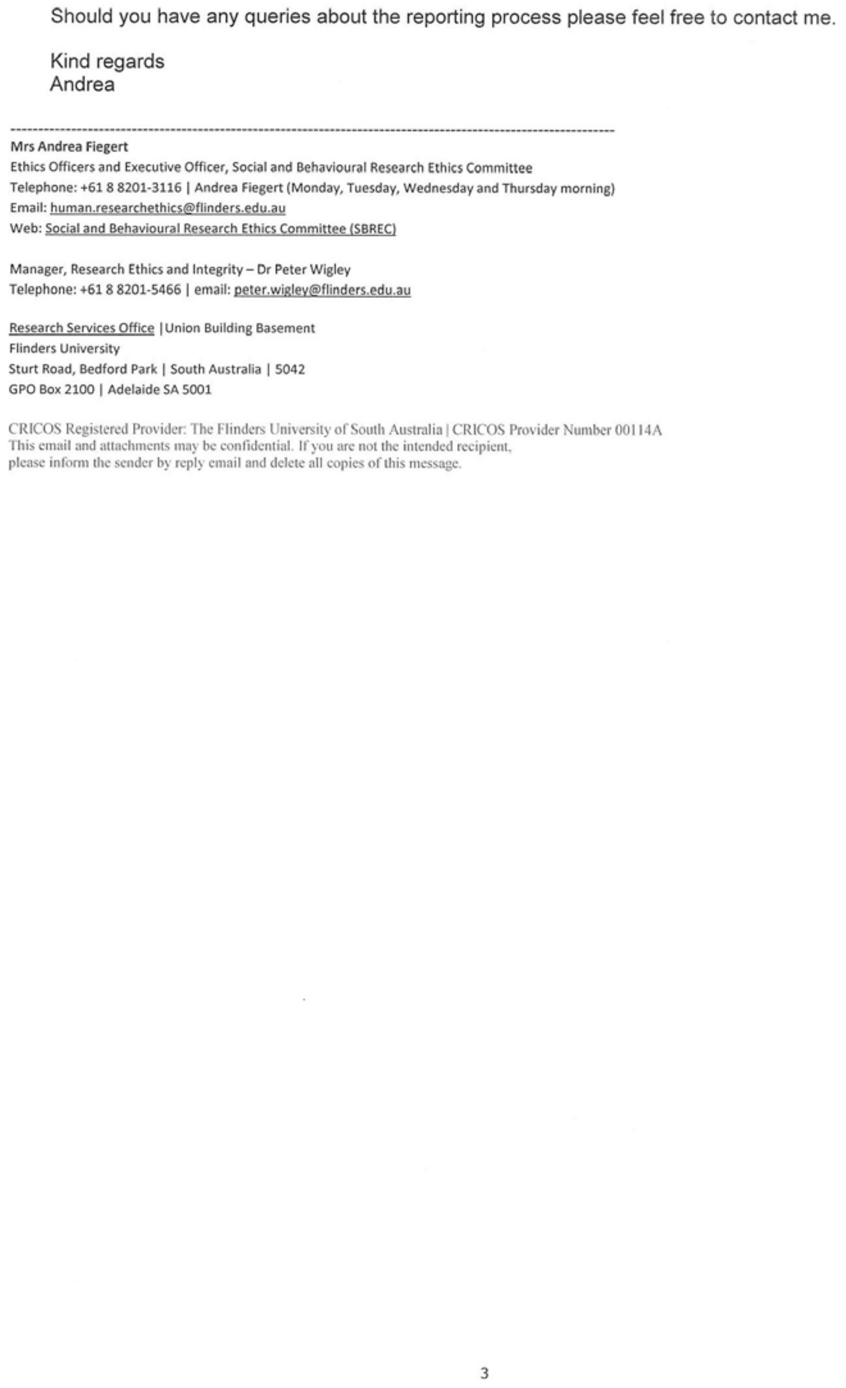
3. **Modifications to Project**
   Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

   - proposed changes to the research protocol;
   - proposed changes to participant recruitment methods;
   - amendments to participant documentation and/or research tools;
   - change in project title;
   - extension of ethics approval expiry date; and
   - changes to the research team (addition, removals, supervisor changes).

   To notify the Committee of any proposed modifications to the project please submit a Modification Request Form to the Executive Officer. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

   Change of Contact Details
   Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. **Adverse Events and/or Complaints**
   Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:
   - any complaints regarding the research are received;
   - a serious or unexpected adverse event occurs that effects participants;
   - an unforseen event occurs that may affect the ethical acceptability of the project.



Should you have any queries about the reporting process please feel free to contact me.

Kind regards
Andrea

Mrs Andrea Fiegert
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Telephone: +61 8 8201-3116 | Andrea Fiegert (Monday, Tuesday, Wednesday and Thursday morning)
Email: human.researchethics@flinders.edu.au
Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au

Research Services Office |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

Appendix Three

FINAL APPROVAL NOTICE

Project No.:	**6059**
Project Title:	An exploration of the quality in Community Access Services for people with disabilities in Australia: Expectations, Needs and Experiences
Principal Researcher:	Mr Ted Evans
Email:	ted.evans@flinders.edu.au
Address:	9 Cornwall Street Lockleys SA 5032

Approval Date:	2 June 2013	Ethics Approval Expiry Date:	**30 December 2014**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comment:

Additional information required following commencement of research:

1. Please ensure that copies of the correspondence requesting and granting permission to conduct the research from all the organisations / departments listed in item 2 of the conditional approval notice are submitted to the Committee *on receipt.* Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee. Please note that data collection should not commence until the researcher has received the relevant permissions (item D8 and Conditional approval response – number 2).

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**
   Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **2 June** (approval anniversary date) for the duration of the ethics approval using the annual progress / final report pro forma. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Your first report is due on **2 June 2014** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

- proposed changes to the research protocol;
- proposed changes to participant recruitment methods;
- amendments to participant documentation and/or research tools;
- change of project title;
- extension of ethics approval expiry date; and
- changes to the research team (addition, removals, supervisor changes).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form to the Executive Officer. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

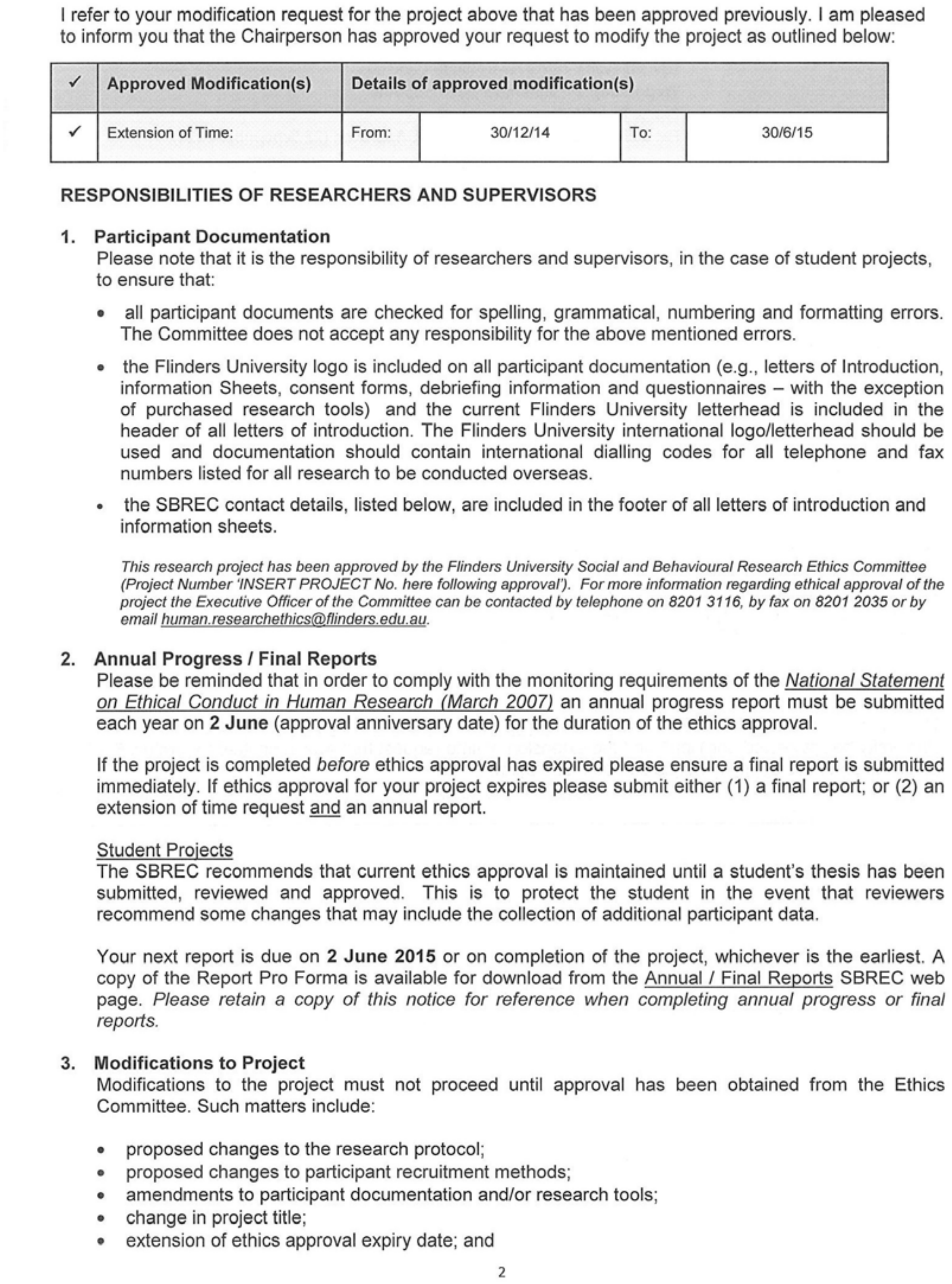
- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Andrea Fiegert
Executive Officer
Social and Behavioural Research Ethics Committee

c.c Dr Brian Matthews
Dr Michelle Bellon

Andrea Fiegert
Executive Officer, Social and Behavioural Research Ethics Committee
Research Services Office |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001
P: +61 8 8201-3116 | F: +61 8 8201-2035 |Web: Social and Behavioural Research Ethics Committee

Appendix Four
Extension to Project No. 6059



I refer to your modification request for the project above that has been approved previously. I am pleased to inform you that the Chairperson has approved your request to modify the project as outlined below:

✓	Approved Modification(s)	Details of approved modification(s)			
✓	Extension of Time:	From:	30/12/14	To:	30/6/15

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**
   Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. **Annual Progress / Final Reports**
   Please be reminded that in order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on **2 June** (approval anniversary date) for the duration of the ethics approval.

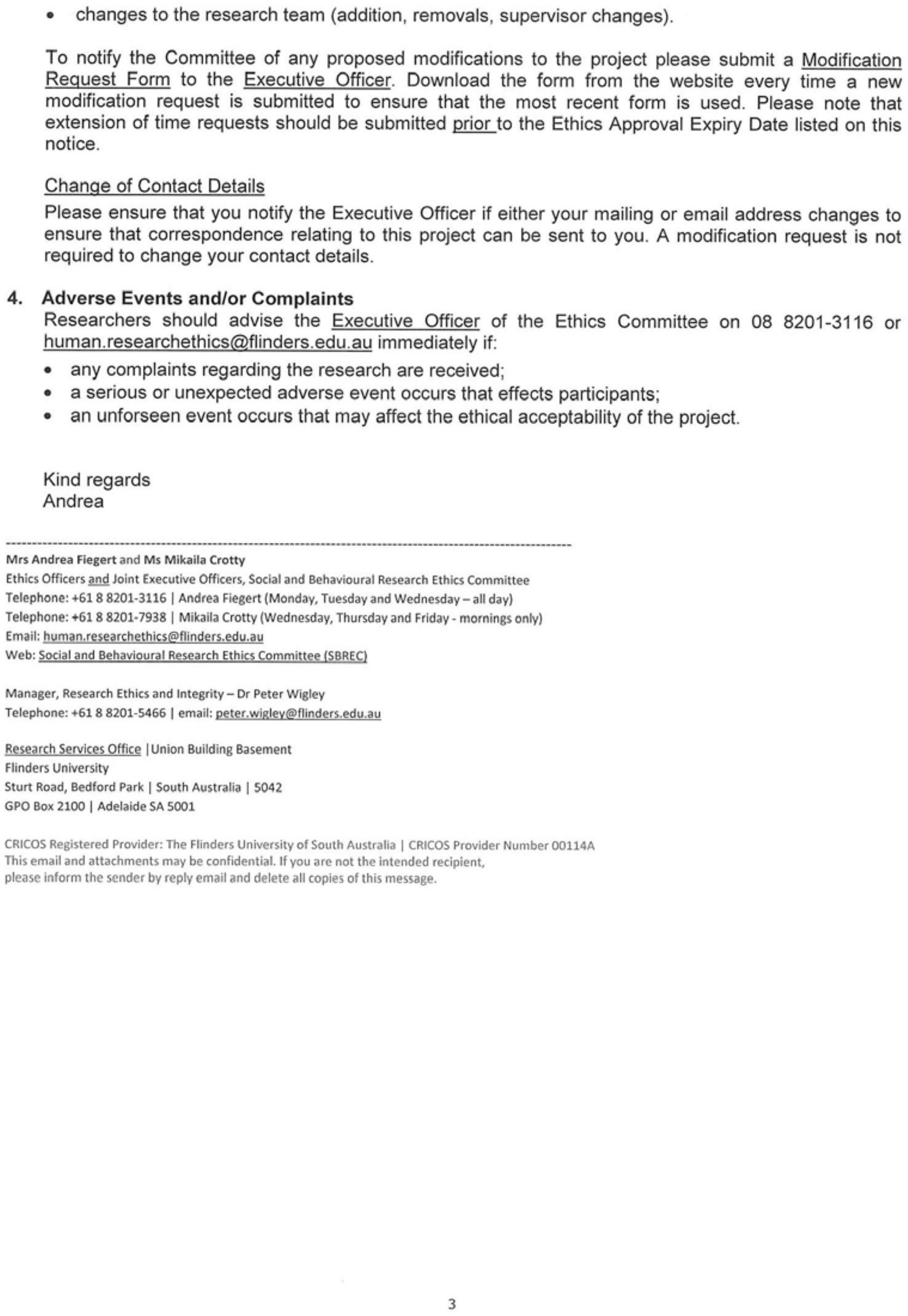
If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects
The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your next report is due on **2 June 2015** or on completion of the project, whichever is the earliest. A copy of the Report Pro Forma is available for download from the Annual / Final Reports SBREC web page. *Please retain a copy of this notice for reference when completing annual progress or final reports.*

3. **Modifications to Project**
   Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

- proposed changes to the research protocol;
- proposed changes to participant recruitment methods;
- amendments to participant documentation and/or research tools;
- change in project title;
- extension of ethics approval expiry date; and



- changes to the research team (addition, removals, supervisor changes).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form to the Executive Officer. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Executive Officer if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

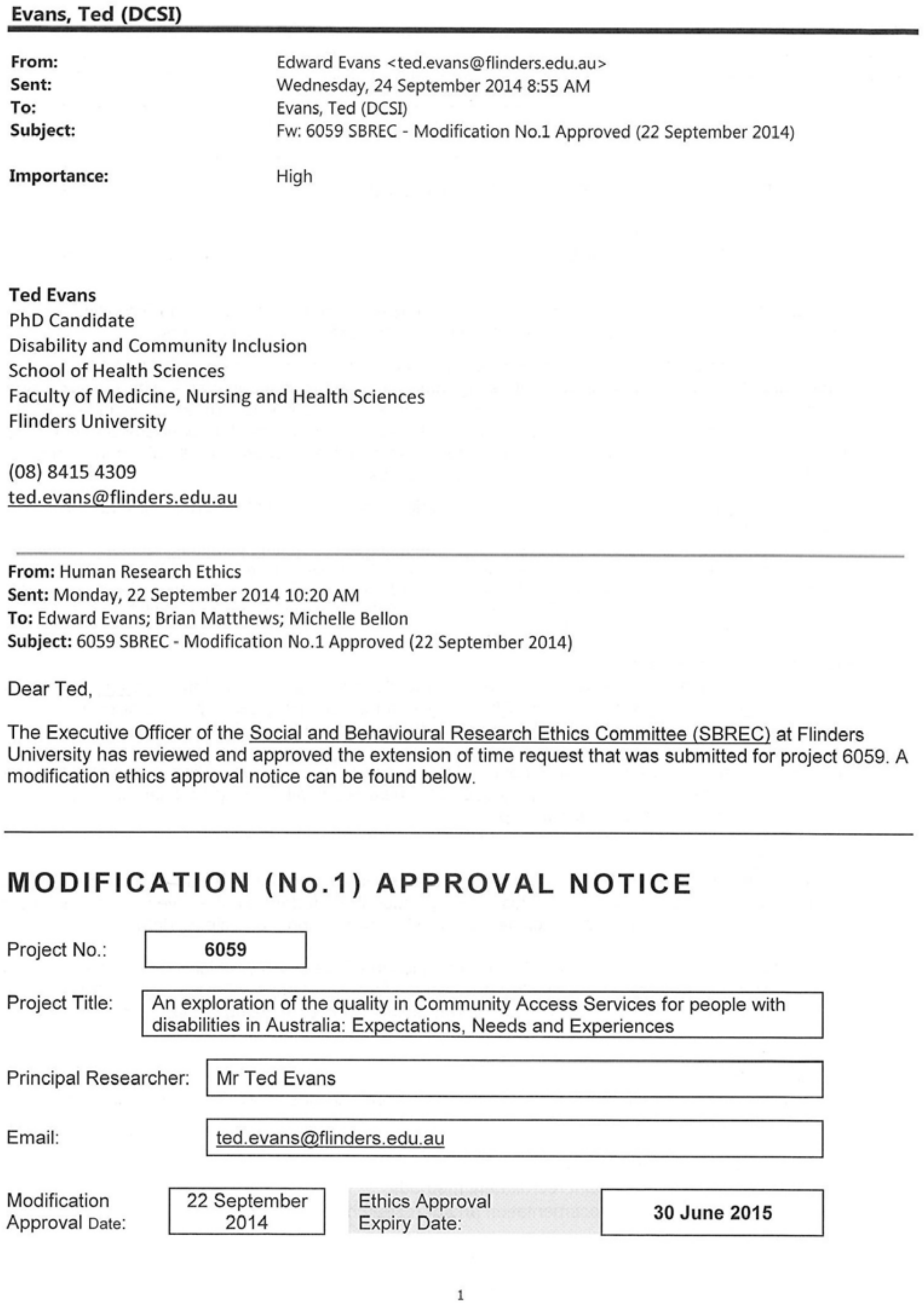
- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Andrea

Mrs Andrea Fiegert and **Ms Mikaila Crotty**
Ethics Officers and Joint Executive Officers, Social and Behavioural Research Ethics Committee
Telephone: +61 8 8201-3116 | Andrea Fiegert (Monday, Tuesday and Wednesday – all day)
Telephone: +61 8 8201-7938 | Mikaila Crotty (Wednesday, Thursday and Friday - mornings only)
Email: human.researchethics@flinders.edu.au
Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au

Research Services Office |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001



Evans, Ted (DCSI)

From:	Edward Evans <ted.evans@flinders.edu.au>
Sent:	Wednesday, 24 September 2014 8:55 AM
To:	Evans, Ted (DCSI)
Subject:	Fw: 6059 SBREC - Modification No.1 Approved (22 September 2014)
Importance:	High

Ted Evans
PhD Candidate
Disability and Community Inclusion
School of Health Sciences
Faculty of Medicine, Nursing and Health Sciences
Flinders University

(08) 8415 4309
ted.evans@flinders.edu.au

From: Human Research Ethics
Sent: Monday, 22 September 2014 10:20 AM
To: Edward Evans; Brian Matthews; Michelle Bellon
Subject: 6059 SBREC - Modification No.1 Approved (22 September 2014)

Dear Ted,

The Executive Officer of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University has reviewed and approved the extension of time request that was submitted for project 6059. A modification ethics approval notice can be found below.

MODIFICATION (No.1) APPROVAL NOTICE

Project No.:	**6059**		
Project Title:	An exploration of the quality in Community Access Services for people with disabilities in Australia: Expectations, Needs and Experiences		
Principal Researcher:	Mr Ted Evans		
Email:	ted.evans@flinders.edu.au		
Modification Approval Date:	22 September 2014	Ethics Approval Expiry Date:	**30 June 2015**

Appendix Five

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CRICOS Provider No. 00114A

Focus group topics

This research explores the service quality of Community Access Services for people with disabilities in Australia.

Within this research four key topics of the research exist including.

1. Expectations particularly how people with disabilities become involved in Community Access Services and what are they expecting from Community Access Services participation
2. What were, or are currently, participants rights/needs from participation in Community Access Services
3. What have been their experiences of Community Access Services
4. What are their recommendations? How can their expectations, needs/rights and experiences of Community Access Services contribute to the service quality and innovation of Community Access Services in Australia co-produced with, and for, people with disabilities?

Appendix Six

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CRICOS Provider No. 00114A

Interview topics for people with disabilities

Within this research a series sub questions were developed relating to four key areas of the research.

Expectations and transition planning: How people with disabilities become involved in community access service participation and what were there expectations

1. How did you become involved in CAS participation?
2. Were you, and your family members/informal primary carers involved in the planning process before leaving secondary education and going to Community Access Services?
3. What expectations and goals did you and your families/informal primary carers have prior to commencing participation in Community Access Services?
4. Were your expectations of participation in Community Access Services recorded i.e. in a transition plan before leaving secondary school?
5. If a transition plan was completed can you recall when this occurred?

What were or are participant's rights/needs from CAS participation?

6. What were or are your needs/goals from participation in Community Access Services?
7. How were Community Access participation goals included in the overall participation goals/plan
8. Were any resources developed to assist participation in Community Access Services i.e. adaptive equipment?
9. Are your Community Access participation goals being met?
10. Are your Community Access participation goals reviewed and if so how frequently are these Community Access participation goals reviewed?
11. Are you able to determine who participates in the Community Access participation goal reviews?

What were or are your experiences of Community Access Services participation?

12. What have been or are your experiences of CAS participation?

Are there any recommendations ?

13. Are there any considerations which could assist your participation in Community Access Services?
14. Are there recommendations which could improve the service quality and innovation of Community Access Services for people with disabilities throughout Australia?

Appendix Seven

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CRICOS Provider No. 00114A

Interview topics for family members/informal primary carers

Within this research a series sub questions were developed relating to four key areas of the research.

Expectations and transition planning: How people with disabilities become involved in community access service participation and what were there expectations

1. How did your family member/person you provide care for become involved in CAS participation?
2. Were you involved in the planning process before they left secondary education and prior to going to Community Access Services?
3. Were you involved in discussing their expectations of participation in Community Access Services and were these recorded i.e. in a this transition plan before leaving secondary school?
4. What expectations and goals did they and your families/informal primary carers have prior to commencing participation in Community Access Services
5. If a transition plan was completed can you recall when this occurred?

What were or are participant’s rights/ needs from CAS participation?

6. What were or are your family members or person you provide care fors needs/goals from their participation in Community Access Services?
7. How were Community Access participation needs included in the overall participation goals/plan
8. Were any resources developed to assist their participation in Community Access Services i.e. adaptive equipment?
9. Are their Community Access participation needs being met?
10. Are their Community Access participation needs reviewed and if so how frequently are these Community Access Service goals reviewed?
11. Are you able to determine who participates in the Community Access participation goal reviews?

What were or are your experiences of Community Access Services participation?

12. What have been or are your family members/person you provide care for experiences of CAS participation

Are there any recommendations ?

13. Are there any considerations, which could assist their participation in Community Access Services?
14. Are there recommendations which could improve the service quality and innovation of CAS for people with disabilities in Australia?

Appendix Eight

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CRICOS Provider No. 00114A

Interview topics for Community Access Service providers

Within this research a series sub questions were developed relating to four key areas of the research.

Expectations and transition planning: How people with disabilities become involved in community access service participation and what were there expectations

1. How do people with disabilities start participating in Community Access Services?
2. Are people with disabilities, family members/informal primary carers involved in the planning process before they leave secondary education and commence participation in Community Access Services?
3. Are participants expectations of your service recorded i.e. in a transition plan prior to them commencing a Community Access Service?
4. If yes, are you able to provide a blank copy of a transition planning form?

What were or are participant's rights/ needs from CAS participation?

5. What are some of the challenges you've experienced in the provision of Community Access Services?

6. Are the expectations and goals of participant’s families/informal primary carers prior to commencing participation in Community Access Services reviewed?
7. How do you determine if there expectations are being met?
8. Are any resources developed to assist participation in Community Access Services i.e. adaptive equipment?
9. How are Community Access Services delivered i.e. Monday to Friday, weekends?

What were or are your experiences of Community Access Services provision?

10. What have been your experiences of providing CAS?

Are there any recommendations ?

11. Are there any other considerations or recommendations, which could assist people with disabilities participation in Community Access Services and the service quality and innovation of services delivered?

Appendix Nine

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CRICOS Provider No. 00114A

Letter of Introduction: Focus Group

Dear Sir/Madam

This letter is to introduce Mr. Ted Evans who is a PhD student in the Department of Disability and Community Inclusion at Flinders University.

He is undertaking research leading to the production of a thesis or other publications on the subject of "An exploration of the expectations, needs and experiences of people with disabilities and family members/informal primary carers participating in Community Access Services in Australia."

He would be most grateful if you would volunteer to assist in this project, by participating in a focus group which covers certain aspects of this topic. No more than 90 minutes would be required.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be identified individually in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 82013448 or by email (Brian.Matthews@flinders.edu.au)

Thank you for your attention and assistance.

Yours sincerely

Brian Matthews
Senior Lecturer

Department of Disability and Community Inclusion

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 4500). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 08 8201 3116, by Fax on 82012035 or by email human.researchethics @ flinders.edu.au.

Appendix Ten

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CRICOS Provider No. 00114A

Letter of Introduction: Interview

Dear Sir/Madam

This letter is to introduce Mr. Ted Evans who is a PhD student in the Department of Disability and Community Inclusion at Flinders University.

He is undertaking research leading to the production of a thesis or other publications on the subject of "An exploration of the expectations, needs and experiences of people with disabilities and family members/informal primary carers participating in Community Access Services in Australia."

He would be most grateful if you would volunteer to assist in this project, by participating in an interview which covers certain aspects of this topic. No more than 60 minutes would be required.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be identified individually in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 82013448 or by email (Brian.Matthews@flinders.edu.au)

Thank you for your attention and assistance.

Yours sincerely

Brian Matthews
Senior Lecturer

Department of Disability and Community Inclusion

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 4500). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 08 8201 3116, by Fax on 82012035 or by email human.researchethics @ flinders.edu.au.

Appendix Eleven

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CRICOS Provider No. 00114A

Letter of Introduction: Questionnaire

Dear Sir/Madam

This letter is to introduce Mr. Ted Evans who is a PhD student in the Department of Disability and Community Inclusion at Flinders University.

He is undertaking research leading to the production of a thesis or other publications on the subject of "An exploration of the expectations, needs and experiences of people with disabilities and family members/informal primary carers participating in Community Access Services in Australia."

He would be most grateful if you would volunteer to assist in this project, by completing a questionnaire which covers certain aspects of this topic. No more than 30 minutes would be required.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be identified individually in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 82013448 or by email (Brian.Matthews@flinders.edu.au)

Thank you for your attention and assistance.

Yours sincerely

Brian Matthews
Senior Lecturer

Department of Disability and Community Inclusion

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 6059). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 08 8201 3116, by Fax on 82012035 or by email human.researchethics @ flinders.edu.au.

Appendix Twelve

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CRICOS Provider No. 00114A

Participant Information Sheet Focus Group

Project description

The purpose of the research is to explore the service quality and innovation in Community Access Services (often referred to as day services) for people with disabilities in Australia.

Participant's role

As a participant in a focus group you will have opportunities to present relevant knowledge and experience of Community Access Services for people with disabilities including expectations, needs and experiences.

Alternatives to participation

Participation within the research may occur through the provision of a written response to the questionnaire (online or postal), participation in a focus group or through an interview if desired.

Research monitoring

The research will be monitored through reviews with Flinders University supervisors both during and at the completion of the focus group process.

Counseling services:

Provision of free counseling services for participants adversely affected by the research may occur, e.g. through Lifeline ph.131114.

Researchers contact details

Mr. Ted Evans
PhD Candidate
Flinders University
GPO Box 2100
Adelaide SA 5001
Ph. 84154309
Email ted.evans@flinders.edu.au

Privacy and confidentiality

Throughout the research no information which identifies an individual will be published in the thesis and confidentiality of all information provided by participants will be respected. Data analysis will occur using Nvivo data analysis software. All focus group transcripts will be retained and will not be available for general viewing.

Participant’s right to withdrawal

Participants can request that information at any stage can be used or omitted at any stage in selected ways. Participation is clearly stated as voluntary and this is confirmed by having participants participation in a focus group of their own initiative.

Funding of the research

Nil

Financial or other relevant declarations of interests of researchers, sponsors or institutions

Nil

Reimbursement of costs to participation

There are no reimbursements of costs for participation in the focus group.

Likelihood and form of dissemination of the research results

There is a high likelihood that the research results will be presented at both conference(s) through conference papers and published in relevant journals.

Expected benefits to the wider community

The research is particularly valuable for the people with disabilities, family members/informal primary carers involved in the research as an opportunity to provide their expectations, needs/rights and experiences of Community Access Services to assist the further development of innovative, quality services which are co-produced with, and for, people with disabilities. The research is beneficial for the providers of Community Access Services as these perceptions and insights together with knowledge gained through the literature review inform providers of alternative models of service delivery which meet the needs of consumers particularly with the introduction of individualised funding. The research is also beneficial for funding bodies and policy makers who are involved in future service provision with an identified increasing need for such services. The research will also contribute to the body of academic knowledge of the subject.

Other relevant information

The research topic has considerable interest for the researcher having professional experience working with agencies which provide Community Access Services with and for people with disabilities, academically in order to contribute to the the academic knowledge regarding the quality and innovation of such services and personally as a father of two teenagers with disabilities.

Appendix Thirteen

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CRICOS Provider No. 00114A

Participant Information Sheet Interviews

Project description

The purpose of the research is to explore the service quality and innovation in Community Access Services (often referred to as day services) for people with disabilities in Australia.

Participant's role

As a participant in a face to face interview you will have opportunities to present relevant knowledge and experience of Community Access Services for people with disabilities including expectations, needs and experiences.

Alternatives to participation

Participation within the research may occur through the provision of a written response to the questionnaire (online or postal) or participation in a focus group if desired.

Research monitoring

The research will be monitored through reviews with Flinders University supervisors both during and at the completion of the interview process.

Counseling services:

Provision of free counseling services for participants adversely affected by the research may occur, e.g. through Lifeline ph.131114.

Researchers contact details

Mr. Ted Evans
PhD Candidate
Flinders University
GPO Box 2100
Adelaide SA 5001
Ph. 84154309
Email ted.evans@flinders.edu.au

Privacy and confidentiality

Throughout the research no information which identifies an individual will be published in the thesis and confidentiality of all information provided by participants will be respected. Data analysis will occur using Nvivo data analysis software. All questionnaires will be retained and will not be available for general viewing.

Participant's right to withdrawal

Participants can request that information at any stage can be used or omitted at any stage in selected ways. Participation is clearly stated as voluntary and this is confirmed by having participants participation in a face to face interview of their own initiative.

Funding of the research

Nil

Financial or other relevant declarations of interests of researchers, sponsors or institutions

Nil

Reimbursement of costs to participation

There are no reimbursements of costs for participation in the face to face interview.

Likelihood and form of dissemination of the research results

There is a high likelihood that the research results will be presented at both conference(s) through conference papers and published in relevant journals.

Expected benefits to the wider community

The research is particularly valuable for the people with disabilities, family members/informal primary carers involved in the research as an opportunity to provide their expectations, needs/rights and experiences of Community Access Services to assist the further development of innovative, quality services which are co-produced with, and for, people with disabilities. The research is beneficial for the providers of Community Access Services as these perceptions and insights together with knowledge gained through the literature review inform providers of alternative models of service delivery which meet the needs of consumers particularly with the introduction of individualised funding. The research is also beneficial for funding bodies and policy makers who are involved in future service provision with an identified increasing need for such services. The research will also contribute to the body of academic knowledge of the subject.

Other relevant information

The research topic has considerable interest for the researcher having professional experience working with agencies which provide Community Access Services with and for people with disabilities, academically in order to contribute to the the academic knowledge regarding the quality and innovation of such services and personally as a father of two teenagers with disabilities.

Appendix Fourteen

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CRICOS Provider No. 00114A

Participant Information Sheet Questionnaire

Project description

The purpose of the research is to explore the service quality and innovation in Community Access Services (often referred to as day services) for people with disabilities in Australia.

Participant's role

As a participant in the questionnaire you will have opportunities to present relevant knowledge and experience of Community Access Services for people with disabilities including expectations, needs and experiences.

Alternatives to participation

Participation within the research may occur through the provision of a written response to the questionnaire (online or postal), participation in a focus group or through an interview if desired.

Research monitoring

The research will be monitored through reviews with Flinders University supervisors both during and at the completion of the questionnaire process.

Counseling services:

Provision of free counseling services for participants adversely affected by the research may occur, e.g. through Lifeline ph.131114.

Researchers contact details

Mr. Ted Evans
PhD Candidate
Flinders University
GPO Box 2100
Adelaide SA 5001
Ph. 84154309
Email ted.evans@flinders.edu.au

Privacy and confidentiality

Throughout the research no information which identifies an individual will be published in the thesis and confidentiality of all information provided by participants will be respected. Data analysis will occur using Nvivo data analysis software. All questionnaires will be retained and will not be available for general viewing.

Participant's right to withdrawal

Participants can request that information at any stage can be used or omitted at any stage in selected ways. Participation is clearly stated as voluntary and this is confirmed by having participants completing the questionnaire of their own initiative.

Funding of the research

Nil

Financial or other relevant declarations of interests of researchers, sponsors or institutions

Nil

Reimbursement of costs to participation

There are no reimbursements of costs for participation in the questionnaire. Costs to participants are nil. The researcher will provide stamped self-addressed envelopes for return of the postal surveys. Surveys will also be available for completion using an online 'survey monkey' format.

Likelihood and form of dissemination of the research results

There is a high likelihood that the research results will be presented at both conference(s) through conference papers and published in relevant journals.

Expected benefits to the wider community

The research is particularly valuable for the people with disabilities, family members/informal primary carers involved in the research as an opportunity to provide their expectations, needs/rights and experiences of Community Access Services to assist the further development of innovative, quality services which are co-produced with, and for, people with disabilities. The research is beneficial for the providers of Community Access Services as these perceptions and insights together with knowledge gained through the literature review inform providers of alternative models of service delivery which meet the needs of consumers particularly with the introduction of individualised funding. The research is also beneficial for funding bodies and policy makers who are involved in future service provision with an identified increasing need for such services. The research will also contribute to the body of academic knowledge of the subject.

Other relevant information

The research topic has considerable interest for the researcher having professional experience working with agencies which provide Community Access Services with and for people with disabilities, academically in order to contribute to the the academic knowledge regarding the quality and innovation of such services and personally as a father of two teenagers with disabilities.

Appendix Fifteen

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CRICOS Provider No. 00114A

CONSENT FORM FOR PARTICIPATION IN FOCUS GROUPS

I …..being over the age of 18 years hereby consent to participate as requested in a focus group for the research project on the service quality of Community Access Services for people with disabilities in Australia.

I have read the information provided.

1. Details of procedures and any risks have been explained to my satisfaction.

2. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference

3. I understand that:

   - I may not directly benefit from taking part in this research.
   - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
   - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my course of study, or results gained.

4. I agree to the transcript being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.

5. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature……………………………………Date…………………...

Guardians signature……………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name Ted Evans.

Researcher's signature………………………………..Date…………………….

Appendix Sixteen

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CRICOS Provider No. 00114A

CONSENT FORM FOR PARTICIPATION IN INTERVIEWS

I …..being over the age of 18 years hereby consent to participate as requested in an interview for the research project on the service quality of Community Access Services for people with disabilities in Australia.

I have read the information provided.

1. Details of procedures and any risks have been explained to my satisfaction.
2. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference
3. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my course of study, or results gained.
4. I agree to the transcript being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed.
5. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature……………………………………Date…………………...

Guardians signature……………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name Ted Evans.

Researcher's signature………………………………..Date…………………….

Appendix Seventeen

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CRICOS Provider No. 00114A

Community Access Services (often referred to as Day Activities) in Australia

Questionnaire

People with a disability (Part A)
and Family/Informal Primary Carers (Part B)

Thank you for taking the time to complete this two part survey.
The confidentiality of any information you provide is guaranteed. You do not need to put your name on this Survey and there are no identifying marks on these forms.

Most questions only require you to **tick the appropriate box.**
If for you there is more than one appropriate answer, **tick all boxes you feel are appropriate.**

Some questions ask you to write some additional information or comments.

The more information you can provide, the better I will be able to determine your expectations, needs/rights and experiences of Community Access Services.

Please note that the survey will be processed anonymously.

It is important that you return the completed survey within 2 weeks of receiving it .

A reply paid addressed envelope is provided for this purpose.

Once again, thank you for your help in completing this survey.

Ted Evans
PhD candidate

Part A: People with a disability

1. **What is your postcode?..............**

2. **What is your relationship with your family member/informal primary carer?**

☐ Son

☐ Daughter

☐ Sibling

☐ Other?..

3. **How did you become involved in Community Access Services?**

☐ School referral
☐ Rehabilitation referral
☐ Attended a disability service information session/expo
☐
Other?...

4. **How long have you been involved in Community Access Services?**

☐ Less than 1 year
☐ 1-5 years
☐ 5-10 years
☐ 10-15 years
☐ 15-20 years
☐ More than 20 years

5. **Were you, and your family members involved in the planning process before leaving secondary education/rehabilitation service and going to Community Access Services?**

☐ No
☐ Yes

If yes, how were you involved?

☐ Attendance at planning meetings
☐ Visiting the Community Access Service
☐ Other ? ....

6. **What expectations and goals did you have prior to commencing participation in Community Access Services? (Tick as many boxes as applicable)**

☐ To continue to develop skills learnt at school
☐ To continue to develop skills learnt at rehabilitation service
☐ To learn new skills
☐ To have fun
☐ To make friends
☐ Other?……..

7. **Were your expectations and goals of participation in Community Access Services recorded in a transition plan before leaving secondary school/rehabilitation service?**

☐ No
☐ Yes

8. **Were any resources developed to assist your participation in Community Access Services?**

☐ No
☐ Yes

If yes, what resources were developed?

☐ Adaptive equipment
☐ Communication devices
☐ Other?…………………………………………………………

9. **Are your Community Access Service expectations and participation goals being met?**

☐ No

If not, why not? Could you provide an example/examples?

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☐ Yes

If yes, could you provide an example/examples?

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10. Are your Community Access Service participation goals reviewed?

☐ No

☐ Yes

If yes, how frequently?

☐ Every 3 months

☐ 3-6 months

☐ 6-12 months

☐ More than 12 months

11. Are you able to determine who participates in the Community Access Service participation goal reviews?

☐ No

☐ Yes

If yes, who else participates with you in reviewing your goals?

☐ Family member

☐ Informal primary carer

☐ Other?..

12. What have been your experiences of Community Access Service participation? (Tick as many boxes as applicable)

☐ Continued to develop skills learnt at school

☐ Continued to develop skills learnt at rehabilitation service

☐ Learnt new skills

☐ Had fun

☐ Made friends

☐ Other ………………………………………………………………………

Could you provide an example/examples?

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13. How could your active participation in Community Access Services be better supported?

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14. Do you have any recommendations/suggestions about ways in which Community Access Services service quality could be improved?

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15. Do you have any recommendations /suggestions about innovative or new ways in which Community Access Services can support people with disabilities?

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Part B: Family member/informal primary carer

1. **What is your postcode?...............**

2. **Were you, involved in the planning process before they left the secondary education/rehabilitation service and prior to going to Community Access Services?**

   ☐ No
   ☐ Yes

   If yes, how were you involved?
   ☐ Attendance at planning meetings
   ☐ Visiting the Community Access Service
   ☐ Other?...

3. **What expectations and goals did you have prior to your family member's/person you provide informal primary cares participation in Community Access Services?**

   For them:
   ☐ To continue to develop skills learnt at school
   ☐ To continue to develop skills learnt at rehabilitation service
   ☐ To learn new skills
   ☐ To have fun
   ☐ To make friends
   ☐ Other ? ……………………………………………………………

4. **Were the expectations and goals for your family member's/person you provide informal primary care's, participation in Community Access Services recorded in a transition plan before they left secondary school/rehabilitation service?**

   ☐ No
   ☐ Yes

5. **Were any resources developed to assist your family member's/person you provide informal primary care's participation in Community Access Services?**

☐ No

☐ Yes

If yes, what resources have been developed?

☐ Adaptive equipment

☐ Communication devices

☐ Other?...

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6. **Are the Community Access Service expectations and participation goals of your family member/person you provide informal primary care being met?**

☐ No

If not, why not? Could you provide an example/examples?

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☐ Yes

If yes, could you provide an example/examples?

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7. **Are their Community Access Service participation goals reviewed?**

☐ No

☐ Yes

If yes, how frequently?

☐ Every 3 months

☐ 3-6 months

☐ 6-12 months

☐ More than 12 months

8. **Are you able to determine who participates in the Community Access Service participation goal reviews for your family member/person you provide informal primary care?**

☐ No

☐ Yes

If yes, who else participates with you in reviewing their goals?

☐ Family member

☐ Informal primary carer

☐ Other?...

9. **What have been the experiences of your family member/person you provide informal primary care in regards to Community Access Service participation? (Tick as many boxes as applicable)**

☐ Continued to develop skills learnt at school

☐ Continued to develop skills learnt at rehabilitation service

☐ Learnt new skills

☐ Had fun

☐ Made friends

☐ Other ? ……………………………………………………………

Could you provide an example/examples?

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10. **Are there any considerations which could assist their participation in Community Access Services?**

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11. Do you have any recommendations /suggestions about ways in which Community Access Services service quality could be improved?
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12. Do you have any recommendations /suggestions about innovative or new ways in which Community Access Services can support people with disabilities?

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Thank you for your participation in this survey

Appendix Eighteen

Government Department	**State**	**Year**	**Document Description and source**	**Inclusion of people with disability and their families/informal primary carers**	**Evidence of people with disabilities/families involvement in consultation including representation from Peak bodies**
Disability Services Commission	WA	2013	*Individualised Funding Policy, Strategic Policy and Programs Branch.* www.disability.wa.gov.au	*People with disability, their families, carers*	*Consultation has occurred with all relevant peak bodies (including People with Disabilities WA) (p. 4)*
Disability Services Commission	WA	2012	*My Way – Project.* www.disability.wa.gov.au	*People with disability, their families, carers*	*'Consultation with more than 1,000 people including people with a disability, their families and carers' (pg.1).*
Department for Communities	WA	2010	*Strategic Plan 2011-2015.* www.communities.wa.gov.au.	*Western Australian citizens*	
Disability Services Commission	WA	2010	*Alternatives to employment program policy framework.* www.disability.wa.gov.au	*Commission staff*	

Disability Services Commission	WA	2007	*Business Rules for new services funded under community support and alternatives to employment programs.* www.disability.wa.gov.au	*Service providers*	
Department of Communities, Child Safety and Disability Services	QLD.	2012	*Strategic Plan 2012-2016.* www.communities.qld.gov.au *Refer individualised funding*	*Queensland Citizens*	
Department of Communities, Child Safety and Disability Services	QLD.	2012	*Your Life Your Choice – host provider model. Handbook for people with a disability, their families and support networks.* www.communities.qld.gov.au	*People with disability, their families, carers and support networks*	*Discussion*
Department of Communities, Child Safety and Disability Services	QLD.	2012	*Your Life Your Choice – self-directed support framework.* www.communities.qld.gov.au	*People with disability, their families, carers and support networks*	
Department of Communities	QLD.	2011	*Disability Services Plan 2011-2014.Individualised funding.*	*People with disability, their families, carers and support networks*	

Department of Family and Community Services	NSW	2012	*Community Participation, Life choices and active ageing Program Guidelines.* www.adhc.nsw.gov.au.	*People with disability, their families, carers and support networks*	*People with disability, their families and carers (p. 4)*
Department of Family and Community Services	NSW	2012	*Living Life My Way Putting people with a disability at the centre of decision-making about their supports in NSW Discussion Paper.* www.adhc.nsw.gov.au.	*People with disability, their families, carers and support networks*	
Department of Family and Community Services	NSW	2012	*Stronger Together A new direction for disability services in NSW 2006-2016.* www.adhc.nsw.gov.au.	*New South Wales citizens*	*'People with disability families and carers have told us they want a range of choices' (p. 3)*
Department of Family and Community Services	NSW	2011	*My life, My Way Choosing the self-managed model for your day program.* www.adhc.nsw.gov.au.	*People with disability, their families, carers and support networks*	*People who shared their personal stories (p. 2)*

Department of Family and Community Services	NSW	2011	*Person-centred and flexible day and post school programs- update for providers.* www.adhc.nsw.gov.au.	*Providers*	*Reference to evaluation reports involving individuals and their families (p. 1)*
Department of Family and Community Services	NSW	2011	*Person-centred and flexible day and post school programs- update for individuals.* www.adhc.nsw.gov.au.	*People with disability, their families, carers and support networks*	*Reference to evaluation reports involving individuals and their families (p. 1)*
Department of Human Services, (Ageing, Disability and Home Care)	NSW	2010	*Aiming High New directions in day programs for adults with a disability.* www.adhc.nsw.gov.au.	*People with disability, their families, carers and support networks*	*Acknowledgements of 22 People with disabilities who shared their personal stories (p. 2)*
Department of Human Services.	VIC	2012	*Disability Services Day Services Guidelines.* www.dhs.vic.gov.au/disability	*People with disabilities parent(s) and providers*	
Department of Human Services.	VIC	2012	*Understanding your options A handbook for Day Services Users.* www.dhs.vic.gov.au/disability	*People with disabilities and parent(s), carer or advocate*	

Department of Human Services.	VIC	2010	*Disability Services Individual Support Package Guidelines.* www.dhs.vic.gov.au/disability	*Regional and disability service provider staff*	
Department of Human Services.	VIC	2010	*Disability Services Community Building Program Practice Guide.* www.dhs.vic.gov.au/disability	*Not specified*	*Building Program Annual Report 2011 reference to examples of people with disabilities involvement in forums*
Department of Human Services.	VIC	2010	*Disability Services Community Building Program Planning and Reporting Framework.* www.dhs.vic.gov.au/disability	*Communinty building program auspice organisatiopns, access officers, DHS Regional officers*	
Department of Human Services.	VIC	2010	*Disability Services Community Building Program Operational Guidelines.* www.dhs.vic.gov.au/disability	*Provide direction for local Government and community organisations*	
Department of Human Services.	VIC	2009	*Evaluation of the Changing Days Initiative* www.dhs.vic.gov.au/disability	*People with disabilities and parent(s), carer or advocate*	*Consultations*

Department of Health and Human Services	TAS	2012	*Disability and Community Services Eligibility Policy for Access to Specialist Disability Services.* www.dhhs.gov.au/disability	*Service providers*	
Department of Health and Human Services	TAS	2011	*Disability and Community Services Eligibility Guidelines for Access to Specialist Disability Services.* www.dhhs.gov.au/disability	*Service providers*	
Department of Health and Human Services	TAS	2012	*Disability and Community Services - Supporting Individual Pathways Guidelines.* www.dhhs.gov.au/disability	*People with disability and their families and carers and people wanting information regarding supporting individual pathways.*	
Department of Health and Human Services	TAS	2011	*Disability and Community Services Filling of Community Access Vacancies Policy.* www.dhhs.gov.au/disability	*Direction for service providers*	

Department of Health and Human Services	TAS	2010	*Disability and Community Services. Fact Sheet Community Access Services*. www.dhhs.gov.au/disability	*People wanting information*	
Disability ACT	ACT	2013	*Response to School leavers with Disability Information Pack.* www.dhcs.act.gov.au/disability	*People with a disability and families/carers*	
Disability ACT	ACT	2012	*Disability ACT Policy Management Framework.* www.dhcs.act.gov.au/disability	*For Disability ACT staff*	*Consultation with affected stakeholders (p. 15)*
Disability ACT	ACT	2009	*Future Directions: Towards Challenge 2014.* www.dhcs.act.gov.au/disability	*People with disability, families, carers*	*Developed by the ACT Disability Strategic Governance group comprising family. Community and government members.(p. 4.)Extensive community consultations.*
Department for Communities and Social Inclusion	SA	2014	*Eligibility for Disability Services and Programs Sector-Wide Policy.* www.dcsi.sa.gov.au	*Service providers*	*Reference to Strong Voices: A Blueprint to Enhance Life and Claim the rights of people with disability in South Australia (p. 3)*

Department for Communities and Social Inclusion	SA	2013	*Community Support Funding to Individuals Guideline.* www.dcsi.sa.gov.au	*People with disability, families, carers*	*Reference to Strong Voices: A Blueprint to Enhance Life and Claim the rights of people with disability in South Australia (p. 3)*
Department for Communities and Social Inclusion	SA	2012	*Disability, Ageing and Carers Day Option Program: Look Book.* www.dcsi.sa.gov.au	*People with disability, families, carers*	
Department for Families and Communities	SA	2011	*Eligibility for Disability Services and Programs Sector-Wide Policy.* www.dfc.sa.gov.au	*Service providers*	
Department for Families and Communities	SA	2011	*Community and Home Support SA Day Option Program Guideline.* www.dfc.sa.gov.au	*Service providers*	
Department of the Premier and Cabinet	SA	2009	*Choices and Connections: The Better Pathways Service Approach for Young People with Disabilities.* www.socialinclusion.sa.gov.au		

Department of the Premier and Cabinet	SA	2008	*Post-School Pathways. How it is and how it works for young people.* www.socialinclusion.sa.gov.au	*People with disability, families, carers, service providers*	*Extensive community consultations from August 2006 to June 2007 with over 750 people with disabilities and their families, peak bodies, advocates and service providers (p. 5)*
Department for Families and Communities	SA	2008	*Intellectual Disability: Day Options.* www.dfc.sa.gov.au		
Department of the Premier and Cabinet	SA	2006	*Better Pathways Consultation Paper.* www.socialinclusion.sa.gov.au	*People with disability, families, carers, service providers*	
Intellectual Disability Services Council	SA	2004	*Day Options including Moving On Program.* www.idsc.sa.gov.au	*People with disability, families, carers, service providers*	
Department of Health –Aged and Disability	NT	2013	*Aged and Disability Program: Keeping our goals in sight.* www.health.nt.gov.au		

Appendix Nineteen

List of Peak Disability Organisations which participated in the Research

Dignity for Disability (SA) – ddsa https://www.surveymonkey.com/s/cas-ddsa

Autism Association of South Australia – aasa. https://www.surveymonkey.com/s/cas-aasa

Down Syndrome Association of South Australia – dsasa. https://www.surveymonkey.com/s/cas-dsasa

Brain Injury Network of South Australia – binsa. https://www.surveymonkey.com/s/cas-binsa

Conductive Education Association of South Australia – cease. https://www.surveymonkey.com/s/cas-ceasa

Carers SA – ci. https://www.surveymonkey.com/s/cas-ci

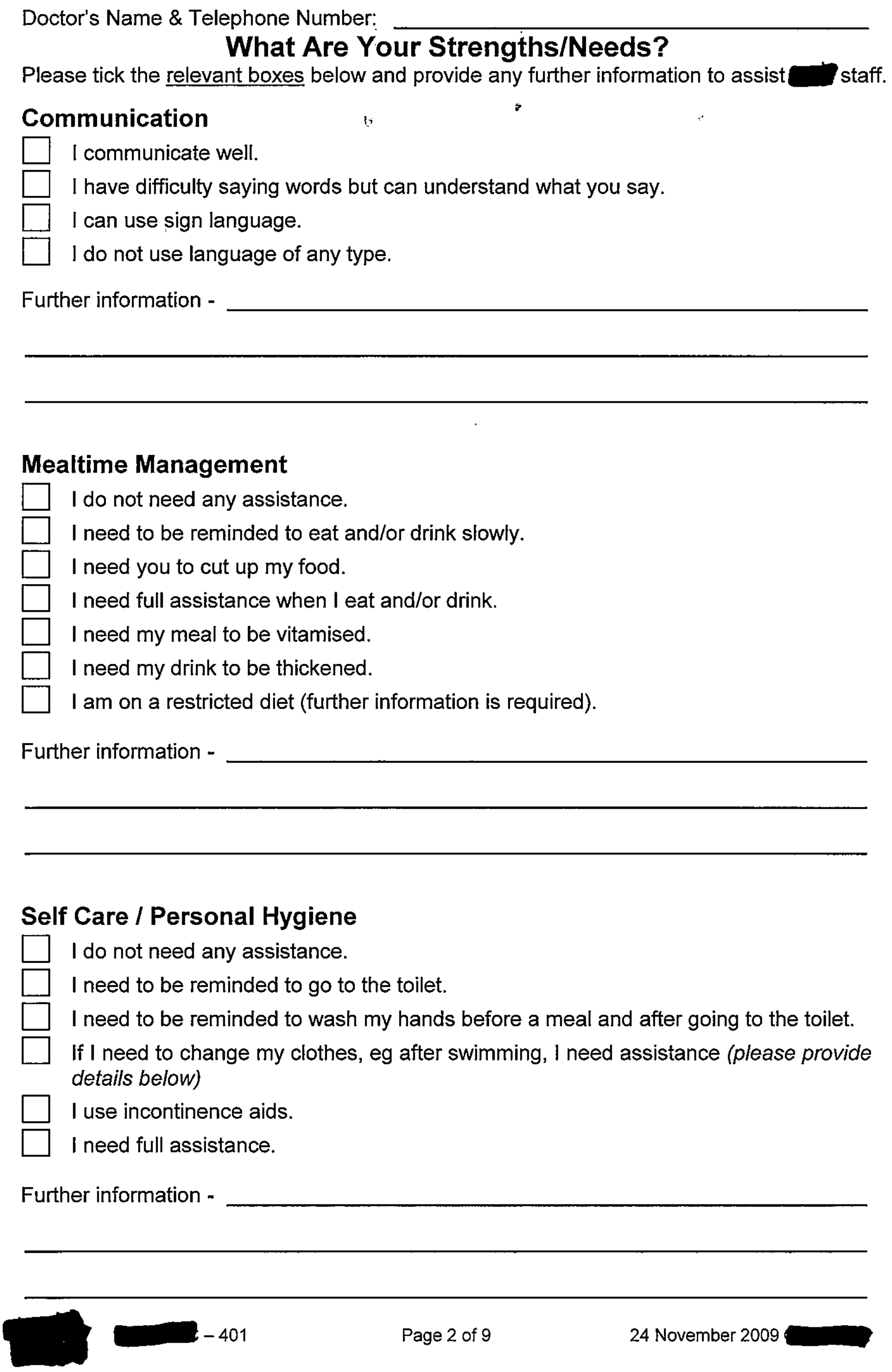
Disability Information and Resource Centre – dirc. https://www.surveymonkey.com/s/cas-dirc

Families4Families (Acquired brain injury support) – ff. https://www.surveymonkey.com/s/cas-ff

Appendix Twenty
Eligibility Assessment Tools in South Australia 2009-2015

1. The Vermont Support Needs Assessment tool Version 4.1 developed by G. Vermont for the State of Victoria, Australia. The Assessment tool contains two sections. Section One: Overview of Functional Status includes: Diagnostic status, vision, hearing, mobility, expressive communication and medical conditions. Section Two Assessment of Support Needs includes Physical support needs, social support needs, daily living skills, management of behaviour issues and safety issues. (Disability SA, 2011).
2. The Disability-Support, Training and Resource Tool 'D-START' was developed by the Wellbeing Research Unit (WRU) of Adelaide University in collaboration with the South Australian Department for Communities and Social Inclusion. D-START provided a computerised assessment of the support needs of adults 16 years of age and over with different types, levels and combinations of disabilities. Independent domains for assessment included Background Information such as their present living circumstances, personal goals, current sources of formal and informal care and personal quality of life, Activities of Daily Living, Health and Medical, Behaviour, Functional Skills, Personal and Contextual factors and key issues for future planning (Kirby, Harries, Guscia, Wilson, & Kaippully Chandrasekharan, 2013).
3. The Vineland Test, Vineland Adaptive Behaviour Scales, (Vineland-11) measures the personal and social skills of individuals. The Vineland Test is used to 'assess what a person actually does, rather than what he or she is able to do'. When adaptive behaviour information is combined with additional information including a person's intelligence, achievement at school and their physical health plans can be developed to address any special needs the person may have. Assessment is made in four domains: Communication, Daily Living Skills, Socialisation and Motor Skills. A teacher and parent version is completed with the parent version being processes either as an interview or a survey (AGS, 2015).

Appendix Twenty One: Assessment



Doctor's Name & Telephone Number: ______________________________

What Are Your Strengths/Needs?

Please tick the relevant boxes below and provide any further information to assist [redacted] staff.

Communication

☐ I communicate well.
☐ I have difficulty saying words but can understand what you say.
☐ I can use sign language.
☐ I do not use language of any type.

Further information - ______________________________

____

____

Mealtime Management

☐ I do not need any assistance.
☐ I need to be reminded to eat and/or drink slowly.
☐ I need you to cut up my food.
☐ I need full assistance when I eat and/or drink.
☐ I need my meal to be vitamised.
☐ I need my drink to be thickened.
☐ I am on a restricted diet (further information is required).

Further information - ______________________________

____

____

Self Care / Personal Hygiene

☐ I do not need any assistance.
☐ I need to be reminded to go to the toilet.
☐ I need to be reminded to wash my hands before a meal and after going to the toilet.
☐ If I need to change my clothes, eg after swimming, I need assistance *(please provide details below)*
☐ I use incontinence aids.
☐ I need full assistance.

Further information - ______________________________

____

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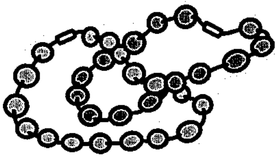
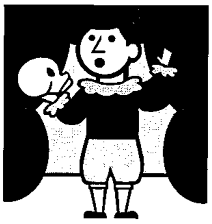
[redacted] [redacted] – 401 Page 2 of 9 24 November 2009 [redacted]

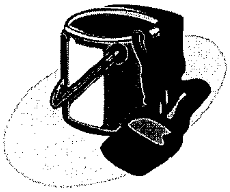
Appendix Twenty Two:

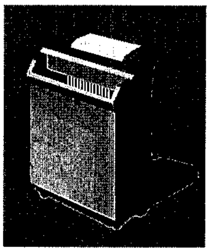
Assessment Using Pictures and Questions


Beading


Work skills/Packaging

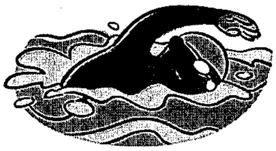

Drama


Graffiti Busters


Office Skills


Hotel Lunch


BBQ & Picnic


Swimming

Quiet Time

__________________ **helped me complete this.**

Suggestions:

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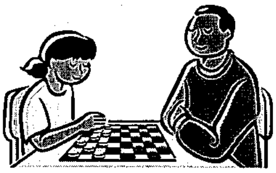
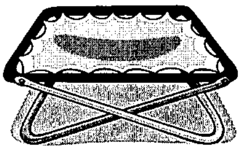
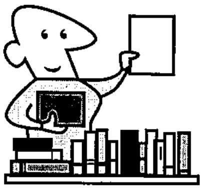
~~G:\IPP 2006\DS~~A Member Review Form.doc – updated ~~November 2006~~



Board Games

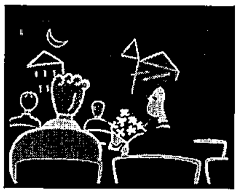


Gym

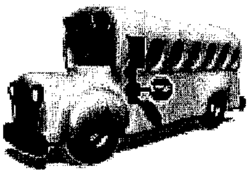


Library

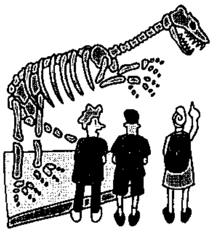
Dancing



Movies



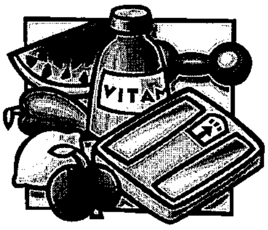
Bus Trips



Museum

Computer

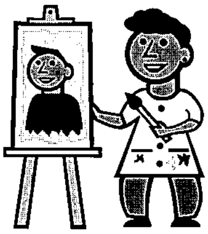
Horse Riding



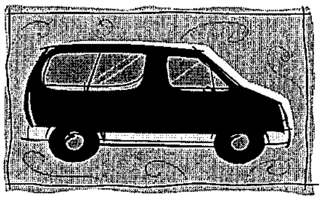
Health & Wellbeing

Roller Skating

Ball Games

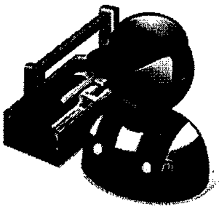


Art

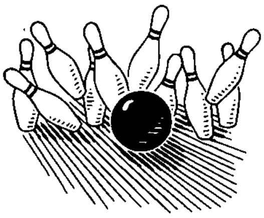


Meals on Wheels

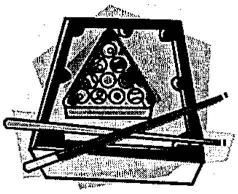
Craft



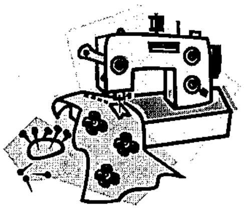
Blokes Shed



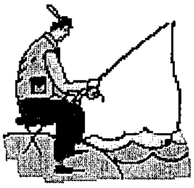
Bowling



Snooker

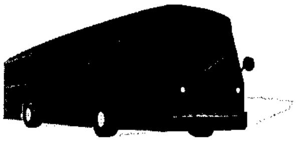


Sewing

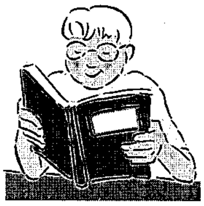


Fishing

Yoga



Public Transport



Reading

Zoo

Please take the time to answer these few questions. However, we are asking that you answer from ___________ perspective, **not** your own.

People like spending time with me because ________________

____

____

____

____

Things I do not want include (i.e. lots of social events)

____

____

____

____

Things I should have include (i.e. sit in a key place that I like)

____

____

____

____

Things I enjoy, like to do, or am good at are _______________

____

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____

____

Things you must know for me to be healthy and safe include (i.e. road sense, medication, diet) ________________________

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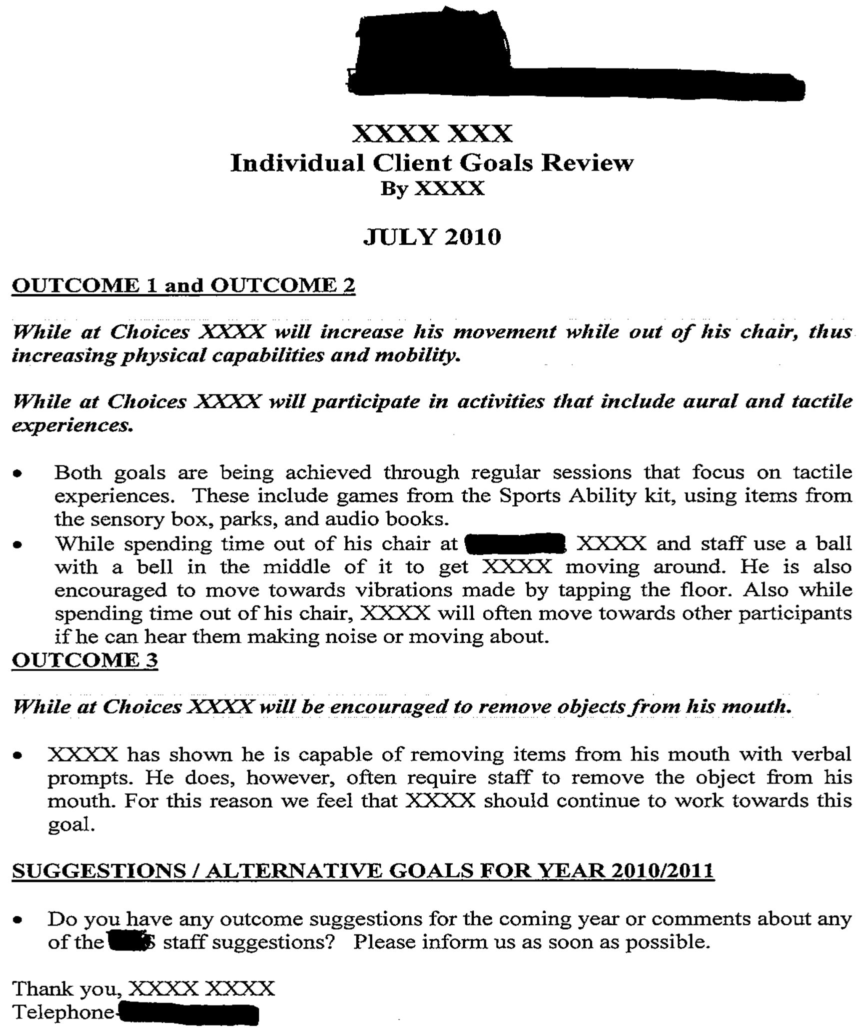
Appendix Twenty Three: Client Goals Review



[redacted]

XXXX XXX
Individual Client Goals Review
By XXXX

JULY 2010

OUTCOME 1 and OUTCOME 2

While at Choices XXXX will increase his movement while out of his chair, thus increasing physical capabilities and mobility.

While at Choices XXXX will participate in activities that include aural and tactile experiences.

- Both goals are being achieved through regular sessions that focus on tactile experiences. These include games from the Sports Ability kit, using items from the sensory box, parks, and audio books.
- While spending time out of his chair at [redacted] XXXX and staff use a ball with a bell in the middle of it to get XXXX moving around. He is also encouraged to move towards vibrations made by tapping the floor. Also while spending time out of his chair, XXXX will often move towards other participants if he can hear them making noise or moving about.

OUTCOME 3

While at Choices XXXX will be encouraged to remove objects from his mouth.

- XXXX has shown he is capable of removing items from his mouth with verbal prompts. He does, however, often require staff to remove the object from his mouth. For this reason we feel that XXXX should continue to work towards this goal.

SUGGESTIONS / ALTERNATIVE GOALS FOR YEAR 2010/2011

- Do you have any outcome suggestions for the coming year or comments about any of the [redacted] staff suggestions? Please inform us as soon as possible.

Thank you, XXXX XXXX
Telephone [redacted]

OUTCOME 3

OUTCOME: While at Choices XXXX will be encouraged to remove objects from his mouth.
ACTION: 1. When XXXX puts something into his mouth, Choices Staff are to verbally ask him to remove the object while touching his knee. 2. If required, Choices Staff are to repeat this process three times and on the third time are to remove the object from XXXX mouth. 3. Choices Staff are to verbally praise XXXX when he removes the object and/or once they remove it on the third time. 4. Choices Staff are to record XXXX response to this outcome in his communication book.

Review Date: [redacted]

Appendix Twenty Four: Implementation Choices

[redacted] DAILY PROGRAMME OPTIONS

CHOICE 1 Vocational Activities

Examples include: Working in community and school gardens, badge selling, volunteering, computer training and tech studies, home maintenance, sewing, library skills, numeracy and literacy instruction, fundraising for Charities, First Aid, home safety, home gardening, hospitality and catering, woodwork instruction etc.

CHOICE 2 Recreational and Social Activities

This includes activities such as swimming, bushwalking, volleyball, ten pin and lawn bowls, parachute games, gym visits, aerobics for fun, swing dancing, belly dancing, tennis, visits to the museum, Port River Dolphin cruises, Melbas Chocolates, fire station, movies, BBQ's, park visits, gallery visits, mini golf, fishing, Music Works, library visits, zoo visits, lazer skirmish, Open Door Disco, Sports Ability, SoundWaves etc

CHOICE 3 Centre Based and Life Skills Activities

Personal care (hygiene, grooming, make-up etc.) handling money, gardening, shopping for groceries, cooking, social development and integration, understanding emotions, social stories, road safety, craft activities eg : bath bombs, candle making, decorated frames, murals, painting, birthday cards, Christmas cards, paper Mache, decorations, gifts, music, aromatherapy, Ipad apps, Wii fit, Zumba, games and general social activity at "home base" etc

Appendix Twenty Five: Evaluation of CAS

Name:			
Address:		Suburb:	Postcode:
Telephone:			
Mobile:			
Email:			
Service being used:			

(The above details are optional)

1. Are you satisfied with the service your family member is receiving (please tick):
   ☐ Very Satisfied ☐ Satisfied ☐ Adequate ☐ Not Satisfied

2. How long have you been using (Organisation Name) Disability Services:

3. How helpful did you find the staff when your family member was first transitioned into our service? (Please advise what you found helpful and anything that could be improved for future transitioning).

4. What do you think of the site your family member is at? What would you like to see more of at the site?

5. How helpful are the staff at the site? Please list some of the best experiences you have had with the staff and some of the experiences that need improving:

____

____

____

____

6. Has your family member enjoyed the activities we run at the sites? What activities has your family member enjoyed the most and are there any activities we don’t have which you would like included on our activities list?

____

____

____

____

7. Do you believe you are getting enough information/updates on the time your family member is spending at the site? If not, what else would you like to know and see?

____

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____

____

8. What are some of the positives for you for having your family member at our service?

____

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9. What do you believe we could do to improve our services for your family member?

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10. Please list the things that you believe work well at the site for your family member:

____

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11. Any other comments:

____

____

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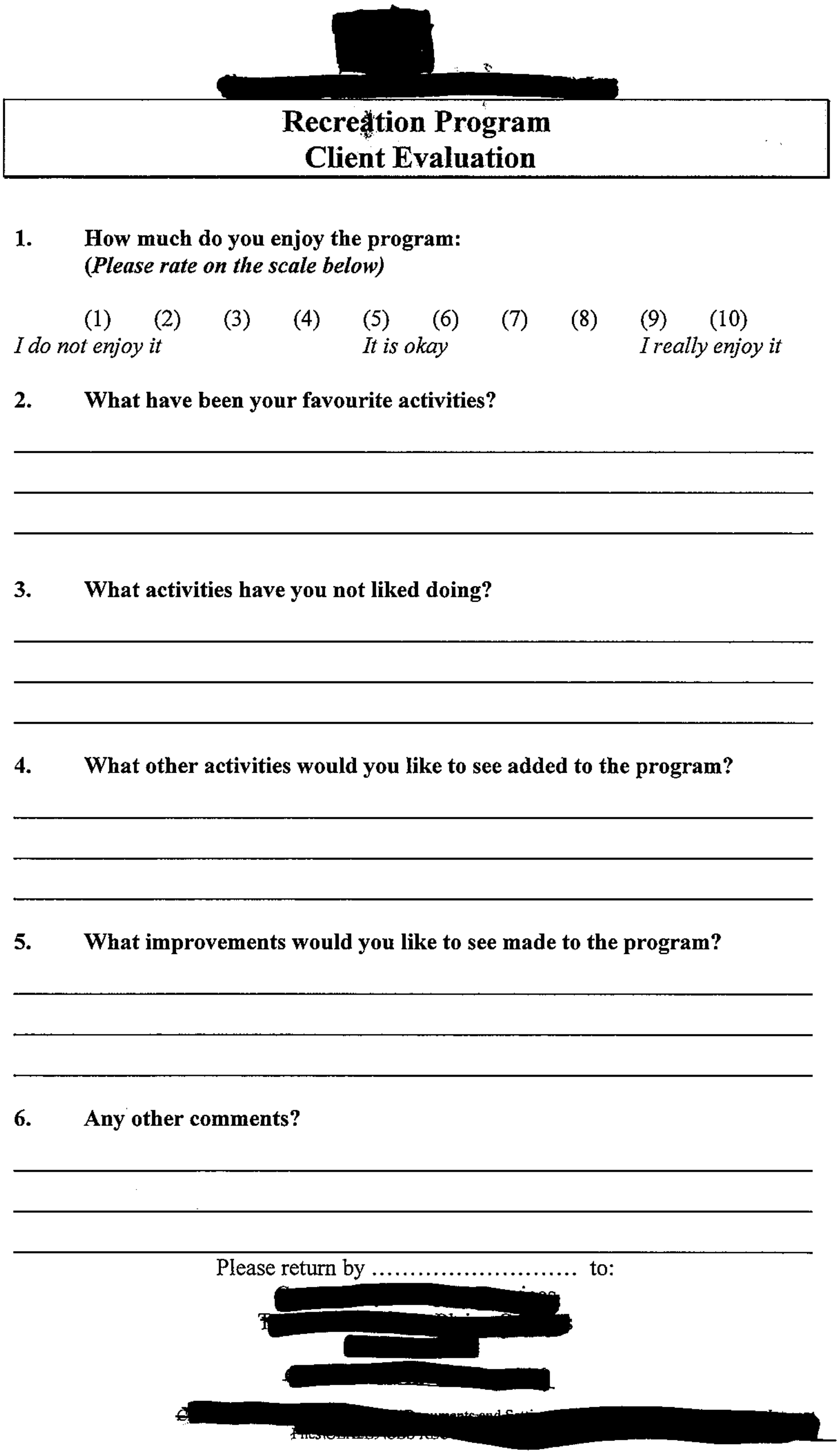
____

Thank you for your feedback. We sincerely appreciate your honest opinion and will take your input into consideration while providing services in the future.

Appendix Twenty Six: Client Evaluation



[redacted]

Recreation Program
Client Evaluation

1. **How much do you enjoy the program:**
(*Please rate on the scale below)*

(1) (2) (3) (4) (5) (6) (7) (8) (9) (10)

I do not enjoy it *It is okay* *I really enjoy it*

2. **What have been your favourite activities?**

3. **What activities have you not liked doing?**

4. **What other activities would you like to see added to the program?**

5. **What improvements would you like to see made to the program?**

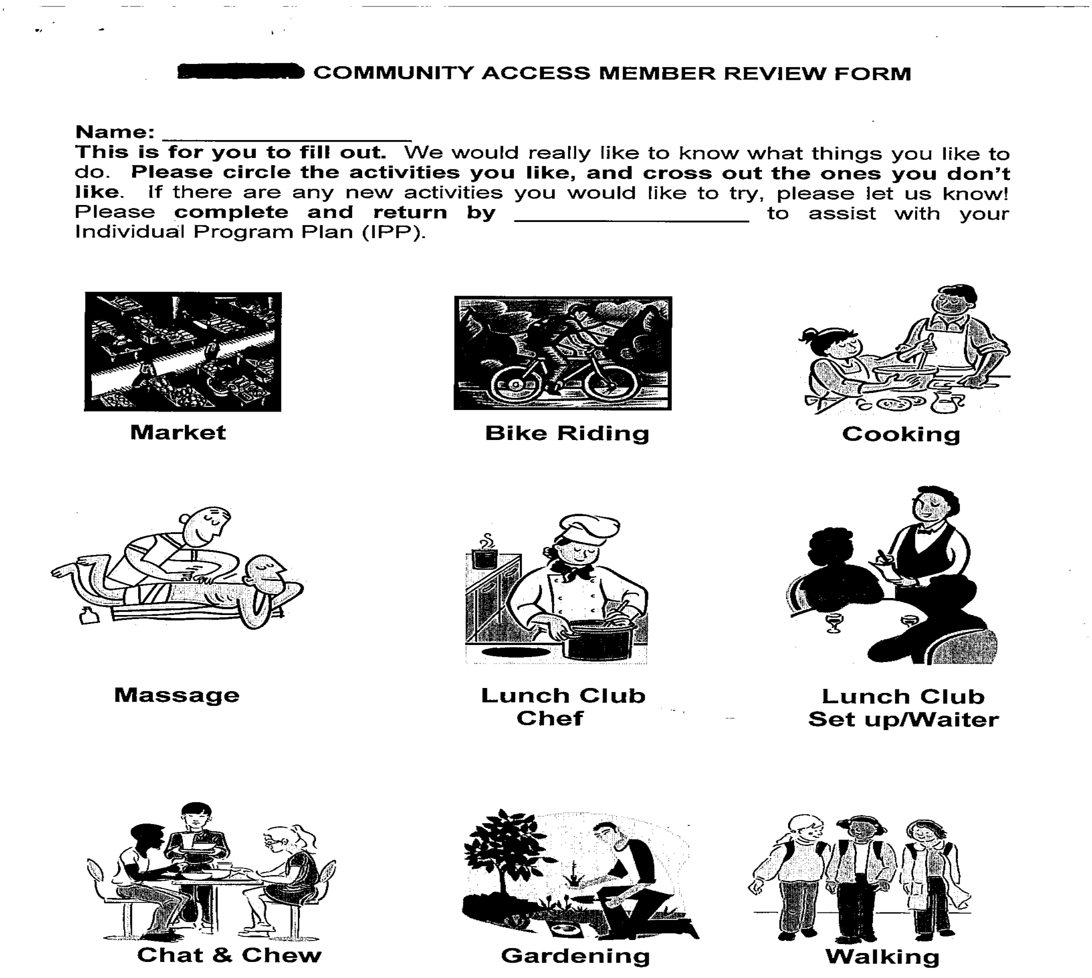
6. **Any other comments?**

Please return by .... to:

[redacted]

[redacted]

Appendix Twenty Seven: CAS Member Review



[redacted] COMMUNITY ACCESS MEMBER REVIEW FORM

Name: ____________________

This is for you to fill out. We would really like to know what things you like to do. **Please circle the activities you like, and cross out the ones you don't like.** If there are any new activities you would like to try, please let us know! Please **complete and return by** ________________ to assist with your Individual Program Plan (IPP).

Market

Bike Riding

Cooking

Massage

Lunch Club Chef

Lunch Club Set up/Waiter

Chat & Chew

Gardening

Walking

Appendix Twenty Eight:

Community Centres and Neighbourhood Houses in the Western Region of Adelaide, South Australia

- Bowden Brompton Community Group (Bowden)
- Bower Cottages Community Centre (Semaphore)
- Camden Community Centre (Camden Park)
- Cheltenham Community Centre (Cheltenham)
- Clarence Park Community Centre (Clarence Park)
- Findon Community Centre (Findon)
- Glandore Community Centre (Glandore)
- Henley and Grange Community Centre (Henley Beach)
- Holdfast Bay Community Centre (Hove)
- Kilburn Community Centre (Kilburn)
- Lefevre Community Centre (Osborne)
- Reedbeds Community Centre (Fulham)
- Seaton North Neighbourhood Centre (Seaton North)
- Taperoo Community Centre (Taperoo)
- The Junction Community Centre (Ottoway)
- and the West Lakes Community Centre (West Lakes)
- Specific services were also located including the Vietnamese Centre (Athol Park)
- Kura Yelo an Aboriginal Arts Centre working with Aboriginal and non-Aboriginal participants (Pt. Adelaide)
- Australian Refugees Association support service (Underdale).