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# IDENTIFYING CLIENT UNMET NEED AND DESIGNING A CONTINUOUS FEEDBACK SYSTEM FOR VISION AUSTRALIA

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- 1. Client Unmet Need
- 2. Vision Impairment
- 3. Feedback Mechanism

This report represents the work of one or more WPI undergraduate students submitted to the faculty as evidence of completion of a degree requirement. WPI routinely publishes these reports on its web site without editorial or peer review.

# **Abstract**

The outcomes assessment program of Vision Australia, a blind and low vision service provider in Australia, evaluates the effectiveness of the current services and delivery model, but provides no way to acquire feedback about which needs are unmet by the current services. The goal of this project was to design a feedback system to evaluate the client unmet need. The feedback mechanisms of other service organizations were assessed to determine which techniques were most appropriate for Vision Australia. Interviews and focus groups were performed with VA clients to establish the current client unmet need. A list of unmet need was identified and a continuous feedback system for Vision Australia was designed.

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# **Executive Summary**

Vision loss is the second most feared medical condition in the world and has a profound impact on the lives of those affected. Currently there are more than 480,000 people who are vision impaired or blind in Australia and the number is expected to almost double to approximately 800,000 by 2024 (Access Economics Pty Ltd, 2004). Vision Australia is the leading provider of services to the visually impaired community in Australia, offering dozens of services to improve the lives of people with low vision and blindness.

Vision Australia has been adjusting its client service delivery model to make it more client-centric and required a new feedback mechanism to be incorporated into this model to identify unmet need among clients. The first deliverable was a list of unmet client needs created through client interviews and focus groups. A mechanism to receive client feedback was the second deliverable for this project.

To accomplish the objectives of this study, the team researched information and statistics regarding blindness in Australia. Vision Australia's outcomes assessment program and Client Insights Survey were also examined. The needs assessment programs of service organizations were reviewed and an in-depth literature review of existing feedback techniques determined which procedures would be most appropriate for Vision Australia. Several methods of receiving client feedback data were identified, including the use of focus groups, interviews and surveys. The team also reviewed methods of analyzing the data to ensure that the data collected could be used effectively.

The team performed nine client meetings and eight focus groups that determined which needs were not met and discovered which methods of data collection were most convenient to

use as a feedback mechanism. Various age groups were interviewed to establish if unmet need was different among younger and older clients.

Based on these interviews and focus groups, the team was able to establish a list of unmet need that was common among the various aged clients. The team identified unmet need including recreation, advertising, independence in the community, and independence at home. Vision Australia offers solutions for recreation, but the activities are geared toward older clients or are not available in all areas. The team suggested that Vision Australia provide more activities, especially for younger clients. Many clients agreed that Vision Australia was difficult to find when their conditions were first diagnosed, revealing a problem with advertisement. While public transportation was an issue among the elderly, it was not a problem for the younger population. Likewise, while older clients expressed little interest in receiving information from Vision Australia via e-mail, younger clients preferred that method of contact. These client opinions provided insight into the differences in coping with blindness among various demographics—an example of why services should be tailored to individuals.

The team received unmet need directly from the clients with little prompting during the focus groups and interviews. Therefore, this preliminary testing shows the system appears to work and should be integrated into Vision Australia's existing outcomes assessment program. Figure 1 shows Vision Australia's existing outcomes assessment program with the addition of our feedback mechanism (red).

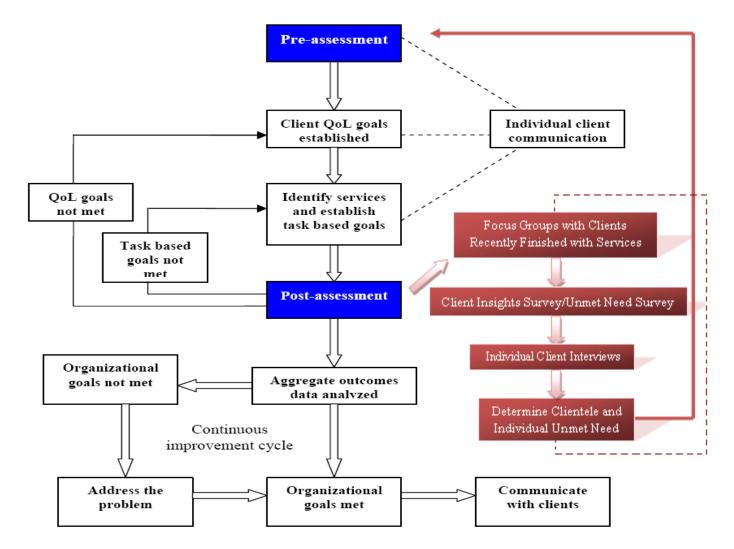


Figure 1: Proposed Feedback Mechanism

By adding a feedback loop after the post-assessment, Vision Australia could determine which needs are not met in addition to determining the effectiveness of the services provided.

As younger generations age, Vision Australia must adjust to their different needs. The suggestions for the implementation of this new feedback mechanism will help Vision Australia change services dynamically as clients have new needs. The determination of unmet need and

this feedback mechanism will improve Vision Australia's ability to determine the needs of and provide services to their clients.

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# **Chapter 1: Introduction**

Around the world the lives of millions are affected by visual impairment and blindness. Although the severity and cause of the impairment varies, people with decreased vision are faced with challenges that affect their ability to lead normal lives. In Australia alone there are more than 480,000 people with visual impairments that require assistance (Access Economics Pty Limited, 2004). Simple tasks such as getting the mail, cooking or navigating one's home become increasingly difficult as the visual impairment worsens. These activities, or "Life Themes," are areas of normal life that become more difficult with vision loss. To help those with lowered visual function, non-profit organizations exist to assist people with low vision adjust to their situations.

Vision Australia is one such organization; formed from a merger of three major organizations for blind people in 2004 with the goal of using their collective experience to create a better future for those who are visually impaired. Vision Australia groups needs into categories, called "Life Themes," and assists people with vision impairments improve functionality and independence within these categories. To better fulfill these needs, Vision Australia has attempted to change their client service delivery model from a service-oriented system to one more focused on these client needs.

In order to focus on client needs rather than current services provided, Vision Australia must implement a feedback mechanism to determine client unmet need. Other service organizations globally have instituted such feedback mechanisms to improve their service delivery by identifying the unmet needs of existing clients (Aaltonen, 1999). Previous research performed in Montgomery County, Texas described methods to determine unmet need of disabled community members (Amy M. Blakeney C. S., 2002).

Converting Vision Australia's client outcomes assessment model from a service-oriented system to a needs-based one required the discovery of a process to determine unmet need. Vision Australia is invested in this philosophy change and wanted to create such a system.

The goal of this project was to design a feedback system to evaluate Vision Australia's client unmet need. To realize this goal, the team met two objectives. The first objective was to determine the client unmet need and the second was to design a feedback system to continuously determine unmet need. By performing focus groups and client interviews, the team was able to determine which needs were not met by Vision Australia—most predominantly advertising, recreation, and independence. The team designed an effective system for Vision Australia to continuously determine client unmet need, which included focus groups, interviews, and an unmet need survey.

# **Chapter 2: Background**

This section explains blindness as it affects thousands of people in Australia as well as briefly describing the history of Vision Australia, whose mission is to ensure that "People who are blind or vision impaired are accessing and fully participating in every chosen facet of life" (Vision Australia, 2005). Vision Australia has formed categories of life called "Life Themes," which contain "Service Modules" to help people with low vision.

To fulfill their mission, Vision Australia must continuously determine the unmet need of their clientele and design their services around each client; this requires a system to continuously obtain client feedback—using such methods as client interviews, focus groups, and surveys. Research performed by others to obtain client feedback is also explained in this section because other service organizations can serve as models for designing such a feedback system. Brief synopses of service organizations throughout the world are given as background for obtaining their feedback mechanisms. Theoretical information about methods of obtaining client feedback can be found in Appendix A.

#### 2.1 Blindness in Australia

Blindness is defined by the Centre for Eye Research Australia to be any person with a 6/60 or less visual acuity or a visual field of less than 10 degrees in diameter. For a person to be declared legally blind, they must be unable to see at 6 meters what a person with normal vision could see at 60 meters, or is unable to see things more than 10 degrees from their point of fixation. According to the 2004 census in Australia, over 480,000 Australians are vision impaired in both eyes, and over 50,000 of these people are completely blind. This number may be a gross underestimation since many residential population based studies exclude institutional and residential nursing homes (Mylan R. VanNewkirk MD, 2000). Although the cause of blindness varies, a vast majority of these causes are age related, as shown in Figure 2 (Australian Bureau of Statistics, 2004) (Access Economics Pty Limited,

2004). As the baby-boomer generation ages, the number of Australians with blindness or visual impairment will double over the course of the next 20 years (Access Economics Pty Limited, 2004).

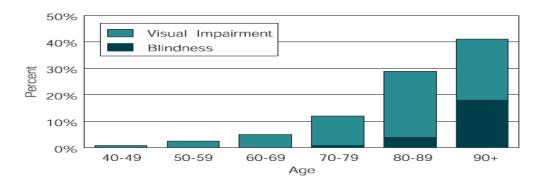


Figure 2: Visual impairment and blindness, % age group, Australia 2004 (Access Economics Pty Limited, 2004

In addition to lowering the affected person's mobility and communication skills, clients with visual impairments are at more than twice the risk of falls (Ivers, 1998), four to eight times the risk of hip fractures (Klein R, 1995), three times the risk of depression (Rovner, 1998), and twice as likely to be emotionally distressed (Scott, 2001). Blindness leads to other serious medical conditions due to its systematic nature and may lead to negative health risk behaviors such as smoking and malnutrition (Attebo K, 1996). Since it is impossible to control the contribution of other sources of death, it is difficult to determine how many deaths are caused each year due to visual impairment. However, research shows a distinct correlation between high mortality and injury rates in populations with visual impairment.

Visual impairments shorten life, decrease the quality of life, increase the risk of other conditions, and limit independence. These factors take a drastic toll on the patient's physical and mental health. There are also socioeconomic impacts, including lower employment rates, possible social isolation, and higher use of medical services, all of which contribute to an earlier need for nursing home care. Considering the growing elderly population, by 2021 nearly 800,000 Australians will be visually impaired. When this number is compounded with the percentage of blind Australians who exhibit other medical conditions as a result of their blindness, visual impairment will be an extremely important health concern in Australia in the next 20 years.

To reduce the impact of these conditions, non-profit organizations exist to help the vision impaired lead normal lives. These organizations believe that by increasing the activity and ease of life for the vision impaired, they can significantly increase their quality of life. By enhancing the ability for people with visual imperfections to manage a normal life, non-profit organizations reduce the risk of emotional instability and depression while encouraging clients to contribute their skills to the community.

# 2.2 Organizations in the Service Industry

People with disabilities deserve the right to lead lives that are comparable to those without disabilities. Organizations in the service industry around the globe provide assistance to those with disabilities. These organizations can be compared to determine the best methods employed, a practice called benchmarking (Camp, 1989). Stated formally, "Benchmarking is the continuous process of measuring products, services, and practices against the toughest competitors or those companies recognized as industry leaders" (Kearns, 1986). These practices will be important for Vision Australia to apply to their practices in order to continuously improve the quality of their services.

There are a few basic steps that an organization must take in order to achieve the best results from benchmarking practices. The first step is to know the strengths and weaknesses of the organization. Next, the organization must know the strengths and weaknesses of the leaders in their industry. Lastly, the most important step is to find the best practices that the leaders of the industry use, and incorporate them into the organization (Camp, 1989). Some of the service organizations include the Royal National Institute of Blind People in the United Kingdom, Kirinari Community Services Ltd. in Australia, Abilities Unlimited in the United States of America, Better Hearing Australia (Vic), and the Victorian Deaf Society.

#### The Royal National Institute of Blind People

The Royal National Institute of Blind People in the United Kingdom provides support and advice to over two million clients throughout Northern Ireland, Scotland, Wales, and England (Royal National Institute of Blind People, 2008). RNIB is one of the United Kingdom's leading charities and offers their clients a variety of assistance, including rehabilitation services (such as lectures and training courses), mobility equipment and other products, as well as a Talking Book service (Royal National Institute of Blind People, 2008).

# Kirinari Community Services Ltd.

Kirinari Community Services Ltd. is a non-profit charity organization that caters to individuals with disabilities. Kirinari provides services in Victoria and New South Wales, which are funded by the Victorian Department of Human Services and the New South Wales Department of Ageing, Disability, and Home Care (Kirinari Community Services, 2006).

# **Abilities Unlimited of Western New England**

Abilities Unlimited, formerly known as the Association for the Support of Human Services (ASHS), provides "services for people of all ages with a primary focus on individuals who have a disability" (Abilities Unlimited of Western New England, 2007). The goal is to enhance the experiences and the skills of people and their families. Their services cater to the changing needs of these individuals. Some of Abilities Unlimited services include an Assistive Communication Technology Center, a Family Support Program, Kamp for Kids, and a Self-Advocacy program (Abilities Unlimited of Western New England, 2007).

## **Better Hearing Australia**

Better Hearing Australia is a non-profit organization run by its members. It is a self-help rehabilitation organization that offers support services for people with hearing impairments across Australia. The objectives of Better Hearing Australia are "to encourage the preservation of hearing of all people, to encourage the use of preventative measures to lower the prevalence of deafness and hearing impairment in the Australian community, and to improve the communication of hearing impaired people, their families and friends" (Better Hearing

Australia, 2007). There are eighteen branches of Better Hearing Australia, which are located in the main cities of Australia.

# The Victorian Deaf Society (Vicdeaf)

The Victorian Deaf Society (Vicdeaf) is the primary service provider for deaf adults in the state of Victoria. The society was established in 1884 as a non-profit organization to specialize in "reference, referral, advice and support" for deaf adults (Victorian Deaf Society, 2008). Deaf people can be isolated from the community through a multitude of challenges including "chronic homelessness, illness, poverty, and an inability to communicate in the community" (Victorian Deaf Society, 2008).

# 2.3 Vision Australia History

Vision Australia, a non-profit organization, was formed by a merger of three major organizations for the blind in 2004. The Royal Blind Society (RBS), the Royal Victorian Institute for the Blind (RVIB) and the Vision Australia Foundation (VAF) joined together to form one foundation to cater to all needs of people with low vision. Collectively these organizations have over 500 years of experience with people who are visually impaired. Their goal was to create a better future for those who have vision loss (Vision Australia, 2006).

The Association for the Advancement of the Blind, later named Vision Australia Foundation (VAF), was originally formed in 1902 to achieve voting rights for people who are blind. At that time, voting was only available for people who could write, depriving Australians with low vision of a human right. VAF earned the blind population the right to vote in federal elections and soon afterward, they earned them the right to vote in state elections. They also played a major role in providing blind people other aids to daily living (ADLs), including a pension and free postage of Braille (Vision Australia, 2006).

One of the most significant contributions made to the blind community was made in 1866 by the Victorian Asylum and School for the Blind, later named the Royal Victorian Institute for the Blind (RVIB). They created the

first school exclusively for children with visual impairments. Up until 1866, blind children had no access to a formal education because teachers were unable to adapt their teaching methods to accommodate them. RVIB's advancement in education for children with low vision was later followed by the Sydney Industrial Blind Institution, later named the Royal Blind Society (RBS), when they provided the first home taught Braille (Vision Australia, 2006).

Soon after, they developed a way to help people with low vision find career opportunities. During the 1800's, the poverty rate was high among Australians who were blind. This problem was addressed by RVIB in 1867, one year after they created their school, with the teaching of basket and mat-making to individuals with low vision. This method was also adopted by RBS and through years of development, blind people were able to make a decent living for themselves (Vision Australia, 2006).

### 2.4 Vision Australia Life Themes and Service Modules

Every person has life needs, which Vision Australia breaks into eight "Life Themes"—communication tools, education, emotional support, employment, independence at home, independence in the community, information, and recreation.

### **Communication Tools**

A number of tools are available for people who are blind to facilitate communication. Vision Australia offers Braille to individuals with low vision, which allows them to communicate in a way other than written English. This system allows young children to acquire literacy skills, which they would otherwise be unable to attain as a result of their extremely low vision. If Braille and other tools were not available, children with low vision would have significant trouble with sentence structure and grammar. There are also tools available that train clients to interpret graphics such as maps, symbols, pictures, etc (Vision Australia, 2007).

#### Education

Vision Australia addresses client need in education at three age levels. In each age level, they offer advice, support, provision and transition to the next age level. The first age level is early childhood, which falls between birth and school entry. At this age, Vision Australia offers advice for families, as well as basic life skills training for young ones. They develop motor skills, dressing, toilet training, and many other skills needed for everyday life. At the school age, Vision Australia offers students a way to balance their special curriculum with the conventional one, as well as strategies for overcoming difficulties with socialization. At the tertiary age (university students and beyond), Vision Australia offers advice for older students such as those who left school early, those looking for a job, and those who wish to change their course of study. Finally, Vision Australia offers grants for students to buy adaptive technology. These grants are offered to clients who are transitioning from the school age to tertiary education (Vision Australia, 2007).

# **Emotional Support**

Vision Australia offers counseling and emotional support for both groups and individuals. Group counseling is a valuable way for clients to adjust to life with vision loss. Counselors support clients in dealing with trauma, responding to changing emotions, feeling less isolated, and other changes that are associated with vision loss. Individual counseling achieves the same goal as group counseling, but on a one-on-one basis (Vision Australia, 2007).

# **Employment**

People with low vision have a disadvantage in acquiring employment and career opportunities. The United States Labor Department explains, "In addition to the 70 percent of the blind who are unemployed, 30 percent of those who are working are considered underemployed in relation to their qualifications" (CNN, 1999). Vision Australia assists their clients with the basic steps in finding employment. They evaluate their skills, determine goals, plan out methods of achieving these goals, and help them accomplish their goals. This cycle is repeated

when new goals are made. Vision Australia offers vocational training in a number of different fields including computers and technology, woodwork, metalwork, literacy, and Braille. This training provides clients with the skills necessary to find a job (Vision Australia, 2007).

# **Independence at Home**

Everyday tasks can be very challenging activities for people with vision loss. Activities such as personal grooming, home maintenance, and movement around the house are tasks that people with low vision struggle with. Vision Australia offers adaptive technology such as magnifiers, screen readers, and speech-enabled software. They also provide training in safety and techniques for performing everyday activities. This helps clients to better understand their vision loss and allow them to lead more normal lives (Vision Australia, 2007).

### **Independence in the Community**

Similar to their services for independence in the home, Vision Australia offers training for independence in the community. The training includes buildings and grounds, public buildings, footpaths, and public transportation. It allows clients to complete everyday tasks such as banking, shopping, and traveling with as little difficulty as possible (Vision Australia, 2007).

#### **Information**

Vision Australia offers their clients a variety of information related to their situations. They provide information regarding services, eye conditions, community resources, and benefits and entitlements. This information helps clients deal with their conditions (Vision Australia, 2007).

#### Recreation

Vision Australia offers recreational services to clients. Some activities include a wide variety of sports such as bowling, cricket, and sailing. These programs are used to assist clients in connecting with their community, building confidence, teaching new skills, and simply having fun (Vision Australia, 2007).

# 2.5 Vision Australia's Current Feedback System

Vision Australia receives client information through their Client Insights Survey and their outcomes assessment program. These two feedback systems are used to determine the effectiveness of the services offered and to evaluate the organization. However, the Client Insights Survey and the outcomes assessment program do not address the unmet need of clients.

# 2.5.1 Vision Australia Client Insights Survey

Vision Australia's Client Insights Survey allows them to "measure the organisation's performance in relation to client experience of contact with the organization" (Vision Australia, 2005). The organization determined that a telephone-administered survey would "make the survey accessible for the majority of our clients and maximize our response rate" (Vision Australia, 2005). The client population surveyed included anyone who was considered a current client of Vision Australia. A current client was identified as "an individual who is presently receiving a service or ceased receiving a service within the last 3 months from the former businesses of RBS, RVIB or VAF and NILS" (Vision Australia, 2005).

The client survey was designed to reach a "statistically significant number of clients from each of the organisation's 19 services" (Vision Australia, 2005). Because this was the first survey of Vision Australia clients after the merger, the percentage of clients that would be unable to reach was unknown. However, the sample size was determined for a 70 percent response rate. Some services such as the deafblind services did not have many clients participating, so the entire clientele who received these services were contacted. Most services had a large number of clientele, so random samples of clients were contacted using SPSS (statistical software). The client survey was delivered by 19 agents from the Customer Development Team in the Marketing and Design Department of vision Australia between September 19 and October 15, 2005 (Vision Australia, 2005). The Vision Australia Market Research and Development Team held training for these agents to give them information about all the services offered by the organization. Administration as to not "introduce preventable bias" and explaining

the "strength of response rating scale" were also part of the training (Vision Australia, 2005). If a client answered "yes" to a question, the agent learned to prompt them by asking "Would that be agree or strongly agree?" and the same was true for a negative response to any question. The agents had to pass an evaluation before they could call clients and calls were monitored by the Team Leader Customer Development throughout the entire surveying process.

Most of the questions on the client survey were answered using the "5-point strength of agreement" (Strongly agree, agree, neither agree nor disagree, disagree, and strongly disagree) (Vision Australia, 2005). Clients were allowed to pass on any question and a few questions required a yes or no response; there were also two questions about equipment that were open ended. The telephone survey from the 2005 Client Insights Survey Report can be found in Appendix B.

Between September 19 and October 15, 2005, the number of completed surveys was 2,707; these were completed over the telephone except for eight deafblind clients who chose to complete the survey in person and one who chose to complete it through the mail. Language interpreter services were used for 18 or 0.6 percent of the telephone interviews and 82.5 percent of the surveys were conducted directly with the client. There were 425 (15.7 percent) surveys that were conducted with parents or guardians of clients under 18 years of age and 1.8 percent of the surveys were conducted with the guardian of an adult client (Vision Australia, 2005). The overall response rate of the survey was 55.4 percent, which was lower than the target response rate of 70 percent. There were seven services that had a response rate higher than 70 percent (reaching as high as 83.3 percent) and there were ten services that had a lower response rate (Vision Australia, 2005).

#### 2.5.2 Vision Australia's Outcomes Assessment Program

Figure 3 shows Vision Australia's outcomes assessment framework that was designed by the Vision Australia 2007 IQP Team from WPI. When a client is first referred to Vision Australia, a service coordinator conducts a pre-assessment where the client is asked a series of questions. During this discussion, usually conducted

over the telephone, the service coordinator obtains crucial information such as emergency contact names and determines which areas of life the client struggles with. An example of a question asked is, "In the past month has your vision impairment affected your ability to: Use public transport?" The questions can be found in Appendix C.

Once this initial contact is complete, the service coordinator refers the client to a staff member. The staff members may help in orientation and mobility (teaching clients to use public transportation, orienting them to their surroundings, etc.), orthoptics (determining magnifiers and lamps clients should use to help them with light problems), occupational therapy (helping a client use household appliances such as stereos, stoves, remote controls, etc.), and other areas of service.

Staff members contact the client to establish goals for services to increase the client's quality of life. The staff members provide the service by visiting clients at their homes or meeting them at the office. After services are performed, a service coordinator contacts the client again to conduct a post-assessment. The post-assessment determines whether the quality to life goals and task based goals were met. The post-assessment questions are the same as the pre-assessment questions. If the goals determined through the pre-assessment process were not met, these goals must be re-established. The outcomes of post-assessments are analyzed to verify that the organizational goals are met. If they are not met, the problem must be addressed in order to continuously improve the services of the organization.

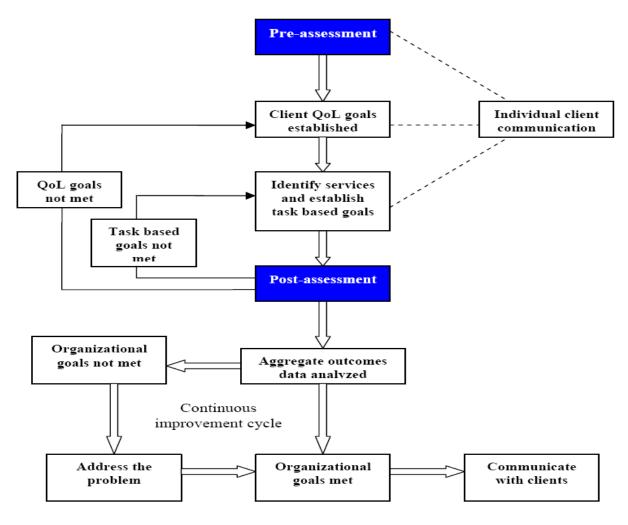


Figure 3: Current Client Service Delivery Model

### 2.6 Literature Review

Literature was reviewed to determine the most appropriate method of obtaining client feedback from individuals with low vision. This information included a literature review performed for Home and Community Care (HACC) services in Australia, several quality of life surveys that are typically used by disabilities organizations, a needs assessment for United Way of Montgomery County, and a study conducted by the Center on Aging at Florida International University.

#### 2.6.1 Literature Review for HACC in Australia

A literature review called "Obtaining consumer feedback from clients of home based care services" by David Cooper and Anne Jenkins was published in January of 1999. The goal of the review was to discuss the advantages and disadvantages of methods of obtaining client feedback in order to determine the best way to collect consumer feedback from clients of Home and Community Care (HACC) services in Australia. David Cooper and Anne Jenkins discussed the best practice models to collect consumer data by analyzing the feasibility of methods based on criteria such as "cost, timeliness, practicality, acceptability to clients, and usefulness to service providers" (Cooper and Jenkins, 1999). Twenty-four Australian consumer surveys from 1996 through 1999 were examined by Cooper and Jenkins to determine which methods were most often used by researchers. In 79 percent of the studies, researchers used self-administered questionnaires, while personal interviews were used in 17 percent of the studies and focus groups and telephone interviews were only used in 13 percent of the studies.

The relationship of the feedback method and the purpose of the feedback were also investigated. The purposes included "consumer satisfaction and opinion of service quality; consumer outcomes; consumer characteristics; need of consumers; consumer expectations and desired service improvements; service experiences and consumer knowledge" (Cooper and Jenkins, 1999). A table comparing the methods used and the purpose of the feedback in each study can be found in Appendix D. The self-administered questionnaires were used by researchers to determine all seven purposes listed above and often the questionnaires collected information on many different topics at once. As Cooper and Jenkins explained, self-administered questionnaires are more cost-effective than most other methods of obtaining client feedback which explains why it is the most common method employed. Each question in a questionnaire can focus on a specific area of interest, which is why they can cover many topics at a time.

Consumer satisfaction was mostly measured by focus groups and telephone interviews because of their personal interaction component. Focus groups are a great place for people to discuss topics and shared experiences,

but "such a forum is less amenable to collecting information on individual consumer characteristics, such as service knowledge, individual need, or expectations about the service" (Cooper and Jenkins, 1999). Telephone interviews are personal but are kept short because interviewees become tired and these interviews are therefore only used for one topic at a time. Personal interviews were not used as frequently because of their high cost.

# 2.6.2 Quality of Life Surveys

Some quality of life surveys include the VisQoL, the LVQOL, the National Eye Institute Visual Functioning Questionnaire (VFQ-25), the LV VFQ-48, the VF-14, and the RBS model for outcomes questionnaire. These surveys measure the quality of life of a respondent who is visually impaired.

The Vision and Quality of Life survey (VisQoL) is a short multiple choice survey. It contains six questions such as "Does my vision make it difficult to cope with the demands in my life?" with answer choices like "My vision: a) has no affect on the ability to cope with the demands in my life, b) does not make it difficult at all to cope with the demands of my life..." (Misajon, 2005). The survey can be found in Appendix E.

Like the VisQoL, the Low Vision Quality of Life Questionnaire (LVQOL) is a short survey, but the questions are answered on a scale of 1-5. The questions are divided into four sections: 1) Distance Vision, Mobility and Lighting, 2) Adjustment, 3) Reading and Fine Work, and 4) Activities of Daily Living. An example of a question on the LVQOL is "Because of your vision, you are unhappy with your situation in life" and the person answers on a scale of 1 to 5, with 5 being "None" and 1 being "Great" (Wolffsohn, 2000). The survey can be found in Appendix F.

The National Eye Institute's Visual Functioning Questionnaire (VFQ-25) is much longer than the VisQoL and the LVQOL. It is a 25 question telephone survey with multiple choice answers. Questions such as "How much difficulty do you have reading street signs or the names of stores?" are answered with choices "1) No difficulty at all, 2) A little difficulty, 3) Moderate difficulty, 4) Extreme difficulty, 5) Stopped doing this because of your

eyesight, 6) Stopped doing this for other reasons or not interested in doing this" (National Eye Institute, 1996/2000). The survey can be found in Appendix G.

The Low Vision Visual Functioning Questionnare-48 (LV VFQ-48) and the Visual Function survey (VF-14) are simple questionnaires that have 48 and 14 question items, respectively. The questions on both questionnaires begin with the phrase "Is it difficult to..." and end with an item on the list, such as "1. physically get dressed" (Stelmack, 2004). The VF-14 is answered on a scale of 0-4 for each question with 0 being no difficulty performing task and 4 being unable to perform task (Stelmack, 2001). The LV VFQ-48 can be found in Appendix H and the VF-14 can be found in Appendix I.

Unlike any of other above mentioned questionnaires, the Royal Blind Society model for outcomes questionnaire is an open ended list that follows Vision Australia's Life Themes. The adult questionnaire has 12 questions and the child version has 8. An example question is "Please consider how your vision impairment affects the different areas of your day to day life. These areas are listed below. 1. Independence in the Community: (eg. shopping; banking; identifying money; using public transport; crossing roads; negotiating stairs, gutter; etc). Please list below any activities in the community that you are wanting to do but are unable to manage because of your vision impairment" (Royal Blind Society, 2002). The RBS model for outcomes questionnaire is closely related to finding the unmet need of individual clients. Both the adult and child questionnaires can be found in Appendix J.

### 2.6.3 United Way of Montgomery County Needs Assessment

Non-profit organizations often create needs assessment programs in order to identify gaps in their current coverage (Renz, 1999). One such need assessment of persons with disabilities performed by the University of Houston for the United Way of Montgomery County was completed to determine which needs were unmet in their county and why (Amy M. Blakeney C. S., 2002). The group created a survey of the population with disabilities in their area and also conducted three focus groups with members of the population or their direct caregivers.

The team recruited residents with disabilities by using advertisements including "newspaper articles, flyers, and outreach by area agencies that provide services to the target population" (Amy M. Blakeney C. S., 2002). Although the original sample size was supposed to be approximately 250 persons, the group was only able to achieve a sample size of 152 residents. This occurred because "several agencies declined to participate because of other commitments or staffing issues" (Amy M. Blakeney C. S., 2002). With this survey data, they were able to determine the core demographics of their target population, including gender, age and disability type. Their survey also contained a qualitative section which used a skip pattern format, "Respondents [were] presented with a service and asked if they have needed it in the past. If the answer was 'no,' they 'skipped' to the next service category's questions. Those who needed a service were asked if they were able to obtain the service with three responses possible: 'yes', 'no' and 'yes, but...' 'Yes, but...' responses were defined as 'yes, I was able to access the service, but there were problems'" (Amy M. Blakeney C. S., 2002). The team then used a computer program, "Statistical Package for Social Sciences," to analyze their quantitative survey data. This analysis provided graphs and charts that were useful for communicating their findings quickly and effectively.

The team used three focus group sessions to "understand the unique experiences of caregivers and/or persons with disabilities in accessing services" (Amy M. Blakeney C. S., 2002). These groups were often conducted with caregivers rather than with the persons with disabilities. The groups were arranged by their respective service providers and prior to the start of the meeting "the facilitator explained the importance of confidentiality and that participation was voluntary" (Amy M. Blakeney C. S., 2002), and each participant was asked to sign a consent form.

### 2.6.4 The Center on Aging, Florida International University Study

Another study performed by The Center on Aging Florida International University in 2004 suggests similar methods for acquiring information about unmet need (The Center on Aging Florida International University, 2004). This study was geared toward the elderly population in six zip codes in Florida. It was designed to estimate

service need to create a plan for improved service delivery. The team utilized several methods of data collection to ensure adequate use of both qualitative and quantitative data. A majority of their data "consisted of 2000 Census measures used as social indicators, as well as State DoEA - compiled service and client profile data (CIRTS), was conducted to establish basic estimates of need" (The Center on Aging Florida International University, 2004).

The team also created a survey of the service providers and performed interviews with several people who were directly responsible for the care. These included clergy, hospital discharge planners, independent elders, and direct caregivers (The Center on Aging Florida International University, 2004). In order to effectively analyze the focus group data, the team divided the types of services into several categories.

The primary problem with this study involves the distinct lack of interest among the target population. Although hundreds of organizations and elders were contacted, the response rate was low, forcing the team to make generalizations based on the few surveys they received and their known census data.

# **Chapter 3: Methodology**

The goal of this project was to design a feedback system to evaluate client unmet need for Vision Australia. The feedback mechanisms of service organizations were assessed and interviews and focus groups with current clients were performed. Using data from these methods, the current client unmet need was determined and a continuous feedback system for Vision Australia was designed. This goal was met by realizing the following objectives:

- 1. Determine the unmet need of the Vision Australia clients
- 2. Design a continuous system for acquiring client comments

The above objectives were achieved using the following techniques:

- The team performed personal and telephone interviews with nine clients and conducted eight focus groups of about eight people each.
- A review of the literature was performed regarding past feedback method research, quality of life surveys, and Vision Australia's Client Insights Survey and outcomes assessment program.
- The team analyzed client feedback mechanisms of service organizations to determine if their methods could be applied to Vision Australia.
- The information gathered from conducting the focus groups and interviews was examined to determine how effective these methods were as feedback systems.

Figure 4 illustrates the flow of the team's objectives and methods. The approximate timeline describing the time employed to attain these objectives can be found in Appendix K.

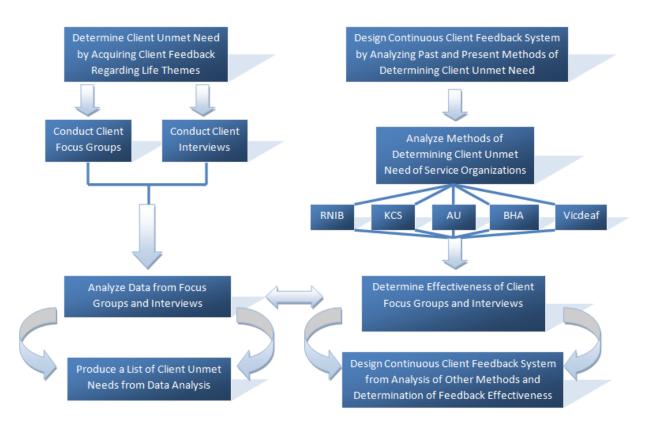


Figure 4: Methodology Flowchart

Figure 4 illustrates the methods used to determine Vision Australia's unmet need and to design a continuous feedback system. There were two routes taken to accomplish these objectives. The first was collecting client data through focus groups and interviews. This information was analyzed to produce a list of client unmet need. The second route was analyzing feedback methods used by service organizations. The organizations contacted were the Royal National Institute of Blind People in the United Kingdom, the Kirinari Community Services Inc. in Australia, Abilities Unlimited in America, Better Hearing Australia (Vic), and the Victorian Deaf Society (Vicdeaf). The data collected through focus groups and interviews were analyzed for effectiveness. The effectiveness examination, literature review, and the feedback mechanisms from service organizations were used to design a system for Vision Australia to continuously determine unmet need of their clients.

## 3.1 Determine Unmet Need

Vision Australia has eight life themes, which were explained in 2.3 Vision Australia Life Themes and Service Modules. Focus groups and interviews were performed to determine unmet need and categorize the need into the eight life themes. Questions were formulated regarding the most important life themes and the unmet needs after Vision Australia's services. Once data were collected, the client responses were analyzed to determine which of the life themes were not being adequately addressed by Vision Australia.

To maintain the integrity of the process, interviewees were informed of the interview or focus group purpose; clients were required to agree to the informed consent document and their anonymity was maintained. The informed consent document as well as the interview and focus group questions can be found in Appendix L. Because of the clients' visual impairments, special concerns were taken into consideration when collecting data.

#### 3.1.1 Interviews

Telephone interviews were conducted with three clients and personal interviews were conducted with six clients. Interviews allowed the questioner to connect with the client, enabling them to understand the client's reasoning and ask further questions to elaborate. Telephone interviews allowed the team to gather information from clients throughout Vision Australia's service area and not restrict them to the population of the Melbourne area. Personal interviews were performed during staff visits to client homes. During these visits, the team also observed the services provided. Observing clients in their daily activities enabled the team to identify their trouble areas without the clients' direct input.

During the interviews, the clients were asked to explain frustrations they have had within the past few weeks due to their vision loss. If they were unable to express any frustrations, additional need questions such as "Have you had trouble with public transportation or seeing signs in the community recently?" were asked. The interview plans and questions can be found in Appendix L.

### 3.1.2 Focus Groups

When the team arrived at the Boronia office of Vision Australia, there were established self-help/support groups and day programs. These allowed people to interact with each other through discussions and activities. The self-help/support groups met once or twice a month and the day programs met once a week. The team contacted the leaders of each self-help/support group to determine days and times to attend their meetings. The day programs were led by members of the Boronia Vision Australia team and their activities included cooking, reading, aquatics, short outings, etc. These open forums allowed for qualitative data to be collected at once from several clients. The focus groups occurred at the following times:

- March 26, 11:00-11:30: Bayswater Day program
- March 28, 1:30-2:00: Boronia Self Help Group
- April 2, 12:30-1:00: Oakleigh Support Group
- April 4, 10:00-10:30: Mount Waverley Day Program
- April 7, 10:15-10:45: Mount Waverley Self Help Group
- April 9, 1:15-2:00: Bayswater Day Program
- April 14, 10:30-11:00: Ringwood Self Help Group
- April 16, 1:30-2:00 Student Group

The focus groups were conducted in a similar way to the client interviews. Each member was encouraged to introduce and briefly describe themselves. The group was asked about frustrations they have had in the past few weeks due to their vision impairments. These questions can be found in Appendix L. Although focus groups were more difficult to control than interviews, they allowed the team to observe trends that occurred within the group. For example, if one participant mentioned an idea that the others agreed with, the team noticed the visual clues that accompanied such an agreement. When ideas were brought up that excited the group or bored them, these clues were noted and included in the analysis. Although this information could not be quantified (Riessman, 1994), it was still useful for determining unmet need.

## 3.1.3 Analyze Client Data

The client descriptions of recent frustrations were separated and analyzed using the life themes. The most important and unmet life themes were identified. Ideas that were discussed in focus groups were addressed in subsequent groups to determine if the majority of the clientele agreed.

The importance of the life themes was determined by counting the frequency that each life theme was discussed during informal conversation. For example, if a client mentioned going on holiday, the team added a mark to the recreation count. However, if the same client brought up that topic later, the team did not add another mark. The life themes that received the most responses were broken down into specific topics that were important to the clients.

When clients explained frustrations that were not addressed by Vision Australia, answers were repeated and were related to their most important life themes. These experiences were categorized into life themes and the frequency during discussion was documented.

Clients were asked their contact preference (telephone, email, written, etc.) if Vision Australia were to conduct an unmet need survey. The client responses were recorded and the frequency of each response was documented.

## 3.2 Design Continuous Feedback System

In order to present Vision Australia with the most efficient system to determine client unmet need, organizations for people with disabilities were contacted regarding their feedback systems. These organizations included the Royal National Institute of Blind People in the United Kingdom, Kirinari Community Services Ltd. in Australia, Abilities Unlimited in the United States of America, Better Hearing Australia (Vic), and the Victorian Deaf Society. Graeme Kelly from the Victorian Deaf Society was interviewed in person (questions found in Appendix M with summary in Appendix N), while the other organizations were interviewed via email.

The interviews and focus groups conducted by the team were also evaluated to determine the methods that produced the most informative data regarding client unmet need. The team formulated recommendations concerning these techniques.

A literature review was performed to analyze quality of life surveys, Vision Australia's Client Insights Survey and outcomes assessment program, as well as other documentation of feedback methods and their applications. Several quality of life surveys were examined for questionnaire length, question and answer type, and complexity of questions. Vision Australia's annual Client Insights Survey and outcomes assessment program were inspected to learn about the current method of feedback chosen by the organization; the survey was compared to the length, question and answer type, and complexity of the surveys used by other service organizations.

A feedback system for Vision Australia to determine client unmet need was designed. The design included conducting focus groups, an unmet need survey, and client interviews after the post-assessment.

# **Chapter 4: Results & Analysis**

The objectives of this project were to determine Vision Australia's client unmet need and to design a feedback system to continuously determine client unmet need. As the methodology in Chapter 3 states, the unmet need was determined by conducting client interviews and focus groups. The continuous feedback system was designed by performing a literature review of feedback systems, by analyzing methods used by service organizations, and by evaluating the effectiveness of the interviews and focus groups conducted. The data resulting from these actions are shown in this section.

## 4.1 Results of Determining Client Unmet Need

The majority of the data collected to determine unmet need came from the focus groups. Client responses were classified under the life themes and these data were compiled to find the most important and improperly addressed life themes. See Appendices O and P for focus group and interview summaries, respectively.

## 4.1.1 Importance of Life Themes

As described in section 3.1.3 Analyze Client Data, the life themes were rated in importance by the clients. Figure 5 illustrates the relative importance of the eight life themes.

# Frequency of Life Theme Topics During Focus Groups and Interviews

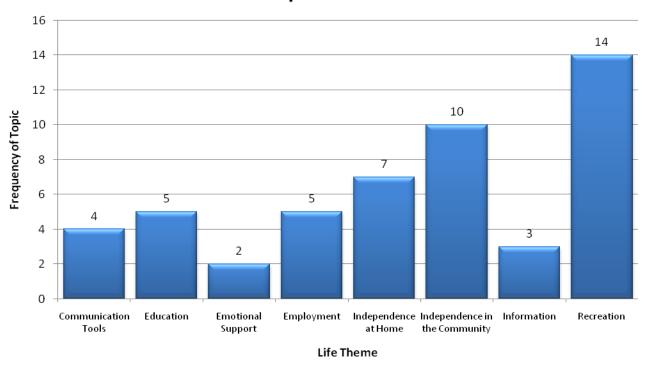


Figure 5: Frequency of Life Theme Topics During Focus Groups and Interviews

The elderly clients rated the themes of recreation, independence in the community, and independence at home high in importance. Most of them discussed recreational activities that kept them busy and their concerns included living independently and traveling in their houses and in the community.

The younger clients, aged 20-40, also rated recreation as highly important, but independence was not as important to them. These clients were either born blind or lost their vision at an early age and therefore have been living with blindness forever. They had little difficulty with independence in the home or in the community. Their worries included recreation, education and employment.

Figure 6 illustrates the specific topics discussed within the most important life themes.

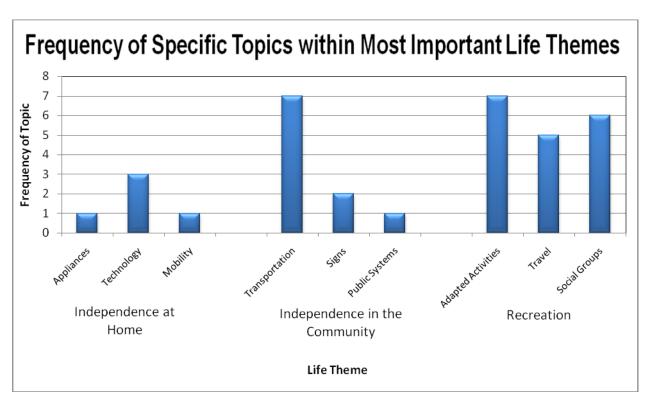


Figure 6: Frequency of Specific Topics within Most Important Life Themes

As was mentioned above, the only life theme that was important to both younger and elderly clients was recreation. Elderly clients who recently lost their sight missed activities that they can no longer do. They wanted the activities to either be adapted so they could continue them or replaced with another activity. Those responses were classified as adapted activities in Figure 6. Many of these clients were also interested in travel. Both young and elderly clients enjoyed their social groups. The elderly clients felt that their day programs and support groups were the best tool to help them cope with their vision loss, whereas the younger clients felt that sports and other active groups were important to them.

The other two life themes pictured in Figure 6 regarding independence only applied to the elderly clients. Transportation was a concern among most of the clients the team spoke with. They expressed concerns about crossing roads and using trains, trams, and buses. Many people also mentioned trouble with taxis. Their concerns

came from the inexperience of transporting without using vision. Independence in the home was also an important issue for people who recently lost their vision.

## 4.1.2 Unmet Need

Figure 7 illustrates the frequency of unmet need when clients responded to questions regarding frustrations. The frustrations discussed were categorized into the life themes as mentioned in section 3.1.3 Analyze Client Data.

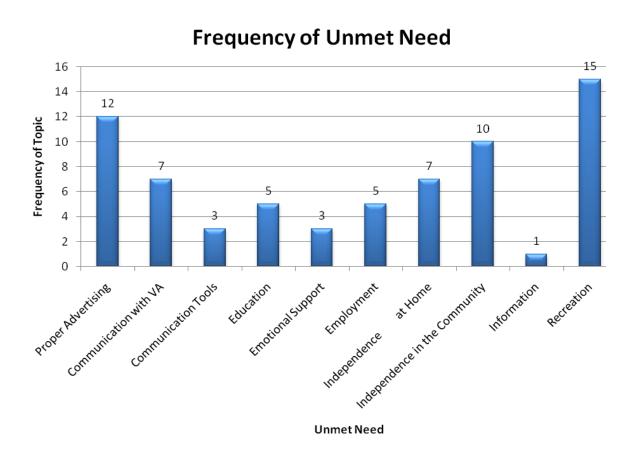


Figure 7: Frequency of Unmet Need

## **Proper Advertising**

Proper advertising does not fall under a life theme, but it is still a very important need among new clients. New clients explained their difficulty in finding Vision Australia. Many of them felt lost for months before a friend or family member heard about Vision Australia. Many ophthalmologists do not tell their patients about the

organization. However, people who have been clients since before the merger did not have this problem so in the past four years, advertising must have decreased.

#### **Communication with Vision Australia**

Clients have explained that since the merger, personal communication with the service coordinators has decreased. According to the clients, service coordinators called each client every three months to see how they were doing. It was always the same service coordinator so the relationship was personal. This has not been happening in the last three to four years. When they do get called, it is not always the same coordinator and sometimes they are located in a different state. If the clients call Vision Australia, they have trouble locating the person they want to speak with. Clients are worried that the organization has become a corporation and is preoccupied with money.

The clients are also worried that very few new members are joining Vision Australia. If this is true, it is consistent with the data received regarding the lack of advertising since the merger. In all, personalized service has decreased and should be addressed by Vision Australia.

## Recreation

Recreation was the most common unmet need among clients of all ages. Elderly clients felt that Vision Australia does a poor job of introducing new activities to replace ones that clients can no longer do. Many of them had hobbies, such as sewing and making dolls, which they enjoyed before they lost their sight. Vision Australia has done nothing to help them replace these activities. Some people said that Vision Australia used to have these activities, however, nobody knew what happened to them or if they still existed.

Clients explained that a holiday program used to exist that allowed clients to travel around the world with assistance. Clients expressed interest in continuing these trips if they were provided.

The team received complaints from younger clients that Vision Australia's recreational activities are geared toward the elderly crowd. None of the younger clients were interested in activities such as bird watching and carpet bowling. Some suggestions for activities they would be interested in included self-defense classes, club dancing, or horseback riding.

## **Independence in the Community**

Though it does get easier with practice, transportation is a great unmet need and needs to be addressed by Vision Australia. Some topics discussed were difficulties with public transportation including trains, trams, and buses. Drivers do not always announce stops sometimes they skip stops all together. The stop button is in a different place in every tram. Signs are too difficult to read or are posted too high. These are issues that clients realize are not Vision Australia's direct responsibility, but they do believe Vision Australia could do a better job of working with the government to make public transportation more consistent and easier for everyone to use.

## **Independence at Home**

Independence at home is an unmet need among elderly clients, but was not an issue with younger clients. Many elderly clients explained that their appliances were difficult to use. Vision Australia does provide services that teach clients to use their appliances; however, some clients were not satisfied with this. Many of them wished appliances could be built with bigger or better colored buttons so they could get the full use out of them. With the existing in-home training, clients are only taught the essentials to live, where appliances with bigger buttons would allow them to have full independence in the home.

## **Education and Employment**

As mentioned earlier, younger clients were concerned with recreation, education, and employment. The agreement among the young clients was that the education services were extremely weak and not very helpful.

There are very few study skills programs and they are scattered around the country. Students with low vision around the country receive different levels of assistance due to the unavailability of teaching services.

Employment was a larger problem since according to the clients, the employment service is almost impossible to use. Registering for the employment service was a grueling process. The clients had to go through Centerlink which was a very difficult agency to deal with. The clients suggested that Vision Australia talk to Centerlink to make the process more accommodating for people with low vision. One client said they should relax the rules for part-time work seekers.

## 4.1.3 Client Suggestions for Obtaining Feedback

Figure 8 illustrates the feedback methods preferred by clients.

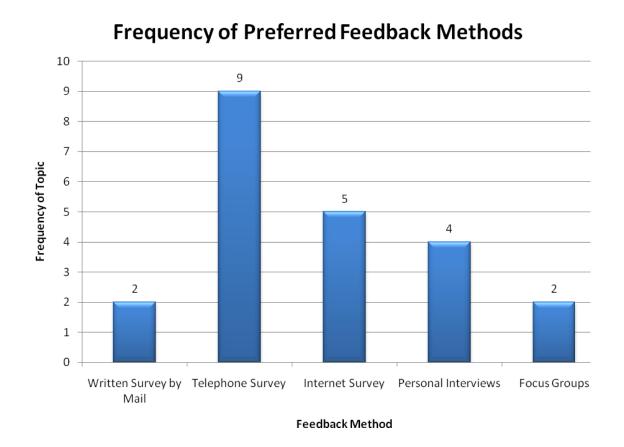


Figure 8: Frequency of Preferred Feedback Methods

The results to questions regarding preferred contact methods were split by age. Elderly clients preferred to be contacted by phone and by mail whereas younger clients preferred to be contacted by email.

An overwhelming majority of the elderly clients preferred contact by telephone. They unanimously agreed that speaking to a person is the best way to communicate their unmet need. Some made suggestions that Vision Australia should call their clients at a set time on a regular basis. For example, a new client should be called every week or two until they are comfortable with their situation. After that the calls can become less regular as the clients adjust. Another suggestion was that Vision Australia should communicate with clients ahead of time so clients can be ready at the phone with ideas at the preset time. Some clients with better vision suggested that a written survey would be acceptable, but they acknowledged that the method for communication would have to be different for each client.

Younger clients, however, did not feel this way. Contact by telephone put them on the spot and they were not comfortable with it. If they were given the questions in advance so they could think about their answers, contact by telephone would be more acceptable. Younger clients agreed that email was the best way to contact them and they would be most likely to respond to an email questionaire.

## 4.2 Feedback System Design

In addition to determining the current unmet need among Vision Australia's clients, Vision Australia needed a feedback mechanism to continuously ascertain the unmet need of clients. Feedback mechanisms of several organizations, quality of life surveys, and Vision Australia's current client feedback system were examined and the interviews and focus groups conducted were evaluated in order to determine the most appropriate feedback system for Vision Australia to employ.

# 4.2.1 Feedback Mechanisms of Service Organizations

Feedback mechanisms of other service-based organizations were examined. These organizations were not necessarily disability-related, but were dedicated to providing services to fulfill the needs of their clients. These

organizations included the Victorian Deaf Society, Kirinari Community Services in Australia, Abilities Unlimited in America, Better Hearing Australia (Vic), and the Royal National Institute for the Blind in the United Kingdom.

## **The Victorian Deaf Society**

On March 27, 2008 the team interviewed Graeme Kelly, a project manager at the Victorian Deaf Society (Vicdeaf) regarding their client feedback mechanisms. Vicdeaf has a project called "The Demand Management Project," which has been outsourced to other companies to determine the changing client need. The survey used for this is called the "Client Satisfaction Survey" and can be found in Appendix Q. This survey is used to gain a better understanding of the client demographics, the recommendations of younger deaf people, and changes in technology for the deaf.

Vicdeaf utilizes a survey that is short and simple because the return rate is significantly higher if the survey is easy to fill out and doesn't take much time. This allows Vicdeaf to receive more information about the trends in the deaf population.

In addition to the Demand Management Project, Vicdeaf works with detailed demographic data from census reports. The 2006 census provided Vicdeaf with information regarding the age, location, education, income, occupation and ethnic background of deaf people in Australia.

## Kirinari Community Services Inc.

Kirinari Community Services Inc. has a survey consisting of about 60 questions (about 50 closed ended and 10 open ended) used to assess the residents' quality of living, safety, health, opinions of the community and their hopes for improvement. This survey is long and is performed in the presence of a staff member. It used some interesting techniques, for example some questions are asked twice in separate places ("Do you go out to eat?"), and the interviewer phrases the question in exactly the same way to see if the answers are consistent. The survey can be found in Appendix R.

## **Better Hearing Australia**

Better Hearing Australia uses a written client survey. The survey (Appendix S) was extremely brief, consisting of only 10 questions total, 9 closed response and one open response. This survey tells the client that positive and negative feedback are welcome.

#### **Abilities Unlimited**

Abilities Unlimited utilizes an indirect survey, where the parents and family of the client are surveyed. This gives the team insight into how younger school age clients can be surveyed, as well as clients that are difficult to communicate with. The survey consists of 5 simple, direct, open ended questions. Abilities Unlimited's family support plan and needs assessment can be found in Appendix T.

#### The Royal National Institute for the Blind

The Royal National Institute for the Blind (RNIB) in the United Kingdom uses a survey to determine the financial needs of their clients. The survey has eight yes or no questions and addresses a large number of clients in all age groups. The response rate of this survey is high. RNIB's Network 1000 Survey Report can be found in Appendix U.

## **Comparison of Feedback Mechanisms**

Each organization utilizes different techniques in to get their desired quality of information, response rate, and sample size. Vision Australia and Vicdeaf utilize short and simple surveys, so they are quick and easy to fill out. Faster, simpler surveys have increased response rates due to the decrease in effort and time commitment on the part of the client. More involved surveys, like Kirinari's, are usually done in the presence of an employee or caregiver. This ensures that the response rate is high and that the client understands all the questions. However, this survey takes longer and is a financial commitment because of its administration.

Better Hearing Australia's survey is simple. The survey gathers the required information using ten questions, minimizing the time commitment of the client. RNIB follows a similar system, except it contains yes or no questions. This is more simplistic, but offers no opportunity for the client to give creative feedback. Abilities Unlimited seems to combine the philosophies of RNIB and Kirinari by using a short survey like RNIB, but using open ended questions like Kirinari. This allows for a large number of creative responses, but answers may lack focus due to the client's interpretation of the questions. The amount of usable data may be decreased.

**Table 1: Comparison of Surveys** 

Survey/ Questionnaire	Question/ Answer Type	Number of Questions	Complexity of Questions	Response Rate (if applicable)
Vicdeaf's	Multiple choice/ Yes or No/ Open ended/ Scale 1- 5	24	Simple	Low (10 or 15%)
Kirinari Community's	Multiple choice/ Yes or No/ Open ended	61	Some simple/ Some complex	N/A
Better Hearing Australia	Multiple choice/ Yes or No/ Open ended/ Scale 1- 5	10	Simple	N/A
RNIB	Yes or No	8	Simple	High
Abilities Unlimited	Open Ended	5	Simple	N/A

## 4.2.2 Quality of Life Surveys

Most of the quality of life surveys asked simple questions that would not confuse respondents. The number of questions varied greatly, ranging from 6 questions in the VisQoL to 48 questions in the LV VFQ-48. Although the LV VFQ-48 was the longest, it was also the simplest questionnaire along with the VF-14. Both questionnaires begin with the phrase "Is it difficult to…" and the end with the items in the list, such as "1. physically get dressed" (Stelmack, 2004). The most common question and answer type was a scale, but some surveys were multiple choice, yes or no, or open ended. Table 2 compares the question and answer types, number of questions, and complexity of questions for the quality of life surveys that were examined.

**Table 2: Comparison of Question Types** 

Survey/ Questionnaire	Question/ Answer Type	Number of Questions	Complexity of Questions
VisQoL	Multiple choice	6	Very simple
LVQOL	Scale 1-5	25	Very simple
VFQ-25	Scale 1-5 or 6	25	Moderate
LV VFQ-48	Yes or No	48	Very simple
VF-14	Scale 0-4	14	Very simple
RBS model	Open ended list	Adult: 12	Complex
		Child: 8	

## 4.2.3 Effectiveness of Interviews and Focus groups

Focus groups provided a broad outline of client unmet need, while interviews provided individual client unmet need. The team determined that these methods of receiving feedback were valid for determining unmet need. The information was received in a time efficient manner. All feedback was useful and provided the team with data regarding unmet need.

## 4.2.4 Feedback System

Figure 9 shows the resulting client feedback mechanism for Vision Australia. The feedback system is shown in red within the outcomes assessment framework designed by the 2007 Vision Australia IQP Team from

Worcester Polytechnic Institute. The system includes focus groups, client survey(s), and personal interviews during the post-assessment stage of the outcomes assessment program.

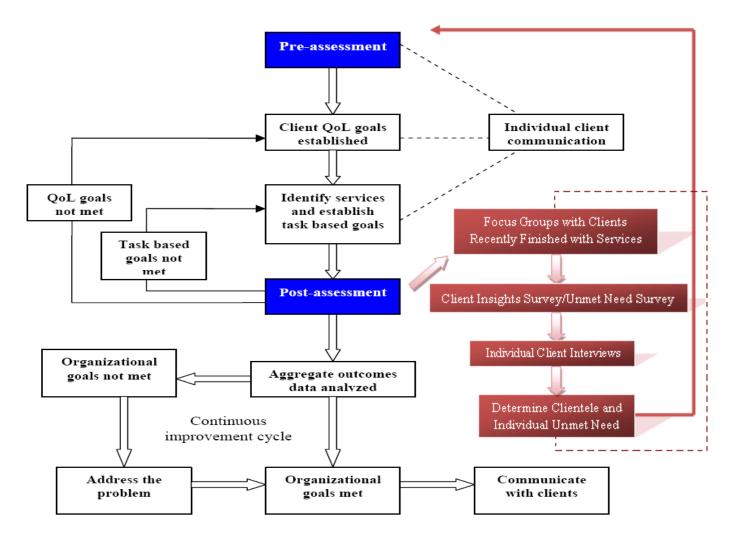


Figure 9: Proposed Feedback Mechanism

## **Focus Groups with Clients Recently Finished with Services**

Once a client has received a service, Vision Australia service coordinators contact them in order to ensure that the service was effective. At this time the organization should also recruit clients into focus groups to discuss unmet needs. The clients could have finished receiving services months or days before they are recruited. These focus groups should be conducted with approximately 8-10 people of varying ages. Each service coordinator should attempt to do one focus group per year, but more frequent meetings may be required if little information is gathered. The service coordinators should use the questions in Appendix L, but these questions are not a strict list. They are discussion points that do not need to be asked if a client has already answered them or if the questions do not apply.

## **Client Insights Survey/Unmet Need Survey**

An unmet need survey should be administered after focus groups so clients have had the opportunity to hear the needs and frustrations of others. This is conducive to the survey since people build from others' ideas constantly. Vision Australia should implement the unmet needs survey in one of two ways—1) unmet need questions should be added to the Client Insights Survey or 2) a separate unmet need survey should be conducted. Either way, this survey should be implemented annually without fail. Vision Australia should continue a telephone survey for the older generation. An email survey could take the place of the telephone survey for younger clients because they are familiar with the technology and preferred this method of contact. Different methods of internet surveys were discussed with Damien McCormick, an adaptive technology consultant, which can be seen in Appendix V. He explained that the best method of surveying the clients on the internet is emailing them because the screen readers used by people with low vision cannot interpret the HTML coding involved in a survey system such as surveymonkey.com.

In agreement with the 2005 Client Insights Survey Report, some questions should be eliminated from the survey. Questions to eliminate include those regarding use of the computer and internet and the internet connection

type because these questions do not help determine the overall satisfaction of the client. Some questions should be combined, such as "Staff are knowledgeable and skilled about Blindness" and "Staff are knowledgeable and skilled about Vision Impairment." The questions "Staff are helpful" and "Staff were good at problem solving to meet my needs" should also be combined.

The unmet need survey should consist of the following questions. The questions should be answered on a scale of 1 to 10, one being no need and ten being the most need.

## After your services from Vision Australia, do you still need help with:

- 1. Communication such as Braille or audio?
- 2. Reading bills, personal mail, and shopping lists, watching TV, operating appliances, or personal care?
- 3. Using public transportation, crossing roads, and banking?
- 4. Relationships and emotional support?
- 5. Crafts, sports, or other recreational activities?
- 6. Education?
- 7. Employment?
- 8. Information about your visual impairment?

To conduct the survey, Vision Australia should outsource to a third party. If this is not possible, service coordinators should call clients about unmet need and agents from the Marketing and Design Department should continue to handle the Client Insights Survey.

Due to receiving unmet need that Vision Australia has services for, clients should be surveyed only after finishing services. It would be unhelpful to determine unmet need from clients in the middle of their services since they may have problems that Vision Australia could solve with another service.

#### **Individual Client Interviews**

One-on-one client interviews should be performed with clients from all age groups at least once a year. The interviews should be conducted after the focus groups and survey, so clients can think of their individual unmet need in advance. Enough of these interviews must be conducted to produce a "saturation" of information, where the interviewer begins to receive the same ideas repeatedly. For a client base the size of Vision Australia's, this should be approximately 80 personal client interviews. These interviews should be performed by a third party, preferably someone who is not affiliated in any way with Vision Australia. The use of a third party will eliminate biased responses.

## **Determine Clientele and Individual Unmet Need**

The data collected should be analyzed to determine client unmet need. Two main types of unmet needs will arise—general and individual. General needs will arise from the focus groups and the survey. Individual needs can be found using client interviews.

General unmet needs should be addressed at the organizational level. For example, one general unmet need found in this study was Vision Australia's lack of publicity. This general unmet need should be submitted to the appropriate department and addressed at the corporate level. The individual needs should be addressed by the service coordinator and new service goals should be produced in accordance with outcomes assessment program.

# **Chapter 5: Conclusions and Recommendations**

This project identified Vision Australia's client unmet need and developed a continuous system to acquire client unmet need. Recommendations regarding the unmet need and feedback mechanism were established.

The most common areas of unmet need described by clients and categorized into the life themes by the WPI team were recreation, proper advertising, independence in the community, and independence at home. Although proper advertising is not a life theme, many clients—especially those joining Vision Australia since the merger—described their difficulties in finding the organization immediately following their low vision diagnosis.

The feedback system was developed to allow Vision Australia to continuously determine unmet need such as those discovered above. The feedback mechanism includes conducting focus groups with clients who have recently finished receiving their services, performing the unmet needs survey alone or as part of the client insights survey, interviewing clients, and determining the clientele and individual unmet need. Using this feedback system, Vision Australia can transition from a service-oriented organization to a client-centric organization by determining unique client unmet need.

The following recommendations appear in the order they should be implemented by Vision Australia, with the recommendations that would meet the needs of more clients first.

#### Recommendations

- 1. Vision Australia should increase publicity through television, newspaper, and radio advertisements as well as posting signs and leaving brochures at doctors' offices.
  - Many clients explained their difficulties in discovering Vision Australia immediately after their diagnosis. By increasing advertising, VA would reach more possible clients and have a greater impact in society.
- 2. Increase communication between the Vision Australia offices.
  - Some VA offices offer services that other offices don't know about. The staff at every office should be knowledgeable of the services offered by the organization even if they are not offered by their office. A more detailed newsletter could be the solution.
- 3. Clients should be telephoned regularly and updated with new services and recreational activities through the client newsletter.
  - The WPI team found some unmet need that could be solved through already existing services. The clients need to be updated with new services and activities whenever they change.
  - Some people are on waitlists and haven't heard from the organization in over a year. Even if clients are on the waitlist, VA should contact them to let them know they haven't been forgotten.
- 4. The selection of books on tape and in Braille in the library needs to be improved.
  - Many clients agree that the selection of books in the library is lacking. The clients requested that newer books be added to the selection; the current books are too old.
- 5. Holidays, both domestic and abroad, should be reinstituted by Vision Australia and more recreational activities for younger clients should be offered.
  - Clients explained that Vision Australia previously offered holidays. They want to continue participating in these events because traveling alone is difficult.
  - Younger clients discussed that the recreational activities offered are geared toward the older generation. They would like to participate in club dancing, self-defense classes, horseback riding, etc.
- 6. Vision Australia should increase the available transportation for clients to get to and from the offices.
  - VA should use volunteer drivers because the clients have difficulty getting to the office. This prevents some clients from accessing services.

Although the WPI project team successfully identified client unmet need and designed a feedback system, they were unable to pursue some ideas discovered throughout the project, such as the following.

#### **Future Work**

- 1. The WPI team did not have adequate time to further test the feedback mechanism designed. Vision Australia should conduct an in-depth test run of the entire system.
- 2. The team had the idea to create a system similar to the Video Relay Interpreting used by the Victorian Deaf Society. Many of Vision Australia's clients have trouble reading their mail or other documents. If a camera was set up in their houses and connected to Vision Australia's computer system, mail and other papers could be read to clients. A project should be conducted in the future to determine the cost effectiveness of introducing a system for this type of remote reading.
- 3. Through speaking with Dennis Hogan at the Building Commission in Melbourne, the team became aware of another possible project. Vision Australia can affect building and public transportation codes. A project should be performed that brings low vision problems with the community to the Building Commission, the Australian Building Codes Board, the Department of Infrastructure, and the Department of Planning and Community Development to increase accessibility for people with visual impairments.

By implementing these recommendations, Vision Australia can successfully transition from a service-based organization to a client-centric needs-based organization.

#### **Works Cited**

Aaltonen, E. (1999). Client-oriented Quality Assessment within Municipal Social Services. *International Journal of Social Welfare*, 131-142.

Abilities Unlimited. (2007). Abilities Unlimited Family Support Plan and Needs Assessment.

Access Economics Pty Limited. (2004). Eye Research Australia. Clear Insight.

Amy M. Blakeney, C. S. (2002). A COMPREHENSIVE NEED ASSESSMENT FOR PERSONS WITH DISABILITIES IN MONTGOMERY COUNTY. Montgomery County, Texas.

Attebo K, M. P. (1996). Visual acuity and the causes of visual loss in Australia. The Blue Mountains Eye Study. *Ophthalmology*, 357-364.

Australian Bureau of Statistics. (2008, January). *Australian Bureau of Statistics*. Retrieved February 24, 2008, from Labour Force, Australia:

http://www.abs.gov.au/Ausstats/abs@.nsf/39433889d406eeb9ca2570610019e9a5/362607ca0519045aca25712b000d0425!OpenDocument

Australian Bureau of Statistics. (2004). Labour Force, Australia. Melbourne: ABS.

Camp, R. C. (1989). Benchmarking: The Search for Industry Best Practices That Lead to Superior Performance. Milwaukee: Quality Press.

CNN. (1999, August 3). Blind hope employers can see through misconceptions. Retrieved January 20, 2008, from CNN: cnn.com

Cooper D, & Jenkins A 1999. Home and Community Care Service Standards Client Appraisal Data Development Project: Literature Review. Canberra: AIHW

Database Systems Corps. (2008, January). *Phone Surveys Using IVR Technology*. Retrieved Feb. 2008, from Call Center Technology: http://www.databasesystemscorp.com/pssurvey.htm

Dougherty, C., Medeiros, A., & Nelson, S. (2007). *Client Outcomes Assessments and Service Model Implementation for Vision Australia*. Worcester Polytechnic Institute.

Douglas, J., Rasmussen, P., & Flanagan, C. (1977). The nude beach. Beverly Hills, CA: Sage.

Fontana, A., & Frey, J. H. (2005). The Interview: From Neutral Stance to Political Involvement. In N. Denzin, & Y. Lincoln, *The Sage Handbook of Qualitative Research* (pp. 695-727). CA: Sage Publications.

Groves, R. M., & Kahn, R. L. (1979). Surveys By Telephone: A National Comparison with Personal Interviews. New York, NY: Academic Press.

Holstein, J., & Gubrium, J. (1995). The Active Interview. Thousand Oaks, CA: Sage Publications.

Ivers, C. A. (1998). Visual impairment and falls in older adults: The Blue Mountains Eye Study. *Journal of American Geriatric Society*, 58-64.

Kearns, D. T. (1986). Quality Improvement Begins at the Top. World 20, 21.

Kirinari Community Services. (2008). KCSL Resident Survey 2008.

Klein R, K. B. (1995). Age-related eye disease and survival. Arch Ophthalmol, 333-339.

Krueger, R. A. (1994). Focus Groups: A Practical Guide for Applied Research. CA: Sage Publications.

Misajon, RoseAnne, Graeme Hawthorne, Jeff Richardson, Jodi Barton, Stuart Peacock, Angelo Iezzi, and Jill Keeffe. (2005). "Vision and Quality of Life: The Development of a Utility Measure". *Ophthalmology & Visual Science* **46(11):** 4007-4015.

Mischler, E. (1986). Research Interviewing: Context and Narrative. Cambridge, MA: Harvard University Press.

Morgan, D. L. (1988). Focus Groups As Qualitative Research. CA: Sage Publications.

Mylan R. VanNewkirk MD, M. L. (2000). Visual impairment and eye diseases in elderly institutionalized Australians. *Ophthalmology*, 2203-2208.

National Eye Institute. (1996/2000). National Eye Institute Visual Functioning Questionnaire.

Renz, R. D. (1999). Theses on Nonprofit Organizational Effectiveness. *Nonprofit and Voluntary Sector Quarterly*, 107.

Riessman, C. K. (1994). Narrative Analysis. London: SAGE Publications.

Rovner, G. (1998). Depression and disability associated with impaired vision: the MoVies Project. *Journal of American Geriatrics Society*, 617-19.

Royal National Institute of Blind People. (2008). Retrieved January 20, 2008, from rnib.org.uk

Scott, O. D.-R. (2001). Emotional distress in patients with retinal disease. *American Journal of Ophthalmology* , 584-589.

Stelmack, Joan. (2001). "Quality of Life of Low-Vision Patients and Outcomes of Low-Vision Rehabilitation." *Optometry and Vision Science* **78(5):** 335-342

Stelmack, Joan. A., Janet P. Szlyk, Thomas R. Stelmack, Paulette Demers-Turco, R. TracyWilliams, D'Anna Moran, and Robert W. Massof. (2004). "Psychometric Properties of theVeterans Affairs Low-Vision Visual Functioning Questionnaire." *Investigative Ophthalmology & Visual Science* **45**(11): 3919-3928

The Center on Aging Florida International University. (2004). *Study of Unmet Service Need Among Elders in 18 Miami- Dade County Zip Codes.* Miami: Florida International University.

Vicdeaf. (2007). Client Satisfaction Survey.

Vision Australia. (2005). *Vision Australia: Blindness and Low Vision Services*. Retrieved 2008, from About Us: http://www.visionaustralia.org.au/info.aspx?page=674

Vision Australia. (2006). *Our History*. Retrieved January 31, 2008, from Vision Australia: http://www.visionaustralia.org.au/info.aspx?page=645

Vision Australia. (2007). *Vision Australia Intranet*. Retrieved 2008, from Service Development Directory for Staff: http://vahome/info.aspx?page=1488

Wolffsohn, James S, and Anthea L. Cochrane. (2000). "Design of the Low Vision Quality-of-Life Questionnaire (LVQOL) and Measuring the Outcome of Low-vision Rehabilitation." *Am. J. Ophthalmol* **130**: 793-802.

# **Appendix A: Methods of Obtaining Client Feedback**

Client unmet need created by weaknesses or unintentional gaps in the services provided by an organization such as Vision Australia are not intuitively obvious, especially considering the recent merger. Determining these short-comings is critical for organizational improvement and determination of client unmet need to occur. There are many ways of obtaining this information, one of which is to contact the clients that utilize the assistance provided by organizations like Vision Australia. The most knowledgeable group of people is usually those members of the community who benefit from the services provided. They usually have the most expertise in determining their own unmet need. Many methods of acquiring client input exist in published literature. Some techniques of client feedback are more advantageous in some situations while others are more beneficial in different circumstances. These methods include, but are not limited to, the wide range of interviewing, client surveying, and conducting focus groups.

## **Interviewing**

Interviews have been a method of obtaining information in many areas of research, including the medical field, the business world, and just about anywhere that data need to be collected. According to Andrea Fontana and James H. Frey, "Both qualitative and quantitative researchers tend to rely on the interview as the basic method of data gathering whether the purpose is to obtain a rich, in-depth experiential account of an event or episode in the life of the respondent or to garner a simple point on a scale of 2 to 10 dimensions" (Fontana & Frey, 2005). The interviewer must trust that their relationship with the respondent that grew through the interactive method of obtaining information did not bias their answers in any way. Although as Mishler states, "interviewing has become a routine technical practice and a pervasive, taken-for-granted activity in our culture" ((Mischler, 1986) quoted by Fontana and Frey, 2005), the knowledge that comes as a result of interviewing can still be tangible evidence. Even though the typical person is increasingly familiar with interviewing techniques since they have become so

commonplace, it is still the trained interviewer who can "recognize when interview participants are 'actively' constructing knowledge around questions and responses" ((Holstein & Gubrium, 1995) paraphrased by Fontana and Frey, 2005). There are many different types of interviewing to be aware of in order to perform successful interviews, some of which include structured and unstructured.

## **Structured Interviewing**

This type of interviewing is very controlled and the relationship between the interviewer and the respondent should be exactly the same in each interview. The questioner asks each respondent the same questions in the same order and the "interviewer controls the pace of the interview by treating the questionnaire as if it were a theatrical script to be followed in a standardized and straightforward manner" (Fontana & Frey, 2005). The responses are recorded in a "coding scheme" that has already been determined. There are many guidelines to be adhered to when conducting a structural interview. The following list of instructions for interviewers was taken directly from an essay written by Fontana and Frey:

- Never get involved in long explanations of the study; use the standard explanation provided by the supervisor.
- Never deviate from the study introduction, sequence of questions, or question wording.
- Never let another person interrupt the interview; do not let another person answer for the respondent or
  offer his or her opinion on the question.
- Never suggest an answer or agree or disagree with an answer. Do not give the respondent any idea of your
  personal views on the topic of the question or survey.
- Never interpret the meaning of a question; just repeat the question and give instructions or clarifications that are provided in training or by the supervisor.
- Never improvise such as by adding answer categories or making wording changes (Fontana & Frey, 2005).

This type of interviewing is very strict and does not allow the interviewer any opportunity to influence the opinions of the respondent. Some methods of conducting a structured interview include "telephone interviews, face-to-face interviews in households, intercept interviews in malls and parks, and interviews generally associated with survey research" (Fontana & Frey, 2005). Three problems that are connected to structural interviews are 1) the respondent could attempt to gratify the interviewer by giving the socially acceptable answer, 2) the method of performing the interview (i.e. telephone or face-to-face) as well as the order and wording of the questions could affect the respondent's answers, and 3) the interviewer's traits or "questioning techniques" hinder good question communication (Fontana & Frey, 2005).

## **Unstructured Interviewing**

Unlike structured interviewing, the unstructured type allows the interviewer to become involved in an open-ended and in-depth discussion with the respondent. Fontana and Frey explain the difference between structured and unstructured interviewing, "The former [structured] aims at capturing precise data of a codable nature so as to explain behavior within preestablished categories, whereas the latter [unstructured] attempts to understand the complex behavior of members of society without imposing any a priori categorization that may limit the field of inquiry" (Fontana & Frey, 2005). Traditional sociologists and researchers abide by several steps involved in "plucking" the fruit from the tree, or obtaining useful information from the respondent. These steps, described in more detail in Appendix B, include:

- "Accessing the Setting
- Understanding the Language and Culture of the Respondents
- Deciding How to Present Oneself
- Locating an Informant
- Gaining Trust
- Establishing Rapport

## Collecting Empirical Material"

(Fontana & Frey, 2005)

There are many ways of "accessing the setting" or finding a way to become a part of the environment in which the respondents interact. This could include acting the same as the members of a certain group of people, such as the example stated by Fontana and Frey taken from Douglas, Rasmussen, & Flanagan where "one might have to disrobe and casually stroll in the nude if he or she is doing a study of nude beaches" (Douglas, Rasmussen, & Flanagan, 1977). The ways of "accessing the setting" may depend in each respondent individually rather than as a group. Any method of starting a casual conversation with a possible respondent counts as "accessing the setting".

Understanding the language and culture of the respondents is very important before attempting to obtain useful information from them. If the interviewer is in an unfamiliar country or part of a country, in which a different language is spoken or the culture is unusual to the interviewer, he or she needs to determine ways of conversing without insulting or misunderstanding the people. This step is also relevant in situations where use of certain terminology or jargon that the typical person would not understand is present. These circumstances could include medical fields, or any other professional field where there are specific terms that a person uneducated in that particular field would misunderstand.

The way the interviewers present themselves is crucial to forming a safe relationship with respondents in which they are willing to answer questions truthfully without the thought of implicating or incriminating themselves. Some things to take note of when "deciding how to present oneself" include wearing certain clothes, other accessories, and acting in certain manners in order not to intimidate or assume a position of inferiority. As stated by Fontana and Frey, "This is very important because once the interviewer's presentational self is 'cast,' it leaves a profound impression on the respondents and has a great influence of the success of the study (or lack thereof)" (Fontana & Frey, 2005).

The next step is locating an informant, someone who is part of the group of interest who could be a "tour guide." This person could be a translator if a different language or terminology is present and could also help with cultural disparity. An interviewer does not necessarily need an informant, but a good informant can prevent many mistakes that could cost time (Fontana & Frey, 2005).

Gaining trust and establishing rapport are two very important aspects of the unstructured interview process. "Gaining trust is essential to the success of the interviews, and once it is gained, trust can still be very fragile. Any faux pas by the researcher may destroy days, weeks, or months of painfully gained trust" (Fontana & Frey, 2005). A thin line exists in establishing rapport between seeing the situation from the point of view of the respondents and keeping the objectivity needed to successfully perform the research. In some situations, the researcher may think that they have created good rapport with the respondents, but it turns out they haven't, "as Thompson (1985) found out in a nightmarish way when he was subjected to a brutal beating by the Hell's Angels just as his study of them was coming to a close" (Fontana & Frey, 2005).

In order to succeed in the unstructured interview, the researcher must take good notes without making it obvious or without making the respondent feel uncomfortable. Some keys things to remember are "(a) take notes regularly and promptly, (b) write down everything no matter how unimportant it might seem at the time, (c) try to be as inconspicuous as possible in note taking, and (d) analyze notes frequently" (Fontana & Frey, 2005).

## **Conducting Focus Groups**

Conducting focus groups is similar to interviewing, but instead of directing questions at one person the moderator opens the floor to a group of people to encourage discussion of a specified topic. The members of a focus group typically have some common thread, which can be as general as visual impairment or as narrow as residents of elderly housing who use a certain brand of cat food. The aggregation of ideas by the group working together is a useful method of obtaining client comments. Put another way, "The hallmark of focus groups is the explicit use of the group interaction to produce data and insights that would be less accessible without the

interaction found in a group" (Morgan, 1988). As Richard Krueger states, "Focus groups produce qualitative data that provide insights into the attitudes, perceptions, and opinions of participants" (Krueger, 1994). Focus groups are more comfortable for the members involved than individual interviews because people can influence and be influenced by others, which resembles real life (Krueger, 1994). Similar to interviewing, a list of questions is developed before the start of the focus group and the moderator guides the group through the discussion topics. Unlike a structured interview, the moderator appears to be spontaneously asking open-ended questions; he or she does not need to pressure the group to agree (Krueger, 1994). According to David Morgan, focus groups are a useful method for data collection in:

- "orienting oneself to a new field;
- generating hypotheses based on informants' insights;
- evaluating different research sites or study populations;
- developing interview schedules and questionnaires;
- getting participants' interpretations of results from other studies" (Morgan, 1988)

Focus groups, like other methods of qualitative research, have their strengths and weaknesses; there are certain situations where focus groups are an excellent method to obtain client feedback and other circumstances where focus groups are lacking in their ability to produce quality data. Richard Krueger describes some additional uses including, "planning (including strategic planning), needs assessment, assets analysis, program design, or market research" (Krueger, 1994). The collective perspectives of the individuals within the focus groups could be a very important asset in determining the unmet needs of Vision Australia's clients.

Focus groups, as with any other method of qualitative research, have their strengths and weaknesses; there are certain situations where focus groups are an excellent method to obtain client feedback and other circumstances where focus groups are lacking in their ability to produce quality data.

They are generally cheaper than other methods and some focus groups are easier and lower in complexity level as well. Although not all focus groups are simple, "when time and/or money are essential considerations, it is often possible to design focus group research when other methods would be prohibitive" (Morgan, 1988). The greatest strength of focus groups "lies in their ability to explore topics and generate hypotheses" (Morgan, 1988). Valuable data can be formed without much input directly from the researcher; many of the ideas generated come strictly from the members of the group as they collaborate to create new thoughts. Because the researcher does not have as much direct input in focus groups as in other methods of feedback, however, the researcher does not have the same level of control in gathering the data as he or she does in other methods such as individual interviews. This can be detrimental to the researcher's data collection and is certainly a weakness of this method. Controlled tactics, such as the individual interview, are more useful to a researcher when "there are a clear set of predefined issues or a strong need to maintain strict comparability across separate interviews" (Morgan, 1988).

A central problem with the interaction of people in a group setting exists in the focus group method of obtaining client feedback. This issue involves the influential role of a group on an individual. According to David L. Morgan, "there are whole lines of research in social psychology that are dedicated to investigating the ways that individual behavior differs from group behavior—for example, individual decision making versus group influence" (Morgan, 1988). When individuals can be strongly persuaded by a group on an issue that was meant to be measured on an individual basis, the researcher's data will be distorted by focus groups and another method of client feedback should be utilized.

## **Client Surveying**

Surveys can be performed in person, over the telephone, through the internet, or by mail. In comparison with other modes of research, surveys are not always as qualitative. People generally don't respond as in depth or accurately when they aren't informed in advance of the research; for example, a person who knows they are being interviewed or are involved in a focus group on Monday morning, most likely would have spent a little time over

the weekend to think about the topics that may be addressed. A person who is busy and receives a telephone call with no prior warning will not be as willing or ready to answer questions on those same topics. Surveys which contain questions that can be responded to with yes or no answers may receive more responses due to the ease of the survey. Questions like these, which need to be very concise, but also very accurate to the information the researcher is studying, are difficult to produce. If the questions are formed intelligently, surveys will most often produce large amounts of data to be analyzed by the researcher. This method of obtaining client feedback is therefore more quantitative than it is qualitative.

One drawback of personal surveys is the "clustering together of the selected respondents in order to reduce travel costs" (Groves & Kahn, 1979). This grouping of respondents reduces the accuracy of the data because the population is not covered completely. Telephone surveys can be increasingly more accurate than the personal survey because the only piece of information necessary is the list of telephone numbers covering relevant population (Groves & Kahn, 1979). Careful determination of the numbers sampled is very important to the precision and success of the telephone survey. If only numbers from previously used telephone lists are used, the people with unlisted numbers will be excluded from the survey. Also, "the fewer the restrictions on the random generation of telephone numbers, the larger the proportion of sample numbers generated that are not working household numbers" (Groves & Kahn, 1979). The method of selecting telephone numbers to survey is most important in performing this type of data collection.

Internet surveys are another valuable resource since they allow for rapid distribution and data collection from a large number of clients simultaneously. However, due to the specific disability (blindness) that affects the client base of Vision Australia, it may be difficult for them to complete such a survey. Considering that Vision Australia offers auditory web services for the blind, such a survey could be feasible.

Many of Vision Australia's clients may not be able to respond to the typical written or internet survey as a result of their visual impairment. One substitute, the telephone survey, is costly because of the man power

involved. An alternative to manual telephone surveys is to perform an automated telephone survey. Computer programs exist that can be used to call large volumes of numbers, play specific messages and record the responses of the person that was called (Database Systems Corps., 2008). Some systems even accept touchtone responses, which is an extremely valuable resource when gathering quantitative data since no verbal communication or interpretation is required. These systems provide a low cost, efficient method of obtaining large quantities of data from clients that would be unable to perform a written survey. These systems can be purchased, or outsourced to other companies to minimize cost and time.

# Appendix B: Vision Australia 2005 Client Insights Survey Questions

## Choose one option for the following questions.

For the purpose of this survey, can you confirm that you:

- Received the services yourself
- Are the guardian of an Adult Client
- Are the parent or guardian of a child client

## **Question 1:** Staff treated me with respect.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

## **Question 2:** Staff are knowledgeable and skilled about Blindness.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

## **Question 3**: Staff are knowledgeable and skilled about Vision Impairment.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

## Question 4: Staff are helpful.

## **Answer Options:**

• Strongly Agree

- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 5**: My service was given in a timely manner, that is, I didn't have to wait too long.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

If you answered disagree or strongly disagree to question 5 please go to question 5a. Otherwise go to question 6.

Question 5a: I was kept informed about any wait or delay in the service.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 6**: I feel the service I received was personalized to my needs.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 7**: Staff were good at problem solving to meet my needs.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree

Pass

**Question 8**: Were you recommended any equipment/aids as part of your service (for example: A magnifier or raised bumps to mark things with).

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

If you answered yes answer question 8a, 8b, and 8c.

If you answered no or pass go to question 9.

Question 8a: I was given a choice of equipment for my needs.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 8b: The staff were good at training me how to use the equipment.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 8c: The equipment was received in a timely manner.

## **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 8d (NILS clients only):** I receive my library material in a format which meets my needs (e.g. Braille, CD, cassette tape).

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 8e (NILS clients only): I find receiving my books, opening, playing, and returning them easy.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 9**: Have you sought equipment from another agency or Company?

### **Answer Options:**

- Yes
- No
- Pass

If you answered yes go to question 9a.

If you pass or answered no go to question 10.

**Question 9a**: Why did you seek equipment elsewhere?

### **Answer Options:**

- Convenience
- Lower Cost
- Item not sold by Vision Australia
- Greater Choice of Products
- Greater knowledge of Product
- Higher level of Customer Service
- Other company was recommended to me
- Other—Please Specify
- Pass

**Question 9b:** What was the item?

**Question 10**: It was simple to join the service. For example: It was easy to find out about the service and find the phone number to call.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 11: Any information I received was in my preferred format. For example: Braille, Large Print, Other Language.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 11a: What is your preferred format?

### **Answer Options:**

- Standard Print
- Large Print
- Audio
- Braille
- Electronic
- Other—Please Specify

Question 12: I was able to get an appointment at a convenient time for me.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 13**: Did you go to a centre for an appointment?

### **Answer Options:**

- Yes
- No
- Pass

If you answered yes go to question 13a and 13b.

If you answered no or pass go to question 14.

**Question 13a**: The place for the appointment was easy to get to and from.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 13b: Once at the appointment it was easy to get around. For example: Signs were easy to see, not too many steps, etc.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 14: The service has helped me develop/maintain my independence in day to day tasks.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 15**: The service has helped me develop/maintain my involvement in family and community activities.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree

Pass

Question 16: I was given any information I needed in a way that was easy to understand.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 17**: Overall, I am satisfied with the service I received.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 18**: I would recommend the service to other people.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

**Question 19**: Were you aware that there is a complaints and suggestions process?

### **Answer Options:**

- Yes
- No
- Pass

If you answered yes go to question 19a.

If you answered no or pass go to question 20.

Question 19a: Have you ever made a formal complaint or suggestion through our process?

### **Answer Options:**

• Yes

- No
- Pass

If you answered yes go to question 19b, 19c, and 19d. If you answered no or pass go to question 20.

Question 19b: My complaint or suggestion was followed up promptly.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 19c: I was kept informed of the progress of my complaint or suggestion.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 19d: My complaint or suggestion was finalized and I was told the outcome.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

Question 20: Do you use a computer?

### **Answer Options:**

- Yes
- No
- Pass

**Question 21**: Do you access the Internet?

### **Answer Options:**

- Yes
- No
- Pass

If you answered yes go to question 21a.

If you answered no or pass go to question 22.

Question 21a: Which of the following connection types do you use to access the Internet?

### **Answer Options:**

- Dialup
- Broadband/Cable
- Satellite
- I'm not sure
- Pass

As you may know Royal Blind Society has merged with Vision Australia Foundation and Royal Victorian Institute for the Blind and National Information Library Service. The last question relates to the newly merged Organization.

**Question 22**: I am confident that the newly merged Organization will provide services which meet my needs.

### **Answer Options:**

- Strongly Agree
- Agree
- Neither Agree Nor Disagree
- Disagree
- Strongly Disagree
- Pass

You have now completed the survey. Thank you for your time in completing this survey. I can assure you that nothing you say in this Survey will be passed on unless you request that it is followed up. The outcomes will be used to improve our service. Lastly, I'd like to let you know that we have a new name—Vision Australia. You can still contact us on our usual numbers, so if you are wanting services anytime in the future, please do not hesitate to call.

# **Appendix C: Vision Australia Common Assessment Template**

p of document

	DETAILS			
Client name				
Client ID				
Assessed by				
Assessment date				
	ther this form is being used as an nation or checklist (only tick one)	Evaluation	Checkl	list
	WOULD YOU LIKE INFOR	RMATION ON		
	Benefits and entitlements you m	ay be eligible for?	(Yes / No)	
	Your v	vision impairment?	(Yes / No)	
	Resources in	your community?	(Yes / No)	
	NEEDS ASSESSMENT	SCALE		
	A little $3 = A$ fair amount $4 = A$ e of other reason $N/A = N$ ot app		at all due to e	yesight
	Q 1: INFORMAT	ION		
In the past month h	nave you:			
Worried about you	r eyesight getting worse?		Scale	
Comments				
Been concerned abo	out visual hallucinations?		Scale	

Comments			
	Q 2 : INDEPENDENCE AT HOME		
In the past n	nonth has your vision impairment affected your ability to:		
Read?		Scale	
Comments			
Write?		Scale	
Comments			
Use the comp	puter?	Scale	
Comments			
Prepare mea	ds?	Scale	
Comments			
Take care housework)?	of yourself (including medication / personal grooming /	Scale	
Comments			
Use the telep	hone?	Scale	
Comments			
Watch TV?		Scale	
Comments			
Do home ma	intenance?	Scale	
Comments			
	Q 3: INDEPENDENCE IN THE COMMUNITY		
In the past n	nonth has your vision impairment affected your ability to:		

Go out by yo	ourself?	Scale	
Comments			
Walk with s	afety and confidence?	Scale	
Comments			
Shop?		Scale	
Comments			
Identify mor	ney?	Scale	
Comments			
Recognise po	eople?	Scale	
Comments			
Use public to	ransport?	Scale	
Comments			
	Q 4 : EDUCATION		
In the past n	nonth has your vision impairment affected your ability to:		
Continue stu	idy at uni, TAFE etc?	Scale	
Comments			
	Q 5 : EMPLOYMENT		
In the past n	nonth has your vision impairment affected your ability to:		
Perform in t	he workplace?	Scale	
Comments			
Look for wo	rk?	Scale	
Comments			

	Q 6: RECREATION / SOCIAL		
In the past r	month has your vision impairment affected your ability to:		
Enjoy social	interactions with friends and family?	Scale	
Comments			
	Q7: EMOTIONAL SUPPORT		
And finally	in the past few months have you:		
Noticed any	changes in your feelings and moods?	Scale	
Comments		1	
Noticed any	changes in your relationships?	Scale	
Comments		<u> </u>	
Worried abo	out coping with every day life?	Scale	
Comments		<u>l                                      </u>	
Felt like a m	uisance because of your eyes?	Scale	
Comments		1	
	ADDITIONAL COMMENTS		
I just wante discussed?	ed to check, are there any other areas of concern for you tha	t we hav	e not
	the questionnaire and or in the discussion that you were conceruseful to make a referral to VA for or were you aware that .		ut

Thanks for taking the time to complete it. Please don't hesitate to contact VA at any time.

NOTE: Have you completed a Needs Identification Summary Form?

# Appendix D: Topics examined in published Australian consumer surveys since 1996, by method (Cooper and Jenkins, 1999)

Author	Satisfaction Quality	Patient Outcomes	Characteristics of Consumers	Needs of Consumers	Need for Improvement/ expectations	Service Experiences	Service Health Knowledge
Questionnaire Method							
Adams, Tyrell- Clark, McLeod, Smith, Billett	Х				Х	х	
Boyhan		Х					
Brown & Lumley	X	Х				X	
Clark, Steinberg, Bischoft	Х		X				
Dillon, James, Ginis	Х	Х					
E-QUAL	Х		Х	Х		Х	
Evans		Х			Х		
Fan, Boldy, Bowen	Х	Х	X	Х		Х	
Frank Small & Associates	Х				Х	Х	
Germain, Manktelow	Х					Х	
Jimmieson, Griffin	Х					Х	
Johnston, Wong	Х						
Lewis, Campain, Wright	Х	Х					
Mackay, Beer, Gilchrist, Woodward	Х						
Phillips, Dennerstein, Farish	Х						71

				ı	1		1
Sanson-Fisher,							
Foot			X				
Stedman,							
Mellsop,							
Yellowlees,							
Clarke	X						
Ciario	^						
Webster,							
Forbes, Foster,							
Thomas, Griffin,							
	V						
Timms	Х						
VA/ - ' - I							
Weisberg,							
Fraser	Х	X					X
Wood	Х		Х			Х	
_							
Personal							
Interview							
Method							
Brown & Doran			X	Х	X		
Dillon, Innes,							
Ginis	X	X					
Girii o		,					
E-QUAL	Х		Х	Х		Х	
L GOME	Λ		Α	Λ		Λ	
Frank Small &							
Associates	Х					X	
Associates						, , , , , , , , , , , , , , , , , , ,	
Mackay, Beer,							
Cilchrict							
Gilchrist,							
Woodward	Х						
F							
Focus Group							
Method							
Frank Small &							
Associates	Х					X	
McDonald	Х	Х					
Stedman,							
Mellsop,							
Yellowlees,							
Clarke	X						
Talantana							
Telephone							
Interview							
Method							

E-QUAL	Х	Х	Х	Х	
Mackay, Beer, Gilchrist, Woodward	Х				
Sawyer, Miller, Pearson, Marino, Homer	Х				
Thomas, Clarke					Х

# Appendix E: VisQoL Items (Misajon, 2005)

Q1	Does my vision make it likely I will injure myself (i.e. when moving around the house, yard neighborhood, or workplace)?
	☐ It is most unlikely I will injure myself because of my vision.
	☐ There is a small chance.
	☐ There is a good chance.
	☐ It is very likely.
	☐ Almost certainly my vision will cause me to injure myself.
Q2	Does my vision make it difficult to cope with the demands in my life?
	My vision
	☐ has no affect on my ability to cope with the demands in my life.
	does not make it difficult at all to cope with the demands in my life.
	☐ makes it a little difficult to cope.
	☐ makes it moderately difficult to cope.
	☐ makes it very difficult to cope.
	☐ makes me unable to cope at all.
Q3	Does my vision affect my ability to have friendships?
	My vision
	☐ makes having friendships easier.
	☐ has no effect on my friendships.
	☐ makes friendships more difficult.
	☐ makes friendships a lot more difficult.
	☐ makes friendships extremely difficult.
	makes me unable to have friendships.
	☐ Not applicable; I have no friendships.
Q4	Do I have difficulty organizing any assistance I may need?
	☐ I have no difficulty organizing any assistance I may need.
	☐ I have a little difficulty organizing assistance.
	☐ I have moderate difficulty organizing assistance.
	☐ I have a lot of difficulty organizing assistance.
	☐ I am unable to organize assistance at all.
	☐ Not applicable; I never need to organize assistance.
Q5	Does my vision make it difficult to fulfil the roles I would like to fulfil in life (e.g., family roles, work roles, community roles)?
	My vision
	☐ has no effect on my ability to fulfill these roles.
	☐ does not make it difficult to fulfill these roles.
	☐ makes it a little difficult to fulfill these roles.
	☐ makes it moderately difficult to fulfill these roles.
	☐ makes it very difficult to fulfill these roles.
	☐ means I am unable to fulfill these roles.
Q6	Does my vision affect my confidence to join in everyday activities?
	My vision
	☐ makes me more confident to join in everyday activities.
	☐ has no effect on my confidence to join in everyday activities.
	☐ makes me feel a little less confident.
	☐ makes me feel moderately less confident.
	☐ makes me feel a lot less confident. ☐ makes me not confident at all.

# Appendix F: LVQOL survey from Wolffsohn et al

Distance Vision, Mobility and Lightin	Distance	Vision.	Mobility	and Lighti	ng
---------------------------------------	----------	---------	----------	------------	----

RΑ	radi

How much of a problem do you have:	None	IV	noderate	6	reat		
With your vision in general	5	4	3	2	1	x	n/a
With your eyes getting tired (e.g only being able to do a task for a short period of time)	5	4	3	2	1	×	n/a
With your vision at night inside the house	5	4	3	2	1	x	n/a
Getting the right amount of light to be able to see	5	4	3	2	1	х	n/a
With glare (e.g dazzled by car lights or the sun)	. 5	4	. 3	2	1	х	n/a
Seeing street signs	5	4	3	2	1_	х	n/a
Seeing the television (appreciating the pictures)	5	4	3	2	1	х	n/a
Seeing moving objects (e.g. cars on the road)	5	4	3	2	1	х	n/a
With judging the depth or distance of items (e.g. reaching for a glass)	5	4	3	2	1	×	n/a
Seeing steps or curbs	5	4	3	2	11 11 11	х	n/a
Getting around outdoors (e.g. on uneven pavements) because of your vision	5	4	3	2	1	x	n/a
Crossing a road with traffic because of your vision	5	4	3	2	1	х	n/a

### Adjustment

Because of your vision, are you:	No	Moderately		Greatly			
Unhappy at your situation in life	5	4	3	2	1	х	n/a
Frustrated at not being able to do certain tasks	5	4	3	2	1	х	n/a
Restricted in visiting friends or family	5	4	3	2	1	x	n/a

	Well		1	F	oorly	Not explained
How well has your eye condition been explained to you	5	4	3	2	1	X

#### Reading and Fine Work

With your reading aids / glasses, if used, how

much of a problem do you have:	None		Moderate		Great		
Reading large print (e.g. newspaper headlines)	5	4	3	2	1	x	n/a
Reading newspaper text and books	5	4	3	2	1	X	n/a
Reading labels (e.g. on medicine bottles)	5	4	3	2	1	х	n/a
Reading your letters and mail	5	4	3	2	1	х	n/a
Having problems using tools (e.g. threading a needle or cutting)	5	4	3	2	1	x	n/a

### **Activities of Daily Living**

With your reading aids / glasses, if used, how

much of a problem do you have:	None		Moderate	(	Great		
Finding out the time for yourself	5	4	3	2	1	X	n/a
Writing (e.g. cheques or cards)	5	4	3	2	1	x	n/a
Reading your own hand writing	5	4	3	2	1	х	n/a
With your every day activities (e.g. house-hold chores)	5	4	3	2	1_	x	n/a

FIGURE 1. The LVQOL. Patients are asked to complete the questions by circling the number most appropriate to how they feel. If they can no longer perform the task because of their vision, they are to circle "x," and if they do not perform the task for nonvisual reasons, to circle "n/a".

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### Appendix G: National Eye Institute Visual Functioning Questionnaire

PB/IA

National Eye Institute Visual Functioning Questionnaire - 25 (VFQ-25)

version 2000

### (INTERVIEWER ADMINISTERED FORMAT)

January 2000

RAND hereby grants permission to use the "National Eye Institute Visual Functioning Questionnaire 25 (VFQ-25) July 1996, in accordance with the following conditions which shall be assumed by all to have been agreed to as a consequence of accepting and using this document:

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version 2000

### Instructions:

I'm going to read you some statements about problems which involve your vision or feelings that you have about your vision condition. After each question I will read you a list of possible answers. Please choose the response that best describes your situation.

-1-

Please answer all the questions as if you were wearing your glasses or contact lenses (if any).

Please take as much time as you need to answer each question. All your answers are confidential. In order for this survey to improve our knowledge about vision problems and how they affect your quality of life, your answers must be as accurate as possible. Remember, if you wear glasses or contact lenses for a particular activity, please answer all of the following questions as though you were wearing them.

# **Visual Functioning Questionnaire - 25**

### PART 1 - GENERAL HEALTH AND VISION

1.	<u>In general,</u> would you say your	(Circle One)
	READ CATEGORIES:	Excellent 1
		Very Good 2
		Good 3
		Fair 4
		Poor 5
2.	경기들은 아이들 경기 하는 경투자가 하는데	say your eyesight using both eyes s, if you wear them) is <u>excellent, good</u> ou <u>completely blind</u> ?
2.	(with glasses or contact lenses	, if you wear them) is <u>excellent, good</u>
2.	(with glasses or contact lenses	s, if you wear them) is <u>excellent, good</u> ou <u>completely blind</u> ?
2.	(with glasses or contact lenses fair, poor, or very poor or are y	s, if you wear them) is <u>excellent</u> , <u>good</u> ou <u>completely blind</u> ? (Circle One)
2.	(with glasses or contact lenses fair, poor, or very poor or are y	s, if you wear them) is <u>excellent, good</u> ou <u>completely blind</u> ?  (Circle One)  Excellent
2.	(with glasses or contact lenses fair, poor, or very poor or are y	s, if you wear them) is <u>excellent</u> , <u>good</u> ou <u>completely blind</u> ?  (Circle One)  Excellent
2.	(with glasses or contact lenses fair, poor, or very poor or are y	s, if you wear them) is <u>excellent, good</u> ou <u>completely blind?</u> (Circle One)  Excellent

<sup>\*</sup> Skip Question 1 when the VFQ-25 is administered at the same time as the SF-36 or RAND 36-Item Health Survey 1.0

3.	How much of the time do yo	ou <u>worry</u> about your eyesight?
		(Circle One)
	READ CATEGORIES:	None of the time 1
		A little of the time 2
		Some of the time 3
		Most of the time 4
		All of the time? 5
4.		ort have you had in and around your eyes ng, or aching)? Would you say it is:
		(Circle One)
	READ CATEGORIES:	None 1
		Mild 2
		Moderate 3
		Severe, or 4
		Very severe? 5

### PART 2 - DIFFICULTY WITH ACTIVITIES

The next questions are about how much difficulty, if any, you have doing certain activities wearing your glasses or contact lenses if you use them for that activity.

5. How much difficulty do you have <u>reading ordinary print in</u> <u>newspapers?</u> Would you say you have:
(READ CATEGORIES AS NEEDED)

(Circ	le One)
No difficulty at all	
A little difficulty	2
Moderate difficulty	3
Extreme difficulty	4
Stopped doing this because of your eyesight	5
Stopped doing this for other reasons or not interested in doing this	6

6.	How much difficulty do you have doing work or hobbies that require
	you to see well up close, such as cooking, sewing, fixing things
	around the house, or using hand tools? Would you say:
	(READ CATEGORIES AS NEEDED)

(Circ	e One)
No difficulty at all	1
A little difficulty	2
Moderate difficulty	3
Extreme difficulty	4
Stopped doing this because of your eyesight	5
Stopped doing this for other reasons or not interested in doing this	6

7. Because of your eyesight, how much difficulty do you have <u>finding</u> something on a crowded shelf?

(READ CATEGORIES AS NEEDED)

OATEOONIEO AO NEEDED	
(Circ	le One)
No difficulty at all	1
A little difficulty	2
Moderate difficulty	3
Extreme difficulty	4
Stopped doing this because of your eyesight	5
Stopped doing this for other reasons or not interested in doing this	6

8. How much difficulty do you have <u>reading street signs or the names of stores?</u>

(READ CATEGORIES AS NEEDED)

(Circ	le One)
No difficulty at all	
A little difficulty	2
Moderate difficulty	3
Extreme difficulty	4
Stopped doing this because of your eyesight	5
Stopped doing this for other reasons or not	
interested in doing this	6

9.	Because of your eyesight, how much difficulty do you have going
	down steps, stairs, or curbs in dim light or at night?
	(READ CATEGORIES AS NEEDED)

(Circ	e One)
No difficulty at all	1
A little difficulty	2
Moderate difficulty	3
Extreme difficulty	4
Stopped doing this because of your eyesight	5
Stopped doing this for other reasons or not interested in doing this	6

10. Because of your eyesight, how much difficulty do you have <u>noticing</u> objects off to the side while you are walking along?

(READ CATEGORIES AS NEEDED)

	le One)
No difficulty at all	1
A little difficulty	2
Moderate difficulty	3
Extreme difficulty	4
Stopped doing this because of your eyesight	5
Stopped doing this for other reasons or not interested in doing this	. 6

11. Because of your eyesight, how much difficulty do you have seeing how people react to things you say?

(READ CATEGORIES AS NEEDED)

CATEGORIES AS NEEDED)	
(Circl	le One)
No difficulty at all	1
A little difficulty	2
Moderate difficulty	3
Extreme difficulty	4
Stopped doing this because of your eyesight	5
Stopped doing this for other reasons or not	
interested in doing this	6

	- 0 -	version 2000
12.	Because of your eyesight, how much difficulty do you hat out and matching your own clothes? (READ CATEGORIES AS NEEDED)	ive <u>picking</u>
		cle One)
	No difficulty at all	1
	A little difficulty	2
	Moderate difficulty	3
	Extreme difficulty	4
	Stopped doing this because of your eyesight	5
	Stopped doing this for other reasons or not interested in doing this	.6
13.	with people in their homes, at parties, or in restaurants ? (READ CATEGORIES AS NEEDED)	
	No difficulty at all	
	A little difficulty	2
	Moderate difficulty	3
	Extreme difficulty	
	Stopped doing this because of your eyesight	
	Stopped doing this for other reasons or not interested in doing this	
14.	Because of your eyesight, how much difficulty do you hat to see movies, plays, or sports events? (READ CATEGORIES AS NEEDED)	
	(Circ	le One)
	No difficulty at all	1
	A little difficulty	
	Moderate difficulty	
	modelate difficulty	•

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Extreme difficulty...... 4
Stopped doing this because of your eyesight .... 5

interested in doing this ...... 6

Stopped doing this for other reasons or not

version 2000

15.		I'd like to ask about <u>driving</u> once in a while?	ı a car. Are yo	u <u>cur</u>	ently driving, at
			(Circle	One)	
			Yes	1	Skip To Q 15c
			No	2	
	15a.	IF NO, ASK: Have you nev	<u>/er</u> driven a ca	r or ha	ive you <u>given up</u>
		<u>unving</u> :	(Circle	One)	
			Never drove .	1	Skip To Part 3, Q 17
			Gave up	2	
	15b.	IF GAVE UP DRIVING: Wa eyesight, mainly for some eyesight and other reason	other reason,		
	15b.	eyesight, mainly for some	other reason,	or bed	
	15b.	eyesight, mainly for some	other reason, s? (Circle	One)	cause of <u>both your</u>
	15b.	eyesight, mainly for some eyesight and other reason	other reason, s? (Circle	One) 1	Skip To Part 3, Q 17
	15b.	eyesight, mainly for some eyesight and other reason Mainly eyesight	other reason, ss? (Circle	One) 1 2	Skip To Part 3, Q 17
	15b.	eyesight, mainly for some eyesight and other reason Mainly eyesight Mainly other reason	other reason, s? (Circle	One) 1 2 3	Skip To Part 3, Q 17 Skip To Part 3, Q 17 Skip To Part 3, Q 17
		eyesight, mainly for some eyesight and other reason  Mainly eyesight  Mainly other reason  Both eyesight and  IF CURRENTLY DRIVING: driving during the daytime you have:	other reason, s? (Circle ons other reasons How much dif	One) 1 2 3 ficulty ces?	Skip To Part 3, Q 17 Skip To Part 3, Q 17 Skip To Part 3, Q 17
		Mainly eyesight  Mainly eyesight  Mainly other reason  Both eyesight and  IF CURRENTLY DRIVING:  driving during the daytime you have:	other reason, s? (Circle ons other reasons How much dif	One) 1 2 3 ficulty ces? One) 1	Skip To Part 3, Q 17 Skip To Part 3, Q 17 Skip To Part 3, Q 17
		eyesight, mainly for some eyesight and other reason  Mainly eyesight  Mainly other reason  Both eyesight and  IF CURRENTLY DRIVING: driving during the daytime you have:	other reason, s? (Circle ons other reasons How much dif	One) 1 2 3 ficulty ces? One) 1	Skip To Part 3, Q 17 Skip To Part 3, Q 17 Skip To Part 3, Q 17

16. How much difficulty do you have <u>driving at night</u>? Would you say you have: (READ CATEGORIES AS NEEDED)

(Circle (	One)
No difficulty at all	1
A little difficulty	2
Moderate difficulty	3
Extreme difficulty	4
Have you stopped doing this because of your eyesight	5
Have you stopped doing this for other	
reasons or are you not interested in	
doing this	6

16a. How much difficulty do you have <u>driving in difficult conditions</u>, <u>such</u> as in bad weather, <u>during rush hour</u>, on the freeway, or in city traffic? Would you say you have:

(READ CATEGORIES AS NEEDED)

### PART 3: RESPONSES TO VISION PROBLEMS

The next questions are about how things you do may be affected by your vision. For each one, I'd like you to tell me if this is true for you <u>all</u>, <u>most</u>, <u>some</u>, <u>a little</u>, or <u>none</u> of the time.

	(Circle One On Each Line)					
READ CATEGORIES:	All of the time	Most of the time	Some of the time	A little of the time	None of the time	
17. Do you accomplish less than you would like because of your vision?	1	2	3	4	5	
18. Are you limited in how long you can work or do other activities because of your vision?	1	2	3	4	5	
19. How much does pain or discomfort in or around your eyes, for example, burning, itching, or aching, keep you from doing what you'd like to		2				
be doing? Would you say:	1	2	3	4	5	

For each of the following statements, please tell me if it is <u>definitely true</u>, <u>mostly true</u>, <u>mostly false</u>, or <u>definitely false</u> for you or you are <u>not sure</u>.

(Circle One On Each Line)

	Ţ	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
20.	I stay home most of the tir because of my eyesight		2	3	4	5
21.	I feel <u>frustrated</u> a lot of the time because of my eyesight		2	3	4	5
22.	I have much less control over what I do, because of my eyesight.		2	3	4	5
23.	Because of my eyesight, I have to rely too much on what other people tell me.		2	3	4	5
24.	I <u>need a lot of help</u> from others because of my eyesight	. 1	2	3	4	5
25.	I worry about doing things that will embarrass myself or others, because of my eyesight	Ī	2	3	4	5

That's the end of the interview. Thank you very much for your time and your help.

## Appendix H: LV VFQ 48 from Stelmack 2004

### TABLE 1. Items Included in the 48-Item Field Test

T7 .	T 7 A	T T 7	TITO
Version	VΑ	LV	VFO

1. Physically get dressed
---------------------------

- 2. Keep clean
- 3. Identify medicine
- 4. Tell time
- 5. Identify money
- 6. Match clothes
- 7. Groom yourself
- 8. Identify food on a plate
- 9. Eat and drink neatly
- 10. Fix a snack
- 11. Prepare meals
- 12. Use appliance dials
- 13. Clean the house
- 14. Handle finances
- 15. Make out a check
- 16. Take a message
- 17. Find something on a crowded shelf
- 18. Find public restrooms
- 19. Get around indoors in places you know
- 20. Get around outdoors in places you
- 21. Get around in unfamiliar places
- 22. Go out At night
- 23. Go down steps in dim light
- 24. Adjust to bright light

- 25. Cross streets at traffic lights
- 26. Use public transportation
- 27. Get around in a crowd
- 28. Avoid bumping into things
- 29. Recognize persons up close
- 30. Recognize persons from across the room
- 31. Read street signs and store names
- 32. Read headlines
- 33. Read menus
- 34. Read newspaper or magazine articles
- 35. Read mail
- 36. Read small print on package labels
- 37. Read print on TV
- 38. Keep your place while reading
- 39. Watch TV
- 40. Play table and card games
- 41. See photos
- 42. Work on your favorite hobby
- 43. Go to movies
- 44. Go to spectator events know
- 45. Play sports
- 46. Do yard work
- 47. Sign your name
- 48. Read signs

## Appendix I: VF-14 survey questions (Stelmack, 2001)

- 1. Read small print, such as labels on medicine bottles, a telephone book, or food labels.
- 2. Reading a newspaper or book.
- 3. Reading a large-print book or newspaper or the numbers on a telephone.
- 4. Recognizing people when they are close to you.
- 5. Seeing steps, stairs, or curbs.
- 6. Reading traffic, street, or store signs.
- 7. Doing fine handwork such as sewing, knitting, crocheting, or carpentry.
- 8. Writing checks or filling out forms.
- 9. Playing games such as bingo, dominos, card games, or mahjong.
- 10. Taking part in sports such as bowling, handball, tennis, or golf.
- 11. Cooking.
- 12. Watching television.
- 13. Daytime driving.
- 14. Nighttime driving.

### Scale 0 = No difficulty performing task

- 1 = A little difficulty performing task
- 2= Moderate difficulty performing task
- 3= Great deal of difficulty performing task
- 4= Unable to perform task

## Appendix J: Questionnaires from RBS model for outcomes

### I. Adult Questionnaire

Please consider how your vision impairment affects the different areas of your day to day life. These areas are listed below.

1. **Visual Activities:** (eg. reading personal mail, bills, newspapers, books; writing phone numbers, shopping lists, cards, letters or notes; filling out cheques, forms; seeing TV; seeing signs, train indicator boards; problems with lighting or glare; problems seeing at night or in the dark; etc).

Please list below any visual activities that you are wanting to do but are unable to manage because of your vision impairment.

2. **Daily Living Skills**: (eg. preparing food; seeing stove/ microwave dials; dialing the telephone; pouring drinks; locating power points/keyholes; operating appliances, remote controls; seeing your watch, clock; using a computer; home maintenance; etc).

Please list below any daily living skills that you are wanting to do but are unable to manage because of your vision impairment.

3. **Independence in the Community:** (eg. shopping; banking; identifying money; using public transport; crossing roads; negotiating stairs, gutter; etc).

Please list below any activities in the community that you are wanting to do but are unable to manage because of your vision impairment.

4. **Personal care:** (eg. identifying clothing; shaving; putting on make-up; cutting nails; managing medication; etc).

Please list below any personal care activities that you are wanting to do yourself but are unable to manage because of your vision impairment.

5	Emotional	needs re	lated to you	r vision im	nairment · (	eg adjusting	to the changes
J.	Linundia	i iiccus i c	iaicu io vou		iban ment. (	ce autusume	to the changes

you are experiencing; managing the changes in roles/relationships with family/friends due to your vision impairment; difficulties planning for the future due to your vision loss; concerns about visual hallucinations; etc).

Please list below any emotional needs related to your vision impairment that you are wanting to discuss.

6. **Social/Recreation:** (eg. craft work; hobbies; sports; social groups; etc).

Please list below any social/recreational activities that you have stopped doing because of your vision impairment and are wanting to be able to perform again.

Also indicate if you are wanting to find out suggestions/ options for social and/or recreational activities.

7. **Educational:** (eg. advice about how your vision impairment may or may not impact on your choice of study and education; information about options for support in the education system

Please list below the type of educational information or assistance that you need.

### 8. Employment:

Royal Blind Society provides specialist employment assistance to people with low vision. We can help if you are having difficulties in finding employment, keeping your present job, considering a career change, or getting a promotion. This includes financial assistance with purchasing adaptive equipment you may need in the workplace.

Would you like further information on Royal Blind Society's employment service?

Please list below any areas of assistance with employment that you may need.

9. **Information:** (eg. information about your vision impairment, community facilities and resources; benefits and entitlements, etc).

Please list below the type of information that you are wanting.
10. <b>Other:</b> Do you have any other concerns that haven't been covered in this questionnaire? Please list below.
11. <b>General Health:</b> Are there any other health problems you have that you would like us to know about? Please list below.
12. Support Networks:
Do you currently receive any support from community services, neighbours, family members etc? Please list below.
If someone other than the client completed this form, please fill in your name, your relationship to the client, and the date that the questionnaire was completed.
Name:
Relationship: Date:
Thank you for taking the time to complete this form.
II. Questionnaire for School Aged Children
Please read this questionnaire and document your child=s specific needs in the space
provided.
<b>1. Visual Skills</b> (e.g. difficulty with: reading textbooks, novels, magazines; losing place while reading; keeping writing on the lines; reading own hand writing; reading the

blackboard/whiteboard/overhead projector; seeing calculator display; seeing computer screen and/or the keyboard; seeing TV; distinguishing between colours; reading signs on

streets/shops/train stations; sensitivity to glare; seeing at night and/or in the dark; using low vision aids etc.).

Please list below any visual skills that your child is unable to perform and that you are wanting your child to manage more easily.

**2. Daily Living Skills** (e.g. difficulty with: eating meals and/or using eating utensils; preparing food, making sandwiches, pouring drinks; using appliances; washing up; making his/her bed; dialing the telephone; applying toothpaste to brush; identifying clothing; tying shoelaces; identifying money etc.).

Please list below any daily living skills that your child is unable to perform and that you are wanting your child to manage more easily.

**3. Social and Emotional** (e.g. strategies to help your child make and maintain friendships; ideas for managing teasing and/or bullying; assisting your child to feel comfortable about speaking up for himself/herself with friends/students/teachers/other adults; ideas for improving your child=s self-esteem; strategies for managing your child's behaviour problems; opportunity to discuss any concerns about your child's vision impairment and its impact on yourselves or your family etc.).

Please list below any social and/or emotional needs related to your child's vision impairment that you or your child would like to discuss further.

**4. Orientation and Mobility** (e.g. difficulty with negotiating stairs, gutters, uneven surfaces; bumping into and/or tripping over obstacles; moving around in dim light and/or in the dark; crossing roads independently; traveling to and from school and/or other locations independently etc.).

Please list below any orientation and mobility skills that your child is unable to perform and that you are wanting your child to manage more easily.

<b>5. Educational/Vocational</b> (e.g. concern regarding impact of your child=s vision impairment on specific subjects; information about options for support in the education/school systems; information about options for work experience or job choice; assistance with finding employment; information about financial assistance including wage subsidy and purchasing adaptive equipment for use in the workplace; information on Royal Blind Society's Employment Service and/or other employment services etc.)
Please list below any educational and/or vocational needs related to your child's vision
impairment that you or your child would like to discuss further.
<b>6. Recreation</b> (e.g. participating in sport and leisure activities enjoyed by other students or siblings; information on social/recreational options; ideas for adapting/modifying an activity that your child enjoys; information about specific sports for people with a vision impairment; opportunities for social and recreational activities with other students who have a vision impairment etc.)
Please list below any recreational needs that you or your child would like to discuss further.
7. Information (e.g. information about your child's vision impairment, any benefits and
entitlements relating to your child's vision impairment, other agencies/services which may be able to help etc.).
Please list below the type of information that you or your child are wanting.

Are there any other concerns that you or your child would like to raise which haven't been covered? Please specify below.

## **School/Funding Information**

8. Other

	Thank you for taking the time to complete this form.
Relati	onship: Date:
Name	:
	e document below the name of the person/s who completed this form, their relationship to the child, and the nat the form was completed.
Type	of doctor (e.g. ophthalmologist, pediatrician etc.):
Docto	r who diagnosed your child's vision impairment:
Teach	er's full name:
Does	your child have an itinerant teacher for vision? If yes, please provide the itinerant
Schoo	l year (e.g. year 2, year 10 etc.):
9 9 9	Mainstream Special Class Special School
Class	type:
9 9 9	Government School Catholic School Independent School
Schoo	ıl type:

Name and address of the school your child attends:

# Appendix K: Methodology Timeline

Task	Week							
	PQP	1	2	3	4	5	6	7
Archival Research								
Service Organization FM Evaluations								
Prepare for Client Interviews and Focus Groups								
Client Interviews								
Client Focus Groups								
Data Analysis								
Create Continuous Feedback Protocol								
Final Documentation and Presentation								

# **Appendix L: Interview and Focus Group Plans**

#### **Interview Consent Form**

We are students at Worcester Polytechnic Institute in Massachusetts, USA. We are conducting a research project on behalf of the Vision Australia to determine the unmet need of Vision Australia's clients. As part of this project we are conducting a series of interviews with key individuals. We have asked you to participate because we believe you have unique knowledge of this issue that will be valuable to the project.

Before we begin, we would like to thank you for taking the time to participate in the interview which will last about (expected duration of interview). Your participation is entirely voluntary. You may refuse to discuss any question or terminate the interview at any time. With your permission we would like to record the interview. The tapes, notes, and subsequent transcripts of the interview will be kept confidential, and will be accessible by only the members of the team and our immediate faculty advisors. Your name will not be used in any subsequent report or publication without your permission.

If you consent to be interviewed at this time, we would ask that you indicate your agreement below (or by verbally consenting).

I agree to participate in the interview		
	Interviewee Signature	Date
	Interviewee Name	
Please initial for permission to record	Interviewee Initials	
Interviewer signature	Date	

## **Focus Group Consent**

We are students at Worcester Polytechnic Institute in Massachusetts, USA. We are conducting a research project on behalf of Vision Australia to determine the unmet need of Vision Australia clients. As part of this project we are conducting a series of focus groups. We have asked you to participate because we believe you have unique knowledge of these issues that will be valuable to the project.

Before we begin, we would like to thank you for taking the time to participate in the focus group which will last about 30-60 minutes. Your participation is entirely voluntary. You may refuse to discuss any question or terminate participation in the focus group at any time. With your permission we would like to record the focus group. The tapes, notes, and subsequent transcripts of the focus group will be kept confidential, and will be accessible by only the members of the team and our immediate faculty advisors. Your name will not be used in any subsequent report or publication without your permission.

For your knowledge, this focus group is primarily being used to assess the unmet need among clients such as yourselves.

## **Client Interview and Focus Group Questions**

- Question 1: Introduce yourself. Please give us your name, age, occupation.
- Question 2: Tell us a story of a time you were frustrated with your low vision within the past few weeks.
- Question 3: Have you had trouble seeing stove/microwave dials or operating other home appliances recently?
- Question 4: Have you had trouble with public transportation or seeing signs in the community recently?
- Question 5: Have you had trouble finding someone to talk to or problems with relationships recently?
- Question 6: Have you been more frustrated with hobbies or other recreational activities lately?
- Question 7: Has your low vision kept you from studying or education?
- Question 8: Have you been having more trouble with employment as a result of your vision loss recently?
- Question 9: Have you had additional trouble with finding information about your vision impairment or community facilities since you've been a client of Vision Australia?
- Question 10: Have you had trouble communicating with people lately?
- Question 11: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

# **Appendix M: Organization Interview Plan**

Hello, we are a group of students from Worcester Polytechnic Institute working with Vision Australia in an attempt to determine the unmet needs of their clients. Although (Organization) and Vision Australia cater to different disabilities, they have similar goals.

Question 1: Does (Organization) have a mechanism for receiving feedback from clients regarding their unmet needs?

Question 2: How does it work?

Question 3: Are there any problems with it?

Question 4: Is there any documentation, including surveys, interview or focus group plans? If so, is it possible for us to view the documentation?

Thank you for your time,

John

Nikki

Steve

# Appendix N: Organization Interview Results

Interview: March 27, 2008

Location: Victorian Deaf Society

Interviewers: Nicole Croteau, John Dieselman, Stephen Rose

Interviewee: Graeme Kelly

## Introductions:

The meeting began with each interviewer introducing themselves. John described how VicDeaf and Vision Australia treat similar clients and have similar goals, which makes this interview relevant.

Question 1: Does VicDeaf have a mechanism for receiving feedback from clients regarding their unmet needs?

- VicDeaf is working on a project called the Demand Management Project. They are engaging in consulting support to look at demographic changes in Victoria. It is important to understand that these changes include age, younger people who are deaf, social changes, and technology changes.
- Some supporting work includes detailed demographic data from Australia's census. The last census in 2006 included good data regarding deafness such as their location, age, education, income, occupation and ethnic background.

Question 2: Are there any other mechanisms VicDeaf uses to receive feedback directly from clients?

VicDeaf uses a survey for all of their services. They keep it simple and short due to the fact that people who are deaf often do not have the education needed to fully understand a complicated, detailed survey. They have to trade off quality in order to get accurate responses. Unfortunately, the return rate is low, probably due to the fact that VicDeaf acts as a paternalistic organization. Their clients expect to receive services from them and do not feel the need to give anything back. Graeme did mention, however, that the younger clients were much more likely to give feedback.

Question 3: Is there any system in place that evaluates what VicDeaf is not doing that they could be doing?

- The demand project mentioned earlier looks at organizations within Australia, and international organizations, using benchmarking techniques to see if there is anything VicDeaf could be doing better.
- It is difficult to receive this information from clients because they struggle with giving feedback.

Question 4: What documentation does VicDeaf have for receiving client feedback that the team can see?

- Graeme mentioned that he is going to email the team with a copy of the client surveys mentioned above.
- He also asked that the team send him a copy of their final report once it is finished.

Interview: April 15, 2008

**Location: Building Commission** 

Interviewers: Nicole Croteau, John Dieselman, Stephen Rose

Interviewee: Dennis Hogan

Introductions:

The meeting began with each interviewer introducing themselves.

Question 1: What sort of work did you do for people with visual impairments in the past?

Mr. Hogan talked about how four years ago, there were no building regulations implemented to help people with vision impairments. He mentioned that some very limited things were in place such as tactile and hand rails, but other than that there was nothing. His project was to come up with a "wayfinding" system, to help people with visual impairments to find things such as the front door, reception, toilets and the exits. Some of the things he implemented were Braille maps and prerecorded messages that would tell the person where they were through a Bluetooth headset when they got within 5 meters of certain locations. He mentioned that they were able to do a trial of their final plan with a building in Brisbane, but due to funding issues they were unable to take it further than that.

Question 2: How did you obtain feedback from the people you were working to assist?

Mr. Hogan did not receive any direct feedback, however, he talked about how this was a great opportunity for Vision Australia to address the needs of their clients. He suggested that Vision Australia gather data from their clients to allow the proper departments to help them. Some departments he mentioned were Building Commission and the Australian Building Codes Board. He also suggested that they talk to Department of Infrastructure with regards to any data related to transportation. Another department he suggested they talk to is the Department of Planning and Community Development. It is important, however, that Vision Australia knows and understands their problems and ideas before they bring them to any organizations.

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#### Email Interview with Sue Keil from RNIB

Hello,

Your query about RNIB's methods of obtaining client feedback was passed to me.

In answer to your question, RNIB is a membership organisation (currently with approximately 10,000 members) and feedback from members is obtained through regular membership and customer surveys.

We also carry out (both in-house and externally commissioned) evaluations of RNIB services giving blind and partially sighted users plenty of opportunity to put forward their views about the services they receive.

In addition, RNIB has a research department, which commissions (and occasionally carries out in-house) social research into the needs and experiences of blind and partially sighted people in the UK. As an example, RNIB is co-sponsor of the Network 1000 project, which is a longitudinal survey of 1000 people in the UK who are registered as blind or partially sighted. Here is the link to the research report:

http://www.vision2020uk.org.uk/library.asp?libraryID=685&section=00010005000

For information I have attached a link to the RNIB research webpage: <a href="http://www.rnib.org.uk/xpedio/groups/public/documents/code/public rnib00">http://www.rnib.org.uk/xpedio/groups/public/documents/code/public rnib00</a> 1971 .hcsp

I hope this gives you some indication of the activities RNIB is involved in, to obtain feedback from blind and partially sighted people - both direct and indirect users of RNIB services.

Best wishes,

Sue Keil
Research Officer
RNIB
105 Judd Street
London WC1H 9NE
Phone: +44 (0) 207 391 2369

#### Email Interview with Robin Gottardi from Abilities Unlimited

Hi Nicole,

I have enclosed 2 tools we use w/families annually to find the needs of the family & to track unmet needs.

This is done w/ a face to face visit, asking - sometimes re-phrasing the questions to make them 'softer'. the Family support plans (FSP) then are filled out, mailed & then approved by DMR- our state agency contract. Throughout the year there is also a modification form for changes. The fsps are used as tools to find what has been used & what unmet needs are for ea family - if you want to call & ask questions of the process it maybe easier...

Also the instructions for filling out the fsp is included - which maybe helpful????

Hope this helps,

Robin

ps if need be I can send them in pdf format...

**Appendix 0: Focus Group Results** 

Focus Group: March 26, 2008

Location: Church of Christ, Bayswater Day Program

Participants (last names withheld): Maureen, Claire, George, Pat, Gwen, Brian

The meeting began with introductions by John, Nikki and Steve who each described their majors, what they do for

fun and what they did for work that previous summer.

Introductions:

Maureen is 68 years old. She lost her sight suddenly 4.5 years ago. She felt lost when it first happen. Her

life is a lot more comfortable now than it would have been without Vision Australia. She is married and

has children who are all grown up.

Claire is 75 years old. She lost half of her vision this past June but is considered legally blind. She is a

school teacher of deaf children and works with her church. She lives in a retirement home. She is a widow

and has five children with grandchildren. She hopes to help as many people as she can who struggle with

low vision.

George noticed his vision going about a year ago when a vein burst near his eyes. He gave up his license

when he noticed his vision going. He can see a mist in front of him which allows him to see figures in

front of him but no specific features.

Pat is from Italy. He had a very strong accent and the team could not understand what he was saying.

Gwen is 85 years old and lost his sight two years ago. She used to make porcelain dolls and did beading,

and is frustrated that she cannot perform these activities anymore.

Brian is 62 years old. He lost his sight in one eye from an accident and in the other eye from a tumor. He

still has 3 percent vision.

Question 2: How has Vision Australia helped you?

The group mentioned that VA has helped them in a large number of ways. The group used their large

library of talking books and other low vision information resources. They have used their occupational

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therapy tools as well in order to gain some function that had been lost with their sight. Essentially the group said that VA had helped them with everything they could have asked for.

## Question 3: Which of the life themes are most important to you?

• Independence at home and independence in the community both received huge responses here, but communication and recreation also receive a few votes. The group said that living, working and traveling on their own is immensely important to them. This is because it allowed the client to maintain some functionality that was lost with their vision.

## Question 4: Where has VA fallen short, and not fulfilled your needs?

- Claire had trouble with the first service coordinator who came to her house. He did not interpret her needs well and didn't leave when she told him she didn't want him there anymore.
- Several of the group participants agreed that they needed more help with technology. Appliances aren't made with bigger buttons and words for people with vision loss, so the group members have had trouble using them. Claire bought a new CD player and she couldn't figure out how to use it.
- The group said that the main problem with VA was finding out about it after they had lost their vision. They expressed feeling lost and alone prior to discovering VA, but once they did find it they're emotional state improved quite rapidly. The group felt that this was a major issue, and that VA should work harder to be recommended by doctors. The team feels that this is a huge problem that should be worked on. Gwen mentioned that Vision Australia should put an ad on TV in order to recruit clients because people with vision loss have had a lot of trouble finding VA, but once they do life gets so much better.
- The ladies of the group described how they used to make porcelain dolls, create tapestry, or sew and they can't do these tasks anymore because of their vision loss. Gwen explained that someone could translate what people used to do to something positive that could replace it. Maureen explained how Penny had pushed her to try knitting again even though she had trouble seeing what she was doing. She said that she and her husband found a way for her to be able to continue this hobby. She proclaimed that VA should have people to challenge the clients to continue doing specific things that did in the past while they could still see.

- Gwen explained that she has trouble with traveling on the trains. Everyone agreed that more ways to see or
  hear the signs and where the trains are going are needed. Having trouble with the trains and buses made
  Gwen feel more housebound.
- George had some other problems involving the systems used in the community. He went to get a Medicare rebate, but he couldn't see the print on the machine so he didn't know which buttons to push. A guy told him the number to press and a paper with the number 49 came out. When they called his number he didn't know which teller to go to because he couldn't see the signs. Someone had to let the teller know that he was visually impaired. He mentioned that this system wouldn't work for people who can't hear either. George couldn't see the bathroom signs so he walked into the women's' bathroom instead of the men's.

Question 5: What is the best method for Vision Australia to contact you?

Gwen started off by saying that conversations are the best way to deliver feedback to Vision Australia.
 This would cover both personal and telephone conversations.

Claire mentioned that phone interviews are a great way to receive feedback from clients. She suggested that phone interviews be scheduled for a set time on a regular schedule. For example, a new client may require a weekly phone call at the same time every week. Then as that client becomes more adjusted, the calls can be tapered down and become less and less regular. The group as a whole was overwhelmingly supportive of this idea.

Focus Group: March 28, 2008

Location: Boronia Office

Participants (last names withheld): Wanda, Shelia, Peter, Wilma, Beryl, Don, Peter, Betty

The meeting began with introductions by John, Nikki and Steve who each described their majors, what they do for

fun and what they did for work that previous summer.

Introductions:

Wanda runs two support groups. She is a public speaker who has been blind her entire life.

Shelia works in a university three days a week running their telephone system.

Peter is a volunteer.

Wilma is retired. She became visually impaired in September of 2001.

Beryl lost her sight overnight twelve months ago. She sees a psychologist to try and get over the loss. She

used to be very active and now uses Vision Australia to help her get back on her feet.

Peter is 77 years old and is legally blind. He spends his time exercising.

Betty is 84 years old and can see some but is legally blind. She ran self-help groups in the past and she

writes a column for the newspaper to inform people who are blind of the services they can receive.

Alan grew up in the Baby-boomer generation. He is a consultant in the city and is working on a research

project in employment for non-profit organizations. He is a representative for the regional client committee

which is the committee which represents clients to the board of Vision Australia.

Question 2: How has Vision Australia helped you?

Betty mentioned that touch typing and screen readers have enabled her to write for the newspaper.

Beryl, who is still learning how to adjust to her blindness, said that the support she has received from her

psychologist has been the most helpful.

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• Peter mentioned that Vision Australia did a great job of making him realize that he was okay. They helped him to understand that his life was not over and that many other people had it much worse than he did.

## Question 3: Which of the life themes are most important to you?

- Communication was brought up 3 times.
- Education was brought up 3 times.
- Emotional Support was brought up 2 times.
- Independence at Home was brought up 1 time.
- Independence in the Community was brought up 1 time.
- Information was brought up 2 times.
- Recreation was brought up 4 times.
- Employment was brought up 2 times.

## Question 4: Where has VA fallen short, and not fulfilled your needs?

- Alan brought up many times that the delivery of information needed great improvement. He feels that they can't produce enough Braille, and they need more Braille displayers. Communication
- Betty wished that would bring back better holidays for those who want to travel. She mentioned that in the
  past, Vision Australia used to organize trips to locations all over the world. She whishes those services
  would come back. Recreation
- Many people agreed that welfare and counseling officers were needed in all of the offices. Emotional Support
- It was also mentioned that many ophthalmologists do not tell their patients about Vision Australia. They all agreed that Vision Australia should do a better job of making themselves known.

- Alan mentioned that Braille is very expensive and he wishes more work was done with colleges and
  universities to make accommodations for their blind students. He is also concerned that there are no
  visiting teachers for tertiary education. Education
- Alan also mentioned that the Vision Australia employment service is very poor. He claimed that the
  training is too basic and that there is only one location. He said that it is too difficult for many clients to
  travel out to Prahran for employment training. He emphasized that employment training is a huge problem
  with Vision Australia. Employment
- Wanda mentioned that Vision Australia needs more support groups like this one. Emotional Support
- It was also mentioned that there used to be sewing/crafts courses that do not exist anymore.

Question 5: What is the best method for Vision Australia to contact you?

A suggestion was brought up that Vision Australia should find volunteers to call every client every year or two. They said that there should be a couple of easy survey questions and that each call should only take 1-5 minutes. They all agreed that it should be done by a third party so that they get honest feedback.

Focus Group: April 2, 2008

Location: Oakleigh Office

Participants (last names withheld): Judy, May, Bob, Mark, Stan, Rachel, Guest Speaker

The meeting began with introductions by John, Nikki and Steve who each described their majors, what they do for fun and what they did for work that previous summer.

Introductions:

Each client said their name

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

- Judy mentioned having trouble with falling over.
- May was disappointed that she has been unable to travel overseas.
- Bob told a story of when he traveled to Sydney with a concession travel card. He was told that his card would work anywhere but when he got into the taxi, the driver would not accept it. He was told cash or nothing.
- Mark wishes the new products coming out were simpler. He claimed that the new technologies were too complicated and difficult to understand. Stan disagreed with Mark saying that the new technologies tell you exactly what to do and he mentioned that persistence is the best way to learn.
- May was having a problem with her Daisy reader, saying that it was reading too fast.

Question 2: Have you been more frustrated with hobbies or other recreational activities lately?

- Rachel says that she loved to cook but is unable to do that anymore. The biggest issue is that she does not know of any cookbooks with large print.
- May mentioned that now that she has had vision loss, there are too many hours in the day to fill. She seemed very interested in the idea of recreational activities such as sports for people who are

blind. Bob also mentioned to her that there are recreational activities available such as water aerobics that one can do if they are sighted or blind.

 Bob also mentioned that there are things happening within Vision Australia that many clients have never even heard of. He wished Vision Australia did a better job of getting information about themselves out there.

Question3: When first diagnosed with your particular condition, was it difficult to find Vision Australia?

• The entire room answered this question with a resounding NO. Nobody in the room had a hard time finding Vision Australia.

Guest Speaker: At this time, a guest speaker came into the focus group to give a talk regarding his experiences and possibilities for these clients. The team took some notes though a good portion of this discussion was not relevant to the project.

- The guest speaker brought up a story about public transportation. In the past, all passengers using public transportation, including people with low vision, had to validate their cards. The speaker found this to be unfair and even potentially dangerous to people with low vision. He worked with the government to get this rule changed and eventually got it so that people with low vision were exempt from validating their cards. This showed the team that Vision Australia does have a voice and can influence government decisions.
- It was also brought up that many branches of Vision Australia offer services and activities that other branches do not even know about. This leaves for the possibility of a more informative staff and/or client newsletter.

Question 4: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

- Rachel mentioned that since every client has different needs regarding communication, it may be better for the service coordinators to ask each client this question, so that the appropriate method can be used for each client.
- Mark suggested that more qualified volunteers be brought in so that more one-on-one questioning could be possible.
- Judy said that her preferred method would be the phone interview.
- Stan also suggested that more trustworthy volunteers would be the best option.

Focus Group: April 4, 2008

Location: Mount Waverley Day Program

Participants (last names withheld): Jean, Carol, Margret, Frances, Tracy, Pat, Bill

The meeting began with introductions by John, and Steve who each described their majors, what they do for fun and what they did for work that previous summer.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

- One participant mentioned that it was frustrating for her that she could no longer watch television or read.
- Two people mentioned that they wished they could sew again.
- Another person mentioned that she wished she could go on a trip to king island.

Question 2: Have you had trouble with public transportation or seeing signs in the community recently?

- Many people mentioned that it was absolutely impossible for them to go out at night under any circumstances.
- Some said that they could only travel by taxi.
- Everyone agreed that they wished they had more transportation options.

Question 3: Have you had trouble finding someone to talk to or problems with relationships recently?

- Nobody in the group expressed any of these difficulties.
- The members mentioned that there are existing groups that take clients out to dinner in restaurants and for nights out.

Question 4: Have you had trouble seeing stove/microwave dials or operating other home appliances recently?

• One member mentioned that she sets off the fire alarm every time she makes toast.

Question 5: Have you had additional trouble with finding information about your vision impairment or community facilities since you've been a client of Vision Australia?

- Most members agreed that Vision Australia should do a better job of getting the word out about themselves. More than half of them did not hear about Vision Australia from their ophthalmologist and wished they had. Everyone suggested that Vision Australia tells ophthalmologists to refer clients to them.
- Suggestions were also made that Vision Australia signs were posted in ophthalmologists' offices.
- One person mentioned that she was unable to go out until her daughter found out about Vision Australia.
- Nobody, however, said they had difficulty with finding information regarding their eye condition.

Question 6: Have you been more frustrated with hobbies or other recreational activities lately?

- Everyone said that they wished they could go out more to places such as parks.
- They also said that they love hearing guest speakers at their day programs.

Question 7: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

- One person said that they really enjoyed face to face discussion, so focus groups and personal interviews would be the best option for her.
- Another person said telephone interviews would be best.

Focus Group: April 7, 2008

Location: Mount Waverley Youth Center

Participants (last names withheld): Gay, Bernice, Nancy, Lawrence, Bill, Peter, Nick, Ray

The meeting began with introductions by John, Nikki, and Steve who each described their majors, what they do for fun and what they did for work that previous summer.

#### Introductions:

• Each client said their name.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

- Gay said that last weekend she went on holiday to Phillip Island with her mother. They went out for lunch together and she felt as if she had to rely on her the entire time. It was frustrating to be unable to do basic tasks without help from her mother. Up until then she felt as if she was a care giver for her parents. This was the first time she felt that her mother had to take care of her, which did not seem natural to Gay.
- Another client mentioned that he needed to catch a train to Glen Waverly. Apparently, there were no trains going there that day due to the weather. He was very lucky that he knew the public transportation system as intimately as he did, and was able to find another way home, but this situation would probably be frustrating for most people.
- One woman talked about an incident when she was shopping with her husband. She began to get a severe pain in her face and her husband had to call an ambulance for her. She wanted to see her eye doctor but they took her to the hospital instead. The hospital found nothing wrong and sent her home. After the pain still did not go away, she finally went to her ear and eye doctor who immediately knew what it was and took care of it.
- Another client described how she often gets disoriented. She cannot go out on her own and actually has to tie a rope to her front porch so she can find her way back when she goes into the yard.
- One person mentioned that even in the doctor's office they can't read the business cards.
- Bill said that one positive was that all of his doctors communicate with each other about his condition. He still has frustrations however because he is entirely dependent on his wife and had never even heard

of a vision impairment card until today. It is also frustrating that he can't read signs, can't drive and can't read phone numbers.

Question 2: When you first began to lose your vision, did you have any trouble finding Vision Australia?

- There was a general agreement that ophthalmologists should do a better job of telling their clients about Vision Australia and their services.
- One client did not find out about it until a friend told her while square dancing.
- Another commented that the Kooyong office was poorly designed. He said that the office was difficult to get around, the color choice were poor and the interior design was generally poor.

Question 3: Have you been more frustrated with hobbies or other recreational activities lately?

- One man talked about how he had just learned how to fence.
- Some people said that there used to be quality living groups that have stopped for a while.

Question 4: What has Vision Australia not done that you feel they could do a better job with?

- One client talked about how they had been waiting for a volunteer reader for a very long time and they have still not come.
- Another person mentioned that they have been waiting for an occupational therapist for 12 months now. It was made apparent that in order for clients to remain known to Vision Australia, it was important for the client themselves to contact Vision Australia on a regular basis. Otherwise the clients may fall through the crack and be forgotten.
- Many people mentioned that they do not hear from Vision Australia unless they specifically request to hear from them.
- One other client mentioned that holidays had been completely abandoned. They wished that Vision Australia would bring back trips abroad.
- Lastly, it was brought up that Vision Australia should do a better job of communicating with their clients a continual update of their services. This person knows there is more offered that he could be receiving, however, if he does not know about it, he can't participate.

Question 5: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

• Phone interviews received the strongest response.

- Focus groups were discussed and it was decided that they are good for people to bounce ideas off of each other, however, they did not work for contacting large numbers of people.
- There was no interest in receiving written surveys because none of them could read.

Focus Group: April 9, 2008

Location: Church of Christ, Bayswater Day Program

Participants (last names withheld): Maureen, Claire, Frank, Peter, Gwen, George, Ted

The meeting began with introductions by John and Nikki who each described their majors, what they do for fun and what they did for work that previous summer.

#### Introductions:

This visit was a follow up on the first focus group. The clients were given a two week period to think about the questions asked before. This was done to see if better data could be obtained by giving clients time to think about their answers.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

- One client talked about the traffic lights not working. This was an inconvenience for her because she was unable to cross the road.
- Maureen mentioned that she still had not found a replacement activity for embroidery. She does some knitting instead.
- One client mentioned how she is sick of listening to the television, daisy player and radio. She likes to stimulate the brain by doing crossword puzzles and other intellectual activities.
- Claire brought up that the children she cared for her were mad that she couldn't do what she used to do for them because of her vision impairment.
- One person was frustrated over the fact that she needs family support. She suggested that Vision Australia have sessions with the entire family to help everyone understand the effects of the client's vision loss.
- A client mentioned that he can't see signs that are high.
- Claire mentioned that she recently had to pay more than needed for a bus ticket because she couldn't tell the difference between them.

- One client mentioned her frustration with having to rely too much on other people to help her with public transportation.
- The overall agreement was that public services are not accommodating enough.

Focus Group: April 14, 2008

Location: Ringwood RSL Club

Participants (names withheld)

The meeting began with introductions by John and Steve who each described their majors, what they do for fun and what they did for work that previous summer.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

- Most participants mentioned that they were frustrated with their vision all of the time.
- One woman told a story of when she got into a taxi that happened to break down while they were driving. She asked the driver to call another taxi for her but he didn't speak English and so he took her with him to the mechanic. The mechanic called a taxi for her and the cost to get home was much higher because of the extra travel. She was frustrated by the extra cost and by not knowing where she was.
- Another woman mentioned a time when she called for a taxi and the dispatcher asked her if she could give the driver directions.
- Many people agreed that they often have problems with taxi drivers not knowing where to go.
- Some suggested that Vision Australia find volunteer drivers and offer more transport options.

Question 2: Have you been more frustrated with hobbies or other recreational activities lately?

- One client brought up the point that Vision Australia has plenty of wonderful recreational activities, however, provide no way of transporting them to them.
- A couple clients mentioned that they wish Vision Australia had a better library service. The audio books often don't work properly, sometimes when they order books the wrong ones come, and many people wished they would record some older books on CD.
- Some participants also brought up the holidays that Vision Australia used to take them on. They wished that service was offered again.

Question 3: Have you had additional trouble with finding information about your vision impairment or community facilities since you've been a client of Vision Australia?

- Many people agreed that calling Vision Australia is a huge hassle because you often get the wrong person, and then the person you want to talk to isn't there.
- Most clients that communication has gotten a lot worse since the merger.
- They mentioned that the organization is too big and there is no way for them to keep track of everyone.
- They also mentioned that it seems like Vision Australia isn't taking any new members. All of the members they know are people who have been there for years.

Question 4: When you first began to lose your vision, did you have any trouble finding Vision Australia?

Most of the members in this group mentioned that they did not have any trouble finding Vision
 Australia. Only a few mentioned that they were lucky because they were referred by friends.

Question 5: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

- They wish Vision Australia would come out and see their clients more often. They were happy to see the students there and they wish it would happen more often.
- Some suggested that focus groups and individual interviews would both be useful.
- None of them had interest in written surveys.
- They suggested that regular phone calls, such as every three months the way they used to, would be
  great. They all wanted to be contacted on a regular basis, which is the way it used to be before the
  merger.

They also suggested that the same person should call them and visit them every time. It is difficult for the clients to constantly have to explain their disability to new people.

Focus Group: April 16, 2008

Location: Prahran Office

Participants (names withheld)

This focus group included four students of university age and one Vision Australia employee in charge of running study seminars for students.

The meeting began with introductions by Nikki, John and Steve who each described their majors, what they do for fun and what they did for work that previous summer.

### Introductions:

- One participant was a fourth year student who attends the University of Melbourne. She studies music and this was her first time attending the study group.
- Another participant was studying animal science and enjoys horseback riding.
- A third student is not currently in school but is looking into fashion design and business.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

- One participant mentioned her difficulty with traveling to rural places. She has no trouble around the city, however, she enjoys horseback riding and has to travel to rural areas to do so.
- One client mentioned her difficulty finding part time work while studying. Many hirers
  discriminate toward her because of her disability and she is unable to get any help because she is
  not an Australian citizen.
- A couple people mentioned difficulties with taxis. Some of them had friends who had been refused by drivers because of their guide dogs, and others mentioned drivers expecting them to be able to tell them how to get places.
- One person mentioned the difficulty of getting material such as text books in an accessible format. She said that it wasn't until the end of her high school career that they got things to her in large print. Until then, she had to ask her friends to read things to her.

Question 2: Have you had trouble with public transportation or seeing signs in the community recently?

- The bulk of the conversation regarding public transportation involved difficulty with trams.
- Many clients mentioned difficulties with drivers not announcing stops, or stopping and not opening the doors.
- They also mentioned that in the trams themselves, the button to call for a stop is in a different place on every tram.
- Overall there is no consistency among the trams. They find it awkward to constantly ask people where they are. They also mentioned that there used to be a conductor along with the driver that they could ask questions, but that does not exist anymore. The drivers are difficult because most of them don't speak English and they are locked away in their booth.
- The issue of crossing roads was also brought up. Many mentioned that not all of the sound tickers work, and in some cases, only one side of the street worked properly.
- If they called the city to come out and fix it, it would only work for a day or so and then it would go back to the way it was.

Question 3: Have you been having more trouble with employment as a result of your vision loss recently?

- It was mentioned that the unemployment rate among people with low vision was very high. It was suggested that this was because employers discriminate a lot.
- The Vision Australia employment service was also mentioned. It was said that registering for the service is a grueling process. The clients have to go through Centerlink which is an agency that has no idea what they are doing.
- It was suggested that Vision Australia talk to Centerlink and try to make the process more accommodating for people with low vision. Maybe they could just relax the rules for people looking for part time work which is a majority of the blind community.

Question 4: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

- Everyone in the group agreed that they did not want to be interviewed on the phone. They did not want to be put on the spot. The only exception would be if they were given the questions in advance so they would have time to think about what they wanted to say.
- Everyone in the group agreed that email was the best way to contact them.
- They said that written mail would be okay, however, most of the time when they ask for Braille, Vision Australia sends it in print anyway.

Question 5: What are your feelings about Vision Australia's merger? How have things changed since?

- All of them agreed that things have made a change for the worse since the merger. They described Vision Australia becoming more like a business and said that they seem to care less about the clients.
- They mentioned that sometimes service coordinator is located in another state and this makes the whole experience much less personal.
- There has been some good; the scholarship money has increased since the merger.
- The education system has been on the decline and they mentioned that help with primary and secondary stages, especially in rural areas is lacking. Even in the cities it was mentioned that there are very few study skills programs.

Question 6: Have you been more frustrated with hobbies or other recreational activities lately?

- All of the recreational activities that Vision Australia offers are for the elderly. These clients are not interested in bird watching or carpet bowling.
- They all agreed that if recreational activities for younger people were offered, they would participate.
- Some suggestions that came up were self defense classes or club dancing. One client who already does horseback riding said she wished something like that was offered.
- The employee present said that even as an employee, she would not know about a lot of the things Vision Australia offers. They may offer things such as sailing, but none of this is reported in the monthly report. She throws out the report every month because the information in it is never relevant to her younger clients.

# **Appendix P: Client Interview Results**

Interview: March 31, 2008

Interviewers: John Dieselman, Stephen Rose

Interviewee: Vision Australia Client

## Introductions:

This client visit was a chance for the team to observe what happens on staff visits with clients. This client was receiving a new telephone with bigger buttons. Her vision began blurring two years ago due to cataracts.

Many of the interview questions were determined to be irrelevant due to the living situation of this particular client. Those questions were omitted prior to the interview.

Question 1: Have you had trouble seeing stove/microwave dials or operating other home appliances recently?

She mentioned that the only piece of equipment she had difficulty with was the telephone.

Question 2: Have you had trouble with public transportation or seeing signs in the community recently?

She said that she could easily take the busses and trains whenever she wished.

Question 3: Have you been more frustrated with hobbies or other recreational activities lately?

This question received the most response. She mentioned that she could no longer read the newspaper or the fine print of her books.

Question 4: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

She mentioned that between phone interviews and mailed surveys, a combination of both would probably be most effective.

Interview: April 1, 2008

Interviewers: Nikki Croteau, John Dieselman

Interviewee: Vision Australia Client, Patricia

Introductions:

This was a client visit with a staff member with the purpose of making it easier for Patricia to listen to

books on tape. The staff member made large print button sheets for the stereo, remote, and cordless phone so that

they were easier to see.

Patricia is an 81 year old client who began losing her vision two years ago, when she started having

problems with depth perception. Since then she has lost her central vision and can't see anything through her right

eye.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

• She mentioned that she falls a lot lately because she cannot judge how far away she is from objects.

It's also very frustrating for her when she runs into people with her walker.

She mentioned that her care giver has to take her into the community because she can't go into

public by herself.

Question 2: Have you been more frustrated with hobbies or other recreational activities lately?

She talked about how she used to cook but she can't do so anymore because she can't see the

measurements.

She also mentioned that she can't drive anymore which is frustrating.

Before she lost her vision, she did a lot of needlework which is also not possible for her anymore.

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Interview: April 3, 2008

Interviewers: Nikki Croteau, John Dieselman, Steve Rose

Interviewee: Vision Australia Client, Isabel

## Introductions:

This was Isabel's first visit to Vision Australia; she was referred by her specialist. She came because she was having trouble with her magnifier and needed a stronger one.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

Isabel mentioned that her favorite hobbies were reading, sewing, and gardening. She could still do gardening and since she was a first time client, Vision Australia was working on her needs for reading and sewing.

Question 2: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

Isabel mentioned that either phone or mail were okay methods for her to give feedback to Vision Australia.

Interview: .	April	8,	2008
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Interviewers: Steve Rose

Interviewee: Vision Australia Client

This was not an actual interview, but a chance to see a client visit first hand.

Question 1: When you first began to lose your vision, did you have any trouble finding Vision Australia?

• The client mentioned that she was extremely lucky to have found Vision Australia. She tried to work around her vision impairment for a year but couldn't manage on her own. She was very surprised that her hospital never told her about Vision Australia.

Interview: April 11, 2008

Interviewers: John Dieselman, Steve Rose

Interviewee: Vision Australia Client

Question 1: When you first began to lose your vision, did you have any trouble finding Vision Australia?

The client mentioned that she sees an ophthalmologist because she has lost her central vision. She lost the ability to drive and was pretty depressed when it first happened. She mentioned that she felt lost. A friend referred her to Vision Australia because she happened to know someone who worked there. The client asked her doctor why he never told her about Vision Australia but never got a straight answer out of him. She claims that the doctors tend to see the medical side of things but not

the personal side.

Question 2: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

She first mentioned that reading and filling out forms is very difficult for her and many other visually impaired people to do. She stated that all written things are hard to handle.

The client talked about how it is always better if you can speak to the client directly because the spoken word is best and easiest for them to handle.

She mentioned that the telephone is most likely the best method because it covers all of the points she mentioned before, and pretty much everybody has access to a phone. She did suggest, however, that Vision Australia alert the clients in advance so not too many calls are missed.

Question 3: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

The client talked about how she used to take long walks on her own or walk down the street and now she can't do that anymore. She feels too unsafe. She wishes it were easier for her to walk around the block.

• She also mentioned a time she called Vision Australia. She just called for a basic inquiry, however, once she finished the call, Vision Australia asked her if she needed anything else. She found it interesting that after six months of not hearing from them, the only way for her to get any help was to call them and ask for it. Otherwise she probably would have been forgotten.

Interview: April 14, 2008

Interviewers: Nikki Croteau, John Dieselman

Interviewee: Vision Australia Client, Bernadette

This was a telephone interview.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

• Bernadette is 23 years old and is frustrated with job hunting. She mentioned that the employment services could be doing a better job of helping clients get experience.

Question 2: Have you been having more trouble with employment as a result of your vision loss recently?

• She mentioned that the people in the employment department are difficult to contact and don't respond very fast.

Question 3: Have you been more frustrated with hobbies or other recreational activities lately?

• She mentioned that she wished there were more recreational activities for young people such as sports, dancing, bush walking and camping.

Question 4: Have you had trouble with public transportation or seeing signs in the community recently?

• She said that she does not have a lot of trouble getting around the city with trams and trains, however, tram stops are a little tricky.

Question 5: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

• Telephone or email would be best for her.

Interview: April 14, 2008

Interviewers: Nikki Croteau, John Dieselman

Interviewee: Vision Australia Client, Tracy

This was a telephone interview.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

• Tracy talked about a time when she got some bills in the mail but couldn't figure out which bill she had to pay.

It's frustrating when she goes to the bus stop and has to ask the driver to read the bus number to her.

She needs help reading her mail.

• She is frustrated with Vision Australia because they told her they would make Braille labels for her CD's 12 months ago, but still have not done so.

She mentioned that Vision Australia is not nearly as accessible since the merger. There are more and longer waiting lists than there used to be. She also mentioned that more people call her from office she's never heard of which isn't helpful for her at all.

Question 2: Have you had trouble with public transportation or seeing signs in the community recently?

• Tracy has a guide dog but said she still has trouble with some platforms. She has trouble finding the buttons to open train doors but other than that she's fine. She takes the bus most of the time.

She also added that the stations don't always announce where the trains are going.

Question 3: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

• Email is the best method for her, as long as she can use the reader for it.

Interview: April 14, 2008

Interviewers: Nikki Croteau, John Dieselman

Interviewee: Vision Australia Client, Alysha

This was a telephone interview.

Question 1: Tell us a story of a time you were frustrated with your low vision within the past few weeks.

Alysha talked about how the library does not have enough books for people her age to read. She
also mentioned that there isn't enough staff to handle the orders they receive. As an overall
comment she mentioned that the library service has gotten worse since the merger.

Question 2: Have you had trouble with public transportation or seeing signs in the community recently?

- She mentioned that trains are okay and the trams could be better.
- She does not have too much trouble with public transportation as a whole though.
- She also does not have any trouble navigating around her home.

Question 3: Have you been having more trouble with employment as a result of your vision loss recently?

• She has not tried to find a job.

Question 4: Have you been more frustrated with hobbies or other recreational activities lately?

• She is satisfied with her recreation.

Question 5: What is the best way for Vision Australia to receive feedback from you regarding unmet needs?

• An email survey is the best way to receive feedback from her.

Interview: April 18, 2008

Interviewers: John Dieselman, Steve Rose

Interviewee: Vision Australia Client

This was not an interview, however, a chance to see a client visit first hand. Therefore, no questions were asked, only observations were made.

### Observations:

The purpose of this visit was for Vision Australia to access what services they should be providing for this client. This was done through basic questions about the client's daily life such as movement around the house, and access to the bathroom. Some difficulties came up such as bumping into the kitchen table and using the stove and oven. It was determined that a smaller kitchen table would be necessary, and another specialist would come out to address the rest of her needs.

# **Appendix Q: Vicdeaf Survey**

FM-VAIS-12



# Client Satisfaction Survey

Vilodeaf

Levrel 4/340-Albert Street East Melbourne 3002 Tel: 9473 1111 TTY :9473 1199

Fax: 9473 1122 Website: viodeaf.com.au

At all times Viodeaf Ausian and Interpreting Service (VAIS) strives to provide the best possible service. To help us provide the service that you need, we are randomly surveying users of the service. Your feedback is invaluable to us; therefore, would you kindly complete the following questionnaire and return it to us as soon as is practicable by email to

vals@vicdeaf.com.au or fax to (03) 9473 11	144			
DATE:				
How did you find out about VAIS?				
■ from a deaf client or employee	☐ from a staff member			
■ from a workplace procedure manual	from the telephone book			
from an Internet search	ur organisation uses VAIS			
personal knowledge	■ unknown			
other (please specify):				
If you were the person who first made of the following:	ontact with the booking office, please answer			
Were you provided with information manage your bookings and what yo	about our service, how to make and ou could expect from us?			
■ yes	■ no			
If so, was this information clear and	easy to understand?			
■ yes	□ no			
What, if anything, could have been	better?			
more written information	more verbal/signed information			
more visual information	more concise information			
other (please specify):				

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Viodeaf Level 4/340Albert Street East Melbourne 3002

Tell: 9473 1111 TTY :9473 1199 Fax: 9473 1122 Website: vicdeaf.com.au

If you were the first person to register your organisation or business via our website booking system, was it easy to register?

■ yes	■ no
If it was difficult, what made it so?	
☐ Instructions not clear	navigation not clear
dther (please specify)	
If you are the person responsible for ma bookings, how easy is it for you to do so	
еаsy	some difficulties but can manage
☐ I often have to ring for help	☐ I get another staff member to do it
If you experience difficulties, what type	are they?
not clear how to save	not clear how to navigate
not clear how to duplicate booking	not clear how to look at bookings
other (please specify)	
Do you use the booking duplication fundal details are identical except for a char	ction (e.g. you have a two day event when nge of date)?
□ yes	■ no
If not, why not?	
Once you have made your booking, how system to monitor its progress in the lea	v frequently do you check it via the online ad up to the booking?
once a week	every couple of weeks or so
□ never	□ other

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How often would you book Interpreters or notetakers through us?

several times a week	once a week
several times a month	once a month
once every couple of months	once or twice a year
If you book Interpreters or notetakers	frequently, how often is the booking filled?
■ always	more than 90% of the time
more than 80% of the time	more than 70% of the time
only 50% of the time	less than 50% of the time
If we have been unable to provide you been informed of this inability to servi	u with an interpreter or notetaker, have you ce in a timely manner?
■ yes	■ no
If the answer to the above question w	as no, how much notice did you receive?
What happened to the event (e.g. Into not provide you with an interpreter or	erview, meeting, training, etc) where we could notetaker?
■ It was cancelled	■ It went ahead without the Deaf person
■ It was postponed	■ It went ahead and we wrote notes
lt went ahead and we communicate	led in a different way—please specify:
	oking at short notice, for example for the same provide you with an interpreter or notetaker?
■ yes	■ no
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Viode

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1 L always late	2 -	3 <b>-</b>	<b>-</b>	5 always arrive before the booked time
1	2 •	3 <b>-</b> -	4	5
unprofessional i dress or manner				dress and manner
Do you ha	ve any suggestion	s on how your Inte	rpreter or notetake	r could improve?
Do you ha	ve any concerns a	bout our service's	confidentiality?	
■ no	■ yes—please s	pecify:		
Are the Im	olces you receive	accurate and easy	to understand?	
yes	no—please sp	ecity:		



Vlodeaf

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1 always late	2  - 	3 <b>-</b> 	-	5 Iways arrive before the booked time
1	2 P	3 <b>P</b>	Ė	5
unprofessional in dress or manner Do you hav	e any suggestion	s on how your inte	rpreter or notetaker	dress and manner could improve?
	e any concerns a	pecify:	confidentiality?	
	olces you receive	accurate and easy	to understand?	

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Do you have any suggestions on how we could improve our service or any other comments that you would like to make?

Would you be willing to have the VAIS manager contact you to disc feedback?	ouss your
no yes—please provide your name and contact details:	

Thank you for taking the time to complete this survey. Your feedback is valuable to us as we strive to provide you with a better service.

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## **Appendix R: KCSL Resident Survey 2008**

# KCSL Resident Survey 2008

#### **Build Rapport With Resident**

- a. Get used to the way people communicate and informally check for consistency in their conversation; and
- b. Introduce yourself to the Resident give your name and where you are from

#### Briefly Explain Why You Are Here

- c. I'm talking with people about what they think about where they live;
- d. Kirinari needs information about what they do well and not so well so they can get better and better; and
- e. The government gives Kirinari money. They want to know how Kirinari is going and any ways they can help make Kirinari better.

#### Voluntary

- f. You don't have to talk to me:
- g. You don't have to answer questions you don't want to; and
- h. You can choose to stop the interview or have a break.

#### **Private And Confidential**

- i. I won't tell anyone what you say;
- j. If people ask me anything about our chat I won't tell them; and
- k. When I write the report, no one can tell what you said

#### Importance Of Everyone Being Safe

I. I will not tell your answers to anyone with one exception. If you tell me something that I think means you are in danger or being abused in some way, I will have to tell people who can help. I have to do this to protect you from further harm. No staff here will know what you say.

#### This Is Not A Test

- m. Please tell me what you honestly feel;
- n. There is no right or wrong answer; and
- o. If you don't understand the question let me know and l'll ask it a better way; and
- p. It is okay to say you don't know to a question.

#### Check people want to proceed.

KCSL Resident Survey -2008

4	What is the gender of the Resident?
a	Male
_ _ _	Female
	What is the age of the Resident?
a a	Under 18
_ ] b	18 – 34
_ c	35 – 44
_ _ d	45 – 54
e	55 65
f	66 +
3	Please indicate the Resident's <b>primary</b> disability (please tick one only)
a a	Intellectual
_ b	Specific Learning / Attention Deficit Disorder
,	Autism
a	Physical
e	Acquired Brain Injury
f	Neurological
g	Deaf Blind (Dual Sensory)
h	Vision
_ i	Hearing
j	Speech
k	Psychiatric
١ 🗆	Developmental Delay
) '	Where was the interview conducted?
	Who was present during the interview?

Pu	rpose	My Self describes the personal, physical and emotional part of Personal Outcomes, the presence of which enables people to explore tomorrow's possibilities and choices.
Ind	licators	Proportion of people who feel safe in their residence & surrounding area Proportion of people are connected to natural support networks Proportion of people who have intimate relationships Proportion of people who feel free from abuse and neglect Proportion of people who exercise rights Proportion of people who experience continuity and security Proportion of people who have the best possible health Proportion of people who decide when to share personal information
I. Do	you feel s	afe living here? (Probe for further comments)
a	Yes, feel	safe here
<b></b> ь	In Betwe	een
c	No, don	't feel safe
d	Unclear	/ No Response
If the re	esident answe	ered <b>c</b> in relation to Question 1, please state below <b>▼</b>
	<b>Q</b>	
<b>2.</b> Do	you feel s	afe in your area/neighbourhood? (Probe for further comments)
a	Yes, feel	safe (unsafe at night okay)
ь	In-betwe	een
c	No, feel	scared — Please Specify
d	Not app	licable (does not go out / not aware)
e	Unclear	/ No Response
If the re	esident answe	ered <b>c</b> in relation to Question 2, please state below ▼
<b>3.</b> Ca	n you be al	one/by yourself as much as you want?
a	Yes, hav	e enough time on own
b	No, wish	n I had more time alone
c		licable - lives alone
d d	Unclear	/ No Response
<b>4.</b> Ca	,	ontact/visit your family as much as you want?
a		e enough family contact
□ ь		n I had more family contact
☐ d		licable — no living family / No Response
	Officical	, ito Response
	,	someone you can talk to about personal matters?
	es, a family es, a staff r	
KCSL Re	sident Sur	vey –2008

□ ° Sometimes □ ° No □ ° Unclear / No Response
6. Do you feel healthy?
□ a Yes, I feel healthy □ b No, I am often feeling ill □ c Unclear / No Response
7. Do you have regular visits to Doctor, Dentist, or other health professionals?
Yes, I have regular visits  No, wish I had more medical checkups Unclear / No Response
8. Can you tell me about what rights you have exercised?
Yes, I have exercised my rights  No, wish I had more opportunity to exercise my rights  I do not understand what rights I have  Unclear / No Response
9. Have there been times when you believed you were treated unfairly?
Yes, I have been treated unfairly No, I have always been treated fairly I do not understand what is fair Unclear / No Response
10. Do you have enough money to pay your expenses?
<ul> <li>Yes, I have sufficient money</li> <li>No, I do not have sufficient money</li> <li>Not Applicable – money is not managed by resident</li> <li>Unclear / No Response</li> </ul>
11. Do you have consistency that you need with staffing?
Yes, I have satisfactory staff consistency No, I do not have satisfactory staff consistency Unclear / No Response
12. Do you know who shares your personal information?
<ul> <li>Yes, I know who has access to my information</li> <li>No, I do not know who has access to my information</li> <li>Unclear / No Response</li> </ul>

KCSL Resident Survey -2008

Му	World	
Pur	pose	My World encompasses the outcomes resulting from connectedness within the community.
Indi	cators	Proportion of people who choose where and with whom they live Proportion of people who interact with members of their community Proportion of people who choose services Proportion of people who live in integrated environments Proportion of people who perform different social roles Proportion of people who choose where they work Proportion of people who use their environments
13. E	oid you cho	ose the people you live with?
a b c d	No, som	ssisted h assistance or chose some of the people who share with neone else chooses for me / No Response
14.	Did you cho	ose to live at (home/residence)?
a b c d	Yes, with No, som	ssisted (includes with family – estate agents) h assistance (from coordinator, service provider) neone else chooses for me / No Response
15.	Oo you like	living here?
a b c d	In Betwe No, don	e where I live een 't like it here / No Response
16.	o you like	the people you live with?
a b c d e e	Some of A few, n No	them, most of the time them, some of the time ot often / No Response
17.	o you wan	t to move out of (home/residence) where you live?
a b c d e e	Yes, for In Betwe No, wan	positive reasons (e.g. closer to home) negative reasons (e.g. don't like it here) een it to spend time here / No Response
18. E	Oo you have	e other friends you like to talk to or do things with?
a b c d	Yes, frie No frien	nds who are NOT staff or family nds are all staff or family; unsure of status ds / No Response

19. Can you see your friends when you want to? (Are there any restrictions placed on when they can see friends?)

KCSL Resident Survey –2008

a	Yes, can see them when I want
_ ь	Sometimes
c	No
	Not applicable - doesn't have friends
_ e	Unclear / No Response
	'
20 D	you sometimes go out to eat? (Consistency Question, do not rephrase)
<b>20.</b> DO	you sometimes go out to eat: (Consistency Question, do not repirase)
a	Yes
Ь	No
c	Unclear / No Response
<b>21.</b> Do	o you go shopping?
a	Yes
	No
□ b	
c	Unclear / No Response
<b>22.</b> Do	you go out for exercise or play sports?
a	Yes
	No, I would like to
_ c	No, I don't want to
d	Unclear / No Response
<b>23.</b> Do	you go out for entertainment?
<b>23.</b> Do	you go out for entertainment? Yes
_	
a	Yes
a	Yes No, I would like to
a b c d	Yes No, I would like to No, I don't want to Unclear / No Response
a b c d	Yes No, I would like to No, I don't want to Unclear / No Response  o you go to church or religious events?
a b c d	Yes No, I would like to No, I don't want to Unclear / No Response  o you go to church or religious events? Yes
a b c d d	Yes No, I would like to No, I don't want to Unclear / No Response o you go to church or religious events? Yes No, I would like to
a b c d d d d d d d d d d d d d d d d d d	Yes No, I would like to No, I don't want to Unclear / No Response  o you go to church or religious events?  Yes No, I would like to No, I don't want to
a b c d d	Yes No, I would like to No, I don't want to Unclear / No Response o you go to church or religious events? Yes No, I would like to
a b c d d d d d d d d d d d d d d d d d d	Yes No, I would like to No, I don't want to Unclear / No Response  o you go to church or religious events?  Yes No, I would like to No, I don't want to
24. Do	Yes No, I would like to No, I don't want to Unclear / No Response  O you go to church or religious events?  Yes No, I would like to No, I don't want to Unclear / No Response  then you want to go somewhere, do you always have a way of getting there or not?
a b c c d d d d d d d d d d d d d d d d d	Yes No, I would like to No, I don't want to Unclear / No Response  o you go to church or religious events?  Yes No, I would like to No, I don't want to Unclear / No Response
24. Do	Yes No, I would like to No, I don't want to Unclear / No Response  o you go to church or religious events?  Yes No, I would like to No, I don't want to Unclear / No Response  then you want to go somewhere, do you always have a way of getting there or not?  Yes, almost always - travel by self, get lift from family or staff Sometimes
24. Do	Yes No, I would like to No, I don't want to Unclear / No Response  o you go to church or religious events?  Yes No, I would like to No, I don't want to Unclear / No Response  then you want to go somewhere, do you always have a way of getting there or not?  Yes, almost always - travel by self, get lift from family or staff Sometimes No, almost never
24. Do	Yes No, I would like to No, I don't want to Unclear / No Response  o you go to church or religious events?  Yes No, I would like to No, I don't want to Unclear / No Response  hen you want to go somewhere, do you always have a way of getting there or not?  Yes, almost always - travel by self, get lift from family or staff Sometimes No, almost never Not applicable - does not have wishes or does not ask to go out
24. Do	Yes No, I would like to No, I don't want to Unclear / No Response  you go to church or religious events?  Yes No, I would like to No, I don't want to Unclear / No Response  then you want to go somewhere, do you always have a way of getting there or not?  Yes, almost always - travel by self, get lift from family or staff Sometimes No, almost never Not applicable - does not have wishes or does not ask to go out Unclear / No Response
24. Do	Yes No, I would like to No, I don't want to Unclear / No Response  O you go to church or religious events?  Yes No, I would like to No, I don't want to Unclear / No Response  then you want to go somewhere, do you always have a way of getting there or not?  Yes, almost always - travel by self, get lift from family or staff Sometimes No, almost never Not applicable - does not have wishes or does not ask to go out Unclear / No Response  O you sometimes go out to eat? (Consistency Question, do not rephrase)
24. Do	Yes No, I would like to No, I don't want to Unclear / No Response  O you go to church or religious events?  Yes No, I would like to No, I don't want to Unclear / No Response  then you want to go somewhere, do you always have a way of getting there or not?  Yes, almost always - travel by self, get lift from family or staff Sometimes No, almost never Not applicable - does not have wishes or does not ask to go out Unclear / No Response  O you sometimes go out to eat? (Consistency Question, do not rephrase) Yes
24. Do	Yes No, I would like to No, I don't want to Unclear / No Response  O you go to church or religious events?  Yes No, I would like to No, I don't want to Unclear / No Response  then you want to go somewhere, do you always have a way of getting there or not?  Yes, almost always - travel by self, get lift from family or staff Sometimes No, almost never Not applicable - does not have wishes or does not ask to go out Unclear / No Response  O you sometimes go out to eat? (Consistency Question, do not rephrase)

KCSL Resident Survey –2008

27.	Did you have a choice of where you work (including school or day placement)?
a b c d	No, I did not have an acceptable choice of where I work Not applicable – spends days at home
28.	Is there anything you can't do because you don't have the proper equipment or modifications?
a   b   c	Yes , some things No, I can do most things
29.	Do you know how to use the appliances and equipment? (stove, microwave, telephone, washer, etc)
a   b   c   d	Yes, some things No
30.	Do you spend time at home AND work with people without disabilities?
a   b   c	No
31.	<b>D</b> o you have any specialised equipment that helps you, such as elbow crutches, hearing aid, wheelchair?
a b c c d d e f	Yes, complete access but lack knowledge of use Yes, limited access / need more devices No Access Not Applicable
32.	Do you have things such as communication boards or interpreters that you need to communicate with people?
a   b   c   c   d   d   e   f	Yes, equipment / interpreter present but lack knowledge of use Yes, limited access / need more equipment / interpreters / locations No Access

Му [	)reams			
Purpose Indicators		My Dreams reflects outcomes associated with discovery, choice and self determination.		
		Proportion of people choose personal goals Proportion of people realise personal goals Proportion of people participate in the life of the community Proportion of people have friends Proportion of people are respected		
<b>33.</b> D	o you choose go	als for yourself?		
a b c d	Yes, lots Yes, sometimes No Unclear / No R			
35. H	ave you attained	any goals in the last year?		
a b c	Yes No Unclear / No R	desponse		
<b>36.</b> D	o you choose wh	nich services you use? (Medical, hairdresser, bank, shopping, etc)		
a b c d e	Yes, with assist Sometimes / S	Some things else chooses for me		
<b>37.</b> D	o you choose ho	w you spend your evenings and weekends? (Do you choose what to do?)		
a b c d d e e	Yes, with assist Sometimes / S	Some things else chooses for me		
<b>38.</b> D	o you have some	one who helps you with your money?		
a b c d d e				
<b>39.</b> C	an you get your r	money when you want it?		
a b c d	Yes, can get mo	oney whenever I want it oney but with some restrictions (e.g. weekly budget) my money when I want it - always need permission desponse		
money, o		things here if you want to, so you can do more things for yourself? (e.g. cooking, looking after your		

☐ a ☐ b	Yes, if want to, most things Sometimes, some things
c	No
d	Not applicable (includes no need, not interested, not able to)
e	Unclear / No Response
41. Aı	re the staff able to understand what you want?
a	Yes, most staff most of the time
□ "	Some staff, sometimes
c	No few staff, rarely
d	Unclear / No Response
42 0	
	o you understand the staff when they talk to you?
a b	Yes, most staff most of the time Some staff, sometimes
	No few staff, rarely
	Unclear / No Response
_	
<b>43.</b> D	o the staff treat you with respect? (Do they treat you like an adult? Are they polite?)
a	Yes, most staff most of the time
b	Some staff, sometimes
_ ·	No few staff, rarely
d	Unclear / No Response
<b>44.</b> D	o they treat everyone with respect?
a	Yes, most staff most of the time
□ •	Some staff, sometimes
c	No few staff, rarely
d	Unclear / No Response
45 W	/hen you get a letter, who opens it?
_	
a □ b	Someone else opens some or all of my mail I open my own mail
	Not applicable, receives no mail
□ ₄	No response, unclear response
<b>46.</b> Di	id you tell that person it was OK to open your letter?
a	Mail is not opened without permission
□ ь	Some mail is opened without permission
☐ c	All mail opened without permission
☐ e	Not applicable, not able to give permission  No response, unclear response
<b>47.</b> D	oes anyone come into your room without asking first? (Targets staff)
a	No-one enters the bedroom without permission
b	Yes people always/sometimes enter without permission
KCSL Res	sident Survey –2008

c d e	Residents only come in without permission Unclear / No Response Not applicable - not able to give permission
<b>48.</b> At	home, are there some things you're not allowed to do?
□ a □ b □ c	Yes No Unclear / No Response
	ent answered <b>a</b> in relation to this Question, please state below ▼
<b>49.</b> At	home, is there anywhere in the (house/building) you can't go?
a b c	Yes No Unclear / No Response
If the resid	ent answered <b>a</b> in relation to this Question please state below <b>▼</b>
<b>50.</b> At	home, does anyone, or has anyone, hurt you?
a b c	Yes No Unclear / No Response
If the resid	ent answered <b>a</b> in relation to this Question , please state below ▼
<b>51.</b> At	home, does anyone threaten you or make you do anything you don't want to?
a b c	Yes No Unclear / No Response
lf the resid	ent answered <b>a</b> in relation to Question 53, please state below <b>▼</b>

<b>52</b> \\/	hen you have a complaint or problem do staff listen to you? Probe for comments if negative answer given					
_						
a	Yes					
ь	Some staff or sometimes					
c	No					
d	Unclear / No Response					
f the resid	lent answered <b>b</b> or <b>c</b> in relation to this Question, please provide further comments below ▼					
<b>53.</b> Ar	re complaints and problems usually sorted out? Probe for comments if negative answer given					
Па	Yes					
□ •						
	Sometimes					
	No					
	Unclear / No Response lent answered <b>b</b> or <b>c</b> in relation to this Question, please provide further comments below ▼					
the resid	ent answered b of this relation to ans Question, please provide further comments below \$					
	<b>Q</b>					
<b>54.</b> Ho	ow would you feel about making a complaint to a support worker or manager? Probe for comments					
a	Comfortable / Okay					
_ □ •	In-between					
$\Box$	Uncomfortable / Not okay					
□□	Don't know					
e	Unclear / No Response					
f the resid	lent answered <b>b, c</b> or <b>d</b> in relation to this Question, please provide further comments below ▼					
	Tresterior animiento a, e en e in remaion de una question, preuse provide jurdier commenta below 1					
	the staff who support you change too often? (Are there too many new staff? Do the staff keep leaving?)					
<b>55.</b> Do	the staff who support you change too often? (Are there too many new staff? Do the staff keep leaving?)					
<b>55.</b> Do	No, they stay, don't change too often					
<b>55.</b> Do	No, they stay, don't change too often Some staff OR sometimes					
<b>55.</b> Do	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving					
<b>55.</b> Do	No, they stay, don't change too often Some staff OR sometimes					
<b>55.</b> Do	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving					
55. Do	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response ow happy/satisfied are you with (service)?					
55. Do	No, they stay, don't change too often  Some staff OR sometimes  Yes, they change too often, keep leaving  Unclear / No Response  ow happy/satisfied are you with (service)?  Satisfied, happy					
55. Do	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response ow happy/satisfied are you with (service)? Satisfied, happy In-between, neither satisfied or dissatisfied					
55. Do	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response ow happy/satisfied are you with (service)? Satisfied, happy In-between, neither satisfied or dissatisfied Dissatisfied, unhappy					
55. Do	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response ow happy/satisfied are you with (service)? Satisfied, happy In-between, neither satisfied or dissatisfied					
55. Do	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response ow happy/satisfied are you with (service)? Satisfied, happy In-between, neither satisfied or dissatisfied Dissatisfied, unhappy					
55. Do	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response ow happy/satisfied are you with (service)? Satisfied, happy In-between, neither satisfied or dissatisfied Dissatisfied, unhappy Unclear / No Response					
55. Do  a b c d  56. Ho  57. (If 6	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response ow happy/satisfied are you with (service)?  Satisfied, happy In-between, neither satisfied or dissatisfied Dissatisfied, unhappy Unclear / No Response  dissatisfied) Why are you unhappy with Kirinari?					
55. Do  a b c d  56. Ho  57. (If a	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response ow happy/satisfied are you with (service)? Satisfied, happy In-between, neither satisfied or dissatisfied Dissatisfied, unhappy Unclear / No Response  dissatisfied) Why are you unhappy with Kirinari? Access to services					
55. Do  a  b  c  d  56. Ho  57. (If o	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response  whappy/satisfied are you with (service)?  Satisfied, happy In-between, neither satisfied or dissatisfied Dissatisfied, unhappy Unclear / No Response  dissatisfied) Why are you unhappy with Kirinari?  Access to services Choice / Self-determination Quality of life					
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55. Do  a b c d  56. Ho  57. (If o  d  c d  c d  c d  c d  c d  c d  c d	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response  Ow happy/satisfied are you with (service)?  Satisfied, happy In-between, neither satisfied or dissatisfied Dissatisfied, unhappy Unclear / No Response  dissatisfied) Why are you unhappy with Kirinari?  Access to services Choice / Self-determination Quality of life Personal development / Community inclusion Relationship with service and staff Quality of service					
55. Do  a b c d  56. Ho  57. (If o d  c d  f	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response  Ow happy/satisfied are you with (service)?  Satisfied, happy In-between, neither satisfied or dissatisfied Dissatisfied, unhappy Unclear / No Response  dissatisfied) Why are you unhappy with Kirinari?  Access to services Choice / Self-determination Quality of life Personal development / Community inclusion Relationship with service and staff					
55. Do  a b c d  56. Ho  57. (If o  d  f  g  g	No, they stay, don't change too often Some staff OR sometimes Yes, they change too often, keep leaving Unclear / No Response  ow happy/satisfied are you with (service)?  Satisfied, happy In-between, neither satisfied or dissatisfied Dissatisfied, unhappy Unclear / No Response  dissatisfied) Why are you unhappy with Kirinari?  Access to services Choice / Self-determination Quality of life Personal development / Community inclusion Relationship with service and staff Quality of service Rights, privacy, confidentiality					

(Can be asked at any stage of the interview)

KCSL Resident Survey -2008

Open Ended Questions and Comments

EQ \A/bet and the best things	ahaut living have?
59. What are the best things	about living nere:
<b>Q</b>	
60. What are some of the thi	ngs you don't like about living here?
61. If you could change anythi	ing about living here, what would you do?
or. If you could change anythin	ing about itting here, titlate troute you do.
<b>Q</b>	
	- A H.J
	• That's all the questions I have.
	<ul> <li>Do you have any questions?</li> <li>Is there anything else you would like to say?</li> </ul>
	1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1
	Thank you very much for your help.

Survey Informat	ion			
I certify that this i		te and complete interv	iew condu	ucted consistent with Kirinari's use
Interviewer's signatu	ire		Date	
Please indicate w	ho you interview	ved .		
Resident		Resident with Assistance		Relative or Friend Advocate Service provider staff
This interview wa	s conducted			
☐ In person		By Telephone		Both In Person and By Telephone
Did the resident f	ail the consisten	cy question?		
Yes		No		
Were there any p Question Number		e questions or responsicult to understand, upset		feel resident understood
General Commer	its / Observation	15		

## **Appendix S: Better Hearing Australia Questionnaire**

# **Better Hearing Australia (VIC) Questionnaire**

At Better Hearing Australia (Vic) we aim to provide a high standard of service to everyone and we care about getting things right. Your views are important because they help us to check that we are giving you the best service possible.

Please help us to help you and others by completing the enclosed questionnaire as soon as possible and returning it to us in the stamped self-addressed envelope provided. It will only take a few minutes of your time.

Th	anking you in anticipation.				
Gv	ven Rosengren, Julie McMillan, Anna Norris				
(H	earing Loss Management Advisors—Service Delivery Staff)				
Na	me (optional):				
1.	1. Where / how did you find out about Better Hearing Australia (Vic)  □ family □ friend □ GP □ advertising □ website				
	□ telephone book □ community directory □ other				
2.	Which of these services did we provide for you?  □ Hearing screening & information				
	□ Staff Training				
	☐ Guest Speaker for your organization or club				
	□ Individual Consultation □ about hearing loss management				
	□ about tinnitus				
	□ other				
	Was the consultation □ in person				
	□ over the phone				
	□ via email				
	□ in writing				
3.	Did the advisor provide you with helpful information?  □ Not helpful □ Helpful □ Very helpful				
	(see over)				

4. What level of understanding did you gain?

	□ No understanding □ Some understanding
	□ A lot of understanding
5.	If you were provided with written information (notes, pamphlets, brochures) how helpful was this?
	□ Not helpful □ Helpful □ Very helpful
6.	Have you acted on some or all of the advice you were given or followed through with recommendations? $\hfill Yes \hfill $
7.	Has the information / advice provided by the advisor enabled you to manage with
	greater independence or helped you to help your client/s manage with greater independence? $\hfill\Box$ Yes $\hfill\Box$ No
	Overall, how satisfied were you with the service provided? ot satisfied 1 2 3 4 5 6 7 8 9 10 Very Satisfied
9.	Would you recommend Better Hearing Australia's (Vic) services to friends / family / colleagues after your experience? $\Box$ Yes $\Box$ No
10	. Please feel free to add any comment. We welcome both positive and negative feedback.
_	
_	
	Thank
vU	<b>u.</b>

# Appendix T: Abilities Unlimited Family Support Plan and Needs Assessment

FAMILY SIIPPORT PLAN	Date Plan Developed:

Individual's Name:	Date of
Parent/Guardian	SS #:
Street Address:	Family Tel #:
City/State/Zip Code:	
	FY of Plan
Lead Family Support	Primary Language of Family is:
Area Office Service	
~	

•	T '1	D (**	
I.	Family	Prof1	le



Type in this space. If you need to add to this area, click at the end of the last word and continue typing.

### **B. FAMILY STRENGTHS/CAPACITIES**

Type in this space. If you need to add to this area, click at the end of the last word and continue typing

	C. SIGNIFICANT ISSUES IDENTIFIED BY THE FAMILY	
Type in this space.	If you need to add to this area, click at the end of the last word and continue typing	

# D. GOALS/VISION FOR INDIVIDUAL'S FUTURE (1-3 YERS, 3 TO 6 YEARS)

Type in this space. If you need to add to this area, click at the end of the last word and continue typing

# E. FUTURE PLANNING AND INFORMATIONAL NEEDS

Type in this space. If you need to add to this area, click at the end of the last word and continue typing

### II. DMR FAMILY SUPPORT SERVICES TO BE PROVIDED

General FS Med	lically Fragile Programs	IFFS-Intensive Flexible Family Supports
A. CORE SERVICES		
Family Support Provider Agency	Service	Frequency/Amount of Hours
INDIVIDUALIZED FLEXIBLE	E SUPPORTS FOR FAMILIES	
{stipends, direct provider agency payments, agency hired staff for families}		

Family Support Provider Agency	Services & Items to Be Purchased	Frequency/AMOUNT OF Hours/
7 11		
		Rates or Total Dollars

# PLEASE NOTE: Remember to submit any required Prior Approvals.

C. SPECIALITY SERVICES	{Autism Support Center. After Scho	ool Programs, Camps, Planned Facility-Based
Respite, Social/Recreational Program	ns} and other DMR funded in-home supports {cl	linical, behavioral, nursing}
Family Support/Specialty Project	Agency	Specify Amount of Service

### III. NON-DMR SUPPORT SERVICES

n; SSI; Home Health Aides}	
Agency	Specify Amount of Service
	a; SSI; Home Health Aides}  Agency

B. RESOURCES TO I	BE PURSUED		
Resource/Issue	Potential Resource/Provider	Estimated Amount of Hours  / Dollars	Responsible Party

			,	1
Please check boxes if complete	ed.			
Family Support Provider Agen	cy Staff have discussed emergen	ncy planning with my family.		
My family has develo	oped a plan in case of an emerger	ncy and/or natural disaster.		
The Department of Mental Rereceives quality services and st	etardation and its contracted pro	oviders need your help in a	ssuring that your family m	ember
My family will comply with a Guidelines and Procedures."	all Departmental requirements as	s specified in the most curren	nt version of the "Family S	upport
My family will participate in provide input to the Departmen	quality assurance activities, sucnt through other approaches.	h as respond to satisfaction	surveys, attend family foru	ıms or
My family will allow in- home	visits as needed.			

My family will provide orientation to staff worker medical needs, and other unique needs and character	rs on the needs of my family member, including emergency procedures, existics.
This only applies to families who choose to use a provide supports.	their flexible funding allocation to directly hire and pay individuals to
My family assumes the responsibility for the review	w of qualifications and the hiring and supervision of individuals hired by
my family, and understands that this is not the response	onsibility of the Family Support Provider Agency. My family will comply
with related Departmental requirements as stated in	the DMR "Family Support Guidelines and Procedures."
Additional Comments/Specifications:	
Family Member/Guardian:	Date:
	Date:
Family Support	Date:
Area Director (or designee):	Date:
Regional Director (or designee):	Date:
Service Coordinator has reviewed the Plan and placed	d the original copy in the individual's case file. SC Initials:

Family gave verbal approval of plan.
Date:
FSPA or DMR Staff Initials:

# **FAMILY SUPPORT PLAN**

The lead Family Support Provider Agency, (as determined by the family and DMR), should complete this plan with input from the family, and individual as appropriate, and with information from any other involved family support provider agencies and DMR staff.

**Family Profile:** This section is intended to provide a brief portrait of the family. This background information should assist in the creation of a plan which is responsive to individual/family goals and needs.

**Family composition**: Provide a brief description of the family unit and any relevant information about the individual and/or parents/caregivers.

**Family Strengths/Capacities**: Highlight family strengths and resources such as a strong natural support network, an involved extended family, solid connections in the community, knowledge about community resources, etc

**Significant Issues** identified by the family in caring for their child/adult family member: Identify extenuating support needs of the individual, caregiver stressors (single or elder caregiver, other family member who is ill or disabled), accessibility problems, language/cultural barriers, social isolation, etc.

Goals/Vision for the Individual: Reflect individual/family goals for the future, such as building more independence in a variety of skill areas (e.g. travel training,

managing a budget, grocery shopping, expanding social activities, learning a hobby, getting a part-time job or volunteer opportunity, etc.). It is expected that the nature of goals will vary based on the age of the individual. The intent is to support the family and individual in thinking and exploring future expectations and is not tied to any specific DMR or program service model. The identified goals may lead to provider or DMR staff assisting to identify information or resources that may be helpful, but does not become the sole responsibility of the agency to fulfill.

**Future Planning/Informational Needs**-Assistance in identifying and anticipating next stages in life and emerging needs, ie. transition, 688, guardianship information, etc.

# **DMR Family Support Services to be Provided**

Put a check next to the boxes to indicate the type of family support services the family will be receiving.

### **CORE SERVICES**

Include the specific **core service elements** that the family will be receiving from your agency for both General Family Support and Enhanced Family Support Programs {Intensive Flexible Family Supports (IFFS) and Medically Fragile Programs.} These services are available to **all** program participants which includes family support coordination and may also include support groups, training/educational sessions, family social events, etc.. Please be specific in the amount and frequency of services, for example: Family Support Coordination 3 times/year; Sibshop- 5 weeks @ 2hours.

# **B. INDIVIDUALIZED FLEXIBLE SUPPORTS FOR FAMILIES**

Put **all** flexible funding and resources provided to the individual family here for both General and Enhanced Family Support programs. This section should encompass **all** individualized supports that are driven by the particular needs of the individual and family including:

**stipends** or **family reimbursement** for the purchase of goods, (e.g. adaptive equipment), or services, (e.g. family hired respite worker for 5 hours/month @ \$12.00/hour)

**direct provider agency payments** for goods or services, (e.g adaptive equipment, lessons, membership, etc). and family-identified, agency-paid respite workers

**agency-hired staff/respite workers** who have been hired by the agency and provide supports to a specific individual/family based on identified needs and from the family's total resource allocation.

Provide the amount of flexible funding, its purpose, and frequency if relevant. Please be specific regarding the services and items to be purchased with this funding. For example: adaptive computer software- \$50.00, respite @ 10 hours/month @ \$15.00/hour, membership at the YMCA for \$250.00, replace hoya lift pads-\$1,000.00, agency hired skill trainer – weekly @ 4 hours.

## SPECIALITY SERVICES TO BE PROVIDED

List all DMR family support specialty services that will be provided (i.e., autism support centers, summer camps, social/recreational programs, planned facility-based respite, after school programs, etc.). Please be specific. Examples include: After school program at Delta Projects, 2 times/weekly; Planned facility-based respite at West Street Inn, 6 times/year.

In addition, list any other DMR funded in-home supports that are being provided to the individual and family, such as behavioral consultation, clinical services, nursing support, etc.

III. Non-DMR Support Services

### A. NON-DMR SUPPORT SERVICES CURRENTLY RECEIVING

Only include the services and entitlements the individual/family is currently receiving that are not funded through DMR (e.g., PCA, other state agency services, After School Program at YMCA, Home Health Aides, SSI, food stamps, fuel assistance, etc.). If these support needs are unmet, include that information in Section "B."

# B. NON-DMR RESOURCES/ISSUES TO BE PURSUED

List additional resources to be pursued that will support the family in caring for their family member and include the individual in his or her community. Under "Potential Provider," list an agency or possible resource to provide services, (if none, put TBD - to be determined). "Responsible Party" would be the person who will follow up or

search out the resource (e.g., family support provider, service coordinator, family, etc.).

If a DOE/DMR application is going to be developed, please include it in this section."

Note FSPA if identified under Potential Provider, otherwise put "TBD."

### **ASSURANCES**

The Assurances must be reviewed with the family prior to their signing off on the Family Support Plan.

### **SIGNATURES**

Please have a family member sign-off on plan, as well as individual (when appropriate). If family signature has not been obtained, please check off block if family gave verbal permission to FSPA staff until actual signature has been secured.

## **DISTRIBUTION OF THE FAMILY SUPPORT PLAN**

After the Area Director or his/her designee has signed the Plan, the Service Coordinator will make sure the original, signed copy is placed in the individual's case file. A copy of the signed Plan will be sent back to the Family Support Provider Agency for their files, and they are also responsible to send a signed copy of the Plan to the family.

# Appendix U: RNIB Network 1000 Survey Report



Supported by



UNIVERSITY<sup>OF</sup> BIRMINGHAM

# Network 1000

# Finance and entitlement:

Visually impaired people's take up of Disability Living Allowance and Attendance Allowance

February 2008

**Graeme Douglas, Sue Pavey and Christine Corcoran** 

# $\label{thm:control} \textbf{Visual Impairment Centre for Teaching and Research} \ (\textbf{VICTAR})$

# **School of Education**

# **University of Birmingham**

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We would like to acknowledge and thank Thomas Pocklington Trust, RNIB, and GDBA for funding Network 1000 Phase 2.

## Executive summary

This report presents findings from Network 1000 Survey 2. The data was collected during interviews with 884 visually impaired people between November 2006 and January 2007. All the participants were registered as either blind or partially sighted and lived in Great Britain. Sampling and analysis accounted for the age distribution of the visually impaired population.

The findings presented in this report focus upon the Disability Living Allowance and Attendance Allowance.

The key findings in relation to Disability Living Allowance (DLA) are as follows:

- An estimated 85% of people aged between 18 and 64 who are registered visually impaired are currently receiving DLA.
- Therefore, an estimated 10,000 people registered visually impaired are currently not receiving the DLA but are eligible to apply.
- The mobility component of the DLA is more commonly received than the care component. It is relatively rare for visually impaired people to receive the higher rate within either the mobility or care components of the DLA.
- There is clear evidence that receiving advice is associated with successful application for DLA.
- Over a quarter of people had to appeal before they received their current rate of DLA.

The key findings in relation to Attendance Allowance are as follows:

- An estimated 64% of people age 65 years and over who are registered visually impaired are currently receiving Attendance Allowance.
- Therefore, an estimated 73,000 people registered visually impaired are not currently receiving Attendance Allowance but are eligible to apply.
- Of those people who receive Attendance Allowance, the majority receive the lower rate.
- There is clear evidence that receiving advice is associated with successful application for Attendance Allowance.
- Over 20% of people had to appeal before receiving their current rate of Attendance Allowance.

Introduction and description of the Network 1000 sample

Background

In March 2004, Vision 2020 UK and the Visual Impairment Centre for Teaching and Research (VICTAR) at the University of Birmingham were commissioned by the Big Lottery Fund to carry out the research project "Network 1000: Surveying the changing needs of visually impaired people". The initial funding was for three years and covered 'Phase 1' of the broader Network 1000 project. Network 1000 Phase 2 started in April 2007 and has been funded by Thomas Pocklington Trust, RNIB and GDBA. Phase 2 aims to further analyse the data gathered in Phase 1 as well as maintain the Network 1000 sample.

The project has four key aims. The first was to establish a consultation network of over 1000 visually impaired people aged 18 and over. The second aim was to adopt a more longitudinal approach to data collection that would enable the project to report and record changes in circumstances over time and enable further comparative data to be evaluated. This report presents some of the *second* round of this data collection.

Thirdly, the project is underpinned by a commitment to consult with visually impaired people. To this end the research team have adopted a collaborative approach to ensure that people with a visual impairment have had an input into the design process.

Finally, the project aims to provide statistically useful data on the changing views, experiences and needs of visually impaired people that can be used to influence service development and provision. Our aim is to report not only the voices of those who have taken part in the survey, but also to ensure that the statistics produced from the survey will enable these voices to be generalised to the wider visually impaired population.

This report draws upon the data collected from 884 visually impaired people. The report focuses upon data relating to Disability Living Allowance and Attendance Allowance.

Description of the sub sample of directly interviewed participants (n=884)

At the time of the Network 1000 Survey 1, the sample consisted of 1007 visually impaired adults split across five age groups (see Douglas, Corcoran and Pavey, 2006). All the participants were on the registers of blind and partially sighted people held by 20 social services departments in England (15), Scotland (4) and Wales (1). This sample of 1007 was split between 960 visually

impaired people who were interviewed directly, and a further 47 Key Informant interviews (in which we interviewed people who were close to the visually impaired person who had learning or communication difficulties). 884 participants were interviewed directly in Network 1000 Survey 2 (a drop of 76). It is the results from these interviews in relation to 'Finance and entitlement' which are presented in this report. In addition, 38 Key Informants were also interviewed in this phase of work, though this data is not reported here.

The weighting used in the analysis in this report is based upon the age distribution of people on the 20 registers used in the sampling. This distribution is almost the same as estimates taken from the official registration figures for England (Department of Health 2003), Scotland (Scottish Executive 2003), and Wales (National Assembly for Wales 2003, note figures are for 2001-2). These figures combined enable an approximate base population and population distribution to be calculated. The Network 1000 survey results can be statistically generalised to this base population.

Table 1: Distribution of the sample across the five age groups of participants in Network 1000 Survey 2 by sex and distribution of population. Base: whole sample of directly interviewed participants (N=884).

Age group	Samp	le (n)	Total sample	Base population
1 150 Broup	Male	Female	(N)	Bust population
18-29	(57)	(76)	(133)	9,000
30-49	(98)	(104)	(202)	28,000
50-64	(100)	(105)	(205)	31,000
65-74	(70)	(90)	(160)	37,000
75+	(65)	(119)	(184)	255,000
Total	(390)	(494)	(884)	* 360,000

<sup>\*</sup>Based upon estimates taken from official registration figures for England (Department of Health 2003), Scotland (Scottish Executive 2003), and Wales (National Assembly for Wales 2003).

As with the Network 1000 Survey 1, the distribution of participants in the Network 1000 Survey 2 remains broadly even in terms of sex (but, as expected, when weighted it suggests a higher proportion of women to men in the population – particularly in older age groups). Due to the migration of some participants from one age group to another, along with the drop-out of some participants, the distribution of participants across the age groups has changed.

The weighting applied in the analyses in this report is the same as that used in Network 1000 Survey 1 analyses, with slight adjustment to scale for the different sample size.

#### Finance and entitlement

#### Introduction

In Network 1000 Survey 1 participants were asked about the different types of income that they received, for example pensions, various allowances, benefits and tax credits, and a range of other types of income. Network 1000 Survey 2 revisited the topic of finances, but rather than adopting such a broad overview, the interview explored two particular benefits in more detail – Disability Living Allowance (DLA) and Attendance Allowance. It is the presentation of these results which is the main focus of this report.

Researchers asked participants directly about their receipt of DLA and Attendance Allowance, plus follow-up questions about the details of the rates received and the process of applying. The DLA and Attendance Allowance were focussed upon in this survey for several reasons. Firstly, both benefits are specifically for people who are 'physically or mentally disabled' (Directgov, 2007). Secondly, both benefits continue to be the subject of a lot of attention by the visual impairment voluntary sector, both in terms of support in the process of application (e.g. RNIB website, Action for Blind People fact sheet) and campaigns (e.g. the cross-sector 'Taken for a ride' campaign in 2007). Thirdly, the rules of who is eligible to apply for both DLA and Attendance Allowance are relatively straightforward (linked to age and presence of a disability). Importantly, eligibility for application is *not* linked to income or to receiving other benefits. Pragmatically, it is a relatively easy benefit to investigate because researchers do not need to ask a series of complex questions about eligibility.

# Perceptions of financial situation

Before focussing upon DLA and Attendance Allowance, it is useful to consider the general financial context that people are experiencing. In both Network 1000 Survey 1 and 2 participants were asked questions about their personal perceptions of their financial circumstances. This included how well they felt they were managing financially, whether there was anything that they had gone without, and whether they had had difficulty paying for their accommodation.

The findings from the surveys suggest that the majority of visually impaired people felt that they were at least 'just about getting by' financially, with only 4% stating they were finding it quite difficult or very difficult. However, perceptions of financial situation were clearly linked with age, with people of working age having a less positive view – 46% of working age people described themselves as 'just about getting by' or worse, compared to 22% of retirement age people. Further, 12% of working age people described themselves as 'finding it quite difficult' or 'finding it very difficult'.

Participants were also asked whether there was anything that they had gone without or had to use less than they needed, because they could not afford it, over the past year. In line with the

previous discussion, visually impaired people of working age were less positive than those of retirement age -32% feeling they had gone without compared with 13% of people of retirement age.

Why do people of working age perceive themselves as financially worse off than people of retirement age? There are a number of possible explanations. Firstly, older people may be generally less likely to report difficulties compared to younger people. Other likely explanations are linked to actual wealth rather than reported perceptions of it. Perhaps the most obvious explanation is the relative low rates of employment amongst visual impairment people of working age compared to the sighted population (an employment rate of approximately a third, see Douglas et al, 2006).

Another explanation could be linked to paying for accommodation. An estimated 29% (n=406 of the sample) of visually impaired adults described themselves as paying for their accommodation (via mortgage or rental payments). Of these, an estimated 15% reported having difficulties keeping up with their housing payments over the previous year (an estimated 16,000 people with a registered visual impairment). This is proportionally more common amongst people of working age. Additionally, paying for accommodation was far more common in younger age groups -62% of those of working age either renting or paying for accommodation with a mortgage compared to 20% of those of retirement age.

These general findings relating to perceptions of financial situation are not explored in any great detail here. A more detailed exploration is planned which will include comparisons with data collected from the sighted population. Even so, the results indicate that significant numbers of people with a visual impairment have difficulty with their finances and this provides a useful context for exploring the take-up of two of the key available benefits – the DLA and Attendance Allowance.

## Disability Living Allowance (DLA)

The DLA is 'a tax-free benefit for children and adults who need help with personal care or have walking difficulties because they are physically or mentally disabled' (Directgov, 2007). It was introduced in April 1992, and can be applied for by people who are under the age of 65 at the time of application, though they can continue to receive the benefit beyond this age. People 65 years of age and older can apply for Attendance Allowance (assuming they do not already receive the DLA).

Of the sample, 539 participants were eligible to have applied for the DLA at time of interview because they were under the age of 65 years. These participants were asked a number of questions relating to the DLA. In the main, the analysis of DLA will focus upon these (539) participants under the age of 65 years, although a section later will also consider those who are 65 years and older who could have applied for DLA in the past.

Table 2. 'Do you currently get the Disability Living Allowance?' by three age groups. Base: all those eligible to apply for the DLA at time of interview (<65 years) (N=539), weighted.

	18-29 %	30-49	50-64	Total weighted %	Total sample (n)	Base Population (nearest 1K)
Yes	82%	81%	88%	85%	(450)	58,000
No	16%	18%	12%	14%	(82)	10,000
Don't know	2%	1%	0%	1%	(7)	1,000
Number interviewed	(132)	(202)	(205)	100%	(539)	68,000

We can estimate that 85% of registered visually impaired people aged between 18 and 64 are currently receiving the DLA. In terms of numbers, there are an estimated 68,000 people registered as blind or partially sighted in Great Britain between the ages of 18 and 64 years (based upon estimates taken from official registration figures for England (Department of Health 2003), Scotland (Scottish Executive 2003), and Wales (National Assembly for Wales 2003)). This allows us to estimate that 10,000 visually impaired people are currently not receiving the DLA but are eligible to apply. Of those not receiving DLA, the majority (69%) reported that

they had never applied while a significant proportion (29%) had applied unsuccessfully (2% could not remember).

### Different components and rates of the DLA

The DLA has two components – a care component and a mobility component. It is possible to receive one or both of these components. Additionally, both the care and mobility components have different rates. The care component has three rates: a highest rate (at time of interview £62.25 per week), a middle rate (£41.65 per week), and a lowest rate (£16.50 per week). The mobility component has two rates: a higher rate (at time of interview £43.45 per week) and a lower rate (£16.50 per week). Perhaps unsurprising a number of people could not remember the details of the components or rates of the benefits they received when asked (e.g. 14% of those receiving DLA did not know which component they received). Nevertheless some useful patterns did emerge, most obviously that the mobility component of the DLA is more commonly received than the care component (77% compared with 66%).

Table 3. Different components of the DLA (by three age groups). Base: all those who reported receiving the DLA (N=450), weighted.

	18-29 %	30-49	50-64 %	Total Weighted %	Total sample (n)
Care component					
Yes	69%	69%	63%	66%	(300)
No	17%	20%	21%	20%	(87)
Don't know	15%	11%	16%	14%	(63)
<b>Mobility component</b>					
Yes	79%	78%	76%	77%	(347)
No	4%	12%	9%	10%	(39)
Don't know	18%	10%	16%	14%	(64)
Number interviewed	(108)	(162)	(180)	100%	(450)

Responses about the rates of benefit received reveals that it is relatively uncommon for visually impaired people to receive the higher rates for either the care or mobility components of the DLA. The mobility component is particularly worth looking at carefully because this has been the subject of some debate elsewhere (e.g. the 2007 'Taken for a ride' campaign). Of visually impaired people who recalled receiving the mobility component of the DLA, 25% received the higher rate (compared with 68% who received the lower rate and 7% who did not remember). This 25% equates to approximately 16% of registered visually impaired people between 18 and 64 years of age (11,000 people). This analysis is returned to below when we consider what are the associated factors with receiving DLA.

Table 4. Rates of the care component of the DLA (by three age groups). Base: all those who reported receiving the care component of the DLA (N=300), weighted.

	18-29 %	30-49	50-64	Total Weighted %	Total sample (n)
Care component					
Highest	12%	9%	14%	12%	(35)
Middle	39%	39%	40%	40%	(119)
Lowest	41%	47%	41%	44%	(130)
Don't know	8%	5%	4%	5%	(16)
Number interviewed	(74)	(112)	(114)	100%	(300)

Table 5. Rates of the mobility component of the DLA (by three age groups). Base: all those who reported receiving the mobility component of the DLA (N=347), weighted.

	18-29 %	30-49	50-64	Total Weighted %	Total sample (n)
Mobility component					
Higher	20%	21%	28%	25%	(81)
Lower	73%	72%	64%	68%	(241)

Don't know	7%	6%	8%	7%	(25)
Number interviewed	(85)	(126)	(136)	100%	(347)

Advice when applying for the DLA and appeal

All participants were asked if they had ever received advice on how to get DLA. Over half (55%) had received advice, while the remainder had not received advice or could not remember (42% and 3% respectively). Those who received DLA were considerably more likely to have received advice about how to get it, although this must be interpreted cautiously. More relevant here is to limit the analysis only to those who have *applied* for DLA. There is clear evidence that receiving advice is associated with successful application for DLA (60% of those who had successfully applied for DLA had received advice, compared to 38% of those who were unsuccessful). This gives a clear indication of the success of the advice given and the importance it has to those applying for DLA. However, there is no evidence that advice is associated with the rate of benefit received (i.e. higher or lower rates).

Those participants who recalled the component and rate of DLA they received were asked whether they got this benefit on first application or whether they had to appeal. Significant proportions of visually impaired people had to appeal (35% for care component and 25% for mobility component). This highlights the importance of appealing in the event of an unsuccessful application, and again, advice in this complex process may well be important.

It is useful to consider what are the factors which are associated with the receipt of DLA. Here we consider the participant characteristics of registration status and employment status as reported in Network 1000 Survey 2. We also considered difficulties with independent living skills as reported by the participants in Network 1000 Survey 1 (see Douglas et al, 2006, p.57).

Table 6. Links between % DLA receipt and other participant characteristics (registration status, employment status, and reported difficulties with independent living skills). Base: all those eligible to apply for the DLA at time of interview (<65 years) (N=539), weighted.

	Weighted % Receiving DLA	Total sample (n)
Registration status (N=537)		
Blind	95%	(274)
Partially sighted	74%	(248)
Unsure	33%	(15)
Employment status (collapsed) (N=501)*		
Employed	69%	(171)
**Not employed	93%	(330)
ILS: Difficulty preparing a meal (N=539)		
Yes	91%	(230)
No / Don't do this task	80%	(309)
ILS: Difficulty with household cleaning (N=539)		
Yes	91%	(225)
No / Don't do this task	80%	(314)
ILS: Difficulty with personal care (N=539)		
Yes	95%	(113)
No / Don't do this task	81%	(426)

ILS: Difficulty getting about the home (N=539)		
Yes	94%	(83)
No / Don't do this task	83%	(456)
TOTAL	85%	(539)

<sup>\*</sup> Sample size is reduced in employment analysis because women aged 60+ are excluded from question about employment

Key observations are presented in the table and summarised as follows:

- People registered blind are more likely to receive DLA than those registered partially sighted (95% and 74% respectively).
- People not employed (including people who describe themselves as unemployed, long-term sick and disabled, retired or a student) are more likely to receive DLA than those employed (93% and 69% respectively). Those describing themselves as long-term sick and disabled are particularly likely to receive the DLA (97%).
- People who report difficulty with independent living skills (including preparing a meal, household cleaning, personal care, and getting about the home) are more likely to receive DLA than those who do not report difficulty.

To some extent these results follow the expected patterns: people with poorer vision and greater reported difficulties with independent living tasks are more likely to receive the DLA. However, it is important to reflect upon the purpose of the entitlement. The mobility component is intended to support those who 'cannot walk or need help getting around' (Directgov, 2007). Visually impaired people are unable to drive and are consequently excluded from the enormous mobility benefits this affords (and related social and economic benefits).

DLA and people 65 years of age and over

As already outlined, the DLA can only be applied for by people under the age of 65 years, although it is possible to continue to receive the DLA after the age of 65. People 65 years or older can apply for the Attendance Allowance (discussed below) if the DLA is not already received. However, the DLA has higher rates than the Attendance Allowance (a maximum weekly rate of £105.70 compared with £62.25 at time of interview). Therefore, there are clear advantages to applying for the DLA if it is possible.

<sup>\*\* &#</sup>x27;Not employed' includes all participants who do not describe themselves as employed in someway and includes those who describe themselves as unemployed, long term sick and disabled, retired, and a student.

Of the sample, 177 participants (an estimated 17% of the registered visually impaired population) were 65 years and over but also described themselves as having a sight problem (and/or another disability) before the age of 65 years. This analysis also accounted for when DLA was introduced in April 1992.

Table 7. Type of benefit received (DLA, Attendance Allowance, or neither). Base: all those eligible to apply for the DLA in the past but now 65+ years of age (N=177), weighted.

	Total Weighted %	Total sample (n)
Receive DLA	53%	(117)
Receive Attendance Allowance	15%	(21)
Receive neither DLA or Attendance Allowance	31%	(36)
Unsure	1%	(3)
Total interviewed	100%	(177)

Approximately half (53%) of those who could have applied for DLA before they were 65 did so successfully. The remaining 47% either did not apply (in the majority of cases) or applied unsuccessfully. It is unclear whether those who never applied would have qualified for the DLA because we are unsure about the severity of their condition at that time. However, data suggests that many were registered blind or partially sighted at that time and many have since successfully applied for Attendance Allowance. This suggests a significant number have missed the opportunity to apply for the DLA, and therefore missed the opportunity that entitlement affords.

#### Attendance Allowance

Attendance Allowance is 'a tax-free benefit for people aged 65 or over who need help with personal care because they are physically or mentally disabled' (Directgov, 2007). Of our sample, 226 of the participants were eligible to apply for Attendance Allowance at the time of the Network 1000 Survey 2. This includes all participants aged 65 or over but excludes those who already received the DLA. Accounting for the age profile of visually impaired people, this sub-sample represents approximately 70% of the registered visually impaired population (252,000 people).

Table 8. Do you get Attendance Allowance? Base: all those eligible (i.e. aged 65+) to apply for Attendance Allowance who are not receiving the DLA (N=226), weighted.

	65-74 %	75+ %	Total weighted %	Total sample (n)	Base Population (nearest 1K)
Yes	38%	65%	64%	(132)	161,000
No	55%	28%	29%	(79)	73,000
Don't know	7%	7%	7%	(15)	18,000
Number interviewed	(58)	(168)	-	(226)	252,000

We can estimate that 64% of registered visually impaired people who are eligible to apply for Attendance Allowance are currently receiving it. This is also linked with age – people 75 years of age and above are more likely to receive it that those between 65 and 74 (65% and 38% respectively). In terms of numbers, there are an estimated 252,000 people registered as blind or partially sighted in Great Britain eligible to apply (based upon estimates taken from official registration figures for England (Department of Health 2003), Scotland (Scottish Executive 2003), and Wales (National Assembly for Wales 2003)). This allows us to estimate that 73,000 visually impaired people are currently not receiving Attendance Allowance but are eligible to apply (and this figure does not include those who did not know whether they received Attendance Allowance).

Of those not receiving Attendance Allowance, the majority (74%) reported that they had never applied while a significant proportion had applied unsuccessfully (21%) or could not remember (5%).

Different rates of Attendance Allowance, appeals and advice received

There are two rates of Attendance Allowance, a higher rate (at time of interview £62.25 per week) and a lower rate (£41.65 per week). Of those receiving Attendance Allowance, just over half (53%) received the lower rate, whilst 29% received the higher rate. Eighteen per cent did not know which rate they received. As with general take up of Attendance Allowance, this is linked with age – people 75 years of age and above are more likely to receive the higher rate than those between 65 and 74 (30% and 14% respectively).

Of those who did receive the allowance, 71% said that they received the rate upon their first application, compared with 23% who said that they had to appeal (6% did not know). This highlights the importance of appealing in the event of an unsuccessful application for Attendance Allowance. The figures allow us to estimate that 36,000 registered visually impaired people, the majority of whom are over the age of 75 years, would have had the complexity of having to apply *and* appeal before receiving the Attendance Allowance to which they are entitled.

Table 9. Rates of the Attendance Allowance (AA) received and process of application (by two age groups). Base: all those who reported receiving Attendance Allowance (N=132), weighted.

	65-74 %	75+ %	Total Weighted %	Total sample (n)
AA Rate				
Higher	14%	30%	29%	(34)
Lower	73%	53%	53%	(76)
Don't know	14%	18%	18%	(22)
AA application				
First application	68%	71%	71%	(90)
Appeal	32%	23%	23%	(36)
Don't know	0%	6%	6%	(6)

Number interviewed	(22)	(110)	100%	(132)

As with the DLA, all participants who were eligible to receive Attendance Allowance were then asked whether they had ever received any advice on how to get it, regardless of whether or not they were currently receiving it or had ever applied for it.

Interestingly, the results were similar to that for DLA; just under half (46%) of visually impaired adults who were eligible to apply for Attendance Allowance confirmed that they had received advice on applying for the benefit, with 47% stating that they had not (the remaining 7% were unsure). Those who received Attendance Allowance were considerably more likely to have received advice about how to get it, although this must be interpreted cautiously.

More relevant here is to limit the analysis only to those who have *applied* for the Attendance Allowance. There is clear evidence that receiving advice is associated with successful application for Attendance Allowance (59% of those who had successfully applied for Attendance Allowance had received advice, compared to 47% of those who were unsuccessful). This gives an indication of the success of the advice given and the importance it has to those applying for Attendance Allowance. However, there is no evidence that advice is associated with the rate of benefit received (ie. higher or lower rates).

Other factors associated with Attendance Allowance benefit

It is useful to consider what are the factors which are associated with the receipt of Attendance Allowance. Here we consider the participant characteristics of registration status and difficulties with independent living skills as reported by participants in Network 1000 Survey 1 (See Douglas et al, 2006, p57).

The results broadly follow the expected patterns: people with poorer vision and greater reported difficulties with independent living tasks are more likely to receive Attendance Allowance. Nevertheless, while this pattern is followed for most of the factors it is not particularly conclusive, and in the case of reported difficulty with 'personnel care' the pattern is reversed. This apparent fragility of association between the variables may be partly due to low numbers and the relative crudeness of the questions asked in the interview about the difficulties people experience with independent living activities. However, it may also suggest that successful application for Attendance Allowance may depend upon factors related to need and circumstances not examined in the interview or perhaps other relatively arbitrary factors such as how much support was received when completing the application form.

Table 10. Links between % Attendance Allowance receipt and other participant characteristics (registration status and reported difficulties with independent living skills). Base: all those eligible to apply for the Attendance Allowance at time of interview (>64 years and not receiving DLA) (N=226), weighted.

	***	Total
	Weighted % Receiving AA	sample
		(n)
Registration status (N=226)		
Blind	69%	(84)
Partially sighted	60%	(139)
Unsure	56%	(3)
ILS: Difficulty preparing a meal (N=226)		
Yes	69%	(72)
No / Don't do this task	61%	(154)
ILS: Difficulty with household cleaning (N=226)		
Yes	75%	(89)
No / Don't do this task	55%	(137)
ILS: Difficulty with personal care (N=226)		
Yes	56%	(32)
No / Don't do this task	65%	(194)
ILS: Difficulty getting about the home (N=226)		
Yes	71%	(33)
No / Don't do this task	62%	(193)
TOTAL	64%	(226)

### Conclusions

In this final short section we reflect upon the key findings in an attempt to begin the debate about the implications of the research. We first consider how to best interpret the findings related to the take-up of DLA and Attendance Allowance, before considering the process of applying for these benefits (specifically findings related to 'appeal' and 'support').

Perhaps a key challenge in interpreting these results is having a position about the 'desired' or 'target' take-up of DLA and Attendance Allowance by people who are registered as blind and partially sighted. Should we expect that all of the population should be eligible for the relevant benefit? This is a difficult debate to unpick given that both benefits involve individual needs assessments of those who apply. Nevertheless, the mobility component of the DLA is an interesting example to explore. The mobility component is intended to support those who 'cannot walk or need help getting around' (Directgov, 2007). Visually impaired people are unable to drive and are consequently excluded from the enormous mobility benefits this affords (and related social and economic benefits). Findings from the Network 1000 Survey 1 showed that people commonly reported that not being able to drive and having to rely on others were key barriers to getting out more (Douglas et al, 2006, p60). It might therefore be argued that those who are registered as blind or partially sighted should *always* be entitled to the mobility component of the DLA. If we take this position it follows that it is unsatisfactory that approximately 14% of those eligible to apply do not receive the DLA, and many of those have applied unsuccessfully.

What is clearly unacceptable is the finding that many visually impaired people have had to appeal before eventually receiving their current rate of benefit (over 20% appealing for both Attendance Allowance and DLA). The process of appealing is no doubt time consuming and stressful, and given the high numbers of successful appeals, it suggests that the initial assessment of applications is both inefficient and insensitive.

Related to the appeals process is the apparent support visually impaired people needed during the application process for DLA or Attendance Allowance. It is encouraging for those giving this advice (e.g. friends, family, voluntary and statutory sector professionals) that this support results in increased likelihood of successful application. Nevertheless, a less positive finding is that people who do not receive advice are less likely to get the benefit when they apply. This suggests that the application process is not very accessible, particularly to those without support networks who may be most vulnerable.

Finally, more work is needed which compares the results in this report to research findings elsewhere – e.g. take-up of benefits by other disability groups, sighted people's perceptions of

their financial situation. This work is planned and the findings should further support our understanding of the barriers faced by visually impaired people in their day to day life.

### References

DEPARTMENT OF HEALTH (2003). Registered Blind and Partially Sighted People: Year ending 31 March 2003. London: Department of Health. ISBN: 1 84182 7983.

Directgov (2007). <a href="http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/index.htm">http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/index.htm</a>. Accessed 12 October 2007.

Douglas, G., Corcoran, C., Pavey, S. (2006). *Network 1000. Opinions and circumstances of visually impaired people in Great Britain: Report based on over 1000 interviews.* Birmingham: Visual Im;pairment Centre for Teaching and Research, School of Education, University of Birmingham (mimeo).

ISBN 0704426048/9780704426047

NATIONAL ASSEMBLY FOR WALES (2003). SSDA900.1: Disability Register 2001-02, Version: 1 Released: 29/05/2003. Processed by the Local Government Data Unit - Wales.

SCOTTISH EXECUTIVE (2003). *Registration of Blind and Partially Sighted Persons 2003*. Unpublished statistics.

- As the results for 'Staff treated me with respect' and 'Staff were helpful' were associated; retain one question for future surveys
- Re-evaluate aims of statement 'I was given any information I needed in a way that was easy to understand' with a view to removing the question if the aims are covered by other statements
- Collapse the statements 'Staff are knowledgeable and skilled about blindness' and 'Staff are knowledgeable and skilled about vision impairment' into one question
- Consider the frequency with which we need to collect information regarding computer and internet usage.

- Clarify equipment questions—presently the 'opt-in' asks about equipment recommendation, but the following questions assume purchase of that equipment (for example, I received my equipment in a timely manner)
- Clarify whether questions regarding seeking equipment elsewhere are required each survey
- Revisit terminology used in the statements—e.g. 'preferred format' and 'problem solving'
- Re-evaluate aims of the statement 'I would recommend the service to other people.' Is the result regarding overall satisfaction a sufficient measure?
- Re-evaluate the wording of the vision and mission statements
- Retain a statement regarding the merger in the short term, however re-assess the required wording before each survey
- Revisit placement of questions (e.g. preferred format and NILS clients)
- Add questions regarding ease to get to & from: -how did you get there (public transport, taxi, car, walked); accompanied or unaccompanied; which centre attended

# **Appendix V: Interview with Damien McCormick**

On 4/23/08 we performed an interview with Damien McCormick, Adaptive Technology Consultant. He was very versed in the use of accessibility technology for the internet. He informed us that there are primarily 3 methods of making the internet accessible to the vision impaired, and explained how these would function if we were to use an online survey (such as surveymonkey.com)

The first method is to use the computers accessibility settings that are included with most operating systems. These settings allow the user to increase font size and adjust contrast ratios so make the screen easier to read for the user. If the client uses this system, it is possible that an automatically generated survey would work, but would suffer some format changes when the settings are applied.

The second method is to use a program that magnifies portions of the screen great amounts to make text clearer to those with low vision. This program allows for larger font size without compromising formatting. However it does make the pages more difficult to navigate, since the user can become "lost" and not know where they are within the page.

The final technique (and the most common) uses screen-reading technology, where a program will actually read the text on the page to the user. This is very useful for pages that are simple and don't contain coding, such as HTML. When viewing a complex page, it will attempt to read the coding, which does not help the client. A majority of generated surveys use technologies that would not be compatible with this technology, and would not be compatible with an automatically generated survey.

Damien then went on to mention that the easiest way to make a survey such as this accessible is to simply email the questions to clients. This way they can type their response to your questions and send you a reply email. This has disadvantages however, since someone will have to read all of the responses, record the responses and interpret the data. This will be no small task, but is most definitely the best way to sample a large number of clients.