

**School of Occupational Therapy**

**Communication Guide Support for Western Australians with Deafblindness:  
A Pilot Project**

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**Declaration**

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

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### **Abstract**

Deafblindness is considered a unique disability and while in many countries there are specialised individualised deafblind services, this is not the case in Australia. This study was designed to be exploratory due to the lack of research which investigates the impact of deafblind services. This study employed a multiple-case study methodology and investigated the impact upon ten individuals with deafblindness who received six months support from a 'communication guide' who has undertaken specialised competency based training in deafblind issues, sighted guide and deafblind communication.

To provide background to this research, literature on four topics was reviewed. These included: deafblindness; quality of life; person-centred approaches; and occupational justice. A meta-analysis was conducted of deafblind literature, with classifications of deafblindness, population rates, functional and health impacts, and services studied. As several authors indicated that deafblindness has an impact upon individuals' quality of life, this concept was explored. Within existing deafblind services, person-centred approaches are extensively employed as a method of achieving improved quality of life for individuals and thus this approach is discussed. Finally a discourse on occupational justice is presented, as individuals with deafblindness do not always have the ability to participate in meaningful occupations and this study provided the opportunity for participants to do so.

This dissertation outlines the key stages for the study, which included: the recruitment of participants; the recruitment and training of communication guides; and the implementation of the communication guide intervention. Mixed methods were employed for data collection, with participants completing pre and post quantitative measures and a semi-structured interview completed at the conclusion of the intervention.

The qualitative and quantitative data indicated there was an overall increase in the quality of life of participants following the communication guide intervention. The results demonstrated all participants achieved better outcomes in individual goals, with statistically significant increase in the Performance and Satisfaction components of the Canadian Occupational Performance Measure. Qualitative data analysis yielded themes which included: identification of competent communication guides skills; an increase in connections and networks; the importance of practical, emotional and advocacy support from the communication guides; and opportunities for service development. These results for ten participants are encouraging and suggest adaption of these techniques might be worthwhile. A larger national study to investigate is recommended.

## Chapter 1 – Background

### Part 1: Understanding Deafblindness

Deafblindness is a unique disability, distinct from single sensory impairments of vision or hearing. Deafblindness can be categorised into congenital or acquired deafblindness, with studies into the prevalence of deafblindness reporting 0.2% (Robertson & Emerson, 2010) to 3.3% (Caban, Lee, Gómez-Marín, Lam & Zheng, 2005) of the population, with deafblindness strongly correlated with age and one study reporting 36% of individuals over the age of 85 years who had deafblindness (Access Economics, 2010). It is generally considered that deafblindness is a condition that is under-reported, especially within the older population. Individuals with deafblindness tend to experience greater difficulties in functional areas (Brennan, *et al.*, 2005; Crews & Campbell, 2004; Grue *et al.*, 2009; Lin, *et al.*, 2004; Raina, Wong & Massfeller, 2004), have more health issues (Capella-McDonnall, 2005; Chia, *et al.*, 2006; Chou & Chi, 2004; Crews, *et al.*, 2004; Heine & Browning, 2002; Lupsakko, *et al.*, 2002), and have higher mortality (Appollonio, *et al.*, 1995; Gopinath, *et al.*, 2013; Lam, *et al.*, 2006;) than those without a sensory impairment or those with a single sensory impairment.

**Definition of deafblindness.** Deafblind is a term that is used when a person has a combination of both impaired vision and hearing. Dual sensory loss is another term that can be used to describe deafblindness (Senses Australia, 2013a). The term deafblind is accepted as the all-encompassing terminology describing all levels of severity, independent of time, order of onset, or age of the person (Wittich, Southall, Sikora, Wantanabe & Gagne, 2013). The unified term *deafblindness* has replaced the hyphenated term *deaf-blindness* in order to reflect the unique needs of individuals who cannot compensate for the loss of one sense with the other (Lagati, 1995). People with deafblindness form a very diverse group due to the varying degrees of their vision and hearing impairments, plus possible additional disabilities (The Australian Deafblind Council, n.d.) and age of onset of the sensory impairments (Dalby *et al.*, 2009a). Only a small proportion of deafblind people have absolutely nil vision and hearing (Senses Australia, 2013a).

The Australian Deafblind Council, which is Australia's national deafblind advocacy organisation, stated: "Deafblindness is described as a unique and isolating sensory disability resulting from a combination of both a hearing and vision loss or impairment which significantly affects communication, socialisation, mobility and daily living" (n.d., What is Deafblindness, para. 1)." Consistent with international definitions, this is a functional definition in that it describes the impact of both a vision and hearing impairment on an individual's function, not the level of impairment. Some researchers and professionals within

the field of sensory impairment consider that an individual is “deafblind” when hearing loss in the better ear is less than 35 decibels and vision is 20/60 or less (Fellinger, Holzinger, Dirmhirn, van Dijk & Goldberg, 2009), however given this definition, deafblindness is not defined by medical assessment of vision and hearing alone but must be supplemented by a functional evaluation of hearing and seeing (Dammeyer, 2010a).

**Classifications of deafblindness.** Individuals can become deafblind for a number of reasons. These include:

- People are born hearing impaired or deaf and blind or vision impaired;
- People are born hearing impaired or deaf and later experience deteriorating sight;
- People are born vision impaired or blind and experience significant hearing loss;
- Injury or disease to the brain or visual and auditory systems after birth; and
- Vision and hearing have both significantly deteriorated due to the ageing process (Senses Australia, 2013a).

People who are deafblind are generally classified into two groups: those who are congenitally deafblind having been born with vision and hearing impairments or having developed both prior to age two (Munroe, in Dalby *et al.*, 2009a); and those with acquired deafblindness, who develop a dual impairment after two years of age.

Common causes of congenital deafblindness include CHARGE syndrome, congenital brain damage, premature birth, cytomegalovirus, chromosomal abnormalities and rubella syndrome (Munroe, 2001; Watters *et al.*, 2004). The predominant cause of acquired deafblindness is the deterioration of vision and hearing loss due to ageing (Robertson & Emerson, 2010; Senses Foundation, 2008; Watters *et al.*, 2004). Other causes of acquired deafblindness include genetically inherited disorders (Usher syndrome), infections such as meningitis, and brain injury (Dalby *et al.*, 2009a).

**Prevalence and incidence of deafblindness.** A number of authors have commented that there has been more research into the prevalence, incidence, impact, and costs associated with having a vision impairment or a hearing impairment than research into deafblindness (Appollonio, Carabellese, Magni, Frattola & Trabucchi, 1995; Brennan, Horowitz & Su 2005; Chia, *et al.*, 2006; Chou & Chi, 2004; Lam, Lee, Gomez-Marin, Zheng & Caban, 2006; Lin, *et al.*, 2004; Lupsakko, Mantjarvi, Kautiainen & Sulkava, 2002).

The prevalence and incidence of deafblindness has been described as difficult to ascertain (Prain, 2005; Watters *et al.*, 2004), with the literature demonstrating differences in

rates across studies. As deafblindness is not considered a unique disability in Australia (and in many other countries) data collection and identification of individuals with deafblindness can be challenging. To determine prevalence and incidence rates, data has not been collected from a database listing people who are deafblind, but by synthesising the information from broad disability databases and cross referencing individuals who have indicated a vision and a hearing impairment.

In Australia over recent years (as in other developed countries), the aetiology of the different causes of deafblindness has been changing. It is challenging to determine overall trends in deafblind prevalence and incidence rates as a result of this changing aetiology due to the lack of existing data. These changes in the causes of deafblindness are in part from immunisation programs for disorders such as rubella and measles that have been effectively implemented, and improved medical procedures for retinopathy of prematurity, leading to the reduction of deafblindness caused by these diseases (Access Economics, 2010; Schiarti, Hoube & Synes, 2008; Senses Foundation, 2008). As increases in technology have led to the survival of very premature infants and young children with severe chromosomal abnormalities, deafblindness due to these causes has increased (Access Economics, 2010; Senses Foundation, 2008). Increased life expectancy has led to the increased incidence of acquired deafblindness, since both hearing loss and visual impairment are strongly age-related (Access Economics, 2010; Senses Foundation, 2008). Sense, a UK organisation (2010) commented that the actual number of people who are deafblind and needing support in the UK would be higher than reported as there is a reliance on self-reporting in surveys and older people often consider their deafblindness as part of getting old, rather than as a disability.

Detailed information on the reported prevalence and incidence of deafblindness is outlined below and summarised in Table 1 (p. 13). This table identifies the author and date of the study, the country within which the study was conducted, the rate for deafblindness in that country, including if this rate was related to congenital or acquired deafblindness, and if the rate was for a specific age range.

A study reviewing the prevalence of concurrent hearing and visual impairment among individuals aged 18 years or older in the US from 1997 to 2002 reported an overall prevalence of 3.3%. The prevalence increased from 1.3% in the 18-44 years age group, to 16.6% in those over 80 years (Caban, *et al.*, 2005). Other North American studies have reported between 5% and 9% of older adults have both a vision and hearing impairment

(Campbell, Crews, Moriarty, Zack & Blackman, 1999; Raina, Wong, Dukeshire, Chambers & Lindsay, 2000).

A report by Robertson and Emerson (2010) which used existing national data sources, estimated that in 2010 approximately 132,000 people in the UK had “severe impairments” of both hearing and vision, which equated to 212 people per 100,000. Robertson and Emerson (2010) utilised 12 national data sources and from these estimated the prevalence rate with a 95% confidence limit. “Severe impairments” were classified as the lower estimate of this confidence limit. They reported that nearly three quarters of all people with “severe impairments” of both hearing and vision were aged 70 or over.

Robertson and Emerson (2010) projected the estimated number of people in the UK with “severe impairments” of both hearing and vision in 2030 (if age and gender specific prevalence rates remain constant) as 245,000, or 343 per 100,000. They suggested that the increases over the next 20 years will be driven by general demographic change, in particular the increase in the number of elderly people aged over 70 years. They commented that health and social care agencies will need to ensure that they provide services and support to meet current levels of need and plan for significant growth in provision over the coming decades.

In 2010, the Danish Resource Centre on Congenital Deafblindness had 63 children and 127 adults registered in Denmark as having congenital deafblindness. This equated to a total prevalence of 1:19,000 in the congenitally deafblind child age group and 1:34,000 for the congenitally deafblind adult age group, which suggests that the prevalence of congenital deafblindness is reducing, possibly due to effective immunisation against diseases such as Rubella. A larger proportion of the children belonged to ethnic minorities compared to the group of adults with congenital deafblindness, (Dammeyer, 2010a) which supports this conclusion. Another explanation may be a higher mortality rate (Dammeyer, 2010a).

The Danish Information Centre for Acquired Deafblind conducted a study in 1996 to determine how many people had both a vision and hearing impairment. They estimated the number of people with acquired deafblindness in Denmark to be 1100, and those with congenital deafblindness to be 150, which equated to an overall prevalence of 25 deafblind people in 100,000 in the population (Mortensen, n.d.). Mortensen (n.d.) reported that 82% of the people with acquired deafblindness in Denmark were deafblind because of age-related vision and hearing loss. He reported that 710,000 people were over 67 years in Denmark at the time, 900 of whom were deafblind because of age-related vision and hearing loss which equated to an incidence of 127 in 100,000 people for this age category.

A study by Watters *et al.* (2004) collected demographic data of people who were deafblind receiving services from various organisations throughout Canada. This study reported the total estimate of people who were deafblind as 3,306, which was the number of deafblind people who were actually identified within the study. This number represented an incidence of 11 persons with deafblindness per 100,000 persons. Watters *et al.* (2004), stated that this incidence of 11 per 100,000 represented almost a 100% increase in the number of people with deafblindness known to Canadian service organisations in 2001. The authors did not comment on why there has been a doubling of individuals who are deafblind receiving services within a four year period, but it may be due to better identification practices or increased funding for this population. The report stated 45.5% of people with deafblindness in Canada were over the age of 61 and 32.3% were congenitally deafblind, compared to 67.7% who had acquired deafblindness. Watters *et al.* (2004) also reported that the Canadian Council of Social Development gathered data through the Canadian Community Health Survey from 2000-2002 on individuals over 12 years with deafblindness. Approximately 69,800 Canadians were identified, which was a prevalence of 232 per 100,000 persons.

Apart from age related deafblindness, based on these prevalence rates, Usher syndrome is the most common cause of deafblindness worldwide (Spandu & Rohrschneider, 2002). Within this communication guide study, being the subject of this dissertation, half (five) of the participants had Usher syndrome. The major symptoms of Usher syndrome are congenital hearing loss and an eye disorder called retinitis pigmentosa, which causes night-blindness and a loss of peripheral vision through the progressive degeneration of the retina (National Institute on Deafness and Other Communication Disorders, 2013). A number of epidemiological studies have specifically investigated the prevalence of Usher syndrome, with a summary contained within Table 2 (p. 14). Estimates of the incidence of Usher syndrome in a number of European countries range from 3.3 (Sadeghi, Kimberling, Tranebjoerg & Moller, 2004) to 6.2 per 100,000 individuals (Hope, Bunday, Proops & Fielder, 1997; Spandu & Rohrschneider, 2002).

A study by Access Economics (2010), suggested that in people aged 85 years or older, the prevalence of deafblindness is over 36%. Access Economics (2010) reported that in 2010, 1.49% (332,400) of the Australian population had deafblindness, of which 97.7% (323,300) were 65 years or older. They predicted that in 2050, 3.02% (1,065,100) of the Australian population are expected to have deafblindness. Another Australian study reported that the prevalence of deafblindness was six percent within a sample of 1972 individuals over the age of 55, with this increasing to 27% in those aged 80 or older (Schneider, *et al.* 2012).

In 2007, Senses Foundation (now Senses Australia) commissioned a study to identify the number, location, age and level of disability of people who were deafblind throughout Western Australia. The project used existing population-based statistical data to determine key outcome objectives related to people who had a vision and hearing impairment. This approach involved the use of the latest data from the Commonwealth/State Territory Disability Agreement National Minimum Data Set and the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (Senses Foundation, 2008). The Australian Institute of Health and Welfare was contracted by Senses Australia to construct specific tables for the project that would supply more accurate information than could be obtained by just focusing on demographic data for individuals who were identified as deafblind. The process of defining the target group for the project involved the Australian Institute of Health and Welfare's use of existing definitions of disability used primarily by the Australian Bureau of Statistics and adjusting these to focus on those with both a hearing and vision disability.

The study found that in Western Australia in 2003, there were 8,800 people who had both a vision and hearing impairment, which equated to a rate of 0.45% of the population. Approximately 6,500 people were over the age of 60. Of the total group of 8,800, many lived in the community but had significant restrictions to their activities of daily living, communication, socialisation and mobility (Senses Foundation, 2008).

Senses Australia commissioned another study in 2013 to identify the number of individuals with a combined vision and hearing disability within Western Australia and across Australia (Dyke, 2013). The project also investigated the age and gender of these individuals, their geographic distribution and degree of activity and participation. This study found 0.35% (7,900) and 0.5% (99,800) of Western Australians and Australians respectively had deafblindness. There was a greater proportion of females (56% in Western Australia and 58% in Australia), 67% of deafblind Australians were over the age of 75, and over half of those with deafblindness in Australia reported a profound or severe core activity limitation and almost a third, a moderate or mild core activity limitation (Dyke, 2013).

Table 1

*Deafblind prevalence / incidence rates*

<b>Author / Date</b>	<b>Country</b>	<b>Prevalence / Incidence</b>
Caban, Lee, Gómez-Marín, Lam & Zheng (2005)	USA	<ul style="list-style-type: none"> <li>• 3.3% in US adults from 1997-2002</li> <li>• 1.3% in the 18-44 years age group</li> <li>• 16.6% in those over 80 years</li> </ul>
Campbell, Crews, Moriarty, Zack & Blackman (1999)	USA	<ul style="list-style-type: none"> <li>• 8.6% of adults aged 70 years or older reported both hearing and vision impairment</li> </ul>
Raina, Wong, Dukeshire, Chambers & Lindsay (2000)	Canada	<ul style="list-style-type: none"> <li>• 5% of adults aged 65 years or older reported both a hearing and vision impairment</li> </ul>
Robertson and Emerson (2010)	UK	<ul style="list-style-type: none"> <li>• 212 per 100,000 people with severe impairments of both hearing and vision</li> <li>• Three quarters of all people with severe impairments of hearing &amp; vision were aged 70+</li> </ul>
Dammeyer (2010a)	Denmark	<ul style="list-style-type: none"> <li>• 5.3 per 100,000 people affected with congenital deafblindness within 0-18 age</li> <li>• 2.9 per 100,000 people affected with congenital deafblindness 18 years or older</li> </ul>
Mortensen (1996)	Denmark	<ul style="list-style-type: none"> <li>• 25 per 100,000 people with deafblindness</li> </ul>
Watters, Owen & Munroe (2004)	Canada	<ul style="list-style-type: none"> <li>• 11 per 100,000 people with deafblindness</li> <li>• 45.5% of people over the age of 61 with deafblindness of total deafblind population</li> <li>• 32.3% congenitally deafblind of total deafblind pop.</li> <li>• 67.7% acquired deafblindness of total deafblind pop.</li> </ul>
Canadian Community Health Survey 2000-2002	Canada	<ul style="list-style-type: none"> <li>• 232.28 per 100,000 people over 12 years with deafblindness</li> </ul>
Access Economics (2010)	Australia	<ul style="list-style-type: none"> <li>• 1.49% of total population with deafblindness</li> <li>• 36% of people aged 85 years or older with deafblindness</li> </ul>
Schneider <i>et al.</i> (2012)	Australia	<ul style="list-style-type: none"> <li>• 6% of individuals over the age of 55 deafblind</li> <li>• 27% of individuals 80 years + with deafblindness</li> </ul>
Senses Foundation (2008)	Australia (Western)	<ul style="list-style-type: none"> <li>• 0.45% of total population with deafblindness</li> </ul>
Senses Australia (2013)	Australia	<ul style="list-style-type: none"> <li>• 0.5% of total population with deafblindness</li> <li>• 67% of deafblind Australians aged over 75</li> </ul>

Table 2

*Usher syndrome prevalence / incidence rates*

Sadeghi, Kimberling, Tranebjoerg & Moller (2004)	Sweden	• 3.3 per 100,000 individuals with Usher syndrome
Hope, Bunday, Proops & Fielder (1997)	England	• 6.2 per 100,000 individuals with Usher syndrome over the age of 15 years
Spandu & Rohrschneider (2002)	Germany	• 6.2 per 100,000 individuals with Usher syndrome

**Impact of deafblindness.** There are a number of physical, cognitive, emotional, social, and occupational changes that occur in the human body across the lifespan (Berk, 2007; Bonder & Wagner, 2001; Boyd & Bee, 2009). Combined vision and hearing impairment is one of these possible changes, with the incidence of deafblindness strongly correlated with increased age (Access Economics, 2010; Caban, *et al.*, 2005; Campbell, *et al.*, 1999; Raina, *et al.*, 2000; Robertson & Emerson, 2010; Senses Foundation, 2008). The majority of studies on the impact of deafblindness have been limited to individuals who are over 70 years of age (Brennan, *et al.*, 2005; Crews & Campbell, 2004), with no studies located investigating the impact of deafblindness on quality of life measures in early or middle adulthood.

In an Australian study of 2015 people using the 36-Item Short-Form Health Survey (SP-36), Chia, *et al.* (2006) found that deafblindness is associated with poorer quality of life than single sensory impairments. A combination of both a vision and hearing loss may have a greater impact on functional ability than a single impairment as the individual is unable to use the other sense to compensate (Glass, as cited in Brennan, *et al.*, 2005). Access Economics (2010) reported that the burden of disease as a result of deafblindness was quite substantial. They estimated the burden of disease using Disability Adjusted Life Years (DALY). One DALY represents the equivalent to losing a year of life at full health (World Health Organization, 2012). The study estimated the amount of years lost to deafblindness in Australia in one year as 47,400.

Crews and Campbell's (2004) analysis of 9447 individuals identified that functional problems increased amongst individuals with deafblindness compared to those with single impairment of vision or hearing, with reported odds ratios being greater in those with deafblindness. An odds ratio represents the odds that an outcome will occur given a particular exposure, compared to the odds of the outcome occurring in the absence of that exposure for the measured outcomes (Szumilas, 2010). Those functional difficulties included

getting out in the community (odds ratio (OR): 4.8); getting out of bed (OR: 3.8); using a telephone (OR: 9.1); cooking (OR: 4.7) and the administration of medicine (OR: 4.0). In a study by Lin, *et al.* (2004) those with deafblindness had the greatest reduction in functional skills (walking, climbing stairs, preparing meals, shopping and housework), compared to only a vision or hearing impairment. A number of studies have found that deafblindness is associated with a reduction in an individual's ability to perform instrumental activities of daily living (Brennan, *et al.*, 2005; Grue *et al.*, 2009; Raina, Wong & Massfeller, 2004). Laforge, Spector and Sternberg (as cited in Dammeyer, 2010b) found that after adjusting for age, sex and cognitive status, people with deafblindness were 3.5 times more likely to experience a functional decline than were unimpaired older adults.

People with deafblindness generally reported considerably poorer health than people with a hearing impairment and poorer health than people with vision impairment (Crews, *et al.*, 2004). People with deafblindness had poorer mobility, increased numbers of falls, increased hip fractures, and increased incidence of osteoporosis, stroke, heart disease and arthritis compared to individuals with only a single impairment (Crews, *et al.*, 2004). A combined vision and hearing loss is strongly associated with reduced cognitive processes (Lin, *et al.*, 2004; Tay, *et al.*, 2006) such as memory (Brennan, Su & Horowitz, 2006; Tay, *et al.*, 2006; Valentijn, *et al.*, 2005), concentration (Tay, *et al.*, 2006; Valentijn, *et al.*, 2005), language (Tay, *et al.*, 2006), and increased states of confusion (Brennan, *et al.*, 2006;), as well as being strongly associated with depression (Capella-McDonnall, 2005), and negatively impacting upon mental wellbeing (Chia, *et al.*, 2006; Chou & Chi, 2004; Heine & Browning, 2002; Lupsakko, *et al.*, 2002). Mortality rates are also increased with deafblindness (Appollonio, *et al.*, 1995; Lam, *et al.*, 2006;) compared to individuals with a single or no sensory impairment. An Australian population based study reported individuals with deafblindness have 62% increased risk of all-cause mortality, compared to individuals with no sensory impairment (Gopinath, *et al.*, 2013).

Congenital deafblindness can have a considerable impact on a person's ability to communicate, as the development of their social interaction and functional communication is reliant on the skills of their communicative partner (Janssen & Rodbroe, as cited in Dammeyer, 2010b). Dammeyer (2010b) hypothesised that cognitive function is related to the communicative abilities of the person who is congenitally deafblind and their communication partner, where limited communicative abilities of the communication partner may affect the cognitive function of the person who is congenitally deafblind. That is, if a person who is congenitally deafblind does not have effective communication with others, their cognitive functioning will be negatively impacted upon.

Dalby *et al.* (2009a) assessed 182 Canadians with deafblindness eligible for ‘intervenor’ services using the interRAI Community Health Assessment and Deafblind Supplement (an assessment that is intended to assess individuals living in the community who may be at risk of a functional decline) and provided information on the characteristics of these individuals. The findings were presented as those with acquired deafblindness and those with congenital deafblindness. Those individuals with acquired deafblindness had an average age of 52.8 years, tended to have never been married, were more likely to be female, and lived in private homes or apartments. Of those with acquired deafblindness, 48.9% did not have a cognitive impairment and 78.5% were able to perform activities of daily living independently. Those individuals with congenital deafblindness were 20 years younger on average, compared to the acquired deafblind group, more likely to be male, never have married and lived with non-relatives, parents or guardians. In the congenital deafblind group, 12.5% had no cognitive impairment, with 25% able to perform activities of daily living independently and only 9.2% having no difficulty performing instrumental activities of daily living.

There were also impairments of communication in participants of the Dalby *et al.* (2009a) sample, with a number of communication modes routinely used. The five most common communication systems were idiosyncratic signs, gestures or behaviours (57.1%); adapted manually coded language (48.9%); speech (43.6%); a tactile method for expressive communication (42.3%) and sign language (40.7%). Over half of those assessed showed moderate to high levels of social engagement (58.7%), however many experienced severe to very severe difficulty interacting with others (67.8%). In terms of orientation and mobility, 76.4% of the sample were independent or received minimal help in familiar indoor environments and 39.8% in familiar outdoor environments. A small proportion of individuals were independent in moving within an unfamiliar indoor environment, with the acquired group being much more likely to be independent than the congenital group.

According to Dalby *et al.* (2009a), the results showed significant differences between those with congenital and acquired deafblindness. These included differences in living arrangements, marital status, communication modes and employment status, which have been outlined above. People with congenital deafblindness in the sample appear to have had a number of challenges including the communication, social interaction, orientation and mobility and activities of daily living. People with acquired deafblindness also have their own challenges, such as losing roles as their dual sensory impairment develops and feelings of loneliness. The findings indicated that although the acquired group had the capacity to

function more independently in the community, given their functional and social skills, they were more socially isolated and more likely to report feeling lonely.

**Economic cost of deafblindness in Australia.** The monetary value of the burden of disease associated with deafblindness in Australia in 2010 was estimated at \$7.9 billion (Access Economics, 2010). This monetary value is the cost of loss of life and wellbeing of deafblind individuals to the Australian economy.

Access Economics (2010) also estimated the financial impact of deafblindness in Australia in 2010, as \$10.5 billion, or 0.81% of Gross Domestic Product. This financial impact was measured according to six main categories:

- Health care expenditure (\$3.45 billion)
- Loss of earning and productivity (\$263.4 million)
- Value of care provided by friends and family (\$6.18 billion)
- Aids, equipment and home modifications (\$87 million)
- Education and support services (\$59 million)
- Losses from transfer payments (\$448 million), which includes the administration costs of the welfare and taxation systems

The overall estimated economic cost of deafblindness in Australia, without those who have deafblindness having any physical, psychological or intellectual disabilities, was \$18.4 billion in 2010. This is a substantial cost which could be reduced, particularly the burden of disease costs, with greater awareness of the disability and support to this population (Access Economics, 2010).

**Funding and services available to adults who are deafblind in Western Australia.** Senses Australia, a Western Australian not-for-profit disability organisation, provides the only specialised service for individuals who are deafblind in the state. Senses Australia provides a short term consultation service related to deafblindness to individuals, families, or organisations. Titled Deafblind Statewide Consultation Program, the service is funded partly via the Disability Services Commission, the state government agency responsible for disability in Western Australia, and partly through charitable fundraising by Senses Australia. Apart from this service, funding allocations and other disability services such as accommodation support, recreation, alternatives to employment, and vocational services are generic.

The Deafblind Statewide Consultation Program (DBSCP) encourages the development of communication and independence for people who are deafblind or sensory impaired with

additional disabilities throughout Western Australia. The DBSCP provides specific education, training, and resources on deafblind issues. The service is staffed with a congenital and acquired deafblind consultant. Support is also available from a speech pathologist, occupational therapist, physiotherapist, and social worker, who are experienced in working with individuals who are deafblind. These staff assess individuals, develop and implement programs to assist, and support them to develop communication and independence. The DBSCP also provides training to the family, direct care workers, teaching staff, and to therapy staff working with people who are deafblind or sensory impaired with additional disabilities. Resources including DVDs, handouts, and booklets are developed through the service (Senses Australia, 2013b).

**Funding and services available to adults who are deafblind in Australia.** As in Western Australia, there is only generic funding available to individuals who are deafblind in Australia. For example, an adult with deafblindness may receive a Disability Support Pension or services via the Home and Community Care (HACC) program which provides basic support to build and maintain people's skills so that they can carry out essential everyday activities and continue to live as independently as possible in the community (Western Australian Department of Health, n.d.). These services may include home cleaning, Meals on Wheels, transportation, or gardening support.

The Australian Deafblind Council (2010) examined the specific services available for people who were deafblind in Australia. It argued that single sensory disability service provider organisations are not effective at meeting the needs of people with deafblindness. Only an organisation in Victoria (Able Australia) and Senses Australia in Western Australia offered deafblind services. Both organisations were State Government funded and also raised their own revenue through general fundraising to support these services. Deafblind services in New South Wales were operated by Vision Australia, but this organisation was only able to provide very limited services of community training, and basic support and was only available to a small area of the State (Australian DeafBlind Council, 2010). Queensland had very limited services while South Australia, Tasmania, and the Northern Territory had none (Australian DeafBlind Council, 2010).

The Australian Deafblind Council (2010) report compared services to people with deafblindness in Australia from 2004-2005. It concluded that the services were inadequate and the level of service provision varied significantly from State to State. The Australian Deafblind Council (2010) commented that in the five years since the initial report, little had changed, with the lack of progress attributable to a lack of government and community

awareness of deafblindness, lack of funding to support services, and lack of available resources.

**International deafblind services and training programs.** Specific deafblind support is available to individuals who are deafblind in a number of European and North American countries to maintain independence in decision making, and provide opportunity for socialisation and community involvement. In these countries, individuals who are deafblind are assessed and are entitled to a level of individual support. In some countries this is enshrined in legislation. In Denmark these support workers are called contact persons (Miner, 2008), in the UK they are communicator guides (Sense, 2012a) and intervenors (Sense, 2012b), in Canada they are interveners (George Brown College, n.d.a), and in the US they are support services providers (Miner, 2008). The roles of these positions are similar between countries, with variations related predominately to where they work, such as in educational settings with students or in the community with adults. However, they are all specifically skilled to be aware of the issues related to deafblindness and to work with the person to be the link between them and the community, thus minimising isolation. Within this study, the individual support provided to participants was titled “communication guide”.

Studies have demonstrated the use of services by those who are deafblind differ significantly from those of the general population (Olson, 2004). The role of the communication guide, contact person, communicator guide, intervenor, intervener, and support services provider is to be the eyes and the ears for people who are both blind and deaf (George Brown College, n.d.b; Hammer & Carlson, 1996; Sense, 2012a). These supports are the link to the world for a person with deafblindness and provide one-to-one communication, environmental information, and sighted guide. They provide practical help with everyday tasks and access to community services such as shopping, attending recreational activities, attending appointments, writing letters, and reading mail. The role of this specialised support is very complex (Olson, 2004). They must constantly observe and interpret the behaviour of individuals whom they support to determine what information is needed, the best way to convey it, and if it has been clearly received (Olson, 2004). They work with the person with deafblindness in informal settings (Royal National Institute for the Deaf UK, n.d.). They are not an interpreter who is generally only utilised in formal settings such as medical appointments (Hammer & Carlson, 1996). Communication guides and other similar supports are seen as a valuable addition to other services such as domestic help (cooking and cleaning) and visits by social workers (Sense, 2012b) and not as a substitute. The more successful they are, the more visual and auditory information the person with deafblindness will want. This

role therefore is not to develop independence with an aim to then remove support, but to provide ongoing support (Olson, 2004).

The UK Government has recommended that as soon as an initial assessment identifies that a person may have deafblindness, Local Government Authorities should arrange a specialist assessment to identify their communication abilities, need for one-to-one human contact, level of social interaction, any support required with mobility, assistive technology that may be beneficial, and the need for any rehabilitation services (Department of Health, UK, 2001). The UK Government also recommended that the assessment should take account of the current and future needs of that person, as it is easier for a person to learn alternative forms of communication before their deafblindness has deteriorated to the point where they are no longer able to use their preferred method of communication (Department of Health, UK, 2001). Key factors that have been identified as barriers to the deafblind population accessing services include misinformation, miscommunication, and lack of basic knowledge about the disability by health professionals (Barnett 2002; Lock 2003).

In 2001 the UK Government published the Guidance “Social Care for Deafblind Children and Adults” (Department of Health, UK, 2001) under the Local Authority Social Services Act 1970. This Guidance is directed towards Local Government Councils and provides a range of strategies, including service provision, for Councils to implement to improve the social care for people with deafblindness. The service provision recommendation is outlined below (Department of Health, 2001, p. 6):

Councils need to recognise the importance of providing appropriate services to deafblind people. This may mean commissioning services that are specifically designed for deafblind people. Those with dual sensory impairment may not be able to benefit from mainstream services. Similarly, as those with one sensory impairment become deafblind they may no longer be able to benefit from services aimed primarily at blind people or deaf people who are able to rely on their other sense.

Councils will want to ensure they are able to access specifically trained one-to-one support workers (eg. Communicator-guides, intervenors, etc), whether from within their own staff, by the use of consortia arrangements or by contracting with independent providers, for those people they assess as requiring one.

In some UK Councils, communicator guides provide one-to-one communication support, sighted guide and practical help with everyday tasks such as shopping and dealing with mail. They also help deafblind people to improve or maintain their independence within their own

home and community and can also help people with deafblindness to access services such as doctors' surgeries, shops and leisure facilities (Sense, 2012a).

Intervenor services to congenitally deafblind children or adults are also provided in some UK Councils. This one-to-one support aims to promote the person's social and personal development, encouraging independence skills and facilitating communication with the world around them (Sense, 2012b). Intervenor support may be provided in the person's home, their local community, in an educational or vocational setting, or a combination of these. Individual programmes focus on daily life experiences and will include encouraging the use of residual vision and hearing, communication, development of cognitive skills, mobility, orientation and social skills.

In the UK, Lewin-Leigh (n.d.) developed the *Standards for Services for Adults who are Deafblind or have Dual Sensory Loss*. This document, commissioned by Sense UK outlines 45 standards for Local Councils to consider improving services for people who are deafblind. One standard in particular relates to communication guides (p. 40):

Communicator Guides\Guide Helps\Intervenors have relevant communication skills (lip speaking, deafblind manual, block, British Sign Language (visual field and co-active), guiding skills, interpersonal skills and an understanding and knowledge of dual sensory impairment.

Danish deafblind people can access contact person support that is granted by the commune according to “The Law about Social Service 98”. The objectives of this social law (Ministry of Social Affairs and Integration, n.d.) are to:

- offer counselling and support so as to prevent social problems
- to offer a number of general services designed to serve as preventive measures at the same time
- satisfy needs resulting from impaired physical or mental function or special social problems

Although this legislation is not specifically related to deafblindness, due to the social impact of the disability on individuals, the Ministry funds contact person support, Deafblind Consultant services, The Danish Resource Centre on Congenital Deafblindness and The Information Centre for Acquired Deafblind, which is part of the National Organisation for Knowledge and Specialist Consultancy. According to Miner (2008), most people who are deafblind in Denmark receive between 10 and 25 hours a week of contact person support, however this can be as much as 50 hours per week.

According to the Danish Association of the DeafBlind (n.d.), the role of the contact person is:

- To visit and communicate with the deafblind person
- To inform about the everyday life, for example by reading the daily paper
- To be the liaison between the deaf-blind person and his/her surroundings
- To translate letters, messages, bills, etc.
- To accompany in grocery shopping, visits, appointments, etc.
- To accompany and be the liaison to the authorities, post office, bank, etc.
- To accompany in activities, courses, etc.
- Practical assistance in the home is not a function cared to by the contact person

A survey of 117 people with congenital deafblindness in Denmark by Dammeyer (2010a), indicated that the ability and skills of communication partners to be important for the communicative abilities of the person who is deafblind. As a result, education and training of communication modes for family members, carers, teachers, and support workers should be provided.

In Denmark there is no education for contact persons and there are no formal demands about any specific educational requirement. The contact person is provided with professional support from deafblind consultants who are also responsible for supervising the contact persons (Danish Association of the DeafBlind, n.d.). A contact person is assigned to a person who is deafblind according to their ability to communicate using the preferred method of the person who is deafblind. For example, if the person who is deafblind uses hand-on-hand adaptive sign language, then the contact person must have this skill.

In Canada, it appears that there is no legislation specifically related to the provision of intervenor services for individuals who are congenitally deafblind however Provincial Governments provide funding to organisations specifically to provide intervenor and other services to individuals who are congenitally deafblind. Intervenor services therefore vary from province to province but are available throughout all Canadian provinces. According to the Deafblind Services Society (2013) which is based in British Columbia, services for individuals who have acquired deafblindness are only offered on a fee for service basis, as no government funding is available for these programs.

In a Canadian study by Munroe (2001), of the 777 individuals with deafblindness surveyed, 69.9% of individuals with congenital deafblindness reported that they received at least 21 hours per week of intervenor services, with 12.3% of individuals with acquired deafblindness receiving this level of support. Additional research by Ronnberg and Borg (as cited in Dalby, 2009a), suggested that services for persons with deafblindness should be planned around how a person functions in mobility, communication, leisure, and social activities, rather than being based solely on hearing and visual deficits.

In Canada, Mamer & Munroe (1999) developed the *National Guidelines for Intervenors*. They outline the progressive skills an intervenor should possess as they become more experienced and competent. They stated the principles of the concept of intervention to be (p. 2):

- A total and unconditional belief in and respect for the individual who is deafblind
- All individuals who are deafblind can benefit from Intervention
- Individuals who are deafblind have a right to access information in their preferred mode of communication
- Intervention is “doing with, not for”
- No assumptions should be made regarding the cognitive ability of an individual with deafblindness
- Intervention is not a “miracle” formula, but it provides the best possible opportunity for persons who are deafblind to gather information, process it and develop communication and concepts
- Never underestimate the importance of the bond between the Intervenor and the individual who is deafblind
- Intervention must always address anticipation, motivation, communication and confirmation

In Ontario, Canada intervenors undergo training for two years at diploma level at George Brown College. The program provides the students with knowledge and skills to work with children and adults who are deafblind, including individuals who are medically fragile (George Brown College, n.d.b). The program combines theory and practical experience, allowing students to learn a variety of alternative communication techniques such as American Sign Language, two-hand manual communication and Braille. Students learn guiding and how to use assistive devices with clients who are deafblind. Graduates can use their skills to work with their clients in schools, hospitals, supported residences, social service agencies, and as freelance intervenors (George Brown College, n.d.b). In Semesters two,

three and four, students are required to complete a 28 day field placement. The College recommended that students complete an introductory American Sign Language course prior to starting this program.

In the USA, there is no national service program offered to people who are deafblind. In 2008 there were 17 established support services providers' (SSP) programs provided to people who are deafblind, whereas only 28% of the American States had any level of SSP service (Bourquin *et al.*, 2006). Support was provided from one hour per week to 20 hours a week, with most receiving three hours per week (Miner, 2008). Some SSP programs were staffed by volunteers and some were remunerated, with funding for these programs being a combination of grants from city and state governments (Miner, 2008).

Bourquin *et al.* (2006) reported that in the US, SSP training is often informal and taught in hands-on workshop format or through life experiences working individually with a person who is deafblind. There are currently no state or national certifications or licensures for SSPs. As many individuals who are deafblind require assistance with communication, transportation, guiding, and aspects of independent living, Bourquin *et al.* (2006) advocated training is focused on these areas and supported implementation of a standardised training program along with a code of conduct.

As with other international deafblind services, a SSP is trained to act as a link between people who are deafblind and their environment. They typically work with a single individual and act as a guide and communication facilitator. There are two key components of an SSP's function (Bourquin *et al.*, 2006):

- 1) The SSP provides access to the community by making transportation available (by car, bus, or other conveyance), and serves as a human guide while walking.
- 2) The SSP relays visual and environmental information that may not be heard or seen by the person who is deaf-blind. This is done in the person's preferred language and communication mode.

An important aspect of the relationship between the person who is deafblind and an SSP is that the person who is deafblind makes all decisions. The SSP can provide information to the individual to assist in considering options, but at no point should the SSP make choices and decisions (Bourquin *et al.*, 2006). In Utah, Alsop (2004) developed a set of competencies for training interveners to work with children and students with deafblindness. Alsop (2004) organised the competencies under eight standards (see Appendix 1) and grouped them as either core competencies or child-specific competencies.

**Recommendations for meeting the growing needs of the deafblind population.** One Australian and two international reports (from Canada and the UK) have been published that provide recommendations for improving services to people who are deafblind and meeting the needs of this growing population (The Australian Deafblind Council, 2010; Sense, 2010; Watters *et al.*, 2004). There are many common themes across these reports. They all identify the need to have specialised services available to people who are deafblind, including individualised support. Recommendations included increasing the number of intervenors (communication guides) to provide services, increasing funding for quality intervention (communication guide) services and for intervenor training programs, provision of appropriate and accessible social care services, and more appropriate services for people who are deafblind. The provision of deafblind consultants to assist other organisations and individuals working with people who are deafblind in relation to communication, orientation and mobility, assistive devices, and employment was also recommended.

The reports identified the need to improve the identification and improved assessment of people who are deafblind to ensure appropriate services and supports can be established. This included an assessment system in deafblind service provision with a national referral system or national database and improved health, and social care assessments. The reports identified the need to provide community awareness and education about combined visual and hearing impairment. Recommendations included promoting better accessibility in public buildings and facilities, improving public transportation services for those who are deafblind, and making public transport organisations be more accountable in the ways they distribute information to people who are deafblind.

Finally the reports outlined a number of recommendations related to population and medical study and government policy. These included the promotion of research of specific genetically based causes of deafblindness, planning and budgeting based on significantly increased future demands and savings from early intervention, ensuring government policy recognises the significant and growing support needed for deafblind people, and conducting an urgent review of deafblindness in the Australian indigenous population.

**Impact of specialist deafblind services.** Little research has been conducted on the impact of communication guide or similar support on people who are deafblind. Only one study was identified reviewing the impact of specialised support (interveners) on the functional skills of 13 adults who had Rubella syndrome, all of whom had intellectual disability (Hammer & Carlson, 1996). The age range of participants was from 24-36 years (average 28 years) at the time of entering the study (Hammer & Carlson, 1996). The study

conducted pre and post evaluations over a four year period using the Functional Skills Screening Inventory (FSSI) and a behavioural checklist specifically designed and normed on persons who are deafblind (Hammer & Carlson, 1996). Participants received intervener support during the four years.

Hammer and Carlson (1996) reported that participants increased their skills in all but one subscale of the FSSI, with no change in the problem behaviour subscale. They reported significant improvements in the subscales of basic skills and concept ( $p < 0.001$ ), communication skills ( $p < 0.002$ ), personal care ( $p < 0.001$ ), and social awareness ( $p < 0.001$ ). Hammer and Carlson (1996) reported that the interveners were also able to evoke a support network for the participants which maintained their services. This, with the positive results of the study and the costs of the intervener service being one third of traditional group home setting being provided for individuals with deafblindness, Hammer and Carlson (1996) commented that the intervener program should not be ignored as an alternative service to group home living.

Hammer and Carlson (1996) recommended further research into this previously unexplored area. As this 17 year old study was the only research identified relating to the impact of intervener or similar specialised support on individuals who are deafblind, this study aims to provide further information on this topic.

In summary, the prevalence rates for deafblindness vary internationally and are uncertain to some extent due to a reliance on synthesized information from broader disability reports and self-reported measures of impairment. However, the picture constructed indicates deafblindness is most prevalent among older age-groups and thus expected to increase into the future. Deafblindness is shown to have wide-ranging impacts at an individual level (in terms of reduced quality of life, daily function, cognition, and increased mortality rate), and some studies suggest impacts vary between those with congenital and acquired types of deafblindness. Deafblindness also has broader society economic impacts. Service development specifically for people with deafblindness in Australia is in its infancy and variations in the availability of services are seen across the country. In Western Australia, Senses Australia provide a Statewide Consultation Program encouraging communication and independence for people who are deafblind. Internationally, specific deafblind support varies as does the quality of training programs for support persons and the legislative framework. However, a number of guidelines exist that outline the important role of individual support for people who experience deafblindness with an understanding that the goal is not to develop

independence with the aim of removing support, but to provide ongoing support as a liaison between the person who is deafblind and his/her surroundings.

## **Part 2: Quality of Life, Person-Centred Approaches and Occupational Justice**

Within this section of the literature review, the concepts of quality of life, person-centred approaches and occupational justice are explored. As deafblindness has been demonstrated to have an impact on an individual's quality of life, it is a relevant area to investigate. The quality of life concept is outlined and a number of definitions provided. Eight core quality of life domains are identified as well as demographic, human factor and environmental indicators of quality of life. The chapter highlights the viewpoint that mixed methods of both quantitative and qualitative assessment is considered best practice when investigating quality of life. It details how a sensory loss has been demonstrated to impact on an individual's quality of life, particularly deafblindness and also how the *United Nation's Convention on the Rights of Persons with Disabilities* (United Nations, 2006) document aims to promote, establish and maintain enhanced quality of life outcomes for people with disabilities.

This study utilises person-centred approaches to establish or reinforce participants' meaningful occupations. As a result, the evidence pertaining to person-centred approaches was critiqued. The literature reviewed demonstrates person-centred approaches are a key method in achieving better quality of life for individuals with a disability. Three aspects of the concept are explored: person-centred planning; person-centred funding; and person-centred actions. The reported benefits of person-centred approaches in relation to quality of life outcomes are outlined as are the negative aspects. Person-centred funding models are described and the current Australian disability service policy move toward this model is explained. Finally person-centred action is described.

As it is the right of every individual to engage in meaningful occupations (Wilcock & Townsend, 2009) and this study facilitated individuals who are deafblind to do this, the concept of occupational justice was also explored. The literature review will provide a number of definitions of occupation. It highlights that humans are occupational beings, where occupation is essential for health and quality of life. It discusses how disability can impact on an individual's occupational ability, both as a result of their impairment and also due to societal belief, creating occupational deprivation. The concept of occupational justice is defined and the principles of the emerging theory are listed.

**Quality of life.** Quality of life is an important concept and measurement framework for assessing quality outcomes, guiding organisations in service delivery, informing broad policy

directions and evaluating personal outcomes. It is increasingly being used in the field of disability (Wang, Schalock, Verdugo & Jenaro, 2010). Quality of life is progressively being updated using the ecological model of disability which views disability as the expression of individual limitations within a social environment and by the social model which views disability as a fundamental aspect of society and as such should be fully accommodated by society (Brown, Schalock & Brown, 2009).

Attempts to define quality of life are not new, with philosophical origins of quality of life including hedonistic theories (the good/pleasant life), desire-fulfilment theories (people have good lives if they have the lives they want to have) and objective pluralist theories (there are objective values that make life good or bad irrespective of what the person thinks) (Fagerlind, Ring, Brulde, Feltelius & Lindbald, 2010). Quality of life has been defined in many different ways, from general requirements for happiness (Prescott-Allen, 2001), to positive life experiences (Campbell, Converse & Rodgers, as cited in Brown & Barrett, 2011).

There is a lack of consensus in the literature regarding the definition and measurement of quality of life (Moons, Budts & De Geest, 2006). One reason for the inconsistent use of the term quality of life may be its diverse origin (Prutkin & Feinstein, 2002). Another may be quality of life is often considered a subjective experience, where one's capability to adjust their perception of what is acceptable can lead to contentment in difficult situations (Ventegodt, Anderson & Merrick, 2003). Through ongoing research into the quality of life notion, a conceptual framework has emerged, where quality of life is considered a multidimensional construct that has both subjective and objective components and it is influenced by personal and environmental factors (Wang *et al.*, 2010).

In a review by Schalock (2004) of 16 published quality of life studies, factors that contributed to personal wellbeing were consistently recognised. The three quality of life factors or higher order constructs that have been identified include: independence; social participation; and well-being. Each of the quality of life factors can be broken down into domains. The domains that have been identified include (Schalock, 2004):

- Independence - personal development, self-determination
- Social participation - interpersonal relationships, social inclusion, rights
- Wellbeing - emotional well-being, physical well-being, material well-being

Wang *et al.* (2010) commented that research has indicated quality of life domains are similar across countries and cultural areas. Claes, Van Hovde, Vandeveld, van Loon and Schalock

(2012) described personal factors that influence quality of life outcomes. These include demographic indicators (such as age, gender, ethnicity, marital status), and indicators of human functioning (such as intellectual functioning, adaptive behaviour, mental health, physical health, speech difficulty, mobility, and support needs). Environmental factors that influence quality of life outcomes include: inclusion; engagement; empowerment; normal rhythm of life activities; individualised supports; support staff activities; and organisation efficacy (Schalock, as cited in Claes, *et al.*, 2012). In terms of quality of life related outcomes, research has indicated enhanced outcomes in the quality of life domains are related to the level of: self-determination; choice; social networks; living status; well-being; community integration; and life satisfaction (Claes, *et al.*, 2012).

According to Claes, van Hove, van Loon, Vandeveldde and Schalock (2010, p. 62), the current approach to measurement of quality of life can be characterised by:

- a) a multidimensional nature involving core domains and indicators;
- b) the use of methodological pluralism that includes the use of subjective and objective measures;
- c) the incorporation of a systems perspective that captures the multiple environments impacting people at the micro, meso and macrosystems levels; and
- d) the increased involvement of persons with disability in the design and implementation process.

A study by Fischer *et al.* (2009) investigating the impact of multiple sensory impairment on quality of life found that impairments in vision and hearing both demonstrated independent effects on quality of life. The study which included the Short Form 36 Health Survey (SF-36) as a health related quality of life measure found that vision impairment had an impact on physical and emotional health and both vision and hearing impairment had an impact on social function. Li-Korotky (2012) identified three studies that linked hearing loss as one factor negatively associated with higher distress, depression, somatization and loneliness. A study which examined the relationship between visual impairment and quality of life among older adults found that higher levels of visual impairment are associated with more depressive symptoms and lower life satisfaction over a three year period (Brown & Barrett, 2011).

As previously discussed, deafblindness is associated with poorer quality of life than single sensory impairments (Chia, *et al.*, 2006). It has been reported that the physical wellbeing of individuals who are deafblind is impacted upon by their disability. Individuals who are deafblind are 3.5 times more likely to experience a functional decline than

unimpaired older adults (Laforge, Spector and Sternberg, as cited in Dammeyer, 2010b). They generally reported considerably poorer health than people with a hearing impairment, poorer health than people with a vision impairment and have poorer mobility, increased numbers of falls, increased hip fractures, increased incidence of osteoporosis, stroke, heart disease and arthritis compared to individuals with only a vision impairment or hearing impairment (Crews & Campbell, 2004).

The age of onset of deafblindness is an important quality of life personal factor for individuals. In a study by Watters *et al.* (2004), people who were deafblind experienced a variety of feelings when they first found out that they were deafblind. Within the study the authors reported that those individuals who experienced hearing loss at a younger age and lost their vision gradually, adjustment to the hearing loss was easier than becoming accustomed to a decrease in their vision. In addition, for those whose hearing and vision decreased more rapidly, adjustment to the loss of these senses was quite difficult. This personal factor is important to consider by service providers that individuals may require great levels of support if experiencing rapid deterioration in hearing or vision.

The literature has demonstrated that disability has an impact on an individual's quality of life, which has been recognised by the United Nations. The *United Nation's Convention on the Rights of Persons with Disabilities* (United Nations, 2006) state socio-political conditions for achieving equality, autonomy, non-discrimination, participation and inclusion in society for people with disabilities. The convention stressed that people with disabilities should be able to participate fully in all aspects of life and specified necessary attitudinal and legal conditions for achieving such participation. Although this convention focuses on the socio-political level, the quality of life construct reflects the dynamics of subjective and objective conditions of life and has become the link between the general values reflected in social rights and the personal life of the individual (Buntinx & Schalock, 2010).

**Person-centred approaches.** As a result of the effort to improve the quality of life for people with a disability, human services are aspiring to deliver quality in what they provide, in order to enhance people's psychological and subjective well-being (Schalock & Verdugo, 2002). This embracement of the quality of life concept by human services has led to them using a person or family-centred framework (Beadle-Brown, 2006). Person-centred approaches have tended to be utilised with people who have an intellectual disability with the vast majority of literature in this field pertaining to this disability group. However person-centred approaches are used extensively by agencies across jurisdictions when supporting people with deafblindness (Bellah, 2004; Moss & Wiley, 2003; Sense, 2013).

Person-centred approaches create a partnership with clients that enable them to identify their needs and tailor services to achieve their goals, using their strengths and natural community supports (Law & Baum, as cited in Law, Baum & Dunn, 2005). Beadle-Brown (2006) outlined how a person-centred approach, using person-centred planning, person-centred funding, and person-centred action, can contribute to a better quality of life for people with a disability. The majority of person-centred literature relates to person-centred planning.

Person-centred planning originated in North America in the 1980s reflecting ideological developments of inclusion and normalisation within the disability field (Robertson *et al.*, 2006). Person-centred planning considers the aspirations and capacities expressed by the individual and attempts to include and mobilise the individual's family and wider social network (Mansell & Beadle-Brown, 2003). Person-centred planning covers a wide range of procedures and guidelines focused on the creation of fundamental changes in the lives of people with disabilities (Claes, Van Hove, Vandeveld, van Loon & Schalock, 2010a). "The purpose of person-centred planning is to develop collaborative, goal-orientated and individualised programs that are focused on community presence, community participation, positive relationships, respect and competency" (Claes *et al.*, 2010a, p. 432). Claes *et al.* (2010a) comment that a review of articles published between 1985 and January 2009, found there was no universal definition of person-centred planning.

Person-centred planning is directly linked to the quality of life domain of self-determination and if well done, can also lead to better interpersonal relationships as well as material, emotional and physical well-being (Beadle-Brown, 2006). Lachapelle *et al.* (2005) evaluated the relationship between self-determination and quality of life of people with an intellectual disability living across four countries and found that this domain was an essential characteristic of individuals achieving a high quality of life. According to Schalock, Verdugo, Bonham, Fantova and van Loon (2008), the evaluation of person-centred planning related outcomes could be done using a quality of life framework that includes indicators of personal development, self-determination, interpersonal relations, social inclusion, rights and emotional, physical and material well-being.

Person-centred planning has been demonstrated to enhance quality of life by facilitating choice, autonomy, personal control and decision making (Beadle-Brown, 2006). There is a significant association between the availability of an individual's existing supports and quality of life outcomes, with person-centred planning having been demonstrated to assist

with the identification, enhancement and establishment of these supports (Petry, Maes & Vlaskamp, 2005; Renty & Roeyers, 2006).

A study by Holburn, Jacobson, Schwartz, Flory and Vietze (2004) examined the relationship between person-centred services for 19 individuals with intellectual disability, compared to 18 who received conventional services. Outcome measures indicated that the quality of life indicators of autonomy, choice making, daily activities, relationships, and satisfaction improved more for those who received person-centred planning. In the UK, Robertson, *et al.* (2006) conducted a longitudinal study that found that the introduction of person-centred planning resulted in a 52% increase in social networks, 2.4 times greater contact with family, a 40% increase in contact with friends, as well as increased community based activities, scheduled day activities and choice, in people with intellectual disabilities. This study found that these benefits came without additional service costs once initial training costs were taken into account.

A longitudinal study by Wigham *et al.* (2008) in the UK of 65 participants, found that the benefits of using person-centred planning were in the areas of activities, social networks and choice. The study also revealed that nearly half of the participants had improved confidence, self esteem or reported being happier. Heller, Miller, Hsieh and Sterns (2000) found that person-centred planning also has an effect on older adults with an intellectual disability in relation to knowledge and choice-making. They found that those who participated in their study and received a person-centred later-life planning training program were able to gain skills and make more choices than a control group.

The literature has reported mixed outcomes for people using person-centred planning. Robertson *et al.* (2006) found that the benefits of person-centred planning had no impact on employment, inclusive social networks, physical activity, physical health, medication or a change in a risky behaviour. Hasnain and Sotnik (2003) reported difficulty in using person-centred planning with individuals from ethnically, linguistically and culturally diverse backgrounds. Robertson *et al.* (2007) reported those with mental health, emotional or behavioural problems, autism or people with more health problems were less likely to receive person-centred planning. Another study found that those individuals with communication difficulties, challenging behaviour or severe intellectual disabilities are often excluded from the planning process (Mansell & Beadle-Brown, 2004).

Claes, Van Hove, Vandeveldde, van Loon & Schalock (2010b) also questioned the impact of person-centred planning, commenting it was difficult to conclude that changes in outcomes

within the studies they reviewed could be attributed to person-centred planning. These authors note that most person-centred planning studies have a small sample size with weak external validity, the studies do not define person-centred planning and the vast majority of these studies do not report on the method of implementing the person-centred planning process, making the replication of the study and ability to demonstrate evidence-based practice difficult. Robertson *et al.* (2006, p. 412) however stated, “Our results suggest that the introduction of person-centred planning had a modest positive benefit on the life experience of people with intellectual disabilities. Overall, there was very little evidence of positive change occurring in peoples’ lives prior to or in the absences of the implementation of person-centred planning.” It appears that research methods investigating person-centred planning need more rigour, but a growing body of evidence into the efficacy of this approach is developing and as a result this study utilises person-centred planning when providing support to participants.

The development of personalised services and supports to meet the needs and aspirations of services users has become fundamental to current social care policies in Australia. In Western Australia, person-centred planning is a key element to the Disability Services Commission (n.d.) white paper “Count Me In: Disability Future Directions” which sets out the State Government’s strategy for the development and delivery of disability services into the future. A key component of this strategy was to ensure person-centred planning is used to guarantee supports are personalised and tailored to the needs of all people with disabilities. The UK and many states within the USA also mandate the use of person-centred planning for people with disabilities (Schwartz, Jacobson & Holburn, 2000; Wigham, *et al.*, 2008).

Currently throughout Australia, person-centred funding models are becoming more evident. This includes personalised funding systems via the development of direct payments and self-directed support. Self-directed support initially involves a process of person-centred planning and then combining all financial resources from existing sources to make the money available to an individual in a variety of ways, giving them control over how they wish to receive their support (Beadle-Brown, 2006). Beadle-Brown (2006) commented that person-centred funding specifically affects the quality of life domains of self-determination and material well-being, with direct payments and self-directed support enabling people to have more control over how the money is spent in order to meet their needs.

Australia is currently undergoing significant disability policy reform, with the Federal Government introducing the National Disability Insurance Scheme trial sites across Australia. The National Disability Insurance Scheme, recommended by the Productivity Commission in

2011, proposed a number of enhancements to the present system, including shifting the platform for the delivery of disability supports to an entitlement basis, and endorsing a person-centred approach to support with self-directed funding arrangements (Wadiwel, 2011). The Disability Services Commission of Western Australia's "My Way" pilot project is another initiative to implement greater person-centred funding arrangements for people with disabilities. "My Way" is a self-directed support and services project, based on the provision of individualised, person-centred planning for the future and person-centred funding to implement the identified strategies to achieve this plan (Disability Services Commission, 2012).

Progress towards personalisation and quality of life for people with disabilities means turning person-centred plans into person-centred action (Mansell & Beadle Brown, 2004). "Only by helping people to participate in meaningful activity and relationships can empower them to make choices, have control over their lives and develop the skills and opportunities for more independence and inclusion" (Beadle-Brown, 2006, p. 7). Person-centred action is about providing just enough support to enable people to participate in meaningful activities and relationship so they gain more control, independence and become more included as a valued member of the community, irrespective of the degree of intellectual or other disability (Mansell *et al.*, as cited in Beadle-Brown, 2006).

**Occupational justice.** The final concept that this literature review explores is occupational justice. As previously reported, individuals with deafblindness have less function and fewer occupations than those without disabilities and those with a single sensory impairment (Crews & Campbell, 2004; Lin, *et al.*, 2004). Occupational justice has been asserted as the right of every individual to be able to meet basic needs and to have equal opportunities and life chances to reach towards their potential, through their engagement in diverse and meaningful occupations (Wilcock & Townsend, 2009). Wilcock and Townsend (2000, p. 84) stated, "Whilst social justice addresses the social relations and social conditions or life, occupational justice addresses what people do in their relationship and conditions for living". The British College of Occupational Therapists (as cited in Wilcock & Townsend, 2009, p. 195) commented that "Occupational justice provides a framework for asking questions about inequities of opportunity for occupational development, or inequities related to lack of appropriate enablement for those living with a disability".

Wilcock (2006) commented that humans are occupational beings, where occupation is a basic need. Occupation was defined by Yerxa (1993, p. 5) as "...units of activity which are classified and named by the culture according to the purposes they service in enabling people

to meet environmental challenges successfully”. Some essential characteristics of occupation are that they are self-initiated, goal directed, experiential as well as behavioural, and socially valued or recognised. They can be constituted of adaptive skills, are organised and essential to the quality of life experienced and possesses the capacity to influence health (Yerxa, 1993). The Canadian Association of Occupational Therapists (as cited in Law, Steinwender & Leclair, 1998, p. 83), described occupation as

...groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity).

Larson, Wood and Clark (2003, p. 16) have provided a simple definition of occupation which describes occupation as “the activities that comprise our life experiences and can be named in the culture”. Reed and Sanderson (as cited in Polatajko *et al.*, 2007, p. 17) provided another simple definition of occupation as “activities or tasks which engage a person’s time and energy; specifically self-care, productivity and leisure”.

Individuals have differing occupational needs, strengths and potential which require differing levels of support in which to flourish (Townsend & Wilcock, 2004). Opportunities and resources to engage in occupation should be available to all people, as occupation is considered a requirement for survival, health and well-being (Wilcock, 2006). Anything therefore that reduces a person’s ability to engage in occupation has the potential to negatively affect the health and well-being of the individual, even to generate pathology (Duxbury, Higgins & Johnson, as cited in Polatajko *et al.*, 2007). This premise is supported for those who are deafblind as evidence has previously been provided demonstrating how individuals with deafblindness have less occupations (Crews & Campbell, 2004; Lin, *et al.*, 2004) as well as poorer quality of life, increased falls, increased incidence of disease, reduced cognitive processes, increase mental health issues and higher mortality rates (Appollonio, *et al.*, 1995; Brennan *et al.*, 2006; Capella-McDonnall, 2005; Chia, *et al.*, 2006; Crews & Campbell, 2004; Lam, *et al.*, 2006; Lin, *et al.*, 2004; Tay, *et al.*, 2006).

Occupations contribute to an individual’s social and self-identify (Unrah, 2004) and allow an individual to explore and learn from the environment, master skills, express individuality and sustain life (Polatajko *et al.*, 2007). Occupations are very personal to individuals. What a person engages in is idiosyncratic to that person, as is the experience they receive from participating in that occupation (Polatajko *et al.*, 2007). When investigating human occupation, it is important not only to evaluate the actual performance of an occupation, but also the level of importance it holds and the degree of satisfaction that it

brings to the individual (Polatajko *et al.*, 2007). A person-centred approach to enabling an individual to engage in occupations should therefore be utilised (Polatajko *et al.*, 2007), where the individual chooses the occupations in which they engage. Utilising this approach, participants within this study were supported to undertake occupations of their choosing.

Occupational justice has been described as a justice of difference, where occupational rights regardless of age, ability, gender, social class or other differences are recognised (Nilsson & Townsend, 2010). Townsend (2003) stated that occupational injustice is an outcome of social policies and other forms of control that structure how power is exercised to limit participation in the everyday occupations of populations and individuals. Societies are typically structured so that some experience social inclusion, privilege and entitlement to choose what they do, while others experience social exclusion and restrictions such as deprivation of full participation in everyday occupations (Whiteford, 2010). Wilcock and Townsend (2009, p. 194) regard an occupationally just world to be one that "...enables individuals to flourish by doing what they decide is most meaningful and useful to themselves and to their families, communities and nations."

Stadnyk, Townsend and Wilcock (2010) proposed four overlapping and compounding forms of occupational justice: occupational alienation; occupational deprivation; occupational marginalisation; and occupational imbalance. Occupational alienation was defined by Hansen (2013, p. 42) as "...the outcome when people experience daily life as meaningless or purposeless". Occupational alienation can further be described as feeling a lack of purpose and a feeling of being disengaged in life (Nilsson & Townsend, 2010).

The World Federation of Occupational Therapists (as cited in Wilcock & Townsend, 2009) commented that many people with disabilities are restricted in, or denied access to, dignified and meaningful occupation in their daily life and their well-being is sometimes compromised through occupational deprivation. Occupational deprivation is considered a state of prolonged preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the control of the individual (Whiteford, 2010). Deafblindness of an individual has been reported to cause significant reduction in their function and occupations (Crews & Campbell, 2004; Lin, *et al.*, 2004), potentially leading to greater incidence of occupational deprivation within this population. Whiteford (2010) however, reported these biological or physical conditions may not be barriers to occupational engagement and satisfaction, if the human environment is supportive. Attitudes and beliefs of others still exert a strong influence on the daily occupations in the lives of people with disabilities, and through increased community education, a future where the occupational

potential of people with a disability can be more fully realised. Townsend and Wilcock (2004) argued that occupational deprivation is a matter of justice and that participation in the range of occupations is the daily means through which individuals exercise health, citizenship and social inclusion.

Occupational marginalisation serves to exclude individuals or groups from opportunity to participate in society's valued occupations, relegating them to invisible or less-valued occupations in which they have very little choice or control (Nilsson & Townsend, 2010). Occupational imbalance is when an individual feels excluded by either having too little to do or too much to do instead of experiencing participation in a range of meaningful occupations (Hansen, 2013).

A theoretical model of occupational justice is developing (Stadnyk *et al.*, 2010). The emerging theory has four principles which outline the rights, responsibilities and freedoms of enablement and is derived from recognition that individuals have occupational needs, strengths and potentials that affect health and quality of life (Stadnyk *et al.*, 2010). These principles are listed below with a brief description:

- Empowerment through occupation - through activities individuals have the ability to enable feelings, behaviours and social structures to develop empowerment
- Inclusive classification of occupations – if occupations are classified hierarchically, individuals who are unable or who do not have the opportunity to perform those occupations deemed more desirable, inequalities in status and wages perpetuate a social class structure between the haves and have-nots
- Enablement of occupational potential - enablement processes would aim to engage all people, regardless of differences, as participants in the decision making about their occupational performance and occupational engagement in society
- Diversity, inclusion and shared advantage in occupational participation – not everyone is able to participate in some occupations; however this principle advocates all people be entitled to participate in occupations that they need or want to. The principle also advocates that communities should share the social and economic advantages of that community

These principles of occupational justice are relevant for all individuals, but particularly for those with a disability, including those who are deafblind, as this group have been demonstrated to have conditions of occupational injustice.

The framework for occupation justice is based in the “environment” classification within models such as the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007). The Canadian Association of Occupational Therapists (as cited in Polatajko *et al.*, 2007) introduced the CMOP-E, where occupational performance is conceptualised as the dynamic interaction of person, occupation and environment (Figure 1).

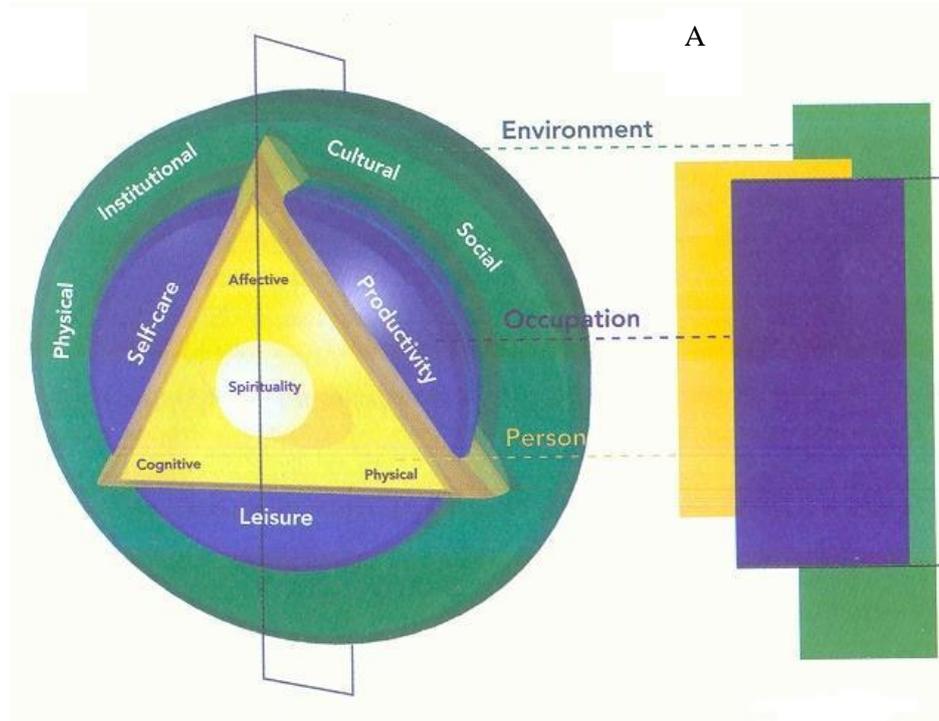


Figure 1. The Canadian Model of Occupational Performance and Engagement

Note. A = Trans-sectional view. From “The Canadian Model of Occupational Performance and Engagement”, by H.J. Polatajko, E.A. Townsend & J. Craik, <http://www.oerafrica.org/FTPFolder/Website%20Materials/Health/Framework%20II/ppt/The%20Canadian%20Model%20of%20Occupational%20Performance%20and%20Engagement.pptx>.

Within the CMOP-E, the person is at the centre of the model, and is portrayed as having three performance components (cognitive, affective and physical), with spirituality at the core. The environment surrounds the person, to indicate that each individual lives within a unique environmental context including cultural, institutional, physical and social aspects. It is though the environment in which occupational injustice occurs (Hansen 2013; Nilsson & Townsend, 2010). Occupation is depicted as the connection between the person and the environment, indicating that individuals act on the environment through occupation. In order to measure these aspects of occupation, the Canadian Occupational Performance Measure (COPM) (Law, (Baptiste) *et al.*, 2005) was developed. The COPM was utilised within this study to assist participants identify those occupations they wished to perform with

communication guide support and self-rate their performance and satisfaction with these occupations.

Part 2 of the literature review explored the concepts of: quality of life; person-centred approaches; and occupational justice. Eight core quality of life domains were identified as well as demographic, human factor and environmental indicators of quality of life. Sensory loss, in particular deafblindness, was demonstrated to impact on an individual's quality of life. The second concept explored was person-centred approaches. It was reported that this approach creates a partnership with people that enables them to identify their needs and tailor services to achieve their goals, using their strengths and natural community supports. Person-centred approaches include planning, funding and action. Person-centred approaches are used extensively by agencies when supporting people with deafblindness. The final concept is that of occupational justice. Humans were reported to be occupational beings, where occupation is a basic need, with individuals have differing occupational needs, strengths and potential which require differing levels of support in which to flourish. Individuals with deafblindness were reported to have less occupations and have been demonstrated to have conditions of occupational injustice.

## Chapter 2 - Research Methodology

This chapter details the research methodology employed by the thesis. Methodology is fundamental in research projects because the methods used within the research become the point of reference for checking the suitability of ideas and issues for empirical investigations (Flick, 2006). This thesis utilised case study research methodology. It is described and a rationale is provided for applying this method. The key stages for the study are also described, which included: the recruitment of the participants; recruitment of communication guides; and the implementation of the communication guide intervention that the participants received during the study. Quantitative and qualitative data collection tools are outlined and their rationale for inclusion into this study presented. Finally, ethical considerations are outlined and storage protocols stated.

### Objective of the Study

The research question for this study was:

*How does a communication guide's support impact on an individual with deafblindness?*

In examining this question, the following sub-objectives were analysed:

- How was the quality of life of the participants affected?
- How was the occupational performance of the participants affected?
- What aspects of the communication guide support did the participants value?
- What aspects of the communication guide support did the participants not value?

### Case Study Research Method

This study utilised case study methodology to investigate how a communication guide's support impacts on an individual with deafblindness. Case study methodology provides tools for researchers to investigate complex phenomena within their contexts. When applied well, it becomes a valuable method for health science research to: develop theory; evaluate programs; and develop interventions (Baxter & Jack, 2008). Yin (2009, p.18) defined case study method as an empirical inquiry that:

- Investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident
- Copes with the technically distinctive situation in which there will be many more variables of interest than data points

- Relies on multiple sources of evidence, with data needing to converge in a triangulation fashion
- Benefits from the prior development of theoretical propositions to guide data collection and analysis.

This definition highlights that case study methods can be used to understand a real-life phenomenon in depth, within the important contextual conditions, as they are highly pertinent to the phenomenon of the study. The definition also shows how case study research comprises an all-encompassing method, covering the logic of design, data collection techniques and specific approaches to data analysis (Yin, 2009).

According to Yin (2009), a case study design should be considered when:

- The focus of the study is to answer “how” or “why” questions
- The researcher cannot manipulate the behaviour of those involved in the study
- Contextual conditions are relevant to the phenomenon of the study
- The boundaries are not clear between the phenomenon under study

This study fits the scope of when a case study design should be considered. The study asks: “How does a communication guide’s support impact on an individual with deafblindness?”. The researcher has no control over the events within the study. The context of being deafblind is essential to be explored and the boundaries between providing communication guide support and being deafblind are difficult to separate.

An important aspect of case study design is determining the unit of analysis (Baxter & Jack, 2008; Yin, 2009). The unit of analysis may be many things, including an individual, a program, or a process. Within this study, the unit of analysis is the individual.

There are a number of different types of case studies and it is important to determine which one will be used. Yin (2009) categorised case studies as explanatory, exploratory or descriptive. This study uses a descriptive case study type, where the impact of communication guide support on individuals who are deafblind is described. Descriptive case studies are in-depth descriptions of the experiences of behaviours of a particular individual or a number of individuals. Descriptive case studies are most typically undertaken to describe some new phenomena or to document a participant’s response to a new intervention (Kielhofner, 2006).

This study is also viewed as a multiple-case holistic design. Yin (2009) outlines four types of designs for case studies: single-case holistic designs; single-case embedded designs;

multiple-case holistic designs; and multiple-case embedded designs. As the name suggests, a single case involves only one case whereas multiple case design contains more than one case. Holistic designs include a single unit of analysis, where no logical sub-units can be identified. Embedded designs include multiple units of analysis, where the researcher is looking for consistent patterns of evidence across units but within a case. Because this study has a number of participants, with only the individual as the unit of analysis, as stated, this study is considered a multiple-case holistic design case study methodology

### **Key Stages of the Study**

**Recruitment of the participants.** The study required participants to meet the following inclusion criteria:

- 18 years or older
- Not having difficulty making informed decisions
- Not having dementia
- Not having a substance abuse habit
- Living in the Perth metropolitan area
- Vision less than 6/21 (20/70) not corrected by glasses (that is, while wearing glasses if prescribed)
- Unable to pass the Whispered Voice Test with hearing aids - a simple and accurate test to determine hearing impairment which is internationally recognised (Pirozzo, Papinczak & Glasziou, 2003)

The inclusion criteria for age was selected so participants were able to provide consent without involvement of a third party such as a parent. To improve the reliability and amount of information obtained from participants, the criterion of: able to make informed decisions; not having dementia; and not having a substance abuse habit were included. Where the participants lived was a criterion as existing support services co-ordinated by Senses Australia were only operating in the Perth metropolitan area. To provide communication guide support in regional or remote areas of Western Australia was deemed beyond the scope of this exploratory study. Participants also needed to provide documentation from an optometrist and audiologist or undergo an assessment by the researcher to meet the additional criteria related to their vision and hearing.

Senses Australia maintained a client database that recorded a number of demographic and individual items including: details of disability; ability to learn (which was based on psychological or medical information); and whether they have deafblindness. Using the criteria of age and level of cognitive ability as a primary screen, 16 people were sent

information on the study and invited to participate. As a result of this process, only one participant was recruited. It is unclear why there was such a limited take up of potential participants.

In order to obtain more participants who were not identified on the Senses Australia client database, an advertisement was placed in The West Australian Newspaper inviting deafblind individuals to join the study. The advertisement was aimed at family and/or friends of possible participants or those participants who had sufficient vision to read a newspaper. As a result of this advertisement, only one person contacted the researcher and unfortunately was not eligible as the person had only a vision impairment. Another approach was required to recruit participants.

Following this, individuals who were on the Senses Australia client database who met the criteria were individually targeted. The intention was that potential participants would be recruited until there were 14 people who were deafblind in the study. The majority of these clients had received either support from the Senses Australia social worker, or through therapy intervention with a speech pathologist or occupational therapist. As these clients had an established relationship with an existing Senses Australia staff member, it was these staff members who approached the clients and their families to explain the purpose of the study. The researcher then organised to meet with the interested clients to screen their eligibility, provide them with further information about the study (see Appendix 2) and obtain their consent (see Appendix 3). To ensure the potential participants were fully informed about the study, those participants who communicated using Auslan were provided with interpreters to translate all the necessary information, and enable participants to clarify any issue or ask any question. For those living with parents, the parents were also included in the discussion to ensure that their son or daughter was able to fully understand what the study involved. For those who lived alone without close family support, an advocate, or a paid support staff who knew the individual's communication ability was present to ensure the person with deafblindness understood the information.

As a result of the recruitment process 11 participants were recruited into the study. One participant withdrew during the course of the intervention; therefore ten individuals fully participated in this study.

**Recruitment of communication guides.** Communication guides were recruited internally from Senses Australia support worker positions and from external advertisement. Senses Australia employed approximately 100 support workers at the time. These support

workers provided accommodation, respite, alternative to employment and recreation support to clients with disabilities. An expression of interest to become a communication guide was distributed to all employees via internal email. It was also sent via colleagues working in other organisations via their networks. From the expression of interest, a number of applications were received. In order to maintain impartiality, the researcher partnered with the Senses Australia deafblind consultant to conduct the interviews for the communication guide positions. The questions asked within the interview related to:

- The experience of candidates working with individuals with disabilities
- Knowledge of deafblind issues
- Values and attitudes towards people with disabilities
- Availability and interests

These questions aimed to obtain information on candidate skills, attitudes and to identify potential participants they may work with. Applicants also had referee checks and successful applicants were required to supply a national police clearance (if these had not been supplied or undertaken previously), sign an employment contract, and complete the organisations' orientation day, if these had not been supplied or undertaken.

The communication guide role was developed using information obtained from similar existing international roles of contact person, communicator guide, intervenor, intervener and support services provider. Key areas of responsibility outlined for the communication guides were:

- To provide visual and auditory information to clients who have deafblindness
- To facilitate the communication of clients who have deafblindness
- To provide sighted guide to clients who have deafblindness

The communication guides completed four days of training prior to commencing services, which was developed by Senses Australia's deafblind consultant (rehabilitation worker), manager of therapy & specialist services (occupational therapist), and speech pathologist, with some sessions facilitated by people with deafblindness. All communication guides were required to meet established competencies, demonstrated through practical and theoretical assessments that reflected the learning objectives.

Using the information gathered, the key learning objectives for the communication guide training for this study were developed and are outlined below:

- To be familiar with client centred practice and use of this approach when delivering services.

- To identify and describe the key issues for people who have a deafblindness.
- To identify procedures and processes which would enable people with deafblindness to participate fully as citizens and to access appropriate services and support so that they can live the lives they want to live.
- Demonstrate an understanding of the function and application of the range of methods that people who have deafblindness may use to communicate.
- To identify the impact of deafblindness on socialisation.
- To identify and discuss how the environment can influence a person with deafblindness.
- Demonstrate methods of enabling a person who has deafblindness to acquire or maintain good movement, mobility and orientation skills.

Communication guides completed the four day competency based training program. Those who completed the training were then matched to participants depending on their communication skills. For example, a participant who used Auslan as their primary method of communication was allocated a communication guide skilled in Auslan.

All communication guides were provided with supervision while employed at Senses Australia. They were required to submit fortnightly timesheets and progress notes. This enabled the researcher to monitor the activities the participants were engaged in and gain an understanding of what the communication guides were doing. A supervisor was also available to speak with the communication guides at any stage, as the need arose. In addition, the communication guides had the opportunity to exchange ideas and knowledge with one another during team meetings, which were held twice during the six month intervention. These team meetings enabled the communication guides to share experiences and problem-solve any issues they may have been having. Both the supervision received by the communication guides and the team meeting allowed the researcher to reinforce that their support was provided in a person centred manner and hopefully be valued by the participants.

**Implementation of the intervention.** This study utilised person-centred approaches as there is a growing body of evidence supporting this method when providing services to individuals with a disability. Intervention was therefore based on the person's preferences, interests and desires. Funding was obtained from the Ian Potter Foundation and the Western Australian Disability Services Commission to provide communication guide intervention for approximately 10 participants for six months.

The Senses Australia occupational therapist initially attended the participant's home for approximately a one and half to two hour meeting. Using the Canadian Occupational Performance Measure, individual goals were developed by the participant. From these goals, Individual Service Plans (ISP) (Somme, Bonin, Lebel, Hebert & Blanchard, 2009). Development of an individualized service plan tool and rules for case, 2009) were developed collaboratively by the occupational therapist and the participant. The goals within the ISP's included activities which could be described as recreational, leisure, social, volunteering, or educational. Family members were present if requested by the participant and for participants who communicated with Auslan, an interpreter was provided. The ISP outlined how and when their allocated hours per week of service were to be used, what activities would be undertaken during the service time to achieve their goals and the objectives of participation in the various activities. The allocated hours varied between participants, ranging from three to a maximum of six hours per week and varied depending on the ability to achieve the goals and activities identified within the ISP. The participant reviewed and authorised the ISP, including agreeing on their allocation of hours before implementation. Hours were flexible and could be changed to meet the needs of the participant. The process from initial meeting to producing the ISP document was approximately two weeks.

Five communication guides were recruited and were matched to participants depending on their communication skills. For example, a participant who used Auslan as their primary method of communication was allocated a communication guide who was skilled in Auslan. The communication guides visited participants at the agreed time(s) each week and provided the allocated hours of service in accordance with the ISP. The participant could also negotiate with the communication guide to change the times or day of the support. If this change of time would be more than six hours, the communication guide was required to obtain approval from Senses Australia. The communication guide maintained a record of activities including information related to frequency and type of activity undertaken. The ISPs were reviewed as required and modifications were made to the plan as required. Intervention was provided for six months.

### **Methods of Data Collection**

Mixed methods were employed for data collection including quantitative and qualitative assessments. Scientists and clinicians investigating quality of life issues have found mixed methods research, which is combining quantitative and qualitative practices, important for both theoretical and methodological reasons (Klassen, Creswell, Clark, Smith & Meissner, 2012). "Quality of life researchers often examine questions that have multiple epistemological, scientific, and clinical foci and are faced with integrating diverse

perspectives, types of evidence, and audiences or stakeholders” (Klassen *et al.*, 2012, p. 377). Undertaking a variety of data collection methodology also provided triangulation of information that increased both the depth and breadth of understanding of the research question (Stake, 2005).

The quantitative and qualitative assessments used within this study are described below.

**Quantitative assessments.** The three quantitative assessments were used within this study. The assessments are described and a rationale as to why they were selected is provided. They were administered by the Senses Australia occupational therapist. The occupational therapist conducted the assessments in one session before the intervention commenced and in one session at the completion of the intervention. The occupational therapist contacted the participants on both occasions using their preferred communication method, either by phone, text or through another person, to organise a time to go to their home and administer the assessments. An Auslan interpreter was provided for those participants who required one.

***interRAI Community Health Assessment and Deafblind Supplement.*** The Community Health Assessment (CHA) is a minimum data set screening tool that enables an assessor to review multiple key domains of function, health, social support and service use (Morris *et al.*, 2010). The instrument was developed for use with adults (18 and older) who reside in the community and is an assessment that is used in Canada and USA to assess, plan and allocate home-based services to individuals typically not receiving formal home-care services (Guthrie *et al.*, 2011; Morris *et al.*, 2010). The CHA investigates the following domains:

- Communication and vision
- Mood
- Psychosocial well-being
- Functional status
- Continence
- Disease diagnoses
- Health conditions
- Oral and nutritional status
- Medications
- Treatment and procedures
- Social relationships
- Environment

Authorisation was obtained from interRAI Australia to use the Australian version of the CHA and DBS.

Particular CHA items which are known as “triggers” also identify a person with specific problems or risks for functional decline who could benefit from further evaluation using a supplement assessment (Morris *et al.*, 2010). One of these supplements is the Deafblind

Supplement (DBS). This supplement was administered to all participants as standard procedure as all participants had been identified as being deafblind.

The CHA and DBS were selected for this study as they are standardised assessments that are valid and reliable for assessing the needs, strengths and abilities of individuals who are both congenitally deafblind or have acquired deafblindness (Dalby, *et al.*, 2009b). The internal consistency and validity of the CHA and DBS has been tested in Ontario, Canada with 182 persons who have deafblindness (Dalby *et al.*, 2009b). Dalby *et al.* (2009b) stated that all subscales demonstrated good to excellent internal consistency, and expected associations provided evidence of convergent validity. Dalby *et al.* (2009b) also stated that this instrument can facilitate service planning for people who are deafblind. As deafblindness is a unique and complex disability, using an assessment specifically designed for people who are deafblind provides more valid health measures of the participants of this study.

The CHA and DBS are detailed assessments and can take up to 50 minutes to administer. The Senses Australia occupational therapist was able to complete some of the questions through observation, but the majority of questions required the participant to respond. Each question within the assessment has a key and is scored accordingly (e.g., 0 = Not in the last three days; 1 = Not in the last three days but often feels this way; 2 = In one to two of the last three days; 3 = Daily in the last three days; 8 = Person would or could not respond).

***Canadian Occupational Performance Measure.*** The occupational performance of participants was measured using the COPM. The COPM was utilised within this study to determine person-centred goals and if there were any changes in the satisfaction and performance of these participant goals following support from the communication guides.

The COPM is based on the premise that occupational performance is the result of the interactions between a person, the environment and the occupation. The COPM was designed for use as an individualised measure to detect change in a person's self-perception of occupational performance over time (Law, (Baptist) *et al.*, 2005). It uses a person-centred approach, as it promotes that an individual's occupational performance is determined by the individual, in terms of their ability to perform certain occupations and their satisfaction with that performance (Law, (Baptist) *et al.*, 2005).

The COPM is a standardised instrument with specific instructions and methods for administering and scoring the test. This tool has been demonstrated to be reliable and is able to be repeated to provide stable results over varying intervals and valid in content, criterion,

and construct (Law, (Baptist) *et al.*, 2005). The COPM is not a norm-referenced measure as it was not designed to assess deviations in occupational performance (Law, (Baptist) *et al.*, 2005).

It is designed as an individual outcome measure, with a semi-structured interview format and structured scoring method. It is administered as a semi-structured interview and takes approximately 20 minutes to perform. The assessment asks the participants to identify up to five problems that they feel are important to them. For each of these problems, participants rate their current performance using a 10 point Likert scale where one is “not able to do it at all” and 10 is “able to do it extremely well”. Participants also rate their satisfaction with this performance, also using a 10 point Likert scale, one is “not satisfied at all” and 10 is “extremely satisfied”. These identified problems form the basis of the goals within the participant’s ISP. No license is required to use this assessment. Change scores between assessment and reassessment using the COPM are the most meaningful scores derived from this assessment (Law, (Baptist) *et al.*, 2005).

**SF-36 Health Survey (Version 2).** The Australian adapted Short-Form Health Survey (SF-36) is a generic outcome measure designed to examine a person’s perceived health status. This 36-Item questionnaire provides health and quality of life information regarding the status of the participants and if the Communication guide has had any impact on these areas. This assessment was used as it has previously been employed to measure the association between vision and hearing impairments and their combined effects on quality of life and is a valid and reliable assessment for use with people who have a sensory impairment (Chia, *et al.*, 2006). The assessment enables data to be collected to allow analysis of the progress of any changes in health or quality of life measures, which was identified as a sub-objective of the study. The SF-36 has been demonstrated to have superior psychometric properties and has been used extensively in Australia for both population health and clinical research (Ware, 2011).

The SF-36 Health Survey items and scales were constructed using the Likert method of summated ratings. Answers to each question are scored and then summed to produce raw scale scores for each health concept which are then transformed to a 0 – 100 point scale (Ware, 2011). The SF-36 Health Survey includes one multi-item scale measuring each of the following eight health concepts (Ware & Sherbourne, 1992):

- physical functioning;
- role limitations because of physical health problems;

- bodily pain;
- social functioning;
- general mental health (psychological distress and psychological wellbeing);
- role limitations because of emotional problems;
- vitality (energy/fatigue); and
- general health perceptions.

The scores are calibrated so that 50 is the average score or norm for the general population. The SF-36 can also be divided into two aggregate summary measures the Physical Component Summary (PCS) and the Mental Component Summary (MCS).

A non-commercial academic license was required and obtained from QualityMetric Incorporated, which included the assessment form, information on its development and the scoring software.

*Data checking of quantitative assessments.* Data was recorded directly onto the assessment forms by the occupational therapist, who then reviewed it and entered it onto an Excel spread sheet. In addition, the researcher reviewed the data on the original assessment forms and the spread sheet to ensure there were no errors for both initial and final assessments.

*Data analysis of quantitative assessments.* Analysis of CHA and DBS, COPM and SF-36 was conducted in collaboration with a Curtin University statistician. As the study is defined as a multiple-case holistic design, it was considered important not only to obtain information relating to changes within each case study, but also obtaining some aggregate pre- and post-comparisons.

Due to the number of variables gathered within the CHA and DBS, only selected variables were chosen for aggregate pre and post comparison using the Paired T-test and the Wilcoxon Signed Ranks Test. Those variables selected are those suggested within the literature as being detrimentally affected by an individual having both a vision and hearing impairment. These include mood, social relationships, ability to perform activities of daily living and ability to get out. Pre-post comparisons of the aggregated COPM goals and SF-36 components were also compared using both a Paired T-test and Wilcoxon signed-rank test. When the COPM results were analysed, individual participation and satisfaction scores were averaged. Those goals that the participant chose not to even commence with were excluded from this analysis.

The paired t-test is a parametric statistical test that assumes the data has come from a type of probability distribution (DePoy & Gitlin, 1998). Data is considered to be paired when there is some link between subjects. For example a group of subjects may be tested under two conditions so that the first score may be directly compared with the second score, commonly used in before-and-after experiments, which are also called repeated measures design experiments, where the same subject is measured twice (Martin & Pierce, 1994).

The Wilcoxon signed rank test is a non-parametric statistical test that does not rely on data belonging to any particular distribution (DePoy & Gitlin, 1998). The Wilcoxon signed ranks test can be used to analyse the results of experiments where the rank of the different scores can be obtained from the raw data, where the different scores can be found either by subtracting paired data values from one another or by calculating the differences between a set of obtained values and a claimed value for a median (DePoy & Gitlin, 1998).

Both a parametric and non-parametric statistical analysis of the quantitative assessment tools used within the study is appropriate as due to the small sample size it is difficult to ascertain if it is probability distributed or not (DePoy & Gitlin, 1998).

**Qualitative assessment.** Semi-structured individual interviews were conducted with all participants at the conclusion of their communication guide intervention. This method was selected as it provides enough structure to enable useful coding and comparison as well as a deeper understanding of the research question (Shaw & Gould, 2001).

The Senses Australia social worker contacted the participants and arranged to attend their home to conduct the semi-structured interview. The interview was digitally recorded with the participant's permission (see Consent Form – Appendix 3). The assessments and interview were completed one to two weeks following completion of the communication guide intervention.

Participants were asked to respond to nine open-ended questions (Bryman, 2008) relating to the communication guide intervention they received:

- In what areas did the communication guide make a difference in your life?
- In what areas did the communication guide make no difference?
- What were some of the best aspects to the communication guide service?
- What were some of the worst aspects to the communication guide service?
- What did you expect from the service and was the service what you expected?

- How did you find the hours of support provided to you? (Was it enough / too much / OK?)
- How did you find the communication guide(s)? (Were they easy to communicate with? Were they responsive to your needs?)
- Did the communication guide(s) have the skills to provide an effective service to you? (What areas could they improve upon?)
- Are there any other comments you would like to make?

*Data checking of qualitative assessment.* All the recorded interviews were transcribed by a professional transcription service into a Word document. The researcher listened to all the interviews to ensure the accuracy by correcting words that had been typed incorrectly, or completing text that the transcription service could not understand, as a number of participants had unclear speech due to their hearing impairment.

*Data analysis of qualitative assessment.* The final semi-structured interviews were analysed using a thematic analysis approach. Thematic analysis is a widely used qualitative analytic method (Roulston, 2001) and is a process for identifying, analysing and reporting patterns or themes within data (Boyatzis, 1998). A theme captures something important about the data in relation to the research question and represent some level of patterned response or meaning (Braun & Clarke, 2006). Braun and Clarke (2006) highlight six phases a researcher goes through when performing thematic analysis. They commented that this process is not necessarily linear but analysis often involves a constant moving back and forward between the entire data set, the coded extracts of data being analysed and the analysis of the data being produced. The six phases are:

- Familiarising self with data
- Generating initial codes
- Searching for themes
- Reviewing themes
- Defining and naming themes
- Producing the report

To assist with this analysis, NVivo (QSR International, 2012) software was utilised. NVivo is a qualitative data analysis computer software package produced by QSR International. It has been designed for qualitative researchers working with very rich text-based and/or multimedia information (QSR International, 2012). The Nvivo software enabled the researcher to complete a structured data gathering and analytical process, with each part of what the participants stated in their interviews being coded to a theme or sub-

theme. This enabled the theme to emerge from the data through groupings of similar phrases. The analysis of the themes that were elicited from semi-structured interviews, were compared by Senses Australia's occupational therapist and social worker. This enabled two additional reviews to ensure accuracy of coding and themes.

### **Ethical Issues**

Ethics approval from The Human Research Ethics Committee at Curtin University was obtained before this study was undertaken (see Appendix 4), using the Application for Ethical Approval of a Research Project Involving Humans (Form A). Ethical considerations included:

- Persons in dependent or unequal relationships or people with an intellectual disability. In order to address this issue, information was provided in the participant's preferred communication method. The researcher also invited potential participants to discuss their participation with someone who was able to support them in making their decision.
- Individuals who were indirectly identifiable by the researcher within the database. In addressing this issue, informed consent was obtained from each participant, where the consent form stated that the data is located in secure storage and that although participants will not be anonymous to the researcher, the information provided will be confidential.
- Dependence upon the service. Participants formally accepted on the consent form that this service was a pilot project and of six months duration only. Participants were prepared for cessation of the intervention by Senses Australia employees, to enable them to manage without the Communication Guide support, however alternative funding was investigated to continue the communication support.
- Bias of the researcher. To reduce the bias of the researcher in this study, data collection was undertaken by another occupational therapist and a social worker working at Senses Australia.

### **Storage and Security**

Data obtained from this research project is subject to the Australian Code for the Responsible Conduct of Research (Australian Government, 2007). As a result all data obtained will be retained by the researcher for five years (from the time of publication) at Senses Australia in secure storage. This data includes ISP's, progress notes, transcripts of interviews, assessment forms and consent forms.

### Chapter 3 - Results

The results of this study are categorised into: individual case study information; analysis of the final interviews; general demographic information of all 10 participants; and analysis of the average combined changes in variables for the quantitative assessment.

#### Case Studies

Each of the 10 participants is represented within this section as an individual case study. Each case contains descriptive information gained from the CHA and DBS. In particular, information is provided relating to the participants' age, living arrangement, cognitive ability, diagnosis (if any), level of education, employment status, vision and hearing. Any changes reported by participants within the CHA and DSC are outlined. Each case also provides information relating to participants' goals obtained using the COPM and records any changes to their performance and satisfaction of these goals at the completion of the intervention. When a participant has not pursued a goal initially identified, this goal has been excluded when calculating average changes in performance and satisfaction. The SF-36 initial and final scores for each participant are also included.

**Case study A.** This participant was a 41 year old man who was born in Australia and spoke English. He lived independently with non-relatives in a private residence. He was independent in his cognitive skills for daily decision making and his short-term memory 'appeared OK' (as categorised by the CHA). Participant A reported he had attended a residential school and a special education program for deaf students. He was enrolled in a computing diploma at the time and did not have employment.

This participant was born with Usher syndrome type two, which means he was born with a congenital sensori-neural hearing loss. He also suffered from Tinnitus. He wore a hearing device and with this could respond to voices at normal volume but did not respond to quiet sounds. He required deliberate cues to be aware when someone else was in the room and missed some part or intent of a message, but was able to comprehend most of a conversation.

Participant A developed a vision loss at approximately 25 years from Retinitis Pigmentosa. He was categorised as having 'severe low vision' in his visual acuity range (less than 20/160 – 20/400) and a 'profound low vision' (8 degrees to less than 16 degrees) in his visual field diameter. He wore glasses but still had difficulty in his distance vision, where he could see and identify faces at conversation distance but not across the room. He had difficulty in dim light, bright light, glare and abrupt changes in illumination. He had some

visual fatigue when performing visual tasks where he had diminished visual endurance but was able to complete normal day-to-day visual activities. He reported his vision has declined in the past year.

Changes in the CHA and DBS as reported by Participant A are outlined in Table 3.

Table 3.

*CHA and DBS changes in Participant A*

<b>Assessment Item</b>	<b>Score at Initial Assessment</b>	<b>Score at Final Assessment</b>
Pursues involvement in activities of residential setting or community	Yes, without Communication Guide support	Yes, only with Communication Guide support
Initiates interactions with others	Yes, only with Communication Guide support	Yes, without Communication Guide support
Reacts positively to interactions initiated by others	Yes, without Communication Guide support	Yes, only with Communication Guide support
Social interactions	Moderate	Minimal
Conflict or anger with family/friends	Eight to 30 days ago	More than 30 days ago
Expressions, including non-verbal of what appear to be unrealistic fears	Present but not exhibited in last three days	Not present
Repetitive health complaints	Present but not exhibited in last three days	Not present
Felt sad, depressed or hopeless in last three days	Not in last three days	In one to two of last three days
Major life stressors over last 90 days	Yes	No
Prefers change in living arrangements	Yes	No
Prefers change in daily routines	Yes	No
Hours of physical activity in the last three days	More than four hours	Three to four hours
In the last three days, number of days went out of the house	Three days	One to two days
Difficulty falling asleep or staying asleep	Exhibited on two of last three days	Exhibited on one of last three days
Frequency complains or shows evidence of pain	Present but not exhibited in last three days	No pain
Intensity of highest level of pain present	Mild	No pain
Consistency of pain	Single episode during last three days	No pain
Pain control	Pain intensity acceptable to person	No issue of pain
Self-reported health	Good	Fair

Number of days of participation in preferred recreation and leisure activities in last seven days	Seven	Five
Employment status	Unemployed, not seeking employment	Unemployed, seeking employment

Participant A identified two goals he wanted to work towards with support from the communication guide. Outlined in Table 4, these goals were related to socialisation and education.

Table 4

*Canadian Occupational Performance Measure results for Participant A*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in av. scores (Ax2 - Ax1)	
	P	S	P	S	P	S
1. To improve social networks.	3	3	7	7	+3	+3
2. Assist with transition to TAFE.	4	4	6	6		

Note. P = Performance, S = Satisfaction

Figure 2 outlines Participant A’s initial and final scores in the eight health concepts of the SF-36 Version 2 assessment. At the initial assessment Participant A scored 53.3 for the Physical Component Summary and 48.1 for the Mental Component Summary. At the final assessment he scored 49.9 for the Physical Component Summary and 43.9 for the Mental Component Summary. Participant A declined in all health concepts except that of ‘general mental health’. His Physical Component Summary reduced by 3.4 and his Mental Component Summary reduced by 4.2.

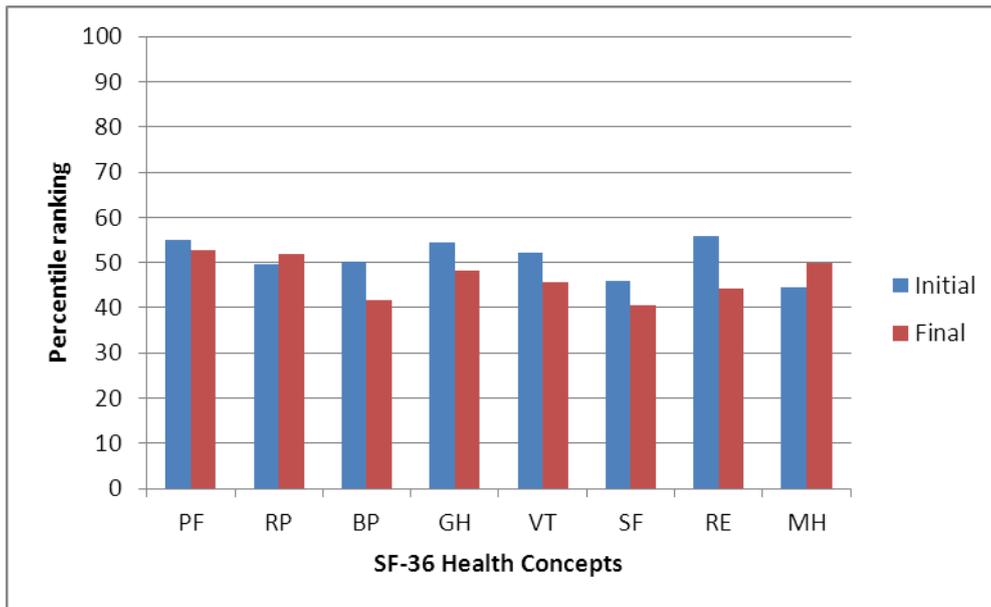


Figure 2. SF-36v2 scale scores for Participant A initial and final assessment

**KEY**  
 PF = physical functioning  
 RP = role limitations because of physical health problems  
 BP = bodily pain  
 GH = general health perceptions  
 VT = vitality  
 SF = social functioning  
 RE = role limitations because of emotional problems  
 MH = general mental health

**Case study B.** This participant was a 49 year old single woman who was born in Australia and spoke English. At the commencement of the study she lived independently in a private residence, but during the course of the study, her mother injured herself so the participant relocated to her mother’s home to provide her with support. She was independent in her cognitive skills for daily decision making and her short-term memory ‘appeared OK’. She was born with Rubella syndrome.

Participant B reported attending a special education program for deaf, blind or deafblind persons. She had completed courses at a technical/trade school (TAFE) and had employment in a supported employment environment.

This participant was born with her vision loss and also suffered from glaucoma. She had profound low vision in her visual acuity range (less than 6/120 – 6/300) and a profound low vision (eight degrees to less than 16 degrees) in her visual field diameter. She wore glasses

but still had moderate difficulty in her distance vision, where she could see but not identify faces at conversation level. She had difficulty with abrupt changes in illumination and had some visual fatigue when performing visual tasks where she had diminished visual endurance but was able to complete normal day-to-day visual activities. She reported her vision has declined in the past five years.

This participant had a congenital sensori-neural hearing loss. She had difficulty in locating sound and wore cochlear implants. With these she could respond to both indoor and outdoor sounds appropriately. She was usually understood when expressing herself, with difficulty finding words or finishing thoughts but if given time required little or no prompting to complete her statements. She usually understood others but missed some part or intent of messages but comprehended most of the conversation.

Changes in the CHA and DBS as reported by Participant B are outlined in Table 5.

Table 5

*CHA and DBS changes in Participant B*

<b>Assessment Item</b>	<b>Score at Initial Assessment</b>	<b>Score at Final Assessment</b>
Primary mode of locomotion indoors	Walking, no assistance	Walking, uses assistive device
Orientation and mobility in daytime in familiar environment - performance	Extensive assistance	Maximal assistance
Orientation and mobility in daytime in familiar environment - capacity	Extensive assistance	Maximal assistance
At ease doing planned or structured activities	Yes, without Communication Guide support	Yes, only with Communication Guide support
Pursues involvement in activities of residential setting or community	Yes, only with Communication Guide support	Yes, without Communication Guide support
Initiates interactions with others	Yes, only with Communication Guide support	Yes, without Communication Guide support
Reacts positively to interactions initiated by others	Yes, only with Communication Guide support	Yes, without Communication Guide support
Adjusts easily to changes in routines in last 30 days	Yes, only with Communication Guide support	Yes, without Communication Guide support
Social interactions	Severe	Moderate
Repetitive anxious complaints/concerns (non-health related)	Not present	Present but not exhibited in last three days

Withdrawal from activities of interest	Not present	Present but not exhibited in last three days
Length of time alone during day	More than two hours but less than eight hours	Eight hours or more
Hours of physical activity in the last three days	Three to four hours	More than four hours
In the last three days, number of days went out of the house	Three days	One to two days
Falls	No fall in last 90 days	No fall in last 90 days, but fell 31-90 days ago
Dizziness	Not present	Present but not exhibited in last three days
Unsteady gait	Not present	Present but not exhibited in last three days
Mammogram or breast exam in last two years	No	Yes
Pneumovax vaccine in last five years	No	Yes
Number of days of participation in preferred recreation and leisure activities in last seven days	Seven	Three

Participant B identified four goals she wanted to work towards with support from the communication guide. These goals are outlined in Table 6, with two of these goals related to communication and two related to socialisation. After the commencement of the communication guide support, Participant B chose not to enrol and study at the educational organisation TAFE or join a gym, therefore goals three and four were not pursued.

Table 6

*Canadian Occupational Performance Measure results for Participant B*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in av. scores (Ax2 - Ax1)	
	P	S	P	S	P	S
1. To improve language, comprehension and communication skills.	1	2	4	4	+2	+2
2. To become involved in a local social group where she can meet new people and develop communication skills.	4	4	5	6	(Goal 3 & 4 not included)	
3. To increase participation at TAFE and meet new people.	1	2	not completed			

4. To establish communication between local gym about needs and goals.	1	0	not completed
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Note. P = Performance, S = Satisfaction

Figure 3 outlines Participant B’s initial and final scores in the eight health concepts of the SF-36 Version 2 assessment. Her component scores were 53.3 for the Physical Component Summary and 62.6 for the Mental Component Summary at the initial assessment and 51.7 for the Physical Component Summary and 56.3 for the Mental Component Summary at the final assessment. Participant B’s scores in ‘physical functioning’, ‘role limitations because of physical health problems’, ‘bodily pain’ and ‘role limitation because of emotional problems’ remained the same from the initial to final assessment. Health concepts of ‘general health’, ‘vitality’, ‘social functioning’ and ‘general mental health’ declined. Her Physical Component Summary reduced by 1.6 and Mental Component Summary reduced by 6.3.

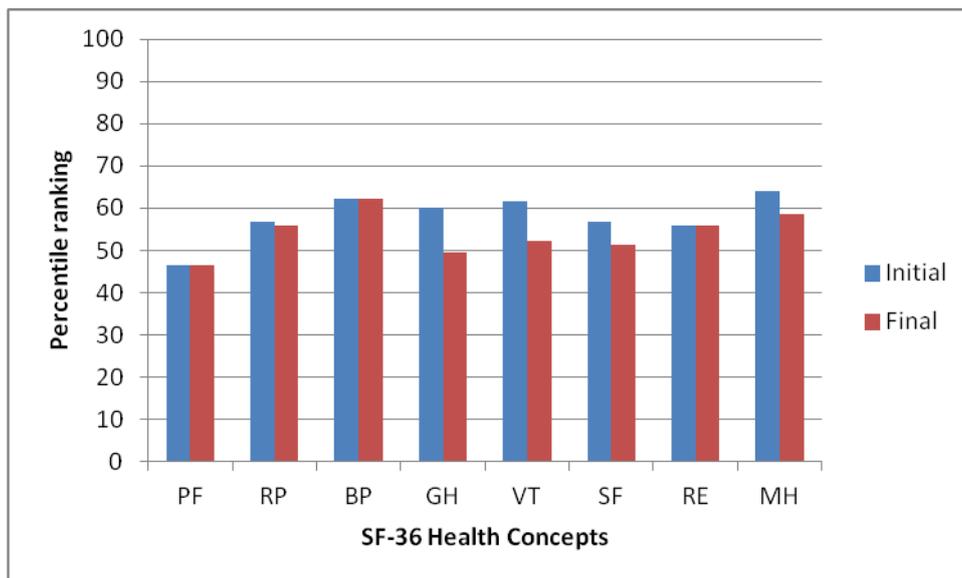


Figure 3. SF-36v2 scale scores for Participant B initial and final assessment

**Case study C.** This participant was a 40 year old woman who was born in Australia and spoke English. She was single and lived with her parents in a private residence but had previously lived in supported living facility. She had minimally impaired cognitive skills for daily decision making and her short-term memory ‘appeared OK’. She was born with Rubella syndrome.

Participant C reported attending a special education program for deaf, blind or deafblind persons and completing high school. She had employment in a supported employment environment.

This participant was born with her vision loss and suffered from glaucoma, cataracts, myopia and a malformed eye. She had profound low vision in her visual acuity range (less than 6/120 – 6/300) and a profound low vision (8 degrees to less than 16 degrees) in her visual field diameter. She wore glasses but still had minimal difficulty in her distance vision, where she could see and identify faces at conversation distance but not across the room. She had difficulty in dim light, glare and abrupt changes in illumination. She had minimal visual fatigue when performing visual tasks where she had diminished visual endurance but was able to complete normal day-to-day visual activities. She reported her vision had declined in the past five years.

This participant had a congenital sensori-neural hearing loss but had no difficulty in locating sound. The participant wore hearing aids and with these could respond to both indoor and outdoor sounds appropriately. She often understood others but misses some part or intent of messages, however with repetition or explanation could often comprehend the conversation.

Changes in the CHA and DBS as reported by Participant C are outlined in Table 7.

Table 7

*CHA and DBS changes in Participant C*

<b>Assessment Item</b>	<b>Score at Initial Assessment</b>	<b>Score at Final Assessment</b>
Primary mode of locomotion indoors	Walking, no assistance	Walking, uses assistive device
Orientation and mobility in daytime in familiar environment - performance	Extensive assistance	Maximal assistance
Orientation and mobility in daytime in familiar environment - capacity	Extensive assistance	Maximal assistance
At ease doing planned or structured activities	Yes, without Com Guide support	Yes, only with Com Guide support
Pursues involvement in activities of residential setting or community	Yes, only with Communication Guide support	Yes, without Communication Guide support
Initiates interactions with others	Yes, only with Communication Guide support	Yes, without Communication Guide support

Reacts positively to interactions initiated by others	Yes, only with Communication Guide support	Yes, without Communication Guide support
Adjusts easily to changes in routines in last 30 days	Yes, only with Communication Guide support	Yes, without Communication Guide support
Social interactions	Severe	Moderate
Repetitive anxious complaints/concerns (non-health related)	Not present	Present but not exhibited in last three days
Withdrawal from activities of interest	Not present	Present but not exhibited in last three days
Length of time alone during day	More than two hours but less than eight hours	Eight hours or more
Hours of physical activity in the last three days	Three to four hours	More than four hours
In the last three days, number of days went out of the house	Three days	One to two days
Falls	No fall in last 90 days	No fall in last 90 days, but fell 31-90 days ago
Dizziness	Not present	Present but not exhibited in last three days
Unsteady gait	Not present	Present but not exhibited in last three days
Mammogram or breast exam in last two years	No	Yes
Pneumovax vaccine in last five years	No	Yes
Number of days of participation in preferred recreation and leisure activities in last seven days	Seven	Three
Managing finance - performance	Limited assistance	Maximal assistance
Managing finance – capacity	Limited assistance	Maximal assistance
Phone use - performance	Setup help only	Supervision
Phone use - capacity	Independent	Supervision
Stairs - performance	Setup help only	Extensive assistance
Stairs - capacity	Setup help only	Extensive assistance
Primary mode of locomotion indoors	Walking, no assistance	Walking, uses assistive device
Involvement in structured activities – formal education	No	Yes
Adjusts easily to changes in routines in last 30 days	No	Yes, without Communication Guide support
Visit with a long-standing social relation or family member	In the last three days	Four to seven days ago
Weight loss of five percent or more in last 30 days	Yes	No
Dental exam in last year	No	Yes

Influenza vaccination in last year	No	Yes
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Participant C identified three goals she wanted to work towards with support from the communication guide. Outlined in Table 8, these goals all related to developing computer and technology skills.

Table 8

*Canadian Occupational Performance Measure individual results for Participant C*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in av. scores (Ax2 - Ax1)	
	P	S	P	S	P	S
1. To improve skills when using the iTunes program on laptop computer.	1	1	9	9	+6.34	+6
2. To improve skills when using the Microsoft word and publisher program on laptop computer.	1	1	9	9		
3. To learn how to download photos from camera to laptop.	5	5	8	7		

Note. P = Performance, S = Satisfaction

Figure 4 outlines Participant C’s initial and final scores in the eight health concepts of the SF-36 Version 2 assessment. She scored 53.6 for the Physical Component Summary and 57.4 for the Mental Component Summary at the initial assessment and 49.0 for the Physical Component Summary and 62.9 for the Mental Component Summary at the final assessment. Participant C’s scores in ‘physical functioning’ and ‘role limitation because of physical problems’ declined from the initial to final assessment. Health concepts that remained the same included ‘bodily pain’, ‘social functioning’ and ‘role limitations because of emotional problems’. Those that improved included ‘general health’, ‘vitality’ and ‘general mental health’. Participant C’s Physical Component Summary reduced by 4.6 and Mental Component Summary increased by 5.5 from the initial to final assessment.

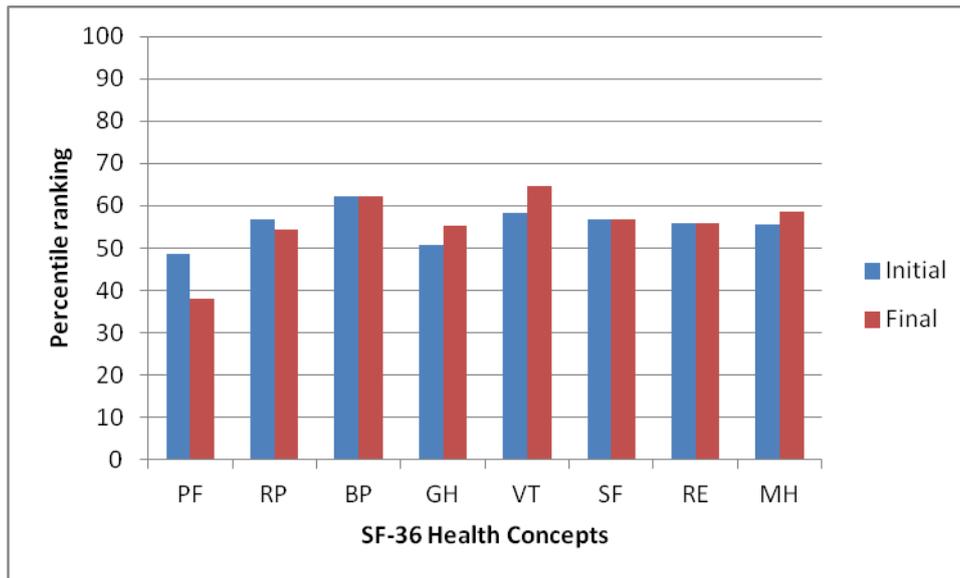


Figure 4. SF-36v2 scale scores for Participant C initial and final assessment

**Case study D.** This participant was a 51 year old single man who was born in Australia and spoke English. He lived in an assisted living or semi-independent living arrangement. He was independent in his cognitive skills for daily decision making and his short-term memory ‘appeared OK’. He reported that he was receiving treatment for delusions and hallucinations at the initial assessment but these were not present at the final assessment. He was born with Usher syndrome type two.

Participant D reported completing high school and technical/trade school. He had employment in a supported employment environment.

This participant was born with a congenital sensori-neural hearing loss. The participant did not wear a hearing device and could not locate sounds. He did not respond to voices at normal volume or quiet sounds. He required deliberate cues to be aware when someone else was in the room and missed some part or intent of a message but was able to comprehend most of a conversation when spoken in a very loud volume in close proximity.

This participant developed a vision loss between 19-64 years from Retinitis Pigmentosa. He had near blindness in his visual acuity range (less than 20/1000 – 20/20000) and near blindness (4 degrees to less than 8 degrees) in his visual field diameter. He did not wear glasses and had severe difficulty in his distance vision, where he had difficult identifying objects and saw only light, colours and shapes. He had difficulty in dim light or at night, bright light, glare, abrupt changes in illumination and subtle contrast differences. He had

severe visual fatigue when performing visual tasks and cannot start normal day-to-day visual activities such as reading. He reported his vision had declined in the past five years.

Changes in the CHA and DBS as reported by Participant D are outlined in Table 9.

Table 9

*CHA and DBS changes in Participant D*

<b>Assessment Item</b>	<b>Score at Initial Assessment</b>	<b>Score at Final Assessment</b>
Meal preparation - performance	Extensive assistance	Independent
Meal preparation - capacity	Extensive assistance	Independent
Ordinary Housework - performance	Maximal assistance	Total dependence
Ordinary Housework - capacity	Maximal assistance	Total dependence
Stairs - capacity	Extensive assistance	Maximal assistance
Primary mode of locomotion indoors	Walking, no assistance	Walking, uses assistive device
Orientation and mobility in daytime in familiar outdoor environment – performance	Total dependence	Maximal dependence
Orientation and mobility in daytime in familiar outdoor environment – capacity	Independent	Maximal dependence
Change in social activities in last 90 days	Decline, not distressed	No decline
Adjusts easily to changes in routines in last 30 days	No	Yes, only with Communication Guide support
Social interactions	Very severe	Moderate
Participation in social activities of long-standing interest	In the last three days	Four to seven days ago
Other interactions with long-standing social relations/family members	Never	More than 30 days ago
Repetitive anxious complaints/concerns (non-health related)	Not present	Present but not exhibited in last three days
Sad, pained or worried facial expressions	Exhibited daily in last three days	Present but not exhibited in last three days
Withdrawal from activities of interest	Not present	Present but not exhibited in last three days
Reduced social interactions	Not present	Present but not exhibited in last three days
Felt anxious, restless or uneasy in last three days	Not in the last three days	Not in the last three days, but often feels that way

Felt sad, depressed or hopeless in last three days	Not in the last three days	Not in the last three days, but often feels that way
Delusions	Diagnosis present, receiving active treatment	Not present
Hallucinations	Diagnosis present, receiving active treatment	Not present
Hours of physical activity in the last three days	Less than one hour	One to two hours
In the last three days, number of days went out of the house	Three days	One to two days
Eye exam in last year	No	Yes
Pneumovax vaccine in last five years	No	Yes
Number of days of participation in preferred recreation and leisure activities in last seven days	Three	Six

Participant D identified two goals he wanted to work towards with support from the communication guide. Outlined in Table 10, these goals were related to transportation and an instrumental activity of daily living (cooking). Participant D chose not to pursue the goal of doing more cooking and to cook different meals with the communication guide.

Table 10

*Canadian Occupational Performance Measure individual results for Participant D*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in av. scores (Ax2 - Ax1)	
	P	S	P	S	P	S
1. To utilise the public transport train lines and explore the wider community, eg. catch the train to one coffee shop so that X becomes familiar with it.	1.5	5	9	9	+7.5	+4
2. To do more cooking and to cook different meals.	2.5	5	not completed		(Goal 2 not included)	

Note. P = Performance, S = Satisfaction

Figure 5 outlines Participant D’s initial and scores in the eight health concepts of the SF-36 Version 2 assessment. Participant D scored 48.2 for the Physical Component Summary and 52.9 for the Mental Component Summary at the initial assessment. At the final assessment he scored 46.0 for the Physical Component Summary and 56.1 for the Mental Component Summary. Participant D’s scores in ‘physical functioning’, ‘vitality’ and ‘social functioning’ declined from the initial to final assessment. Health concepts that

remained the same included 'role limitation because of physical problems', 'bodily pain' and 'role limitations because of emotional problems'. Those that improved included 'general health' and 'general mental health'. Participant D's Physical Component Summary reduced by 2.2 and Mental Component Summary increased by 3.2 from the initial to final assessment.

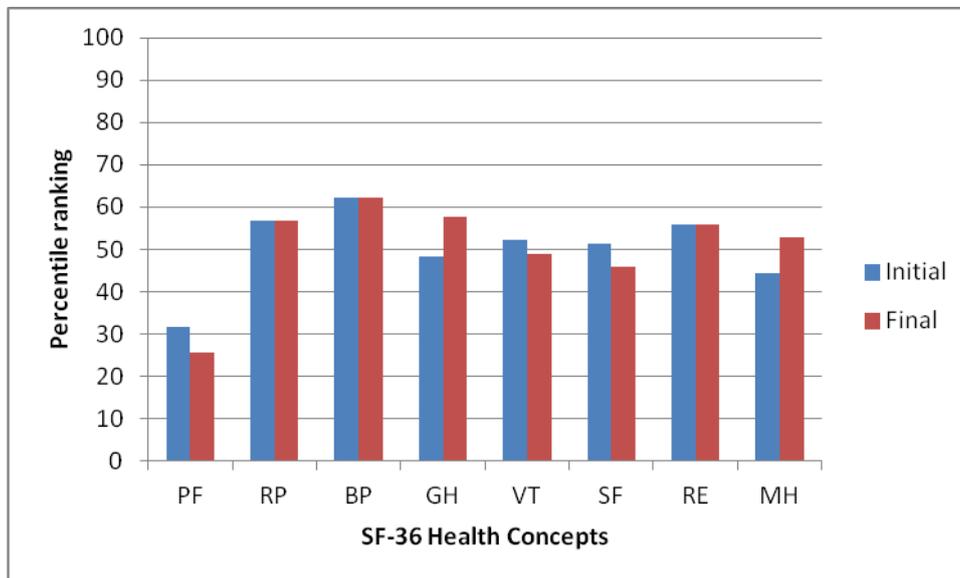


Figure 5. SF-36v2 scale scores for Participant D initial and final assessment

**Case study E.** This participant was a 46 year old woman who was born in Australia and spoke English. She was single and lived by herself in a private residence. She was independent in her cognitive skills for daily decision making and her short-term memory 'appeared OK'. Participant E reported that she was receiving treatment for anxiety and depression at the initial assessment. At the final assessment her anxiety was not present, her depression was present but she was not receiving treatment and she was being monitored for schizophrenia but having no active treatment. She was born with Usher syndrome type two.

Participant E reported completing high school at a mainstream school and some college/university education. She had employment in a competitive employment environment.

This participant was born with a congenital sensori-neural hearing loss. The participant wore cochlear implants and with these could respond to voices at normal volume, quiet sounds and sounds indicating danger indoors but required a quiet setting to hear well. She required deliberate cues to be aware when someone else was in the room.

This participant developed a vision loss between 19-64 years from Retinitis Pigmentosa. She had profound low vision in her visual acuity range (less than 20/400 – 20/1000) and near blindness (4 degrees to 8 degrees) in her visual field diameter. She used sight enhancement devices and had adaptive devices to assist her. She had minimal difficulty in her distance vision, where she could see and identify faces at conversation distance but not across the room. She had difficulty in dim light, bright light, glare abrupt changes in illumination and subtle contrast differences. She had minimal visual fatigue when performing visual tasks where she had diminished visual endurance but was able to complete normal day-to-day visual activities. She reported her vision has declined in the past year. This participant used a guide dog to assist her outdoors and in unfamiliar environments.

Changes in the CHA and DBS as reported by Participant E are outlined in Table 11.

Table 11

*CHA and DBS changes in Participant E*

<b>Assessment Item</b>	<b>Score at Initial Assessment</b>	<b>Score at Final Assessment</b>
Change in social activities in last 90 days	No decline	Decline, distressed
Involvement in structured activities – formal education	No	Yes
Adjusts easily to changes in routines in last 30 days	Yes, only with Communication Guide support	Yes, without Communication Guide support
Conflict or anger with family/friends	In the last three days	More than 30 days ago
Crying, tearful	Exhibited on one to two of last three days	Not present
Withdrawal from activities of interest	Present but not exhibited in last three days	Not present
Reduced social interactions	Present but not exhibited in last three days	Not present
Felt anxious, restless or uneasy in last three days	Daily in last three days	Not in the last three days
Felt sad, depressed or hopeless in last three days	Daily in last three days	Present but not exhibited in last three days
Lonely	Yes	No
Length of time alone during the day	One to two hours	Eight hours or more
Anxiety	Diagnosis present, receiving active treatment	Not present
Depression	Diagnosis present, receiving active treatment	Diagnosis present, monitored but no active treatment
Schizophrenia	Not present	Diagnosis present, monitored but no active treatment

Prefers change in living arrangements	Yes	No
Prefers change in daily routines	Yes	No
Falls	No fall in last 30 days, but fell 31-90 days ago	No fall in last 90 days
Difficulty falling asleep or staying asleep	Exhibited in last three days	Exhibited on two of last three days
Colonoscopy test in last five years	Yes	No
Number of days of participation in preferred recreation and leisure activities in last seven days	Three	Four

Participant E identified four goals she wanted to work towards with support from the communication guide. Outlined in Table 12, these goals relate to orientation and mobility, access and employment.

Table 12

*Canadian Occupational Performance Measure individual results for Participant E*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in av. scores (Ax2 - Ax1)	
	P	S	P	S	P	S
	1. To orientate to new community and environment.	3	3	8	8	+4.25
2. To access local community services and available resources.	3	3	8	6		
3. To set up new home environment in a way that makes it easy to locate and find things.	6	6	8	10		
4. Transitioning from working three days a week to working 5 days a week at current place of employment in the city.	5	5	10	8		

Note. P = Performance, S = Satisfaction

Figure 6 outlines Participant E’s initial and final scores in the eight health concepts of the SF-36 Version 2 assessment. Participant E scored 67.8 for the Physical Component Summary and 28.6 for the Mental Component Summary at the initial assessment. At the final assessment she scored 57.7 for the Physical Component Summary and 42.3 for the

Mental Component Summary. Participant E’s scores in ‘physical functioning’, ‘general health’ and ‘social functioning’ declined from the initial to final assessment. Health concepts that remained the same included ‘role limitation because of physical problems’ and ‘bodily pain’. Those that improved included ‘vitality’, ‘role limitations because of emotional problems’ and ‘general mental health’. Participant E’s Physical Component Summary reduced by 10.1 and Mental Component Summary increased by 13.7 from the initial to final assessment.

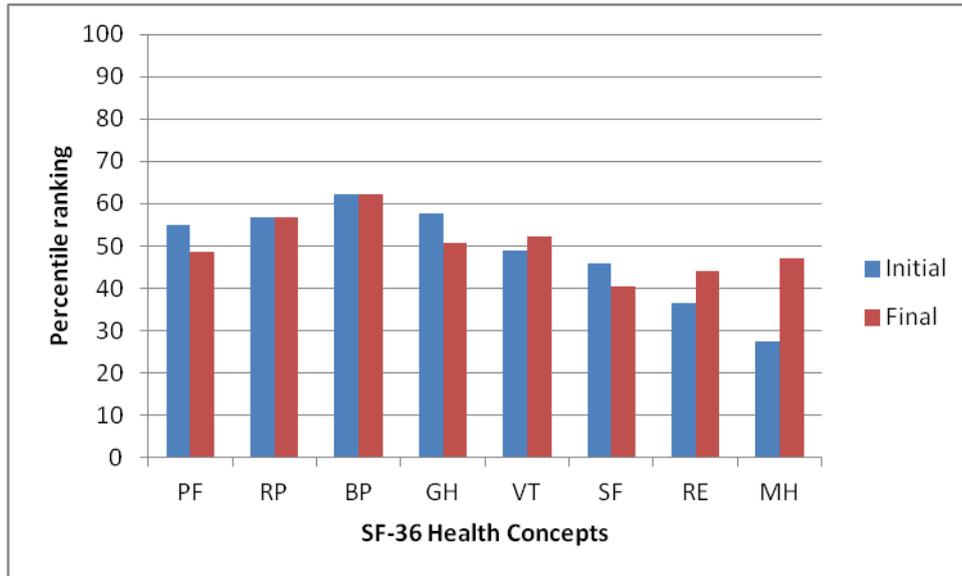


Figure 6. SF-36v2 scale scores for Participant E initial and final assessment

**Case study F.** This participant was an 81 year old widowed man who was born in Burma and spoke English at home. He lived in an assisted living or semi-independent living arrangement. He was independent in his cognitive skills for daily decision making and his short-term memory ‘appeared OK’. Participant F reported completing high school. He was retired from employment.

This participant developed a hearing loss at the age of 10 years due to a bomb detonating in close proximity. He also suffered from tinnitus. The participant wore hearing aids and even with these still had difficulty locating sounds. With his hearing aids he was able to respond to quiet sounds, voices at normal volume and sounds indicating danger indoors. He required a quiet setting to hear well. He did not require deliberate cues to be aware when someone else was in the room.

This participant developed a vision loss between 19-64 years from glaucoma and cataracts. He had near blindness in his visual acuity range (less than 20/1000 – 20/20000)

and near blindness (4 degrees to less than 8 degrees) in his visual field diameter. He wore glasses but still had moderate difficulty in his distance vision, where he could see but not identify faces at conversation distance. He had difficulty in bright light or daylight and glare. He had moderate visual fatigue when performing visual tasks and was unable to complete normal day-to-day visual activities such as reading. He reported his vision had declined in the past 90 days.

Changes in the CHA and DBS as reported by Participant F are outlined in Table 13.

Table 13

*CHA and DBS changes in Participant F*

<b>Assessment Item</b>	<b>Score at Initial Assessment</b>	<b>Score at Final Assessment</b>
Stairs - performance	Supervision	Limited assistance
Stairs – capacity	Supervision	Limited assistance
Orientation and mobility in daytime in familiar outdoor environment – performance	Limited assistance	Independent
Orientation and mobility in daytime in familiar outdoor environment – Capacity	Limited assistance	Independent
Orientation and mobility in daytime in unfamiliar environment – performance	Maximal assistance	Extensive assistance
Orientation and mobility in daytime in unfamiliar environment –Capacity	Maximal assistance	Extensive assistance
Involvement in structured activities – formal education	No	Yes
Involvement in structured activities – volunteerism	No	Yes
At ease doing planned or structured activities	Yes, only with Communication Guide support	Yes, without Communication Guide support
Visit with a long-standing social relation or family member	In the last three days	Eight to 30 days ago
Crying, tearful	Present but not exhibited in last three days	Not present
Reduced social interactions	Present but not exhibited in last three days	Not present
Lonely	Yes	No
Hours of physical activity in the last three days	Less than one hour	One to two hours
Recent falls	Yes	No
Dizziness	Present but not exhibited in last three days	Not present

Fatigue	None	Minimal
Influenza vaccination in last year	No	Yes
Number of days of participation in preferred recreation and leisure activities in last seven days	Seven	Six

Participant F identified four goals he wanted to work towards with support from the communication guide. Outlined in Table 14, these goals relate to communication and access. Participant F's first goal was to be able to write letters to friends and family, some of who were overseas, however this goal was not pursued by the participant during the intervention.

Table 14

*Canadian Occupational Performance Measure individual results for Participant F*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in av. Scores (Ax2 - Ax1)	
	P	S	P	S	P	S
1. To be able to write letters to friends and family, some of who are overseas.	1	3	not completed		+6.66	+4.8
2. To organise letters and mail in way that is easy to access.	2	3	8	8	(Goal 1 not included)	
3. To go to Belmont Forum or to Morley shopping centres for lunch or cup of tea during some weekly visits.	1	5	8	8		
4. To organise telephone contacts into a way that makes it easier to read and access.	2	3	9	9		

Note. P = Performance, S = Satisfaction

Figure 7 outlines Participant F's initial and final scores in the eight health concepts of the SF-36 Version 2 assessment. Participant F scored 39.4 for the Physical Component Summary and 60.4 for the Mental Component Summary at the initial assessment and 35.7 for the Physical Component Summary and 64.9 for the Mental Component Summary in the final assessment. Participant F's scores in 'role limitation because of physical problems', 'general health' and 'social functioning' declined from the initial to final assessment. Health concepts that remained the same included 'physical functioning', 'bodily pain' and

‘role limitations because of emotional problems’. Concepts that improved included ‘vitality’ and ‘general mental health’. Participant F’s Physical Component Summary reduced by 3.7 and Mental Component Summary increased by 4.3 from the initial to final assessment.

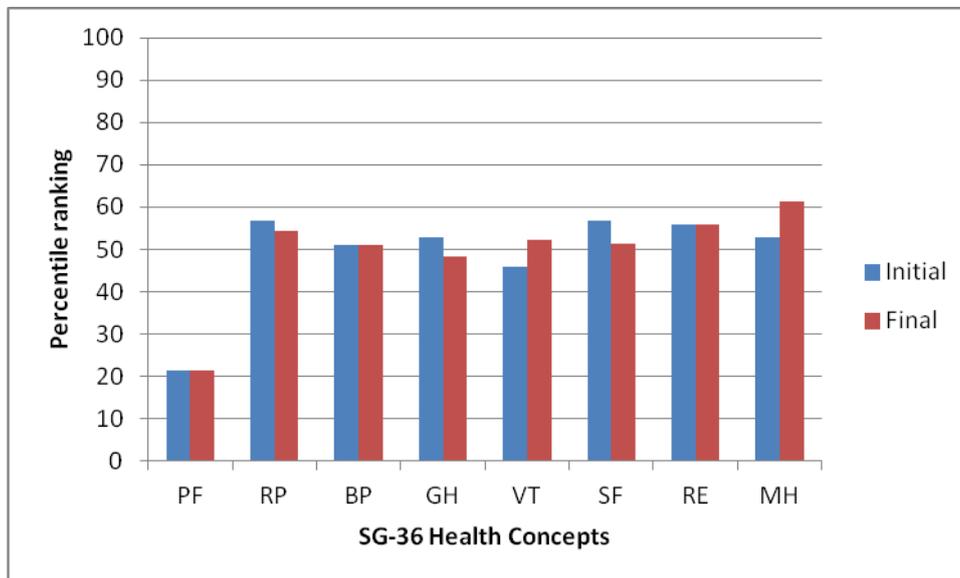


Figure 7. SF-36v2 scale scores for Participant F initial and final assessment

**Case study G.** This participant was a 54 year old single woman who was born in Holland and spoke English at home. At the commencement of the study she lived independently on her own in a private residence, but during the course of the study, she relocated to living in an assisted living or semi-independent living environment. She was independent in her cognitive skills for daily decision making and her short-term memory ‘appeared OK’. She was born with Usher syndrome, unknown type.

Participant G reported attending a special education program for deaf, blind or deafblind persons at a residential school. She had completed high school and courses at a technical/trade school. She was neither employed, nor seeking employment.

This participant was born with a congenital sensori-neural hearing loss. The participant wore hearing aids and with these could locate sounds, respond to voices at normal volume, quiet sounds and sounds indicating danger indoors but required a quiet setting to hear well. She missed some part or intent of messages but comprehended most conversations. She did not require deliberate cues to be aware when someone else was in the room.

This participant developed a vision loss between 0-2 years from Retinitis Pigmentosa. She had near blindness in her visual acuity range (less than 20/1000 – 20/20000) and near blindness (4 degrees to less than 8 degrees) in her visual field diameter. She used sight enhancement devices, orientation and mobility devices and adaptive devices to assist her. She had minimal difficulty in her distance vision, where she was able see and identify faces at conversation distance but not across the room. She had difficulty in dim light, bright light, abrupt changes in illumination and subtle contrast differences. She had minimal visual fatigue when performing visual tasks where she had diminished visual endurance but was able to complete normal day-to-day visual activities. She reported her vision had declined in the past 90 days.

Changes in the CHA and DBS as reported by Participant G are outlined in Table 15.

Table 15

*CHA and DBS changes in Participant G*

<b>Assessment Item</b>	<b>Score at Initial Assessment</b>	<b>Score at Final Assessment</b>
Stairs - performance	Independent	Limited assistance
Stairs - capacity	Independent	Limited assistance
Primary mode of locomotion indoors	Walking, no assistance	Walking, uses assistive device
Other interaction with long-standing social relation/family member	More than 30 days ago	Eight to 30 days ago
Strong and supportive relationship with family	No	Yes
Crying, tearful	Present but not exhibited in last three days	Not present
Felt sad, depressed or hopeless in last three days	Not in the last three days, but often feels that way	Not in the last three days
Major life stressors over last 90 days	Yes	No
Reports having a confidant	No	Yes
Falls	One fall in last 30 days	No fall in last 30 days
Recent falls	Yes	No
Dizziness	Exhibited on one of last three days	Present but not exhibited in last three days
Unsteady gait	Exhibited daily in last three days	Present but not exhibited in last three days
Frequency complains or shows evidence of pain	Exhibited on one to two of last three days	Present but not exhibited in last three days
Consistency of pain	Constant	No pain
Pain control	Pain intensity acceptable	Controlled adequately by therapeutic regime
Self-reported health	Fair	Good
Dental exam in last year	Yes	No

Influenza vaccination in last year	No	Yes
Mammogram or breast exam in last two years	No	Yes
Number of days of participation in preferred recreation and leisure activities in last seven days	Three	Four

Participant G identified two goals she wanted to work towards with support from the communication guide. Outlined in Table 16, these goals were related to communication and community involvement. Participant G chose not to pursue the goal of playing the piano as a volunteer with the communication guide.

Table 16

*Canadian Occupational Performance Measure individual results for Participant G*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in av. scores (Ax2 - Ax1)	
	P	S	P	S	P	S
	1. To improve communication skills to locate and use different services in the community as she pleases, E.g. seamstress to make clothes.	6	6	10	10	+4
2. To play the piano as a volunteer at Royal Perth Hospital.	2	5	not completed		(Goal 2 not included)	

Note. P = Performance, S = Satisfaction

Figure 8 outlines Participant G’s initial scores in the eight health concepts of the SF-36 Version 2 assessment. Participant G scored 35.0 for the Physical Component Summary and 45.4 for the Mental Component Summary in the initial assessment and 36.5 for the Physical Component Summary and 59.0 for the Mental Component Summary in the final assessment. Participant G’s scores in ‘physical functioning’ and ‘role limitations because of emotional problems’ declined from the initial to final assessment. Health concepts that remained the same included ‘general health’ and ‘vitality’. Those concepts that improved included ‘role limitation because of physical problems’, ‘bodily pain’, ‘social functioning’ and ‘general mental health’. Participant G’s Physical Component Summary increased by 1.5 and Mental Component Summary increased by 13.6 from the initial to final assessment.

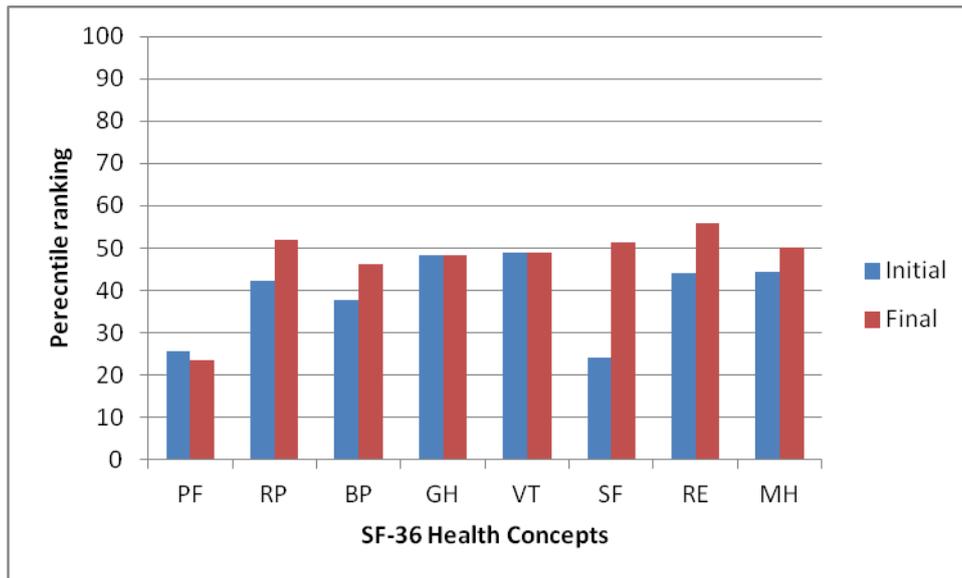


Figure 8. SF-36v2 scale scores for Participant G initial and final assessment

**Case study H.** This participant was a 51 year old married man who was born in England and communicated using Auslan. He lived with his partner in a public rental residence. He was independent in his cognitive skills for daily decision making and his short-term memory ‘appeared OK’. He was born with Ushers syndrome, unknown type.

Participant H reported attending a special education program for deaf, blind or deafblind persons and completing Seafood Processing at TAFE. He was unemployed but was seeking employment.

This participant was born with a congenital sensori-neural hearing loss. The participant did not wear hearing aids and has no useful hearing. He required deliberate cues to be aware when someone else was in the room.

This participant developed a vision loss between 0-2 years from Retinitis Pigmentosa. He had profound low vision in his visual acuity range (20/400 – 20/1000) and profound low vision (eight degrees to less than 16 degrees) in his visual field diameter. He used sight enhancement devices, sight substitution devices and had adaptive devices to assist him. He had minimal difficulty in his distance vision, where he could see and identify faces at conversation distance but not across the room. He had difficulty in dim light or at night, bright light or daylight and glare or stray light. He had moderate visual fatigue when performing visual tasks and was unable to complete normal day-to-day visual activities such as reading. He reported his vision had declined in the past year.

Changes in the CHA and DBS as reported by Participant H are outlined in Table 17.

Table 17

*CHA and DBS changes in Participant H*

Assessment Item	Score at Initial Assessment	Score at Final Assessment
Involvement in structured activities – formal education	No	Yes
Reacts positively to interactions imitated by others	Yes, only with Communication Guide support	Yes, without Communication Guide support
Adjusts easily to changes in routines in last 30 days	Yes, only with Communication Guide support	Yes, without Communication Guide support
Visit with a long-standing social relation or family member	In last three days	Four to seven days ago
Prefers change in recreational and leisure activities	No	Yes
Reports having a confidant	No	Yes
Hours of physical activity in the last three days	Less than one hour	One to two hours
In the last three days, number of days went out of the house	No days out	Three days
Dizziness	Present but not exhibited in last three days	Not present
Fatigue	Minimal	None
Influenza vaccination in last year	No	Yes
Number of days of participation in preferred recreation and leisure activities in last seven days	Three	Two

Participant H identified only one goal he wanted to work towards with support from the communication guide. Outlined in Table 18, this goal related to recreation.

Table 18

*Canadian Occupational Performance Measure individual results for Participant H*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in Av. Scores (Ax2 - Ax1)	
	P	S	P	S	P	S
To join a local fishing club.	6	6	7	10	+1	+4

Note. P = Performance, S = Satisfaction

Although Participant H did not join a fishing (he was assisted to fish in the river with the communication guide and was supported on a day charter fishing trip), he rated his goal higher at the conclusion of the intervention, even though he did not achieve it.

Figure 9 outlines Participant H’s initial and final scores in the eight health concepts of the SF-36 Version 2 assessment. Participant H scored 33.3 for the Physical Component Summary and 48.6 for the Mental Component Summary in the initial assessment and 41.9 for the Physical Component Summary and 53.5 for the Mental Component Summary in the final assessment. None of Participant H’s scores declined from the initial to final assessment. Health concepts that remained the same included ‘role limitations because of emotional problems’. Those concepts that improved included ‘physical functioning’, ‘role limitation because of physical problems’, ‘bodily pain’, ‘general health’, ‘vitality’, ‘social functioning’ and ‘general mental health’. Participant H’s Physical Component Summary increased by 8.6 and Mental Component Summary increased by 4.9 from the initial to final assessment.

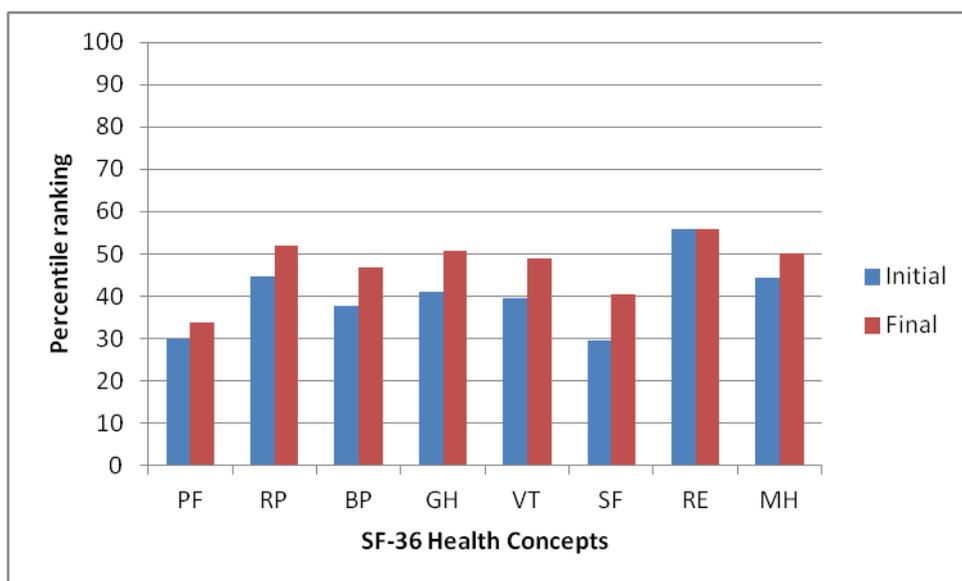


Figure 9. SF-36v2 scale scores for Participant H initial and final assessment

**Case study I.** This participant was a 40 year old married woman who was born in Australia and communicated using Auslan. She lived with her partner in a public rental residence. She was independent in her cognitive skills for daily decision making and her short-term memory ‘appeared OK’. This participant was born with Rubella syndrome.

Participant I reported attending a special education program for deaf, blind or deafblind persons and completing high school. She was unemployed but was seeking employment.

This participant was born with a congenital sensori-neural hearing loss. The participant was fitted with a cochlear implant but had no useful hearing. She required deliberate cues to be aware when someone else was in the room.

This participant was born with a vision loss. She had profound low vision in her visual acuity range (less than 20/400 – 20/1000) and profound low vision (eight degrees to less than 16 degrees) in her visual field diameter. She used sight enhancement devices, sight substitution devices and had adaptive devices to assist her. She had minimal difficulty in her distance vision, where she could see and identify faces at conversation distance but not across the room. She had difficulty in dim light or at night, glare or stray light and abrupt changes in illumination. She had minimal visual fatigue when performing visual tasks where she had diminished visual endurance but was able to complete normal day-to-day visual activities. She reported her vision had declined in the past five years.

Changes in the CHA and DBS as reported by Participant I are outlined in Table 19.

Table 19

*CHA and DBS changes in Participant I*

<b>Assessment Item</b>	<b>Score at Initial Assessment</b>	<b>Score at Final Assessment</b>
Ordinary housework - performance	Independent	Limited assistance
Ordinary housework - capacity	Independent	Limited assistance
Phone use - performance	Total dependence	Limited assistance
Phone use - capacity	Total dependence	Limited assistance
At ease doing planned or structured activities	Yes, only with Communication Guide support	Yes, without Communication Guide support
Visit with a long-standing social relation or family member	More than 30 days age	In last three days
Lonely	Yes	No
Time alone	Less than one hour	More than two hours but less than eight hours
Major life stressors over last 90 days	No	Yes
Prefers change in paid employment	No	Yes
Prefers change in recreational and leisure activities	No	Yes
Hours of physical activity in the last three days	Less than one hour	One to two hours
In the last three days, number of days went out of the house	Three days	One to two days

Frequency complains or shows evidence of pain	No pain	Present but not exhibited in last three days
Intensity of highest level of pain present	No pain	Mild
Consistency of pain	No pain	Intermittent
Pain control	No issue of pain	Pain intensity acceptable
Self-reported health	Fair	Good
Influenza vaccination in last year	No	Yes
Pneumovax vaccine in last five years	Yes	No
Number of days of participation in preferred recreation and leisure activities in last seven days	Two	Four
Employment status	Employed	Unemployed, seeking employment
Employment arrangements	Competitive employment	Unemployed, seeking employment

Participant I identified two goals she wanted to work towards with support from the communication guide. These goals both related to instrumental activities of daily living and are outlined in Table 20. Participant I chose not to pursue her second goal with the communication guide of participating in some gardening around home.

Table 20

*Canadian Occupational Performance Measure individual results for Participant I*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in av. scores (Ax2 - Ax1)	
	P	S	P	S	P	S
	1. To learn to prepare simple and easy meals for dinner.	6	5	7	9	1
2. To participate in some gardening around home.	4	1	not completed		(Goal 2 not included)	

Note. P = Performance, S = Satisfaction

Figure 10 outlines Participant I’s initial and final scores in the eight health concepts of the SF-36 Version 2 assessment. Participant I scored 41.1 for the Physical Component Summary and 63.3 for the Mental Component Summary in the initial assessment and 38.1 for the Physical Component Summary and 55.7 for the Mental Component Summary in the final assessment. All but one of Participant I’s scores declined from the initial to final assessment. The health concept that did not change was ‘vitality’. Participant I’s Physical

Component Summary decreased by three and Mental Component Summary decreased by 7.6 from the initial to final assessment.

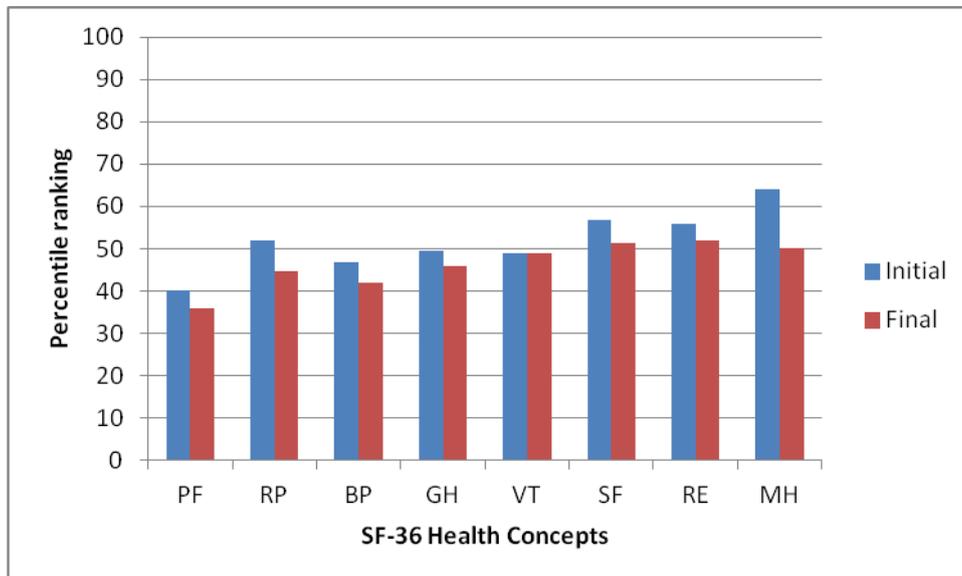


Figure 10. SF-36v2 scale scores for Participant I initial and final assessment

**Case study J.** This participant was a 71 year old single man who was born in Australia and communicated using Auslan. He lived alone in a private residence. He had moderate independence in his cognitive skills for daily decision making, where he had some difficulty in new situations. His short-term memory ‘appeared OK’.

Participant J reported completing high school and attending a special education program for deaf, blind or deafblind persons. He had retired from employment.

This participant developed a hearing loss before the age of two year due to unknown causes. The participant did not wear a hearing device and had no useful hearing. He did not respond to quiet sounds, voices at normal volume, loud noises and sounds indicating danger indoors. He required deliberate cues to be aware when someone else was in the room.

This participant developed a vision loss between 19-64 years (approximately aged 61 years) from macular degeneration and glaucoma. He had near blindness in his visual acuity range (less than 20/1000 – 20/20000) and near blindness (4 degrees to less than 8 degrees) in his visual field diameter. He did not wear glasses and had moderate difficulty in his distance vision, where he could see but not identify faces at conversation distance. He had difficulty in dim light or at night, bright light or daylight, glare, abrupt changes in illumination and subtle contrast differences. He had moderate visual fatigue when performing visual tasks and

was unable to complete normal day-to-day visual activities such as reading. He reported his vision had declined in the past 90 days.

Changes in the CHA and DBS as reported by Participant J are outlined in Table 21.

Table 21

*CHA and DBS changes in Participant J*

<b>Assessment Item</b>	<b>Score at Initial Assessment</b>	<b>Score at Final Assessment</b>
Ordinary housework - performance	Extensive assistance	Total dependence
Ordinary housework - capacity	Extensive assistance	Total dependence
Shopping - performance	Extensive assistance	Maximal assistance
Shopping - capacity	Extensive assistance	Maximal assistance
Orientation and mobility in daytime in unfamiliar environment – performance	Independent	Limited assistance
Orientation and mobility in daytime in unfamiliar environment – capacity	Independent	Limited assistance
Change in social activities in last 90 days	Decline, not distressed	Decline, distressed
Pursues involvement in activities or residential setting or community	Yes, only with Communication Guide support	No
Initiates interactions with others	Yes, without Communication Guide support	No
Reacts positively to changes in routines in last 30 days	Yes, without Communication Guide support	Yes, only with Communication Guide support
Adjusts easily to changes in routines in last 30 days	Yes, only with Communication Guide support	No
Participation in social activities of long-standing interest	Eight to 30 days ago	Four to seven days ago
Visit with a long-standing social relation or family member	Eight to 30 days ago	More than 30 days ago
Strong and supportive relationship with family	Yes	No
Reduced social interactions	Present but not exhibited in last three days	Exhibited daily in last three days
Prefers change in recreational and leisure activities	Yes	No
Reports having a confidant	Yes	No

In the last three days, number of days went out of the house	Three days	One to two days
Difficulty falling asleep or falling asleep	Exhibited daily in last three days	Exhibited on two of last three days
Colonoscopy test in last five years	No	Yes
Dental exam in last year	No	Yes

Participant J identified four goals he wanted to work towards with support from the communication guide. These goals relate to community access and recreation and are outlined in Table 22.

Table 22

*Canadian Occupational Performance Measure individual results for Participant J*

Goal/s	Assessment (Ax 1)		Assessment (Ax 2)		Change in av. scores (Ax2 - Ax1)	
	P	S	P	S	P	S
1. Catch public transport to local shopping centre.	4	4	8	8	4.66	1
2. Attend football game	5	5	9	10		
3. To fly to Albany for the day catching the morning flight and spending the day exploring Albany, returning on the evening flight.	0	0	not completed			
4. To attend a Fremantle Dockers home game at Patterson’s stadium.	2	4	8	8		

Note. P = Performance, S = Satisfaction

Figure 11 outlines Participant J’s initial and final scores in the eight health concepts of the SF-36 Version 2 assessment. Participant J scored 37.7 for the Physical Component Summary and 45.5 for the Mental Component Summary in the initial assessment and 43.7 for the Physical Component Summary and 43.7 for the Mental Component Summary in the final assessment. Participant J’s scores in ‘social functioning’ declined from the initial to final assessment. Health concepts that remained the same included ‘role limitation because of physical problems’, ‘role limitations because of emotional problems’ and ‘general mental health’. Those concepts that improved included ‘physical functioning’, ‘bodily

pain', 'general health' and 'vitality'. Participant J's Physical Component Summary increased by six and Mental Component Summary decreased by 1.8 from the initial to final assessment.

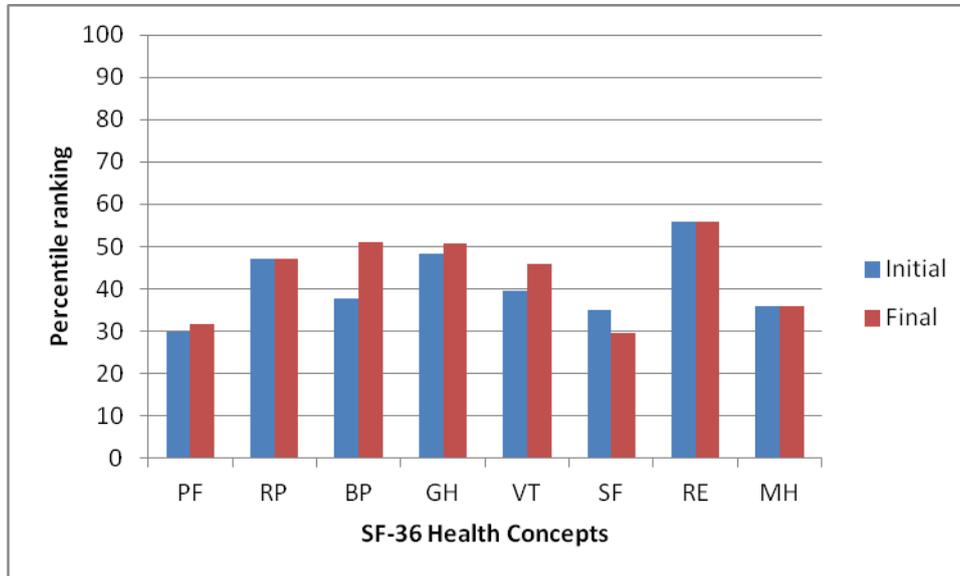


Figure 11. SF-36v2 scale scores for Participant J initial and final assessment

### General Demographic Summary

The results outlined below provide an overview of a number of selected demographics from the cohort, obtained from the final CHA and DBS assessment tool. The information included is:

- Age of participant
- Residential or living status
- Age of onset of vision loss
- Diagnosis related to the vision loss
- Visual acuity range Visual field diameter
- Age of onset of hearing loss
- Diagnosis related to hearing loss
- Type of assistive devices or supports used by participants

**Age.** The age of participants is described in Figure 12. The majority of participants were aged below 60 years, with three between 40-44 years, three between 50-54 years and one each between 45-49 years and 55-59 years. The two other participants were aged between 70-74 years and 80-84 years.

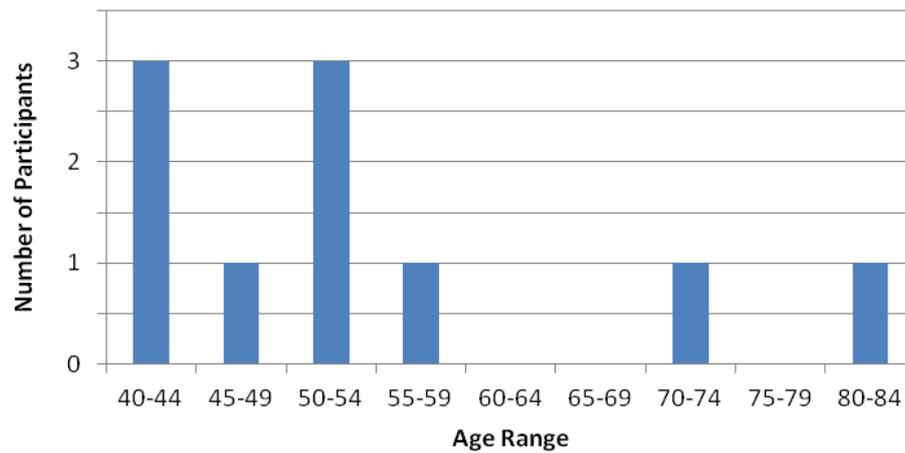


Figure 12. Age of participants

**Residential status.** Six of the participants resided in a rental home or with their parents who owned their home. Four participants lived in accommodation with support, including meal preparation and cleaning. During the course of the intervention, one participant moved from living independently by herself in a private residence to assisted or semi-independent living.

**Age of onset of vision loss.** Two participants developed their vision loss either at birth or prior to the age of two. Eight participants developed their vision loss in adulthood, from between the ages of 19-64 years.

**Diagnosis related to the vision loss.** The causes of participant vision loss are provided in Figure 13. All diagnoses outlined in the DBS assessment tool have been included in Figure 3 to demonstrate the common causes of vision impairment. A number of participants had multiple causes of vision loss. The diagnosis forming the largest number in the participants within this study was due to glaucoma, with six participants experiencing this disease. Retinitis pigmentosa was the second highest with five participants experiencing this condition. Other diagnoses experienced by participants included macular degeneration (2), myopia (2), missing or malformed eye (2) and other (1).

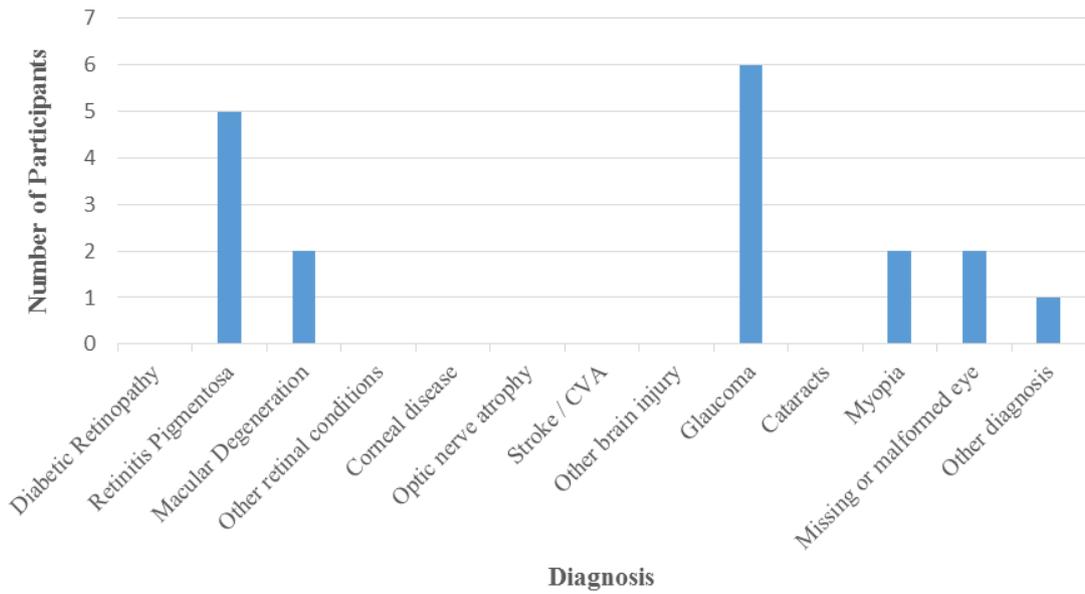


Figure 13. Diagnosis related to vision loss of participants

**Visual acuity range and visual field diameter.** Without low vision devices the visual acuity of participants fell between “severe low vision” and “near-blindness” (as defined by the DBS). The majority of participants (six) had “profound low vision”, which is vision less than 20/400 to 20/1000. Three participants were classified as having “near-blindness”, which is less than 20/1000 to 20/2000. One participant had “severe low vision”, which is less than 20/160 to 20/400 visual acuity. Half (five) participants had “profound low vision” of eight to 16 degrees and five were classified as having “near-blindness”, which is a visual field diameter of four to eight degrees.

**Age of onset of hearing loss.** The majority (eight) of participants developed their hearing loss at birth or before the age of two years. Two participants developed their hearing loss between the ages of three and 18 years.

**Diagnosis related to hearing loss.** The cause of eight of the participants’ hearing loss was related to congenital syndromes. Five participants had Usher syndrome and three had Congenital Rubella syndrome. One participant in the congenital syndrome category also suffered from tinnitus or ear noise. One participant’s hearing loss was caused by perforated ear drums and one participant did not know the cause of his hearing loss.

**Type of assistive devices or supports used by participants.** Participants within the study used a range of assistive devices or supports. These are outlined below in Figure 14. All participants used adaptive devices, which could have included specialised lighting,

contrast adaptations or enlarged display clock. Eight participants used sight enhancement devices, such as magnifiers, video magnifiers or adapted computer systems with enlarged display for reading. Six participants used sight substitution devices, such as simple tactile or speech output devices or adapted computer systems with speech output. Six participants used hearing devices, such as hearing aids, FM systems or cochlear implants. Four participants used orientation and mobility devices, such as a long cane and one participant used a guide dog.

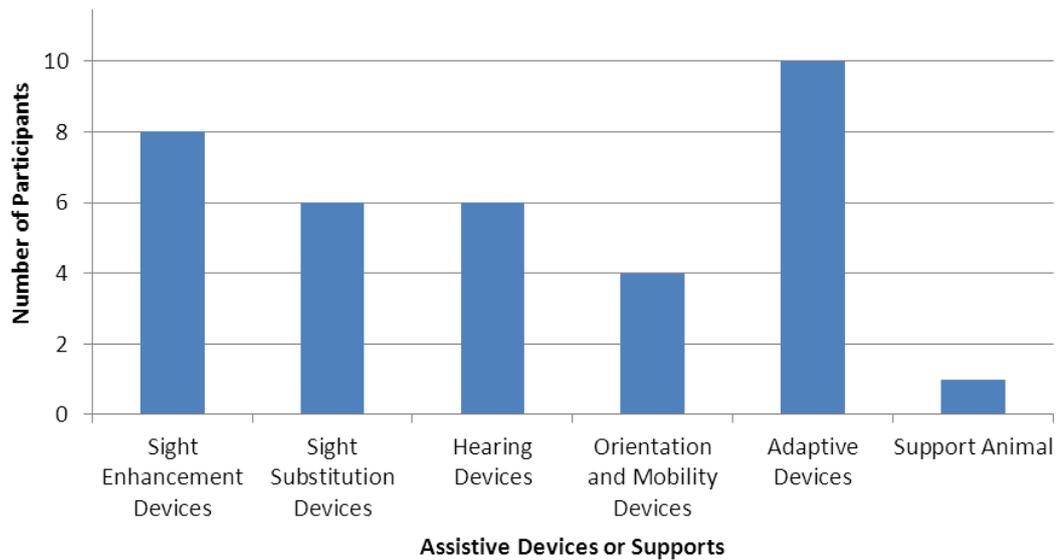


Figure 14. Assistive devices or supports used by participants

### Analysis of Qualitative Findings

At the completion of the intervention, all participants were interviewed to obtain qualitative information relating to the communication guide support they received. Due to the nature of thematic analysis method, after analysing the data several themes and sub-themes were identified. These are outlined in Table 23. The table identifies the percentage of overall data that has been allocated to each theme (the percentage of characters allocated). Following Table 23, each of the themes are individually discussed.

Table 23.

*Themes and sub-themes from participants' experiences*

Theme	% of total data	Sub-themes
Support Provided by Communication Guides	23%	<ul style="list-style-type: none"> <li>• Practical support</li> <li>• Emotional support</li> <li>• Advocacy</li> <li>• Flexibility &amp; availability of communication guide</li> <li>• Resources provide by communication guides</li> <li>• Expectations of communication guide service</li> </ul>
Connections and Networks	17%	<ul style="list-style-type: none"> <li>• Community</li> <li>• Friends</li> <li>• Transport</li> <li>• Paid support</li> <li>• Supporting others</li> <li>• Family</li> </ul>
Quality of Life	13%	<ul style="list-style-type: none"> <li>• Emotional wellbeing</li> <li>• Physical wellbeing</li> </ul>
Challenges	12%	<ul style="list-style-type: none"> <li>• Difficulties communicating with others</li> <li>• Other people's attitudes or conflict</li> <li>• Issues with delivery of communication guide services</li> <li>• Poor environmental access</li> <li>• Lack of information</li> <li>• Issues with other organisations</li> <li>• Lack of finances</li> <li>• Lack of support</li> <li>• Difficulties in completing activities</li> </ul>
Participant Positive Feedback on Communication Guide Services	12%	<ul style="list-style-type: none"> <li>• Communication guide communication skills</li> <li>• General comments about communication guide</li> <li>• Communication guide sighted guide skills</li> <li>• Allocation of communication guide time</li> </ul>
Personal Characteristics	9%	
Goals and Desires	7%	<ul style="list-style-type: none"> <li>• Fulfilment</li> </ul>
Occupation	5%	<ul style="list-style-type: none"> <li>• Leisure</li> <li>• Instrumental activities of daily living and activities of daily living</li> <li>• Education</li> <li>• Employment</li> </ul>
Person-Centred Approach	2%	

**Support provided by communication guides.** The largest theme that was identified from participants was regarding the support they received from their communication guide, with 23% of the total data. A number of sub-themes were identified. These are outlined in Figure 15 and include the percentage of data for each sub-theme. The largest sub-theme was related to "Practical support", with 55%. Other sub-themes included "Emotional support" (22%), "Advocacy" (14%), "Flexibility and availability of the communication guides" (6%),

“Resources provided by the communication guide” (2%) and “Expectations of the communication guide service” (1%).

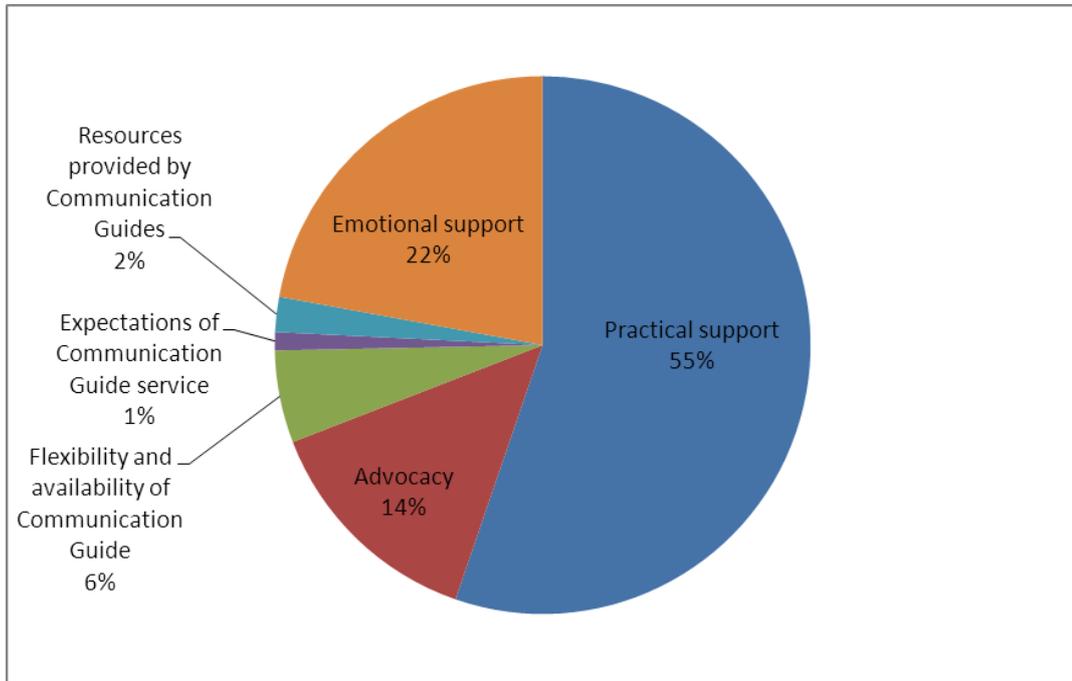


Figure 15. Percentage breakdown of “Support provided by communication guides” sub-themes.

The total data per sub-theme was one analysis that has provided information on the weighting of each sub-theme. Another analysis conducted was to calculate the number of participants that each sub-theme had attributed to it. This is outlined in Figure 16. The weighting of “Flexibility and availability of the communication guides”, “Advocacy”, “Expectations of the communication guide service” and “Resources provided by the communication guide” were not ranked consistently with the percentage of total data for the theme. Some participants discussed some sub-themes in greater detail than others.

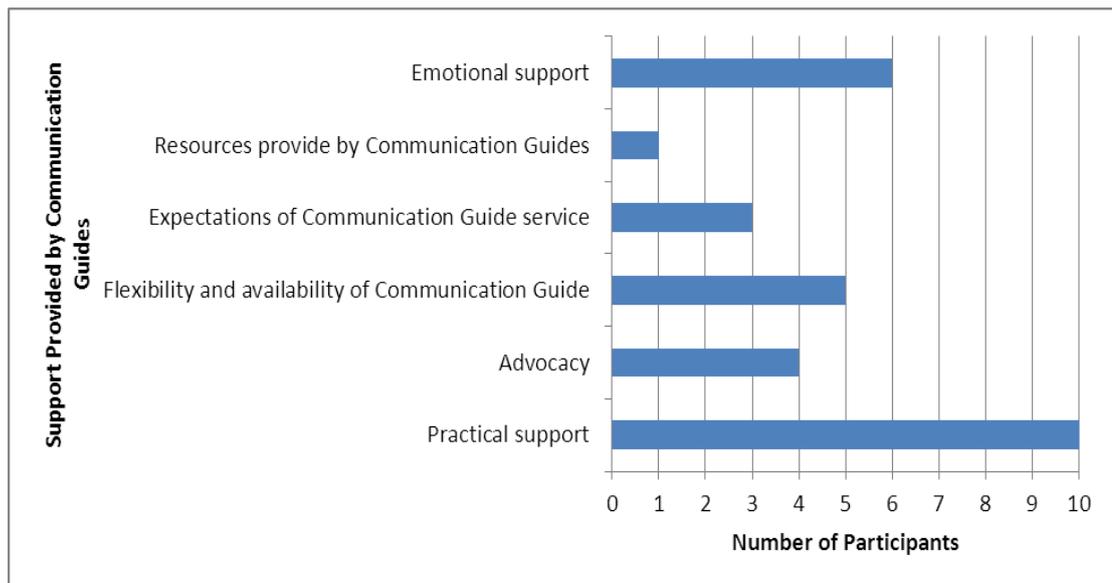


Figure 16. Number of participants per “Support Provided by Communication Guides” sub-themes.

**Practical support.** All participants experienced practical support from their communication guide. Practical support varied from participant to participant. Examples include:

“They would help tie the hooks up because [Participant] wasn’t able to see the hooks and the fishing line, and especially if it was quite far down the rod, it would be very hard for [Participant] to see where the hook was, so they did, they definitely helped [Participant] find the hook and put the bait on” (Participant I, personal communication, November 29, 2011).

“[Communication Guide] was good to help me cut the paper when I can’t see what I’m cutting. So that was good” (Participant B, personal communication, November 1, 2011).

“And she altered my house, just this cupboard was here blocking the window, she took it and put it the other side, and all that she did for me” (Participant F, personal communication, December 6, 2011).

“Like, how this thing works, how this, like, my bed, this here, you see. I had it this way, the window there, you know, my bed, yeah, but then she, you know, so she said it is not good that way. She turned my bed this way, the wall there, you know, and then ... So the light was coming out that way, so, like, it work better too” (Participant F, personal communication, December 6, 2011).

She's brilliant at looking things up on the internet, information where I can't find it, and there was some legal stuff for jury duty that she found, and we got that sorted and I'm off their list now" (Participant G, personal communication, December 19, 2011).

***Emotional support.*** Six participants commented that they received emotional support from their communication guide. Examples included:

"...yeah, and able to give me moral support when I was struggling" (Participant A, personal communication, September 27, 2011).

"There are some situations where I do need better help and maybe encourage and just someone being there, someone to talk to" (Participant A, personal communication, September 27, 2011).

"It's something that you really need because it enables you to not get stuck, to not be disheartened" (Participant G, personal communication, December 19, 2011).

***Advocacy.*** Four participants described how their communication guide supported them through advocacy. Examples included:

"...she phoned them up and made the appointments and yeah, they very willingly helped and she was able to negotiate the time" (Participant A, personal communication, September 27, 2011).

"She was able to meet up with the lecturer and explain my situation" (Participant A, personal communication, September 27, 2011).

"Yeah, it was just nice to have that weight off my shoulders with the things that she would ... she helped with advocating, yeah" (Participant E, personal communication, February 9, 2012).

"She was going to fight for your best" (Participant G, personal communication, December 19, 2011).

***Flexibility and availability of communication guide.*** Half the participants commented on the flexibility and availability of the service they received from their communication guide. Comments included:

“It was good that it was flexible. Yeah, just fit in with her time and my time and meet up a certain place at a certain time” (Participant A, personal communication, September 27, 2011).

“... and be very flexible with everything. That was what was really good” (Participant E, personal communication, February 9, 2012).

**Expectations of communication guide service.** Three participants made comments regarding expectations of the communication guide service. Two participants discussed that they were not sure what to expect from the service and one stated that the service had gone beyond their expectations.

**Resources provided by communication guides.** One participant described that the communication guide typed out some recipes from a book in very large print which improved his independence and choice of meal options.

**Connections and networks.** The second largest theme to emerge from the overall data at 17% was related to connections and networks. The percentage of data for each sub-theme is outlined in Figure 17. “Community” was the largest sub-theme at 56% and “Friends” was second largest with 25%. Other sub-themes included “Transport” (7%), “Paid support” (5%), “Supporting others” (4%), and “Family” (3%).

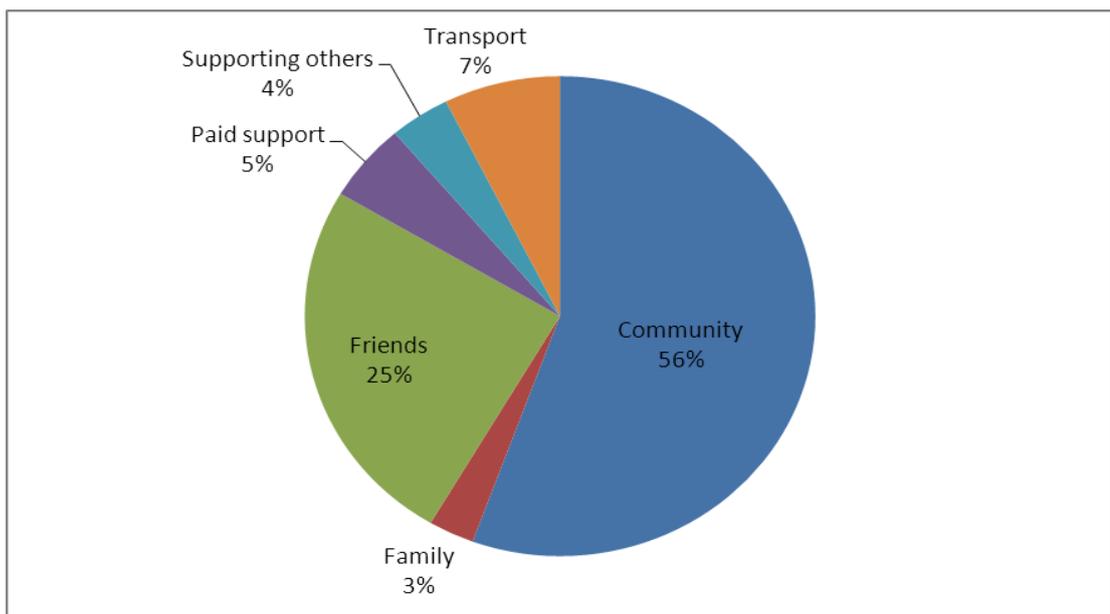


Figure 17. Percentage breakdown of “Connection and Networks” sub-themes.

The number of participants that each sub-theme had attributed to it is outlined in Figure 18. The sub-themes were consistent in their ranking using this analysis with the percentage of total data for the theme. “Community” had the most participants at nine and “Friends” had the second most with seven participants. “Transport” had five participants allocated to this sub-theme, “Paid support” four participants, with “Supporting others” and “Family” just one.

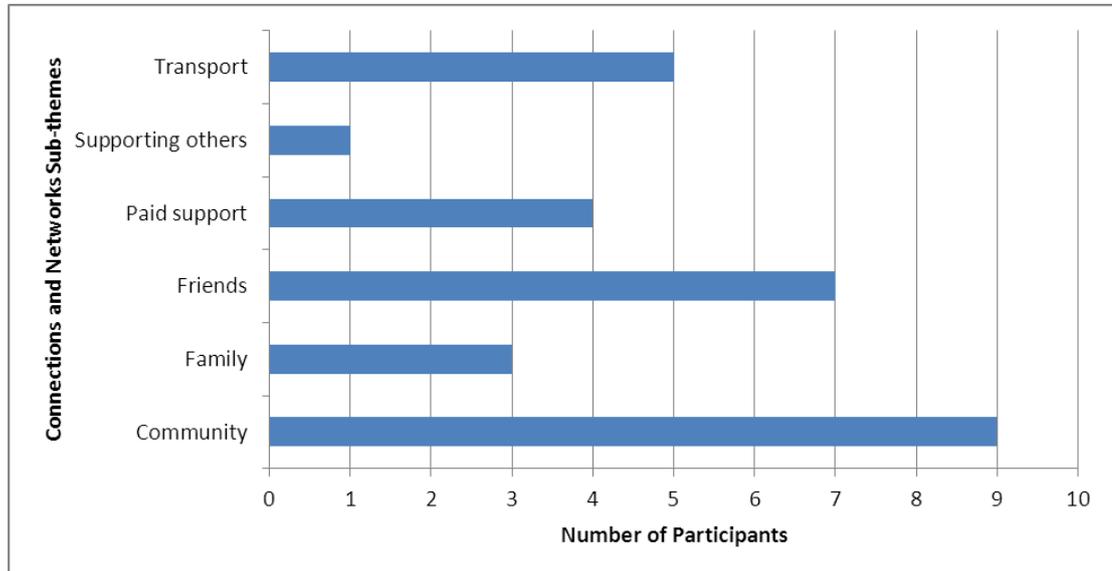


Figure 18. Number of participants per “Connection and Networks” sub-themes.

**Community.** Participants commented on community access with the support of communication guides. Examples included:

“Sometimes I like to go shopping if I need to buy something like some clothes or something but I don’t like to go too often” (Participant J, personal communication, February 7, 2012).

“We went to Apple” (Participant C, personal communication, November 29, 2011).

“The knitting club was good, it was really quiet, and there wasn’t any other noise in the background” (Participant B, personal communication, November 1, 2011).

“And the Blind Institute for doing scrapbooking” (Participant B, personal communication, November 1, 2011).

“We used to go and get the train to Midland to a coffee shop” (Participant D, personal communication, December 1, 2011).

“Yes, she took me also, at church Sunday we have a concert there” (Participant F, personal communication, December 6, 2011).

“We went to Bunnings or to IKEA” (Participant F, personal communication, December 6, 2011).

**Friends.** One participant discussed within this sub-theme about developing friendships through the assistance of the communication guide. An example included:

“... so I could stay there a bit longer and enjoy people’s company a bit more” (Participant A, personal communication, September 27, 2011).

One participant reminisced about old friends:

“He plays the guitar and he sings. He’s from [*suburb*], and the other friend that plays the banjo, he lives in [*suburb*]. Just down the road” (Participant F, personal communication, December 6, 2011).

Two participants also discussed how they felt they had developed friendships with their communication guide(s). Examples of these comments include:

“Before when I was just talking with [*Communication Guide*], [*Participant*] did say it was really great and [*Communication Guide*] and [*Communication Guide*] were great friends of [*Participant*], and they helped” (Participant I, personal communication, November 29, 2011).

“Well, the project may be finished but the friendship isn’t” (Participant G, personal communication, December 19, 2011).

**Transport.** Participants commented on how they used public transport during the communication guide service. Comments included:

“We went on the train to Bunbury” (Participant J, personal communication, February 7, 2012).

“But that was a free bus ride from Beatty Park, so there were lots of people who came on that particular bus, which was good” (Participant J, personal communication, February 7, 2012).

Other participants discussed how the communication guide transported them in their own vehicles. Via the Participant Information Sheet, the Participant Consent Form and the communication guide training, participants and communication guides were made aware that the communication guide service did not include providing transport. This was to reduce any dependency developing during the six month service. Some communication guides decided to ignore this and provided transport in their private vehicles. Examples of participant comments include:

“...then when [*Communication Guide*] came, she came in their car, she took me with their car. Then we were using her transport. We didn't use public transport” (Participant F, personal communication, December 6, 2011).

“And it's just being able to get to places and get things which you can't do on public transport” (Participant G, personal communication, December 19, 2011).

**Family.** In this sub-theme, participants discussed their family, which included giving presents to their grandmother, parent health issues, family visiting and difficulties with a sister.

**Paid support.** Participants within this sub-theme discussed other paid supports they received which assisted some to go shopping, locate employment and to access recreational activities.

**Supporting others.** One participant made comments about how they have supported other individuals with a hearing impairment with advice on equipment and leisure activities.

**Quality of life.** This theme was third largest, with 13% of all the data. The percentage of data for each sub-theme is outlined in Figure 19. The largest sub-theme identified was “Emotional wellbeing – positive emotional experiences” with 59% of the total data for this theme. The second largest sub-theme was “Emotional wellbeing - new experiences” with 20%. The other sub-themes included “Emotional wellbeing – mental health” (8%), “Emotional wellbeing – isolation” (7%) and “Physical wellbeing” (6%).

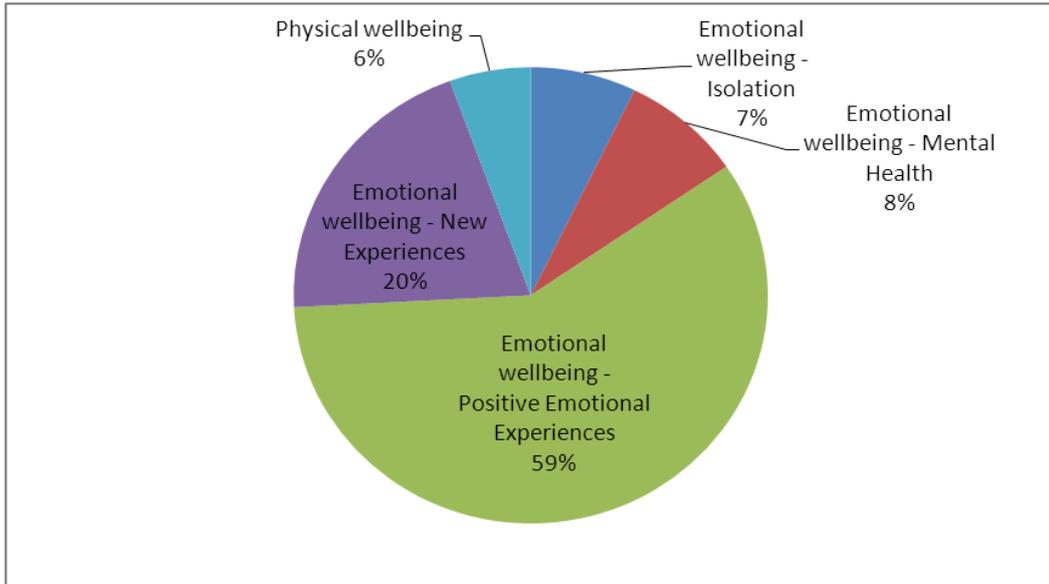


Figure 19. Percentage breakdown of “Quality of Life” sub-themes.

The number of participants attributed to each sub-theme is outlined in Figure 20. The largest sub-theme identified was “Emotional wellbeing – positive emotional experiences” with all 10 participants referenced to this sub-theme. The second largest sub-theme was “Emotional wellbeing - new experiences” with five participants. These two rankings are consistent with their ranking when using the percentage of total data for the theme weighting. The third largest, with four participants, was “Emotional wellbeing – isolation”. “Physical wellbeing” had three participants and “Emotional wellbeing – mental health” had just one participant however “Emotional wellbeing – mental health” had more percentage of total data as one participant discussed mental health issues in more depth.

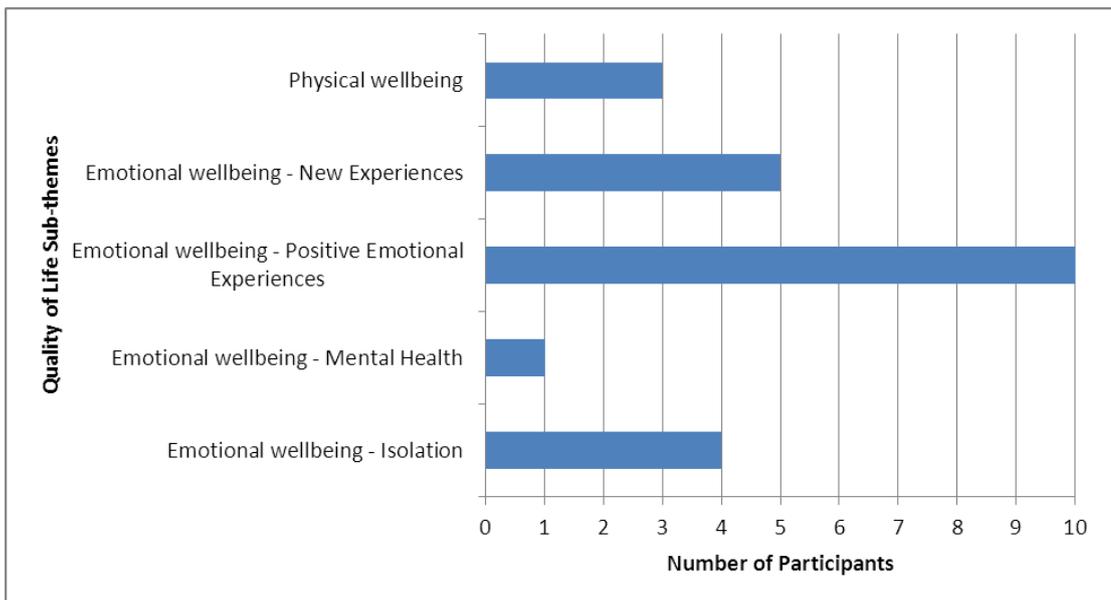


Figure 20. Number of participants per “Quality of Life” sub-themes.

*Emotional wellbeing.* The sub-theme of emotional wellbeing is categorised into four different aspects that were elicited from the participants' feedback. These included positive emotional experiences, new experiences, isolation and mental health.

*Positive emotional experiences.* The vast majority of positive experiences described by the participants were in relation to the support they received from the communication guide. Examples include:

“It does, it makes a big difference. I feel a lot more confident than I was in the previous years” (Participant C, personal communication, November 29, 2011).

“...normally, like, might have cleared out in half an hour but being able to persuade me to stay a bit longer and get a bit more enjoyment” (Participant A, personal communication, September 27, 2011).

“I wasn't expecting it to be as helpful as it was – that's for sure” (Participant E, personal communication, February 9, 2012).

*New experiences.* Half the participants stated they had new experiences via the communication guide pilot project. Examples included:

“There were things that I hadn't seen before or done before” (Participant H, personal communication, November 29, 2011).

“The first time I ever had note takers, and that was a real eye-opener. I didn't realise how useful they are” (Participant A, personal communication, September 27, 2011).

*Isolation.* Four participants made comments regarding isolation they have experienced. Examples included:

“Yeah, I do get a bit left out” (Participant B, personal communication, November 1, 2011).

“You withdraw, you just don't want to do anything anymore because everything is too hard. It's no worry the hearing and the seeing but the walking is too hard, the sitting is too hard. Everything becomes too hard” (Participant G, personal communication, December 19, 2011).

*Mental health.* One participant discussed their depression and an episode that was experienced during the communication guide pilot project.

*Physical wellbeing.* Three participants made comments related to their physical wellbeing. One participant discussed his sore back, one stated the exercise she were undertaking was good for her health and one commented on physical problems and pain he encountered.

**Challenges.** A number of challenges were described by the participants. Some of these pertained to service related issues of the communication guide support, but also challenges encountered in everyday life. The theme of Challenges was equal fourth largest with 12% of all the total data. Figure 21 provides a breakdown of the sub-themes that emerged from participants. It provides the percentage of each sub-theme in relation to the qualitative data allocated to this theme. The sub-theme of “Difficulties communicating with others” was the largest with 27% of the data attributed to the theme of Challenges. Equal second largest sub-themes were “Other people’s attitudes or conflict” and “Issues with delivery of communication guide services” with 17% of the data. “Poor environmental access” had 13% of the data and “Lack of information” 12%. Other sub-themes included “Issues with other organisations” (7%), “Lack of finances” (3%), “Difficulties in completing activities” (2%) and “Lack of support” (2%).

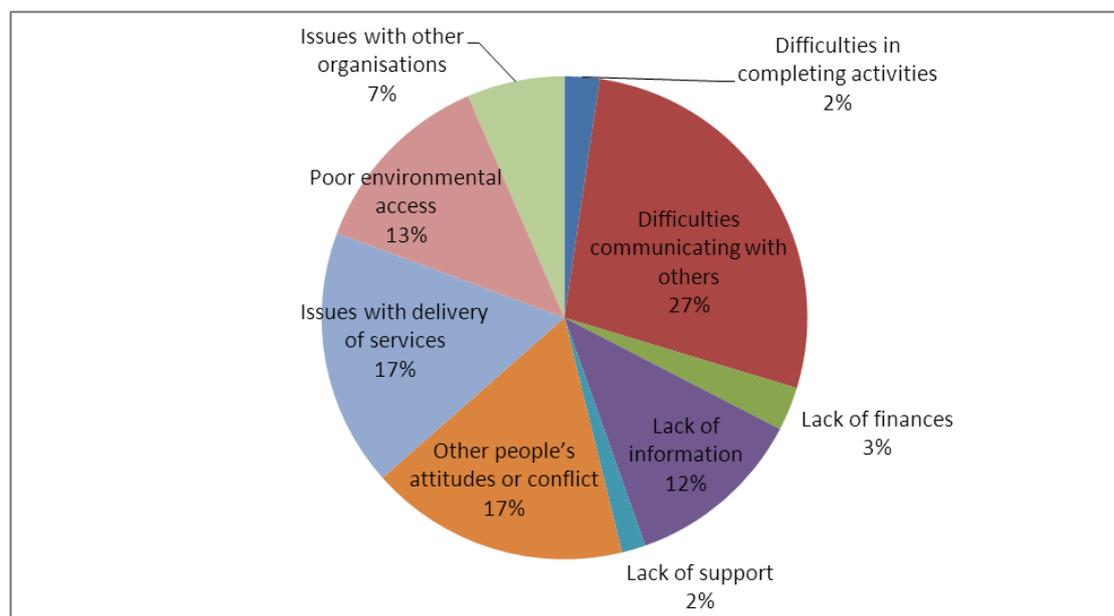


Figure 21. Percentage breakdown of “Challenges” sub-themes.

The number of participants attributed to each sub-theme is outlined in Figure 22. The largest sub-theme identified was “Lack of information”, with seven participants. “Issues with

delivery of services” was second, with six participants. Equal third was “Poor environmental access” and “Difficulties communicating with others”, with four participants. The other sub-theme weightings were “Other people’s attitudes or conflict” with three participants, “Difficulties in completing activities” two participants, and “Issues with other organisations”, “Lack of support” and “Lack of finances” with one participant. The weighting of numbers of participants per sub-theme is different from the percent of data weighting for the sub-themes. The issue of “Difficulties communicating with others” was only discussed by four participants, however these comments generated the most data for the theme. In contrast, seven participants (the most of any sub-theme) expressed views on “Lack of information” but this accounted for only 12% of the data.

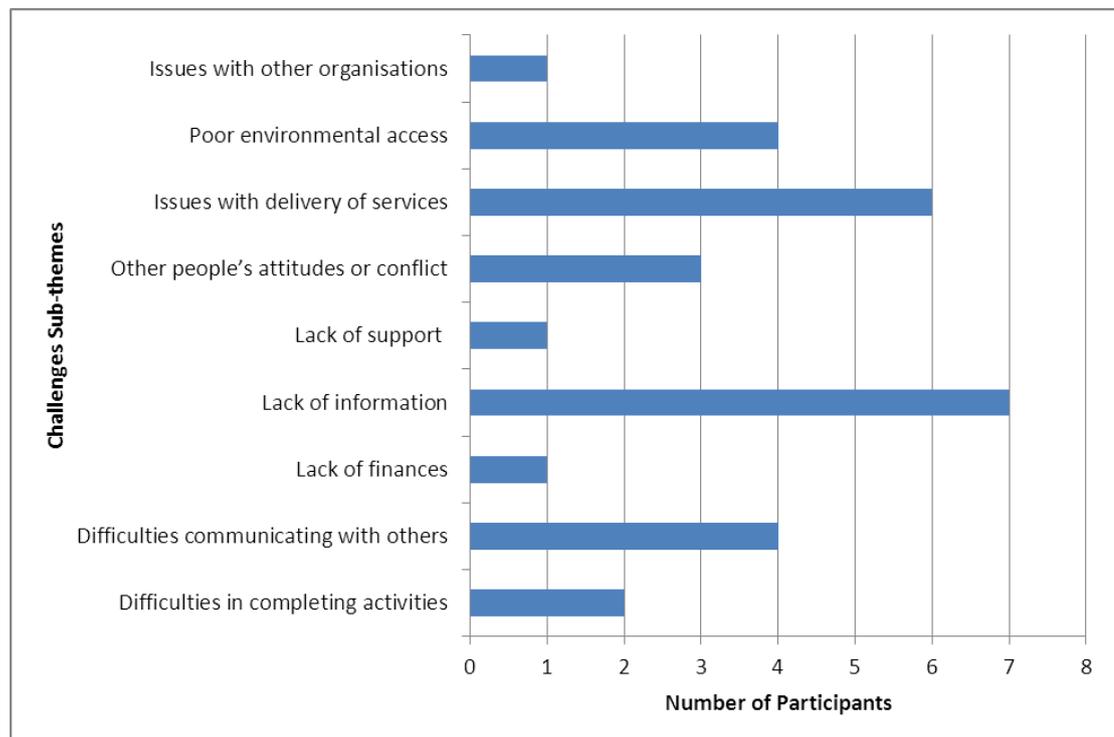


Figure 22. Number of participants per “Challenges” sub-themes.

***Difficulties communicating with others.*** Four participants within this sub-theme described how they have difficulties communicating, particularly within group settings and noisy environments. Examples included:

“I find it really awkward because sometimes I can’t hear and can’t see, so someone come up to me and if they don’t know me, don’t know my personality and I can’t make it out. I miss out. So to have a normal conversation it can be quite awkward” (Participant A, personal communication, September 27, 2011).

“It was a little bit hard. It’s quite noisy because they had one big room, they had a knitting group and then we got scrapbooking, and it was quite difficult” (Participant B, personal communication, November 1, 2011).

“...the constant stream of information you miss makes you a different person than somebody who doesn’t miss all the information” (Participant G, personal communication, December 19, 2011).

**Lack of information.** This sub-theme related to participants not being clear about aspects of the communication guide service. A participant initially thought that he would be attending a group for deafblind people, another one was unclear on the amount of time she would receive and another queried if the service was continuing after the six months.

**Issues with delivery of communication guide service.** One communication guide who provided services to two participants also worked as an interpreter. As a result, this communication guide had a busy schedule which impacted on availability, pace and length of time that could be provided to participants. Examples of comments related to this issue included:

“I felt a little bit rushed sometimes. Sometimes [*Communication Guide*] would have other commitments she have to go to so it was a little bit rushed because she might have another job she had to go to, so I wasn’t very comfortable with being rushed all the time. But I understand and I had to accept it but I didn’t like it. I don’t like to be rushed. I tried to be patient but it was hard” (Participant J, personal communication, February 7, 2012).

“She wasn’t able to come on the weekends, only on a Saturday morning” (Participant A, personal communication, September 27, 2011).

On another occasion, at a social event that a communication guide supported the participant to attend, the communication guide became angry at how another person was treating the participant. The participant commented on this situation:

“...so [*Communication Guide*] got angry, she sat at the table watching us. Yes, she didn’t like that idea, that lady telling me not to play. So she got angry, [*Communication Guide*] got angry with that lady. I said, “No, don’t say anything”, I told her” (Participant F, personal communication, December 6, 2011).

***Other people's attitudes or conflict.*** Within this sub-theme, participants described how other people react to their disability. An example included:

“Usually people don't really understand. It's a lot to be deaf and blind, and they have all these preconceived ideas and get all enthusiastic but don't really understand the situation. So if they don't understand, they can't really help” (Participant A, personal communication, September 27, 2011).

Other comments within this sub-theme related to difficulties with family, boarders and at a social engagement where individuals were disagreeing on the structure of the event.

***Poor environmental access.*** The comments attributed to this sub-theme all related to poor access to recreation and education facilities attended with the support of their communication guide. An example included:

“One of the classes, the classroom was really awkward the way it was set up. You've got a lecture desk right at the back and you've got the whiteboard at the front and the screen projecting onto the whiteboard at the front while the lecturer's at the back, so if I sit at the back, I can't see the screen; if I sit at the front I can't hear the lecturer” (Participant A, personal communication, September 27, 2011).

***Difficulties in completing activities.*** Two participants outlined difficulties they had completing activities. These activities included painting and performing group work in relation to educational assignments.

***Issues with other organisations.*** The comments attributed to this sub-theme related to only one participant who had problems with a prospective employer, an educational organisation and a social club during the course of the communication guide service.

***Lack of support.*** One participant described that there was no support for three months to go swimming.

***Lack of finances.*** One participant explained that to use taxis to undertake the leisure activity of choice was cost prohibitive.

**Participant positive feedback on communication guide services.** This theme was the equal fourth largest, with 12% of the total data. The percentage of data for each sub-theme is outlined in Figure 23.

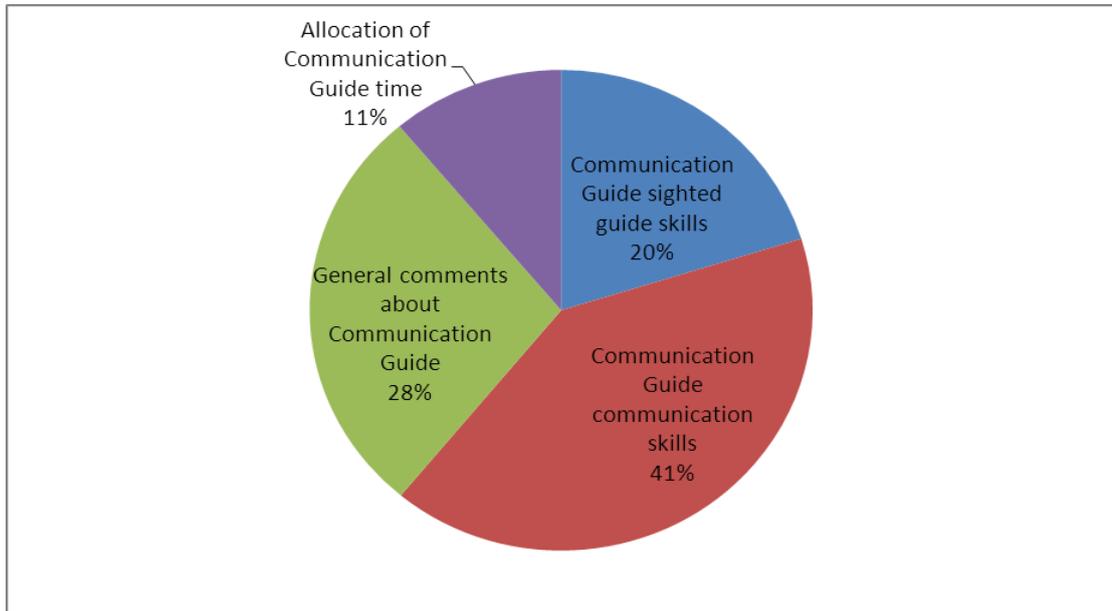


Figure 23. Percentage breakdown of “Positive Feedback from Participants” sub-themes.

The number of participants attributed to each sub-theme is outlined in Figure 24.

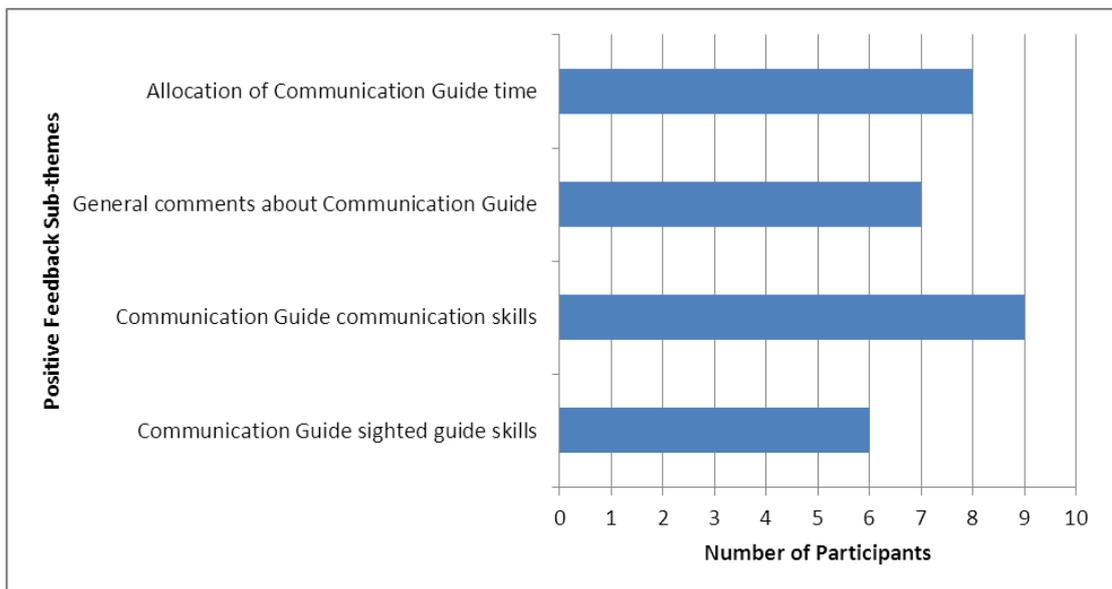


Figure 24. Number of participants per “Positive Feedback from Participants” sub-themes.

**Communication guide communication skills.** Nine participants made positive comments on the communication skills of the communication guides. Examples included:

“It was great; it was easy to communicate because we were able to use sign so it was easy” (Participant A, personal communication, September 27, 2011).

“She was good. She was quite easy to communicate with, she finger spelt and signed. That was good” (Participant J, personal communication, February 7, 2012).

“She tried to make sure I can hear what someone’s saying” (Participant B, personal communication, November 1, 2011).

“...she responded when I needed” (Participant B, personal communication, November 1, 2011).

“...very easy to communicate and very responsive” (Participant A, personal communication, September 27, 2011).

“Well, she’s extremely conscious of making sure that I understand them and she knows how to speak to me properly” (Participant E, personal communication, February 9, 2012).

*General comments about communication guide.* Seven participants made positive comments about their communication guide, including:

“I really trust her” (Participant C, personal communication, November 29, 2011).

“I felt safe with her” (Participant C, personal communication, November 29, 2011).

“She was very well trained” (Participant C, personal communication, November 29, 2011).

“She is so special” (Participant C, personal communication, November 29, 2011).

“She did have a bit of skill” (Participant B, personal communication, November 1, 2011).

“Yeah, very proactive” (Participant A, personal communication, September 27, 2011).

“She was very effective in most areas” (Participant A, personal communication, September 27, 2011).

“She was amazing. But just in general ... very caring person. Her skills were terrific” (Participant E, personal communication, February 9, 2012).

“Oh yes, she didn't only have the skills, had an attitude that was so helpful, so willing to learn, so willing to adapt” (Participant G, personal communication, December 19, 2011).

***Positive perception of allocation of communication guide time.*** This sub-theme was lowest in terms of overall data for the theme, however was second highest in terms of participants' comments. This indicates that most participants were satisfied with their allocation of time for their communication guide support but did not discuss the point in detail. Comments included:

“Those hours were perfect” (Participant C, personal communication, November 29, 2011).

“Definitely found it plenty, I mean, because I work and I could have had more hours but I didn't need it. So it was definitely exactly what I needed” (Participant E, personal communication, December 19, 2011).

***Communication guide sighted guide skills.*** There were a number of comments discussing the sighted guide skills of the communication guides. Examples included:

“Just a little bit hard in the dark areas, I need a bit of a guiding help which was great that I got that. Definitely on the floor, I can't see if it's in the dark, I can't see whether it's steps or ... So it's good to have the help and guide” (Participant H, personal communication, November 29, 2011).

“...when we go out in the community, she lets me know when there's a step, or when we get on the trail, she lets me know” (Participant C, personal communication, November 29, 2011).

“I know I'm in the train but when we go up the steps or something, she lets me know” (Participant C, personal communication, November 29, 2011).

“She walks slowly and looks for me what I want” (Participant F, personal communication, December 6, 2011).

**Personal characteristics.** This theme accounted for nine per cent of the total data. Participants made comments which were identified as personal characteristics and these

characteristics each formed a sub-theme. Personal characteristics were comments that participants made about themselves that reflected their traits or qualities. The percentage of data for each sub-theme is outlined in Figure 25. Twenty sub-themes were identified from the participants. The largest sub-themes of participants’ personal characteristics included “Accepting”, “Anxiety” and “Disappointment” with 11% of total data for the theme and “Perseverance” and “Determination” with 10%.

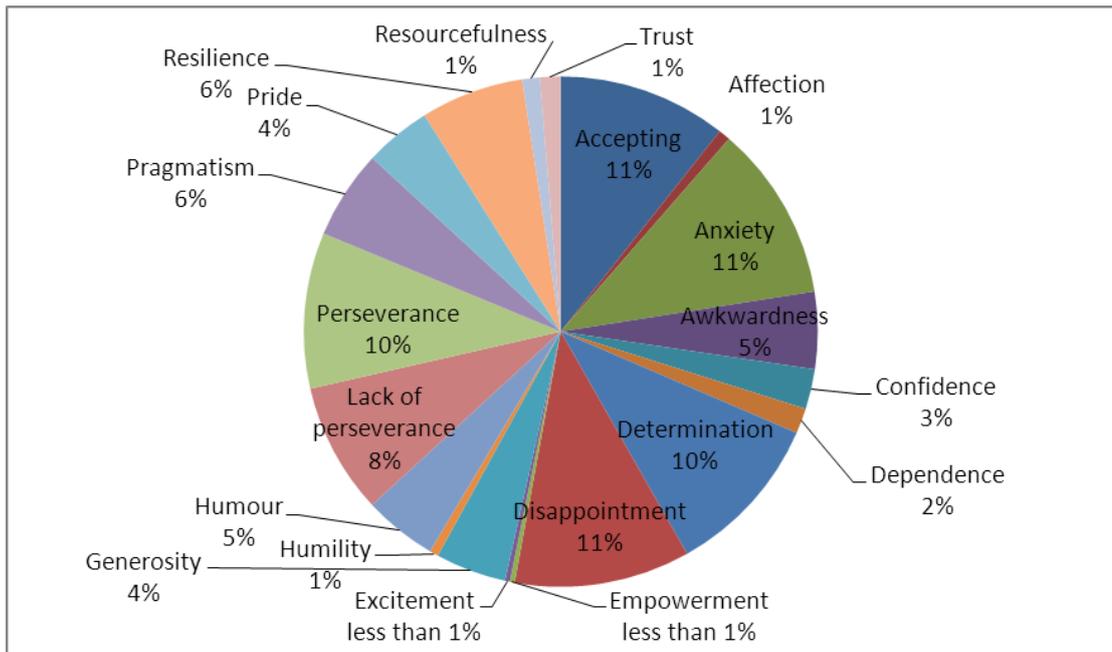


Figure 25. Percentage breakdown of “Personal Characteristics” sub-themes.

The number of participants attributed to each sub-theme is outlined in Figure 26. The largest sub-themes identified were “Disappointment” and “Determination” with five participants and “Resilience”, “Pride”, “Generosity”, “Anxiety” and “Accepting” with four participants.

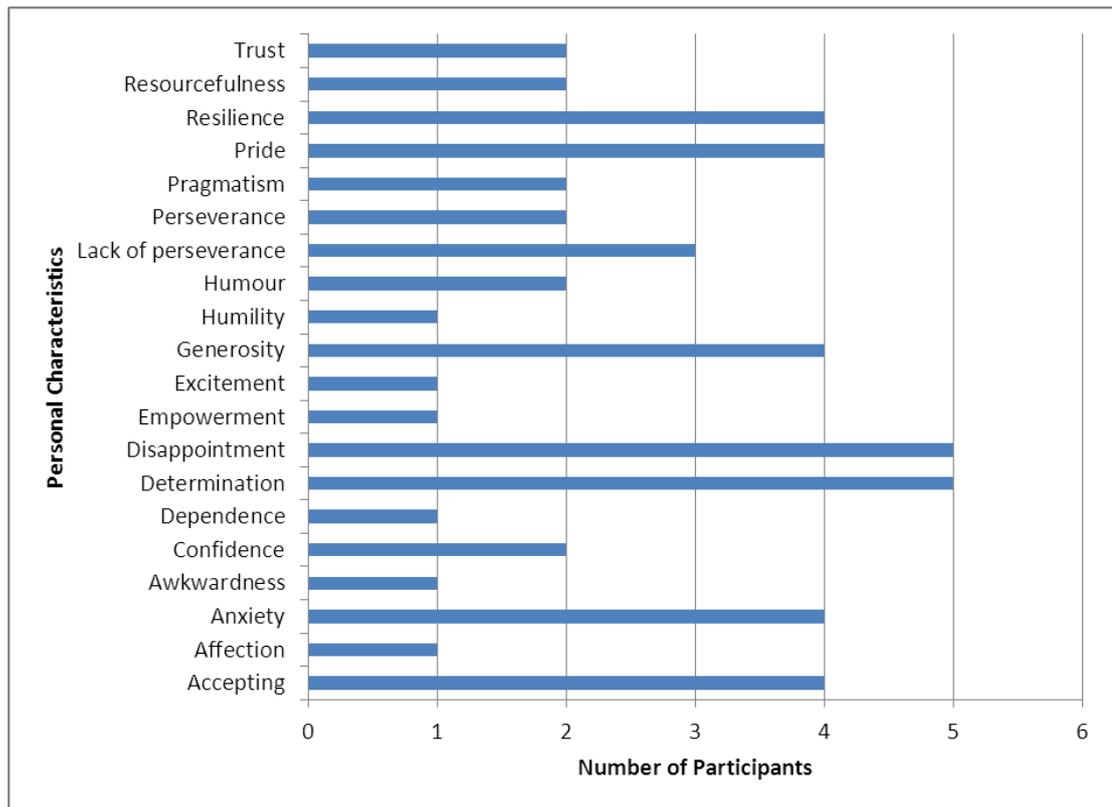


Figure 26. Number of participants per “Personal Characteristics” sub-themes.

A large range of participant personal characteristics has been identified. These characteristics were identified when participants were discussing a range of topics, with some examples including their disability, their communication guide, the service they receive, a social situation, leisure activities or a vocational situation.

**Goals and desires.** All participants expressed an aspiration to achieve a goal. Of the total data, seven per cent was allocated to this theme. Within this sub-theme all the participants’ goals established from completing the COPM were included. Participant goals related to developing friends, improving communication skills, participation in education, participating in recreation, accessing the community and instrumental activities of daily living. Participants also discussed activities and skills they would like to achieve. Some examples included:

“To improve my life with my computer skills” (Participant C, personal communication, November 29, 2011).

“Achieve even more” (Participant C, personal communication, November 29, 2011).

“There’s another couple of things I wouldn’t mind some help with. And as I said, that could change to even more things in the near future. So it would be nice to be able to turn to that” (Participant E, personal communication, February 9, 2012).

“I really hope that the program will continue in Senses because it is an absolutely necessary program and if it can be flexible enough for you to make a phone call and say, ‘Hey, I’m really stuck on this one, can I get a communication guide for this or that’, it is invaluable” (Participant E, personal communication, February 9, 2012).

Only one sub-theme “Fulfilment” was identified in the theme of Desires. This sub-theme related to participants expressing that they had fulfilled or accomplished their desire or goal they had identified in their IFP. Comments included:

“I achieved everything I wanted to learn” (Participant C, personal communication, November 29, 2011).

“We sat down the other day and [*Occupational Therapist*] and I sat down the other day and went right through every goal and everything was achieved, everything” (Participant E, personal communication, February 9, 2012).

**Occupation.** Of total data collected, this theme accounted for five per cent. The percentage of data for each sub-theme is outlined in Figure 27. By far the greatest sub-theme in Occupation identified was “Leisure”, with 88% of the total data. Other sub-themes included “Instrumental activities of daily living and activities of daily living” (10%), “Education” (1%) and “Employment” (1%).

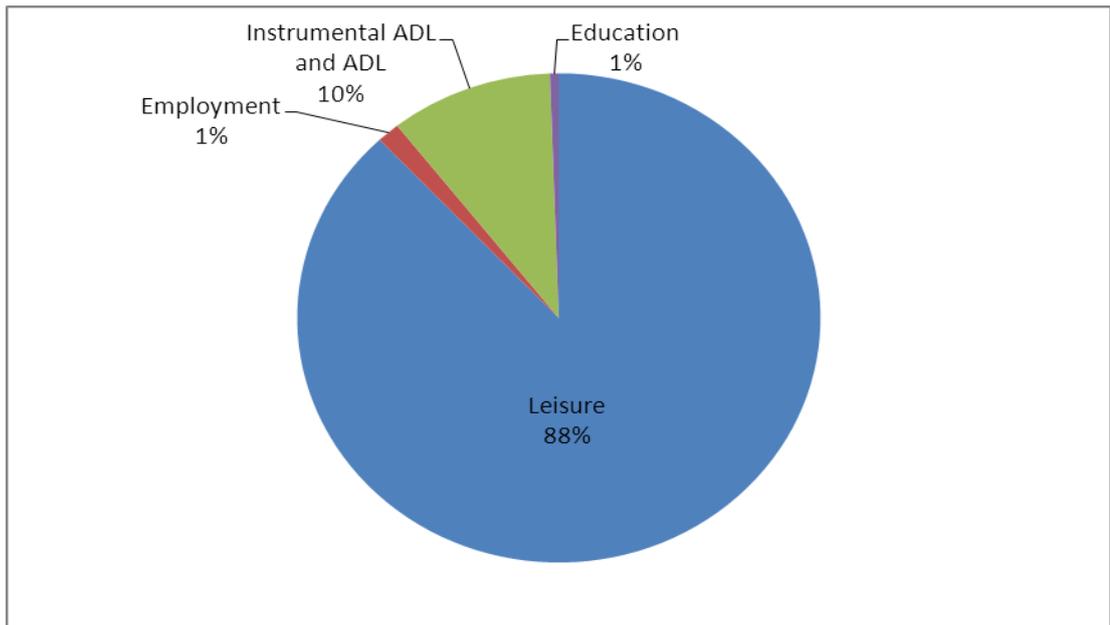


Figure 27. Percentage breakdown of “Occupation” sub-themes.

The number of participants attributed to each sub-theme is outlined in Figure 28. The sub-theme ranking was consistent with the percentage data analysis. “Leisure”, the largest sub-theme had eight participants; “Instrumental activities of daily living and activities of daily living” six participants; “Employment” two participants; and “Education” one participant.

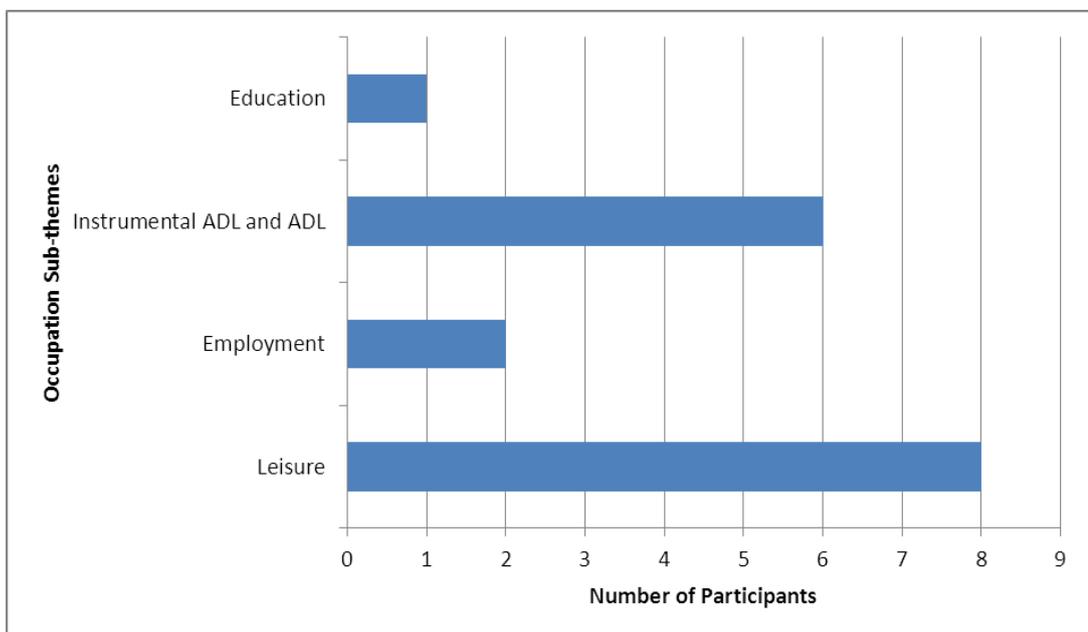


Figure 28. Number of participants per “Occupation” sub-themes.

**Leisure.** This sub-theme was discussed by eight participants. Leisure activities included fishing, crabbing, watching dolphins, watching football, swimming, listening to music,

photography, craft, knitting, attending a café, ten pin bowling, archery, listening to current affairs, attending concerts, singing, playing musical instruments and painting.

*Instrumental activities of daily living and activities of daily living.* Six participants made reference to instrumental activities of daily living or activities of daily living during their interviews. These activities included cooking and shopping and examples included:

“With the cooking we learnt ... we started off with soup and then we did other things like quiches and ... roast meat and things like that” (Participant C, personal communication, November 29, 2011).

“I started cooking from that day and then I cook at home in between” (Participant C, personal communication, November 29, 2011).

“...helpful in shopping” (Participant G, personal communication, December 19, 2011).

*Employment.* In this sub-theme, one participant commented he was looking for work and another stated she was employed.

*Education.* One participant utilised the communication guide to support him with formal education.

**Person-centred approach.** This theme was the smallest of all the themes, with two per cent of total data and two participants attributed to it. The participants discussed how the service was person-centred, with examples including:

“And then really went out of her way to find exactly what I did need, because [*Communication Guide*] knew what I didn't need and what I did need, and to be able to sit down and talk to her and be very flexible with everything. That was what was really good” (Participant E, personal communication, February 9, 2012).

“Tailoring it to ... that's what I found, because the best part was that it was tailored to my needs” (Participant E, personal communication, February 9, 2012).

### **Quantitative Assessment Results – average aggregate pre-post comparison**

As discussed in methodology, this study is defined as a multiple-case holistic design. It was therefore considered important not only to obtain information relating to changes within

each case study, but also to obtain some aggregate pre- and post-comparisons. The three quantitative assessments used; the CHA and DBS, COPM and the SF-36 have been statistically analysed using the averages from all participants of selected variables.

**interRAI Community Health Assessment and Deafblind Supplement.** Those variables selected for aggregate pre-post comparison are outlined below. Variables related to: participant psychosocial state; relationships and interactions; engagement in occupations; level of support required; and ability to move about, were selected as the literature clearly identified that these areas are impacted upon in an individual who is Deafblind.

- Average of indicators of possible depression, anxious or sad mood, observed in last three days
- Average of participants' self-reported mood in last three days
- Average of social relationships
- Feeling of loneliness
- Length of time alone
- Average of instrumental activities of daily living performance
- Average of instrumental activities of daily living capacity
- Average of activities of daily living self performance
- Level of activity in last three days
- Number of times in last three days where they went outside
- Any involvement in structured activities
- Number of occasions of recreation or leisure activities in last seven days
- Average of level of support required to be involved
- Orientation and mobility performance
- Orientation and mobility capacity
- Level of difficulty based on presumed ability to interact with others as independently as possible

The mean of the variables in each group was calculated at time (pre and post), the difference in mean scores was then obtained (time post minus time pre) and p-values (from the t-test and the non-parametric Wilcoxon signed rank test) were calculated. See Appendix 5 for calculations. No p-values reached statistical significance, however the variable loneliness ( $p=0.08$ ) and social interactions ( $p=0.08$ ) indicated the changes in mean scores were approaching statistical significance (t-test).

**Canadian Occupational Performance Measure.** Changes in the aggregate averages of participant performance and satisfaction were analysed. The summary quantities for changes in these variables and the p-values (from the t-test and the non-parametric Wilcoxon signed rank test) are provided in Appendix 6. The changes in performance and satisfaction were positive and these changes were significantly greater than zero, showing that a difference did occur and was statistically significant.

**SF-36 Health Survey (Version 2).** Analyses of this assessment are based on the mental (MCS) and physical (PCS) summary scores (see Appendix 7). The two summary scores have a mean of 50 and SD=10 if the data were collected on adults in the USA in 1998. A high score indicates a good quality of life. The mean scores on both MCS (initial = 42.33, final = 43.96) and PCS (initial = 46.17, final = 45.09) summary scores were less than the US average. From baseline to follow-up, the change in the MCS score was small and positive, while the change in the PCS score was small and negative. Neither of the changes were statistically significant either on the t-test (comparing mean scores), or the non-parametric signed rank test.

## Chapter 4 - Discussion

The discussion of the results within this chapter are framed by the research question of: “How does a communication guide’s support impact on an individual with deafblindness?” In order to determine the impact of the communication guides, the sub-objectives are explored in the context of the study’s multiple-case holistic design, where individual participant and aggregate participant results are discussed. The sub-objectives outlined for this study included:

- How was the quality of life of the participants affected?
- How was the occupational performance of the participants affected?
- What aspects of the communication guide support did the participants value?
- What aspects of the communication guide support did the participants not value?

### **How was the quality of life of the participants affected?**

The participants’ quality of life was specifically reviewed using the SF-36v2. This health survey is a generic outcome measure designed to examine an individual’s perceived health status. It measures eight health concepts and can also be divided into two summary measures, the Physical Component Summary (PCS) and the Mental Component Summary (MCS), which are scored out of 100. There were no statistically significant changes within the sample from the initial to final assessment using this tool however there were some individual changes. The change in the average aggregate PCS for all participants was -1.85, with seven participants scoring lower in the final assessment and three scoring higher. The change in the average aggregate MCS for all participants was +2.71, with seven participants scoring higher in the final assessment and three scoring lower. With the changes being minor, it is difficult to ascertain if participants’ quality of life has been affected using this assessment.

However participants did report a statistically significant increase in the outcomes of their individualised COPM goals. Schalock (2004) commented that one of the three quality of life factors or higher order constructs that has been identified is ‘independence’. The domains within this factor include ‘personal development’ and ‘self-determination’. With participants creating their own goals and with each participant being able to perform every goal better and each participant being more satisfied with their performance of their goals, this significant increase clearly demonstrated an improvement in all participants’ quality of life.

Another of the three quality of life factors or higher order constructs identified is 'social participation' (Schalock, 2004). Dalby *et al.* (2009a) commented that though individuals with acquired deafblindness had the capacity to function more independently in the community, given their functional and social skills, were more socially isolated. Stuen (as cited in Heine & Browning, 2002) suggested that individuals with sensory loss, including deafblindness often feel disorientated, lack coping strategies, feel unconfident, frustrated, embarrassed and vulnerable, which can result in an increased dependence on carers, loneliness and increased social isolation.

There were changes in the participants' levels of social participation however it is difficult to ascertain if these changes could be attributed to the communication guide intervention. One of these changes relates to loneliness. In the initial assessment, three participants reported being 'lonely'. At the final assessment there were no participants who reported being lonely, which demonstrates a positive change in the quality of life in this area of these three participants.

Changes in levels of social relationships (participation in social activities of long-standing interest; visit with a long-standing social relation or family member; other interaction with long-standing social relation or family member) from the initial to the final CHA assessment tended to remain consistent, with 21 out of 30 being the same. Within the ten participants there was an increase in levels of socialisation in four of the 30 items and a decrease in five items. Although the communication guides were trained to have a comprehensive understanding of issues related to deafblindness, sighted guide and how to work in a person-centred manner, they did not have the skills to support participants to improve their relationships with long-standing friends or their family. If participants felt that this was an area they would like assistance with, a referral to a social worker, who has skills in counselling and family systems, could have been initiated by the communication guide or deafblind consultant.

When asked within the SF-36v2 if their physical health or emotional problems interfered with their normal social activities with family, friends, neighbours or groups, four participants reported a slight decline in this area, three reported a slight improvement and three reported no change from initial to final assessment. Another question within the assessment asked participants how much of the time their physical health or emotional problems interfered with their social activities. Six participants reported no change, four reported improvement and one reported a decline. As stated, it is difficult to determine if the communication guide intervention was a factor for these changes.

Within the DBS assessment, participants were rated by the assessor on their perceived level of support required to interact with others. This is recorded in Table 24. The assessor felt that some communication guide support was required for all participants in some way.

Table 24

*Participant Results for “Social Interactions” from Deafblind Supplement*

<b>Level of support required</b>	<b>Number at Initial Assessment</b>	<b>Number at Final Assessment</b>
<b>None</b> – able to interact with others with communication guide in all situations	0	0
<b>Minimal</b> – can interact in familiar AND unfamiliar environments, BUT requires communication guide in complex situations	2	3
<b>Moderate</b> – can interact in familiar environments BUT requires communication guide in ALL unfamiliar situations	6	6
<b>Severe</b> – can interact in familiar BUT requires communication guide in with unfamiliar people	1	1
<b>Very Severe</b> – requires communication guide to interact with individuals in familiar environments	1	0

Six participants self-reported that their ability to be ‘involved in community activities and with others’ changed from needing communication guide support to do this at the initial assessment to not requiring communication guide support at the final DBS assessment, in one or two items (out of six items). There were nine items in total out of 60 that participants reported they no longer required communication guide support. This section from the DBS is outlined in Table 25. This was surprising as according to Olson (2004), the more successful communication guides are, the more visual and auditory information the person with deafblindness will want, with the role not to develop independence with an aim to then remove support, but to provide ongoing support.

Table 25

*Participant Results for “Sense of Involvement” from Deafblind Supplement*

Social Skill	Assessment Time	Scoring – Number of Participants		
		No	Yes, only with communication guide support	Yes, without communication guide support
At ease interacting with others	Initial	0	6	4
	Final	0	6	4
At ease doing planned or structured activities	Initial	0	6	4
	Final	0	5	5
Pursues involvement in activities of residential setting or community	Initial	0	5	5
	Final	1	5	4
Initiates interactions with others	Initial	0	5	5
	Final	1	3	6
Reacts positively to interactions initiated by others	Initial	0	5	5
	Final	0	4	6
Adjusted easily to changes in routines in last 30 days	Initial	2	4	4
	Final	1	1	8

It is difficult to ascertain why participants felt more able to be involved without communication guide support. According to participants, their levels of social relationships remained similar, so it is unlikely that they had many more opportunities to practise these skills with their communication guide. Perhaps the support provided by the communication guides enabled the participants to develop a sense of confidence which translated into feeling more capable in this area. Emotional support was a theme identified within the qualitative data and this support may have been a factor in improving participant confidence.

Participants had a positive outlook which may have also promoted their confidence. Within the semi-structured interview post intervention, the theme of “personal characteristics” was identified. These personal characteristics were not related to the communication guide service as personality and individual values are not easily influenced. It was surprising to observe that the majority of participant personal characteristics were positive, with a 65% result. This was in light of any hardship participants may have encountered throughout their life, including dealing with deafblindness and its associated impacts. In addition to participants having positive personal characteristics, all also reported

having a 'consistent positive outlook' and nine participants reported that they 'found meaning in day-to-day life'.

Participants D and E, both with Usher syndrome type two reported psychiatric conditions which had improved from the initial to the final assessment, which indicates an improvement in their quality of life. Little research has been focused on psychiatric and psychological issues of individuals with Usher syndrome (Dammeyer, 2012). The frequency of psychosis in individuals with Usher syndrome varies significantly within the research, with one study reporting 23% of 114 individuals being psychotic (Hallgren, as cited in Dammeyer, 2012) and another reporting 4.5% in a sample of 133 (Nuutila, as cited in Dammeyer, 2012), however Dammeyer (2012) stated that there is no higher prevalence compared to the general population.

Participant D reported that he was having treatment for delusions and hallucinations at the initial assessment but these were not present at the final assessment. This participant did not wear a hearing device, could not locate sounds and did not respond to voices at normal volume or quiet sounds. He had near blindness in his visual acuity range (less than 20/1000 – 20/20000) and near blindness (4 degrees to less than 8 degrees) in his visual field diameter. It has previously been reported that individuals with almost no hearing and vision can experience visual and/or auditory hallucinations (Bolduc, Brisette & Lefebvre, 2004). It has not been clearly established why an individual who is deafblind may experience such severe symptoms but research indicates that sensory deprivation may encourage the appearance of hallucinations and this phenomenon has been observed in sensory deprivation experiments with subjects without sensory impairment (Bolduc *et al.*, 2004). The greater socialisation and communication that occurred via the communication guide intervention may have been a factor in the reduction of this participant's delusions and hallucinations.

At the final assessment Participant E reported a diagnosis of schizophrenia was present and it was being monitored but with no active treatment. This participant also reported at the initial assessment she was experiencing anxiety and depression and was receiving active treatment for both these conditions. At the final assessment this participant reported her anxiety and depression were present but being monitored with no active treatment. A number of studies have found an association between deafblindness and depression (Capella-McDonnall, 2005; Chia, *et al.*, 2006; Chou & Chi, 2004; Heine & Browning, 2002; Lupsakko, *et al.*, 2002). Belsky (as cited in Heine & Browning, 2002) noted that individuals with poor sensory acuity feel more isolated and limited as they can no longer do things they enjoy, often feel vulnerable, are less secure and self-confident, have decreased self-esteem,

and are often exhausted and depressed. The support of a communication guide may have benefited this participant.

There were changes in self-reported mood from the initial to final CHA assessment in three participants. Participant D's self-reported mood declined however the moods of Participants E and G increased. Participant E initially reported spending one to two hours alone during the day with this increasing to eight hours or more at the final assessment; however Participant E also initially reported loneliness which was not present at the final assessment. This indicated Participant E was spending more time alone but was less lonely.

Sixteen of the changes in the CHA and DBS were associated with the prevention of disease through medical tests, exams and vaccinations. Thirteen of the changes indicated that the preventative action had occurred between initial and final assessments. It may be inferred that merely asking questions related to these preventative actions at the initial assessment has facilitated some action by the participant or their families to seek out the medical test, exam or vaccination. Anecdotal information, gathered from conversations between participants and the Senses Australia occupational therapist supported this claim. Although these preventative measures cannot be related to the communication guide service participants directly received, it resulted from the process of being assessed for the communication guide service. Dalby *et al.* (2009a) reported that in a sample of 182 individuals who were deafblind, the vast majority did not receive these important preventative health measures which suggested that there may be unmet health-related needs in this population. Conducting a comprehensive assessment with individuals who are deafblind, such as the CHA and DBS, may therefore improve the health outcomes and physical wellbeing for this population.

A personal factor that influences quality of life outcomes includes indicators of human functioning. These comprise intellectual functioning, adaptive behaviour, mental health, physical health, speech difficulty, mobility and support needs (Claes *et al.*, 2012). The communication guide intervention has limited ability to impact on these personal factors of human functioning. Although the communication guide may not directly impact on an individual's mental or physical health, they may become aware of health issues and support them to seek appropriate treatment.

Environmental factors that influence quality of life outcomes include inclusion, engagement, empowerment, normal rhythm of life activities, individualised supports, support staff activities and organisation efficacy (Schalock, as cited in Claes *et al.*, 2012). The communication guide intervention embraced person-centred approaches in the delivery of

services. Individual supports are the instrument for improving quality of life, with organisations bridging the individual to their community through person-centred approaches. The concept of quality of life provides the framework to integrate the increased demands for quality services, personal outcomes, quality improvement and program accountability (Schalock *et al.*, 2008).

### **How was the occupational performance of the participants affected?**

The COPM was used within this study to assist participants to develop person-centred goals and detect changes in their self-perception of occupational performance over time. The COPM purports that an individual's occupational performance is determined by the individual, in terms of their ability to perform certain occupations and their satisfaction with that performance. Participants identified a range of specific goals that they wanted to achieve with communication guide support. These goals related to:

- Socialisation
- Community access
- Community involvement
- Recreation
- Communication
- Employment
- Education
- Orientation and mobility
- Instrumental activities of daily living
- Computer skills

The results clearly showed that the occupational performance of each participant increased from the commencement of the communication guide support. The aggregate performance of the occupations that all participants identified and chose to target demonstrated a statistically significant increase in both t-test (0.0004) and signed rank test (0.002) from the initial to final assessment. The aggregate satisfaction of the occupations all participants chose to target also demonstrated a statistically significant increase in both t-test (<0.0001) and signed rank test (0.002) from the initial to final assessment.

The CHA and DBS also contained information regarding participant occupational performance. Within this study, all but one of the participants were scored as requiring some assistance with functional activities, with eight reporting needing "extensive assistance" or higher in an instrumental activity of daily living, such as: housework; shopping; or managing

medications. This reflects other studies that have indicated individuals who are deafblind have greater functional problems than those with a single or no sensory impairment in areas of walking, climbing stairs, preparing meals, shopping, housework, getting out in the community, getting out of bed, using a telephone and administration of medicine (Crews & Campbell, 2004; Lin, *et al.*, 2004).

From the initial to the final CHA and DB assessments, five participants reported that their activity levels had increased, with one decreasing and four remaining the same. Given that aspects of the communication guide intervention was to provide sighted guide and possibly to increase access to their community (based on individual goals), this improvement in half of the participants may be related to the communication guide intervention. The participant who had less activity levels reported symptoms of depression which may have negatively impacted upon his activity levels at the time.

Within the 'Functional Status' section of the CHA assessment, which investigated self-assessment of performance and capacity of participants' instrumental activities of daily living and activities of daily living, the vast majority of items remained the same from the initial to the final assessment. This is what was expected as communication guides intervention tended not to support participants within these areas (except cooking, which was identified as a goal for a participant). There were however 24 items (out of 218 that were assessed) where participants rated themselves as requiring greater levels of support at their final assessment. Participant I's rating in the item of housework changed from "independent" to "limited assistance". At the final assessment she reported that she had recently received in-home funded cleaning support and now did not have to complete this activity. Although her rating demonstrated a decline in her ability to perform that occupation, it is reasonable to assume that this would not have changed. Half (12) of these items in which participants indicated a decline within 'Functional Status' were associated with mobility ('using stairs', 'locomotion' and 'indoor locomotion'). Given that aspects of the communication guide intervention was to provide sighted guide and possibly to increase access to their community, this reduction in scores related to participant mobility is unexpected. One possible explanation is that to achieve their goals, participants may have increased walking during the study and as a consequence become more aware of mobility issues.

It has previously been identified that individuals who are deafblind have fewer occupations (Crews & Campbell, 2004; Lin, *et al.*, 2004) and are potentially at greater risk of occupational injustice, in particular occupation deprivation and occupational imbalance. The concept of occupational justice outlines it is the right of every individual to be able to meet

basic needs and to have equal opportunities and life chances to reach towards their potential through their engagement in diverse and meaningful occupations (Wilcock & Townsend, 2009). Through the engagement of a communication guide, individuals with deafblindness can seek to reduce their risk of occupational injustice.

A study by Watters *et al.*, (2004) discussed with people who are deafblind what occupations they performed on a typical day. They reported that several factors influenced the activity levels of an individual who was deafblind. Those who possessed sufficient sight and vision to live independently tended to be involved in more occupations than those who were less independent. Those who had access to the support of intervenors (communication guides) participated in greater numbers of occupations as a result. "It is clear that in order to participate in many community activities; they can only do so with the involvement of an intervenor" (Watters *et al.*, 2004, p. 21). In the study, community services that people who were deafblind found difficult to access included taking walks, shopping, going to the bank, doing volunteer work, attending recreation programs, social events, using public transport and accessing some public buildings. Some also found it difficult to complete home-based occupations such as cooking or reading without intervenor (communication guide) support.

Without exception, all deafblind focus group participants in the study by Watters *et al.* (2004) indicated the major obstacle to accessing services in the community related to the unavailability of sufficient intervenor (communication guide) services. They commented that participants in their study described the necessity to depend on friends and family to provide intervenor (communication guide) services when paid or volunteer intervenor (communication guide) services were unavailable, with some afraid their dependence would negatively impact on these relationships.

Senses Foundation (2008) found that only 181 of the 8,800 individuals who were deafblind identified in Western Australia were accessing formal disability services. This was despite 48% reporting a profound or severe level of disability and from at least one third to half of the individuals reporting always needing help within each of the described key life activities. This finding is reflective of the findings of other research which reports that the lower proportions of people with a deafblind disability accessing services than other disability groups is due to a number of barriers to access (Zazove & Doukas, 1994). Lock (2003) also stated that it is well documented that sensory impaired persons demonstrate difficulties accessing health care and communicating with health care professionals.

It has been clearly shown that the occupational performance of all participants demonstrated a statistically significant increase. Evidence suggests that without communication guide support, individuals who are deafblind will continue to encounter occupational injustice.

### **What aspects of the communication guide support did the participants value?**

Within the qualitative data, participants have described a number of examples of how they have valued the communication guide support. This information is predominately detailed in the themes of “Support provided by communication guides” (see Figures 15 & 16) and “Participant positive feedback on communication guide services” (see Figures 23 & 24). The theme “Support provided by communication guide services” accounted for 23% of the entire qualitative data, with the largest type of support provided being “practical support”, which was 12.57% of the entire qualitative data, followed by “emotional support”, which was 5.03% of the entire qualitative data. Practical support related to assistance made by communication guides that helped participants perform activities within the home or community. Often it was support to see or hear an activity, or interaction that enable the participant to successfully carry it out. Based on these relatively large percentages, it is reasonable to conclude that participants valued the practical and emotional support provided by the communication guides.

Participants valued the skills of the communication guides, as detailed in the theme “Participant positive feedback on communication guide services”. In particular, participants valued the sighted guiding and communication skills of the communication guides. This feedback indicates that the recruitment and training of the communication guides in this area was of a high standard. Regarding sighted guiding, communication guides underwent comprehensive practical training in the community, as both a guide, as well as simulated person with deafblindness.

As discussed, people with deafblindness appear to have a number of challenges, including social interaction. Dalby *et al.* (2009a) reported that in a sample of 182 individuals who were deafblind, over half showed moderate to high levels of social engagement (58.7%), although many experienced severe to very severe difficulty interacting with others (67.8%). This is highlighted within this study where four participants discussed their difficulties communicating with others. Participants did comment that the communication guide helped them to interact with others by providing them with information they had missed and ensuring they did not miss interactions from others.

With four of the participants communicating using Auslan, it was essential to provide these participants with a communication guide who was proficient in using this method of communication. The Australian Deafblind Council (2010) recommended that single sensory disability service provider organisations are not effective in meeting the needs of individuals who are deafblind. A study by Watters *et al.* (2004) also suggested that services for individuals who are deafblind should be provided by an organisation with expertise and a mandate to serve people who are deafblind. The assumption is that due to the unique needs of this population, there would be a lack of properly trained staff within those single disability organisations who are able to assist people who are deafblind.

The pairing of the communication guides with participants was also valued by participants. Communication guides were matched according to their communication skills (eg. Auslan), but also interests and personality. This is evident by the comments relating to the communication guide communication skills as well as the many comments contained within the subtheme “General comments about communication guides” of the “Participant positive feedback on communication guide services” theme.

Participants appeared to value the communication guides’ advocacy. Although communication guides were provided training to be the eyes and ears of the person who is deafblind without filtering information, and not doing for but doing with, many communication guides took on the role of advocate. This included contacting organisations on participants’ behalf. This is potentially an area that could be expanded within the communication guide training.

Eight participants made comments that their allocation of communication guide time was adequate, with some commenting that they would like more if available. In comparison to Danish people who are deafblind, who receive between 10 and 25 hours per week of contact person support, with some receiving as much as 50 hours (Miner, 2008), the participants receive much less. Munroe (2001) commented that in a Canadian study, 69.9% of individuals with deafblindness received at least 21 hours of intervenor services and 12.3% of those with acquired deafblindness receiving this level of support. Miner (2008) reported that SSP support was provided from one hour to 20 hours per week. Communication guide support should be provided based on goals and relative need, that is, those with greater impairment receiving greater levels of support. This differing levels of support should be possibly in the proposed National Disability Insurance Scheme, which is currently being trialled throughout Australia.

Five participants commented on the flexibility and availability of their communication guide. This demonstrated a person-centred approach by the communication guide service. According to Beadle-Brown (2006), person-centred planning has been demonstrated to enhance quality of life by facilitating choice, autonomy, personal control and decision making. The communication guide training incorporated person-centred approaches and it is apparent that the communication guides embraced this approach with positive results.

Participants and communication guides were made aware that the communication guide service did not include providing transport however some communication guides decided to ignore this and transport participants in their private vehicles. In other similar services, such as SSP's in some US states, transport is made available (Bourquin *et al.*, 2006). With five participants commenting on the benefits of this, it is an aspect valued by some participants and should be considered in future communication guide services.

#### **What aspects of the communication guide support did the participants not value?**

Participants provided a number of comments relating to aspects of the communication guide support that they did not value. These included being rushed, when the communication guide was not available on some days and/or times, when a communication guide became angry, and not receiving sufficient information regarding the service.

One participant commented that due to their communication guide working as a sign interpreter and being busy in this role, he felt rushed when performing activities and did not enjoy this feeling. This participant also commented that the communication guide was not always available on his preferred day, reporting "She wasn't able to come on the weekends, only on a Saturday morning" (Participant J, personal communication, February 7, 2012). Another participant who this communication guide supported also commented that she was "very busy". This sense of being rushed and not being available on the preferred day indicated that the communication guide and this part of the service were not being delivered in a person-centred manner.

Another participant reported that their communication guide became angry at another person when supporting him at a social event. This participant appeared to feel uncomfortable with this. The participant further reported that the communication guide then took the musical instrument from him and packed it away. This behaviour does not demonstrate person-centred approaches or fit with the guiding principle of being a communication guide where they are only the eyes and ears of the individual who is deafblind and do not make decisions for them. Although some participants commented on

the communication guides positive person-centred approach, this was not consistent within the service.

Five participants commented on lack of information specifically related to the communication guide service. Four of these participants felt that they did not have sufficient information prior to the service commencing, with two participants initially under the assumption that they would be attending a group for deafblind people and another stating that their communication guide “did not receive any guidelines which was holding her up a bit”. One participant was unclear on the amount of time they would receive and another queried if new funding would be available to continue the communication guide service after the six month period. This lack of information is despite participants being provided written and verbal information in their preferred method for communication.

According to Thompson *et al.* (2009, p. 136), “Support needs are based on the premise that human functioning is influenced by the extent of congruence between individual capacity and the environment in which that individual is expected to function.” Individualised supports, through person-centred planning can address mismatches between a person’s personal competencies and environmental demands and can enhance an individual’s functioning and outcomes. For example a communication guide can develop an individual’s mobility through sighted guide and their communication through interaction and implementation of additional supports, if that is what the individual chooses to seek assistance with. An individual with deafblindness may want assistance to walk to their local shop. Through the use of a communication guide, they can learn the route and together overcome obstacles, which may allow the individual the ability to independently walk to that shop. Similarly with communication, they can work with the individual to develop their ability to request items at the shop but also work with the shop assistant to understand the impact of deafblindness on the individual and teach skills related to the individual’s preferred communication method. Individuals with deafblindness, however may never develop independence in all aspects of their life.

Support provided to individuals with a single sensory disability, such as those with a vision impairment or a hearing impairment, is often to improve their functioning or competencies to develop independence. This is generally not the case for individuals who are deafblind. As previously stated, the more successful a communication guide is, the more visual and auditory information the person with deafblindness will want. This role therefore, is not to develop independence with an aim to then remove support, but to support this ongoing need. A communication guide is the deafblind person’s link to the world; to

information about the environment. A communication guide has been successful when the need for intervention increases rather than decreases as the person with deafblindness grows and wants more and more information about the world (Olson, 2004). Olson (2004, p. 3) states, “For all other supportive positions, success is measured by how independent the person becomes and how much support can be removed. It is the exact opposite for someone who is deafblind.”

Within Australia, deafblindness has only recently been identified as a distinct disability group by the Federal Government. Children from birth to six years who are deafblind can access the Better Start funding. The Better Start website states the following in reference to children who are deafblind: “All children with a diagnosis made by a specialist multidisciplinary team which includes an ophthalmological and audiological evaluation (therefore application of a threshold is not necessary) will be eligible” (Better Start, 2013). Although this recognition by government disability policy makers that deafblindness is unique and requires specific intervention, this does not apply to anyone older than six years of age. Given the positive outcomes of this study, it would be worth the Federal Government considering supporting a communication guide service within a National Disability Insurance Scheme model for all deafblind Australians.

The Australian DeafBlind Council advocates for an appropriate assessment system for funding allocation to people who have deafblindness. They support an assessment that understands the issues of a person with deafblindness and is associated with individual funding levels. Reports from Australia, Canada and the UK all discussed the need to have specialised individual services available to people who are deafblind. Communication guide services were considered a priority. The provision of deafblind consultants to assist other organisations and individuals working with people who are deafblind in relation to communication, orientation and mobility, assistive devices and employment was also recommended.

## Chapter 5 - Conclusions

Within this study, the literature related to deafblindness was reviewed. This unique disability was defined and the causes of deafblindness identified. International, national and state prevalence data related to this disability were reported, and the impacts of being deafblind described. The economic impact of deafblindness within Australia was detailed and recommendations for meeting the growing deafblind population outlined. The literature review also explored funding options and generic disability services provided to people with deafblindness in Western Australia, Australia and internationally. International communication guide training programs were examined and finally the impacts of specialised deafblind services on people who are deafblind are reported.

Literature that related to the concepts of quality of life, person-centred approaches and occupational justice was also reviewed. The concept of quality of life was reviewed as deafblindness has been demonstrated to have an impact on an individual's quality of life. Quality of life domains as well as demographic, human factor, and environmental indicators of quality of life were outlined. The literature reviewed of person-centred approaches demonstrated it to be a key method in achieving better quality of life for individuals with a disability. The three aspects of the concept are explored: person-centred planning; person-centred funding; and person-centred actions. As individuals with disability are at risk of occupational injustice and the concept of engaging the participants who were deafblind in meaningful occupation to enhance quality of life was fundamental to this study, the concept of occupation justice was also explored.

The key stages for the study included the recruitment of the communication guides; the recruitment of the participants and the implementation of the communication guide intervention. The research question that this study explores is "***How does a communication guide's support impact on an individual with deafblindness?***" In examining this question, the following sub-objectives were analysed:

- How was the quality of life of the participants affected?
- How was the occupational performance of the participants affected?
- What aspects of the communication guide support did the participants value?
- What aspects of the communication guide support did the participants not value?

This study utilised multiple-case holistic design case study methodology to investigate how the communication guide support impacted upon an individual with deafblindness. Mixed methods were employed for data collection including quantitative and qualitative

assessments. The final semi-structured interviews were analysed using a thematic approach. A number of themes from the qualitative data emerged and these, in order of weighting were:

- Support provided by Communication Guides
- Connections and networks
- Quality of life
- Challenges
- Participant positive feedback on Communication Guide services
- Personal characteristics
- Desires
- Occupation
- Person-centred approach

Individual case studies were analysed and pre-post comparisons of the selected aggregated variables within the CHA and DBS, COPM goals and SF-36 components were compared using both a Paired T-test and Wilcoxon signed-rank test. Only the changes in aggregate COPM goals were statistically significant.

Overall there was an increase in the quality of life of participants. Participants reported increases in both emotional and physical well-being within their interviews as a result of the communication guide support. They discussed the new experiences and occupations in which they were able to participate with their communication guide support and expressed both in their interviews and the COPM their increased satisfaction with these occupations.

The results clearly showed that the occupational performance of each participant increased from the commencement of the communication guide support. The performance component of the COPM demonstrated a statistically significant increase in both t-test (0.0004) and signed rank test (0.002) from the initial to final assessment. The satisfaction component of the COPM also demonstrated a statistically significant increase from the initial to final assessment in both t-test (<0.0001) and signed rank test (0.002).

There were a number of aspects of the communication guide support that the participants valued. These included the sighted guide and communication skills of the communication guide, the practical and emotional support provided by the communication guide, in particular the allocation of communication guide time, the flexibility and availability of the communication guide and the transport provided by the communication guide. Those aspects that the participants did not value included when the communication guide service was not

being person-centred and when participants were unclear initially about what the service provided.

This study was exploratory in nature due to the lack of research currently available on the impact of deafblind services. It does not seek to generalise results and conclusions to the deafblind population but instead provide an understanding of the deafblind service and assist future research. Based on the literature and outcomes of this study, the following recommendations are made:

**Recommendations.**

**1. *Replicate this study nationally with a larger sample.***

To validate the outcomes of this study and to enable results to be generalised to the Australian deafblind population, a larger national study is required. A larger study would enable more detailed analysis of quality of life impacts and aggregate scoring. It would provide better scope to assess for confounders to demonstrate more rigorously the direct impact of the communication guide service.

**2. *Communication guide training is provided within the disability, education and aged care sectors.***

Communication guides require unique skills to effectively work with individuals who are deafblind. Training of communication guides based on the competency based practical and theoretical program established by Senses Australia or other similar programs, will ensure individuals who are deafblind have access to suitably skilled staff.

**3. *Communication guide training is accredited and a national register of communication guides is developed.***

Communication guides require unique skills to effectively work with individuals who are deafblind. Accreditation will ensure those employed to work as communication guides are competent to provide effective services to these individuals. A national register aims to provide easy access to services by individuals who are deafblind, with the information located in one repository. This register could have accessibility features that would enable most individuals who are deafblind to access the information. The register would also develop the profession by providing a network from which to operate.

**4. *Health and aged care agencies undertake training related to deafblindness.***

Due to the ageing Australian population and the higher incidence of deafblindness in older individuals, health and aged care agencies will encounter greater number of individuals who are deafblind. To ensure their services are effective, staff working in these areas should have an awareness of deafblind issues and how to access specialist deafblind services and information.

**5. *National Disability Insurance Scheme to enable individuals who are deafblind to fund communication guide services in all States and Territories.***

With the National Disability Insurance Scheme currently evolving in Australia, there is an opportunity to implement contemporary deafblind services, such as communication guide support within its structure. As the National Disability Insurance Scheme is effectively an entitlement scheme, there should be an option for an individual who is deafblind to choose to engage a communication guide utilising the resources allocated to them. Within a Western Australian context, communication guide support could also be considered in relation to the My Way project. Within the My Way project, individuals and families are supported to develop a vision and goals for their future and are resourced in relation to this vision. If an individual who is deafblind aims to improve access to their community or social participation, the communication guide service could be utilised to achieve this result.

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**Appendix 1.** Competencies for Training Interveners to Work with Children and Students with Deafblindness – Standards (Alsop, 2004)

- Standard 1- Demonstrate knowledge of deafblindness and its impact on learning and development
- Standard 2- Demonstrate knowledge of the process of intervention and the role of the intervener and have the ability to facilitate that process
- Standard 3- Demonstrate knowledge of communication including methods, adaptations and the use of assistive technology and have the ability to facilitate the development and use of communication skills
- Standard 4- Demonstrate knowledge of the impact of deafblindness on psychological, social and emotional development and have the ability to facilitate social and emotional well-being
- Standard 5- Demonstrate knowledge of sensory systems and issues, covering all five senses and the ability to facilitate the effective use of the senses
- Standard 6- Demonstrate knowledge of motor, movement and orientation and mobility strategies that are appropriate for people who are deafblind and have the ability to facilitate orientation and mobility skills
- Standard 7- Demonstrate knowledge of the impact of additional disabilities on the person who is deafblind and have the ability to provide appropriate support
- Standard 8- Demonstrate professionalism and ethical practices

**Appendix 2.** Participant Information Sheet**Participation Information Sheet****“Communication Guide Pilot Project”**

Senses Foundation is Western Australia’s primary service provider to and advocate for people with a dual sensory loss. It has obtained funding to conduct a pilot project to explore the impact of specialised support for people with both a vision and hearing loss. It has approached Curtin University of Technology, Centre for Research into Disability and Society to conduct this pilot project.

Matthew Wittorff, Manager of Life Skills & Family Services at Senses Foundation is evaluating the intervention provided in this pilot project as part of completion of a higher degree by research at Curtin University of Technology.

In this pilot project, 14 people who have a dual sensory loss will be recruited and provided with 6 months of weekly specialised support provided by “Communication Guides”.

Participation in this project will involve receiving the weekly support and completing a number of questionnaires before, after 3 months and at the end of the support. At the end of the support, a semi-structured interview will be conducted for approximately an hour where information about what aspects of the service worked well and what didn’t will be gathered.

This project is aiming to determine if the Communication Guide support causes any changes in the quality of life (general health, mental health, social activities and performing daily activities), of the participants.

In order to be eligible, participants must have a vision and hearing impairment, be 18 years of age or older, be able to make informed decisions, not have dementia or certain mental health conditions and live in the Perth metropolitan area.

For those accepted into the pilot project, an Individual Service Plan (ISP) will be developed with the individual, regarding how and when their allocated hours per week of service will be used, what activities are to be undertaken during the service time and the objectives of participation in the various activities. The ISP will include activities which can be described as recreational, leisure, social, volunteering, or educational. The allocated hours will vary between participants from 3 - 6 hours per week. The hours will be determined by the goals and activities identified within the ISP, with sufficient time (up to 6 hours) to implement these activities. Intervention will be provided for 6 months.

Participants can withdraw from this study at any time without penalty.

This study has been approved by the Curtin University Human Research Ethics Committee. If needed, verification can be obtained either in writing to the Curtin University Human Research Ethics Committee:

C/- Office of Research and Development  
Curtin University of Technology  
GPO Box U1987  
Perth WA 6845

Or by telephoning 9266 2784 citing OTSW-14-2010.

If you have any queries relating to this pilot project, please contact:

Matthew Wittorff

Co-Investigator

Curtin University of Technology

Ph: 9473 5458

[Matthew.wittorff@senses.asn.au](mailto:Matthew.wittorff@senses.asn.au)

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#### Funding Bodies:



Ending the isolation.



**Appendix 3.** Consent Form for Research Subjects



**Study title:**  
**‘Communication Guide  
 Pilot Project’**

Researchers: Professor Errol Cocks, Assoc. Professor Angus Buchanan, Matthew Wittorff

1. I.....(name) of .....  
 (address) hereby consent to take part in the research project entitled ‘Communication Guide Pilot Project’.
2. I have read the Participation Information Sheet for this study and understand its contents. I have had the nature and purpose of the research project, so far as it affects me, fully explained to my satisfaction by the Participation Information Sheet. My consent is freely given.
3. I understand that if I agree to participate in the research project I will also be asked to complete a number of questionnaires. This will take approximately 30-40 minutes and include questions about my marital status, living arrangements, level of education, sensory impairments, general health, social functioning, mental health, ability to get out, and ability to perform daily activities. These questionnaires will be administered at the beginning, mid-point and end of the project.
4. I understand that if I agree to participate in the research project I will receive free services from a Communication Guide. These services will be of a recreational, leisure, social, volunteering, or educational nature and agreed to by me and the researchers. These services will be delivered on a weekly basis, from three to six hours per week over a six month period.
5. I understand that after the research project, these services provided by the Communication Guide cannot continue and the services will be limited to only six months.
6. I understand that the Communication Guide will not provide transport to attend appointments or activities, but will assist me to physically access a taxi or public transport.
7. I understand that while information gained during the research project may be published in the form of a report or a journal article, my personal results will not be identified in any way in those publications. I also understand that due to the small sample size, even though the data will be de-identified, the researcher may be able identify participants.
8. I understand that the information provided by me will be kept confidential so far as the law allows. This form and the data will be stored separately in a locked office at Senses Foundation. Data entered onto a computer will be kept in a computer accessible only by password by a member of the research team. The de-identified survey data will be retained for a period of 7 years and then destroyed. If further studies take place, then additional ethics approval will be required.
9. I understand that I may withdraw from the research project at any stage without penalty, including loss of the Communication Guide service.

Signed ..... Date .....

**Researcher to Complete**

I ..... certify that I have explained the nature and procedures of the research project to ..... and consider that she/he understands what is involved.

Signed ..... Date .....

**PLEASE SIGN AND RETURN TO:**

**Matthew Wittorff  
COMMUNICATION GUIDE PILOT PROJECT  
Curtin University of Technology  
Centre for Research into Disability and Society  
Level 2, Building 401, Kent Street, BENTLEY, WA, 6102**



**Appendix 4.** Approval memorandum from Curtin University Human Research Ethics Committee

memorandum



<b>To</b>	Professor Errol Cocks, Associate Professor Angus Buchanan and Matthew Wittorff
<b>From</b>	Teena Bowman
<b>Subject</b>	Protocol Approval <b>OTSW-14-2010</b>
<b>Date</b>	12 July 2010
<b>Copy</b>	

School of Occupational Therapy and Social Work

**Human Research Ethics Committee**

TELEPHONE 9266 3600  
 FACSIMILE 9266 3636  
 EMAIL [t.bowman@curtin.edu.au](mailto:t.bowman@curtin.edu.au)

We are pleased to advise that your Application for Approval of Research with Minimum Risk for the project **Communication Guide Support for West Australians with Dual Sensory Loss: A Pilot Project** has been approved.

Approval of this project is for a period from **9 July 2010 – 8 July 2011**. If you have not completed your research by the expiry date, a new application must be submitted.

If at any time during this period changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise us immediately. The approval number for your project is **OTSW-14-2010**. Please quote this number in any future correspondence.

*Please Note: The following standard statement must be included in the information sheet to participants:*

This study has been approved by the Curtin University Human Research Ethics Committee. If needed, verification can be obtained either by writing to the Curtin University Human Research Ethics Committee, C/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth 6845 or by telephoning 9266 2784 citing OTSW-14-2010.

If you have any questions regarding the above, please do not hesitate to contact me.

Yours sincerely

**Teena Bowman**  
 HDR Student Administrator  
 Centre for Research into Disability and Society  
 Curtin Health Innovation Research Institute  
 School of Occupational Therapy and Social Work

**Appendix 5.** Statistical analysis of the interRAI Community Health Assessment and Deafblind Supplement

Variable	Number
Average of indicators of possible depression, anxious or sad mood, observed in last three days	01
Average of participants' self-reported mood in last three days	02
Average of social relationships	03
Feeling of loneliness	04
Length of time alone	05
Average of instrumental activities of daily living performance	06
Average of instrumental activities of daily living capacity	07
Average of activities of daily living self performance	08
Level of activity in last three days	09
Number of times in last three days where they went outside	10
Any involvement in structured activities	11
Number of occasions of recreation or leisure activities in last seven days	12
Average of level of support required to be involved	13
Orientation and mobility performance	14
Orientation and mobility capacity	15
Level of difficulty based on presumed ability to interact with others as independently as possible	16

Selected variables pre-post mean, median, range and standard deviation.

Variable	N	Min.	Median	Max.	Mean	Std Dev
VarPre01	10	0.00	0.28	0.56	0.23	0.22
VarPost01	10	0.00	0.11	0.67	0.18	0.23
Diff01	10	-0.44	0.00	0.22	-0.06	0.20
VarPre02	10	0.00	0.00	2.00	0.40	0.70
VarPost02	10	0.00	0.17	1.33	0.33	0.44
Diff02	10	-1.67	0.00	0.67	-0.07	0.64
VarPre03	10	0.67	1.92	2.67	1.70	0.67
VarPost03	10	0.67	1.83	2.17	1.63	0.54
Diff03	10	-0.50	-0.08	0.50	-0.07	0.27
VarPre04	10	0.00	0.00	1.00	0.30	0.48
VarPost04	10	0.00	0.00	0.00	0.00	0.00
Diff04	10	-1.00	0.00	0.00	-0.30	0.48

VarPre05	10	0.00	2.00	3.00	1.90	1.20
VarPost05	10	0.00	3.00	3.00	2.40	0.97
Diff05	10	0.00	0.00	2.00	0.50	0.85
VarPre06	10	0.00	0.80	4.75	1.67	1.76
VarPost06	10	0.00	1.00	4.88	1.79	1.76
Diff06	10	-0.36	0.00	0.63	0.13	0.29
VarPre07	10	0.00	0.80	4.75	1.64	1.75
VarPost07	10	0.00	1.00	4.88	1.78	1.75
Diff07	10	-0.36	0.00	0.75	0.14	0.31
VarPre08	10	0.00	0.00	0.33	0.03	0.11
VarPost08	10	0.00	0.00	0.33	0.03	0.11
Diff08	10	0.00	0.00	0.00	0.00	0.00
VarPre09	10	1.00	2.00	4.00	1.90	0.99
VarPost09	10	2.00	2.00	4.00	2.30	0.67
Diff09	10	-1.00	0.50	1.00	0.40	0.70
VarPre10	10	0.00	3.00	3.00	2.60	0.97
VarPost10	10	2.00	2.00	3.00	2.40	0.52
Diff10	10	-1.00	-0.50	3.00	-0.20	1.23
VarPre11	10	0.00	0.00	0.50	0.15	0.24
VarPost11	10	0.00	0.25	1.50	0.35	0.47
Diff11	10	-0.50	0.00	1.00	0.20	0.42
VarPre12	10	2.00	3.00	7.00	4.20	1.99
VarPost12	10	2.00	4.00	6.00	4.10	1.29
Diff12	10	-4.00	0.00	3.00	-0.10	2.02
VarPre13	10	0.83	1.58	2.00	1.45	0.42
VarPost13	10	0.50	1.67	2.00	1.50	0.50
Diff13	10	-1.17	0.17	0.50	0.05	0.47
VarPre14	10	1.00	1.67	4.00	1.83	0.95
VarPost14	10	1.00	1.50	3.67	1.80	0.91
Diff14	10	-1.33	0.00	1.00	-0.03	0.58
VarPre15	10	1.00	1.67	2.67	1.63	0.58
VarPost15	10	1.00	1.50	3.67	1.80	0.91
Diff15	10	-1.33	0.00	1.67	0.17	0.77
VarPre16	10	1.00	2.00	4.00	2.10	0.88
VarPost16	10	1.00	2.00	3.00	1.80	0.63
Diff16	10	-1.00	0.00	0.00	-0.30	0.48

---

Statistical significance of changes from time pre to time post using parametric T-test and the non-parametric Wilcoxon signed rank test.

Group	p-value (t-test)	p-value (signed rank test)
01	0.40	0.50
02	0.75	1.00
03	0.46	0.42
04	0.0811	0.25
05	0.0957	0.25
06	0.20	0.19
07	0.20	0.19
08	.	.
09	0.1039	0.22
10	0.62	0.53
11	0.1679	0.31
12	0.88	0.99
13	0.74	0.18
14	0.86	1.00
15	0.51	0.63
16	0.0811	0.25

**Appendix 6.** Statistical analysis of Canadian Occupational Performance Measure

Canadian Occupational Performance Measure pre-post aggregated mean, median, range and standard deviation

Variable	N	Min.	Median	Max.	Mean	Std Dev
AXCPERF	10	1.00	4.13	7.50	4.04	2.32
AXCSAT	10	1.00	4.00	6.00	3.66	1.39

*Statistical significance of changes from time pre to time post in the Canadian Occupational Performance Measure using parametric T-test and the non-parametric Wilcoxon signed rank test.*

Variable	p-value (t-test)	p-value (signed rank test)
AXCPerf	0.0004	0.0020
AXCSat	<0.0001	0.0020

**Appendix 7.** Statistical analysis of SF-36

SF-36 pre-post aggregated mean, median, range and standard deviation

Variable	N	Minimum	Median	Maximum	Mean	Std Dev
MCS1	10	21.68	43.21	52.23	42.33	8.30
MCS2	10	35.55	45.06	53.69	43.96	5.38
mcschange	10	-9.14	2.23	13.88	1.63	6.30
PCS1	10	32.23	45.82	67.41	46.17	10.93
PCS2	10	35.74	44.04	57.59	45.09	7.34
pcschange	10	-9.81	-2.65	9.70	-1.08	5.70

SF-36 univariate procedure with MCS change as variable

N	10	Sum Weights	10
Mean	1.631814	Sum Observations	16.31814
Std Deviation	6.2951397	Variance	39.6287838
Skewness	0.2554822	Kurtosis	0.89015114
Uncorrected SS	383.287224	Corrected SS	356.659054
Coeff Variation	385.775566	Std Error Mean	1.99069796

Statistical significance of MCS changes from time pre to time post in the SF-36 using parametric T-test and the non-parametric Wilcoxon signed rank test.

Variable	p-value (t-test)	p-value (signed rank test)
MCS	0.4335	0.4316

SF-36 univariate procedure with PCS change as variable

N	10	Sum Weights	10
Mean	-1.083801	Sum Observations	-10.83801
Std Deviation	5.69923053	Variance	32.4812286
Skewness	0.61354495	Kurtosis	0.26197432
Uncorrected SS	304.077304	Corrected SS	292.331058
Coeff Variation	-525.85581	Std Error Mean	1.80225494

Statistical significance of PCS changes from time pre to time post in the SF-36 using parametric T-test and the non-parametric Wilcoxon signed rank test.

Variable	p-value (t-test)	p-value (signed rank test)
MCS	0.5624	0.4922