

**Department of Psychology and Counselling** School of Psychology and Public Health

# FINAL REPORT TO NATIONAL DISABILITY INSURANCE AGENCY

30 September 2016

# Reviewing Assistance Animal Effectiveness

Literature review, provider survey, assistance animal owner interviews, health economics analysis and recommendations

# **ENQUIRIES**

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#### WHAT IS THIS REPORT?

This report has been prepared for the National Disability Insurance Agency (NDIA). The NDIA is tasked with providing Australians with disability the reasonable and necessary supports they need to achieve their goals and live an ordinary life. Some Australians with disability currently use assistance animals as a disability support. Therefore, the NDIA commissioned a group of expert researchers from La Trobe University to review the effectiveness and cost-benefits of assistance animals, such that decisions made around assistance animal provision could be based on the latest available scientific evidence. In order to accomplish this task, the research team undertook a review of existing scientific literature, a survey of assistance animal provider organisations, consultations with current owners of assistance animals in Australia, and a health economics analysis.

The existing evidence base supporting use of dogs to assist vision- and hearing-impaired individuals is considered established, so this study focused on use of AAs in other roles. Some data are included about traditional guide and hearing dogs throughout the report. This information is presented solely to provide context for the use of assistance animals in management of other impairment types.

### **CONTRIBUTORS**

La Trobe University is an Australian public institute founded in 1964. The university currently has over 36,000 students and is rated among the top three universities in Victoria, and the top ten in Australia.

#### **AUTHORS**

**Dr Tiffani Howell** was responsible for daily management of the project, including reviewing existing scientific evidence around assistance animal effectiveness, data collection and analysis for the provider survey and consultations, and writing the report. She completed her PhD at Monash University in 2013 and is a research fellow in the School of Psychology and Public Health at La Trobe University. She has extensive experience in research on animal welfare, dog-owner relationships, and dog behaviour, including surveys, focus groups, and behavioural studies.

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#### **REPORT ADVISORS**

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#### **RESEARCH ASSISTANTS**

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**Ms Jessica Woodhead** helped collate and summarise existing peer-reviewed academic literature about assistance animal effectiveness.

Mr Nick Rutter located assistance animal provider organisations worldwide.

#### **ACKNOWLEDGEMENTS**

We appreciate the insights provided by the respondents in the assistance animal provider survey, and we are grateful to the current owners of assistance animals who took the time to talk to us about their experiences.

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#### **EXECUTIVE SUMMARY**

Assistance animals (AAs) have been used for decades to assist those with vision- and hearing-impairments to successfully navigate through their communities. More recently, AAs have been used to help people manage other types of impairments, such as mobility impairments, autism spectrum disorder (ASD), psychiatric illnesses, epilepsy, and diabetes. In order for the National Disability Insurance Agency (NDIA) to determine whether these animals should be provided as part of the National Disability Insurance Scheme (NDIS), it is important to understand how effective they are, and whether they represent good value-for-money. The evidence base for guide dogs for the hearing- and vision-impaired is considered established; therefore, an analysis of their effectiveness was beyond the scope of the commissioned study. Information about these AAs is included in this report exclusively to provide a reference for comparison with AAs helping their owners manage other types of impairments.

To achieve our objectives, we:

- 1. undertook a literature review of available peer-reviewed research, including 64 studies on AA effectiveness:
- 2. created and administered a survey for AA provider organisations to detail selection, training, and accreditation practices;
- 3. consulted 19 current owners of an AA, in order to document the lived experience of individuals with disability, which is of interest to the NDIA. This sample was opportunistic, not representative, and included individuals with vision (3 adults) and mobility (2 adults) impairments, 1 adult and 3 children with ASD/developmental disorders plus 7 parents of children with an impairment of this kind, 2 adults with psychiatric disorders, 1 adult with epilepsy, and 1 adult with diabetes (the total number exceeds 19 due to co-morbidities);
- 4. examined the health economics literature to determine whether AAs represent value-formoney relative to other types of supports.

A summary of the results for all four components of this project is provided below.

### 1. LITERATURE REVIEW

One of the most important findings to come out of our review of the peer-reviewed scientific literature is that the existing evidence base is weak, but generally positive. While nearly all available studies report that AAs are beneficial, serious methodological limitations abound. These include: lack of controls; generally small sample sizes, with case studies over-represented; and heavy reliance on subjective outcome measures, particularly self-report methods. Furthermore, all existing research on AAs focuses entirely on dogs. No other species is represented in the literature, even though horses and monkeys are sometimes used as AAs overseas and other animals, such as guinea pigs, have been shown to have positive effects on relevant outcomes, such as lowered arousal in children with ASD, in other settings. Despite these limitations, AAs appear to provide benefits for owners from a variety of different impairment cohorts. Based on a review of 64 existing peer-reviewed research articles, it can be concluded that AAs provide their owners with companionship and emotional support. Additional benefits include improvements in:

- Quality of life
- Independence (including reduced dependence on formal and informal carers)
- Self-esteem
- Social interactions
- Mental health
- Community participation

- Economic engagement
- Perceived physical safety
- Family relationships (for individuals with some psychiatric and developmental disorders)

Some of the disadvantages reported in the academic literature were financial and time costs associated with keeping an AA, lack of public awareness about AAs, and undesirable animal behaviour. The undesirable behaviours were cited particularly by parents of children with an AA for autism spectrum disorder (ASD). We were unable to find any existing research on AAs for adults with ASD, so the effects of these animals on the lives of these individuals are unknown.

Several recent, well-designed studies examining the effectiveness of therapy animals other than dogs, such as guinea pigs on children with ASD, provide a template for the type of study designs that should be implemented in future research exploring the effects of AAs on owners with disability. These studies include large sample sizes, a control group, and several treatments for comparison purposes, such as presence of a toy, a person, or a therapy animal. All of these research design elements serve to strengthen the evidence base in support of therapy animals, and should be adapted for use in AA research.

#### 2. PROVIDER ORGANISATION SURVEY

AA provider organisations worldwide, with websites in English, were recruited to participate in a survey about selection, training, accreditation practices, and any cost-saving innovations they had implemented. A total of 42 respondents completed the survey, including 16 in Australia.

Respondents in the survey indicated that they exclusively used dogs for AA work; no other species was represented. They reported looking for physical health and temperament traits when selecting animals. Desirable physical traits included an appropriate weight/size for the impairment they would be assisting, healthy genetic background, and some respondents reported a breed preference (e.g. Labrador retriever, Great Dane). Temperament traits included a calm demeanour, confidence, intelligence, and a willingness to work with people.

Respondents described the training practices used by the AA provider organisation they worked for. The two types of training undertaken were 1) training for public access rights, and 2) training for specific tasks to assist the person's needs. Public access training typically took one year, and included early-age socialisation as well as obedience training. Training for impairment-specific tasks also typically took one year; these were often taught after public access training was complete, but some diabetes and epilepsy alert AA organisations trained both simultaneously.

Cost-saving innovations typically centred around improved:

- client services, such as optimised AA-client matching;
- AA selection, through working with certain breeders, or developing the organisation's own breeding program;
- training practices, such as use of puppy raisers or clients who owned the AA from puppyhood, positive reinforcement training, and mobile technologies to enable trainers to access clients quickly.

Animal welfare was typically measured based on veterinary reports and observations of the AAs by representatives of the organisation during routine visits with owners. A few respondents mentioned the importance of ensuring that the AA did not become too stressed by the work.

#### 3. ASSISTANCE ANIMAL OWNER CONSULTATIONS

A total of 19 individuals with an AA to help them manage a disability participated in a series of consultations aimed at better understanding the nature of the AA-owner relationship. The participants were self-selected, having responded to an advertisement about the study distributed via social media, AA provider organisations, and the NDIS website. They included:

- 3 adults with a vision impairment
- 2 adults with a mobility impairment
- 1 adult with ASD/developmental disorder
- 3 children with ASD/developmental disorder
- 7 parents of a child with ASD/developmental disorder
- 2 adults with generalised anxiety or another psychiatric disorder
- 1 adult with epilepsy
- 1 adult with diabetes

The total number exceeds 19 due to co-morbidities.

The main advantages of AA ownership cited by owners were similar to those reported in existing scientific literature, such as increased independence, improved social interactions, companionship, and assistance with specific, impairment-related tasks. The main disadvantage reported was a lack of education around the role and rights of AAs in public spaces.

Owners generally reported a positive relationship with their provider organisation, although there were exceptions, including two owners whose AA had lost its public access rights due to behavioural problems. Several owners indicated that there was a general lack of support when an owner lost an AA due to old age or illness, and during the transition to a new AA. This issue was also underappreciated in existing research on AAs, as was consideration of animal welfare. However, owners reported that they prioritised their AA's welfare, and ensured that the animal had plenty of downtime.

Economic benefits through using AAs were reported by owners in the consultations. These included:

- attendance at school among children who previously could not attend;
- employment among individuals who previously could not work;
- reductions in paramedic call-outs, hospital visits, and medication due to better management of medical conditions like diabetes;
- reduced reliance on taxis among individuals with a vision impairment.

All owners agreed that the NDIA should fund AAs as part of the NDIS; however, there was disagreement about whether the NDIA should fund *all* associated costs, or just the costs that are specific to AAs, rather than being associated with companion animal ownership *per se*.

# 4. HEALTH ECONOMICS ANALYSIS

There is not a great deal of evidence on the cost-effectiveness of AAs. What literature there is points to the potential for benefits including increased employment and reduced demand on formal care. It is unlikely, however, that such cost-offsets will always exceed the costs of an AA program. Thus, at present we are left with the need to value the impact of the program on quality of life in order to judge whether the investment is worthwhile.

#### 5. RECOMMENDATIONS

Based on existing evidence from the review of scientific literature, the provider organisation survey, the assistance animal owner consultations, and the health economics analysis, we created a series of recommendations for the NDIA, the community in general, and researchers.

### For the NDIA, we recommend that:

- 1. The decision on whether an AA is a reasonable and necessary support should be made at the level of the individual, based on:
  - a. the severity and impact of the disability on the person's life,
  - b. the specific supports able to be provided by an appropriately selected and trained AA, which we suggest should be at least three tasks that directly and clearly mitigate the impact of the owner's disability (and thus cost of alternate supports), and
  - c. the person's ability to manage the needs of an AA, either alone or in conjunction with their support system.

Within the scope of this study, there is currently no robust evidence in the literature attesting to the general effectiveness of AAs or their value for money as a support for people with disability. The limited evidence available along with the lived experience of users of AAs, suggests a range of potential benefits. These benefits may be relevant for consideration of reasonable and necessary funding under the NDIS for a range of potential participant supports, in addition to those already established and therefore excluded from this review (i.e. vision guide dogs and hearing dogs).

- 2. While there were a range of potential benefits of AAs for children with ASD identified during the study, the use of tethering to an animal to prevent a child from bolting should not be the primary basis for consideration or funding of an AA. We note such restraint is not permitted in most Australian states and territories without an appropriate behaviour support plan, and there remain questions about the impact of such a role on the animal's welfare.
- 3. That costs for maintenance of an NDIS funded AA should meet expenses above what a pet owner would expect to incur (e.g. training, veterinary insurance, specialised harnesses/jackets, special diet). For individuals with severe financial hardship, all associated maintenance costs may require consideration. Available evidence does not, at present, allow determination of the total costs of acquiring, training and maintaining an AA over the course of its lifetime, so a market approach is recommended.

### For existing and potential future AA provider organisations, we recommend that:

- 4. Training practices should typically include training for public access rights, as well as impairment-specific tasks tailored to the needs of the owner. Public access rights require a high level of control over the AA by the owner (or owner's support network) and a high level of obedience by the AA when it is working. Impairment-specific tasks will vary depending on owner needs, but the AA should be capable of performing at least three tasks on command, which clearly mitigate the impact of the disability on the owner.
- 5. Animal welfare must remain a top priority. Government funding for AAs will likely mean an increase in the number of animals deployed for this purpose. It will be imperative for provider organisations to continue insisting on the high level of animal welfare that they currently expect from their staff and clients.

6. All potential clients should be educated on what should realistically be expected from an AA, which is a living animal, rather than a machine. Complaints about undesirable AA behaviour by some parents of children with ASD suggest that some dogs may not be sufficiently trained or that some clients may have unrealistic expectations of AAs. In particular, it is not permitted in many states of Australia for children with ASD to be restrained through tethering to an AA without an approved behaviour support plan. Although use of an AA may be recommended for other reasons, parents should be reminded that they remain responsible for their child's care at all times, and cannot reasonably pass this responsibility to any animal.

### To the community in general, we recommend that:

- 7. Education about public access rights for AAs should be a priority for all councils within Australia, so that individuals with AAs will not have to face the rejection and discrimination that they currently encounter on a regular basis.
- 8. An independent body should be identified or set up to certify all AAs in Australia, to ensure that all AAs are trained to the same standards and to prevent larger organisations from establishing accreditation monopolies. This national oversight would facilitate community confidence in the quality of accredited assistance animals. Specific training requirements are likely to vary with the intended application so should be accommodated within this process.
- 9. Existing and potential future AA owners should be encouraged to participate in training their own dog, with appropriate assistance, to utilise owner expertise and to mitigate the growing costs of preparing an AA. The level of involvement will need to be appropriate to the capability of the individual, and many would not possess the skills necessary to train an animal fully to the level required for public access and for the specific tasks needed to help them manage their disability. People without these abilities or unwilling to take up this role (because of other commitments) should not be excluded from AA ownership solely for this reason.

### To researchers we recommend that:

- 10. More studies are needed to strengthen the evidence base around AA effectiveness and costeffectiveness, incorporating large sample sizes with proper controls.
- 11. Behavioural research, examining training and selection practices for AAs, may improve success rates for provider organisations over time.
- 12. Animal welfare research in companion animal species is warranted to determine what resources and living conditions are required by animals used as AAs, in order for them to experience a positive welfare state.

#### 1. INTRODUCTION

Assistance dogs have traditionally been employed to assist individuals with physical disabilities, such as vision or hearing impairments, and those with limited mobility. These dogs have played an important role in permitting many individuals to live as independently as possible. More recently, dogs, and other animal species, have been used to provide assistance to people with chronic mental illnesses or developmental disorders, such as autism, post-traumatic stress disorder, and generalized anxiety disorder. Some assistance animals (AA) may even help inform their diabetic owner of a potentially fatal change in the owner's blood sugar levels, or warn epileptic owners that a seizure is forthcoming. The evidence base supporting widespread use of AAs is small, but attracting the attention of a growing number of researchers around the world. Preliminary research suggests that some AAs may be of considerable benefit to individual owners. However, it is unclear how beneficial an AA may be when compared to other options, especially when considering value-for-money. This is of utmost relevance to government agencies, such as the National Disability Insurance Agency (NDIA), tasked with coordinating plans for individuals who could benefit from an AA. The aim in this project, commissioned by the NDIA, was to accumulate, interrogate and report on existing evidence pertinent to this issue. We did this by conducting a literature review, surveying providers, interviewing end-users and performing a health economics analysis.

#### 2. REVIEW OF EXISTING EVIDENCE

For the first part of this project, a comprehensive review of available scientific literature was conducted. This located 64 academic articles related to AAs, including nine review articles. This does not include a much larger number of studies examining the effectiveness of therapy animals. For the purposes of this study, we defined AAs as 'animals that live with, and provide specific support for, an individual with an impairment'. The term 'service animal' is synonymous with AA. A therapy animal, by contrast, is defined by the peak body representing human-animal interaction organisations as an animal which is part of 'a goal oriented, planned and structured therapeutic intervention directed and/or delivered by health, education and human service professionals...focused on enhancing physical, cognitive, behavioural and/or socio-emotional functioning of the particular human client' [1].

All 64 relevant academic publications focused solely on dogs. While other species have been used in studies examining the effectiveness of therapy animal work, only dogs were represented in AA research. Organisations and individuals exist who have trained horses, monkeys, and other types of AAs [2, 3]. However, there are no published data available for these animal types. This is likely due to the relative ubiquity of dogs compared to other species. Historically, dogs were the only animal species with legal recognition as an AA in some jurisdictions, although this is changing. For instance, in the USA, the beginning of the Americans with Disabilities Act (ADA) states that "from March 15, 2011, only dogs are recognized as service animals under titles II and III of the ADA", but they then add a provision for similarly trained miniature horses to also act in this capacity [4]. The 2009 amendments to the Australian Disability Discrimination Act (DDA) 1992 also permit other animal species to be considered as AAs, provided they meet eligibility criteria relating to training and behaviour [5]. Due to the relatively recent recognition of animal species other than dogs for this type of work, it is recommended that future research into AA effectiveness include these species.

The following summary of findings divides the research by disability or impairment, highlighting the main methods used in research, the key results, and the limitations of the studies. AAs for hearing and vision impairments (i.e. guide dogs) are already covered by the NDIS. As such, their relevance in this review is solely to provide context for the work taking place in the rest of the field. This is followed by

a general discussion of the entire field's limitations, along with suggestions for using some recent therapy animal research as an example of well-designed studies for AA researchers to follow in the future. First, a summary of the number of peer-reviewed articles per category, as well as the number characterised by specific factors that limit the quality of their findings, is provided in Table 1. Some articles reported mixed methods (e.g. behavioural observations and interviews) studies, so the number of articles listed in the 'design types' column exceeds the total number of articles for that impairment. Also, some articles focused on more than one impairment type (e.g. mobility and hearing impairments), so the total number of papers exceeds 64.

Table 1: Number and quality of peer-reviewed articles found on assistance animal effectiveness, by category

Area	Number of Design types & number of Limitation type &			Limitation type &	
papers		papers	number of papers		
Vision &	Total: 12	Behaviour/Physiology	1	no controls in place	5
Hearing	Vision: 6	Surveys or interviews	10	sample size 10 or fewer	1
	Hearing: 6	Review	1	self-report outcomes only	8
Mobility	21	Randomised Controlled Trial	1	no controls in place	8
impairments		Behaviour/Physiology	6	sample size of 10 or fewer	7
		Surveys or interviews	13	self-report outcomes only	10
		Reviews	2		
Post-	3	Surveys or interviews	3	no controls in place	3
traumatic				sample size of 10 or fewer	2
stress				self-report outcomes only	3
disorder					
Epilepsy &	Total: 19	Behaviour/Physiology	8	no controls in place	10
Diabetes	Epilepsy: 11	Surveys or interviews	9	sample size of 10 or fewer	9
	Diabetes: 8	Review	2	self-report outcomes only	9
Autism	8	Behaviour/Physiology	1	no controls in place	4
spectrum		Surveys or interviews	4	sample size of 10 or fewer	3
disorder		Reviews	3	self-report outcomes only	4
General	5	Behaviour/Physiology	1	no controls in place	3
		Surveys or interviews	4	self-report outcomes only	3
		Review	2		

### **2.1 HEARING & VISION IMPAIRMENTS**

There were six studies related to hearing impairments, and six for vision impairments. Apart from one review and one behavioural study, all studies were survey- or interview-based. Three of the hearing studies will be reported in more detail in the mobility section (section 2.2), as they covered both hearing and mobility impairments [6-8].

Overall, the results of these studies suggest that AAs provide owners with greater independence in completing their daily tasks, a feeling of physical safety or security, improved mental and physical health, and enhanced social interactions with other people [6-13]. One of the most important benefits of the AA in some of these studies, both for people who already owned one and for prospective owners, was companionship [11-14]. This phenomenon may go some way towards explaining why, among guide dog owners whose partnership with their dog comes to an end, high levels of distress may occur [15]. In a survey of 75 owners, distress levels were highest in owners whose dog had died, had been withdrawn from the partnership, or had been rehomed through the guide dog organisation. Lower levels of distress were found in owners whose dog retired and continued to live in their home as a pet, or who was placed into a home that the owner chose [15].

The bond between AAs and their owners is an important consideration: the level of emotional support and companionship provided by these animals should not be underestimated, but neither should it be exaggerated. Among respondents who had had a guide dog and then spent time without one, quality of life was reduced in many, but not all, owners [11]. The respondents who reported a reduction in quality of life indicated a loss of mobility, friends, and companionship. However, some of the owners enjoyed having a break from looking after a dog, or they enjoyed not having to deal with an unsuitable dog. For these respondents, quality of life actually *increased* after the partnership with their dog ended [11].

One study related to recommended training, selection, and evaluation practices for guide dogs [16]. It correlated the results of behavioural tests completed on 43 potential guide dogs, with whether or not the dog was ultimately successful in its guide dog training. Of the 43 dogs, 19 ultimately passed guide dog training. According to this study, dogs that are more highly lateralised (i.e. have a strong preference to use one paw over the other) are more likely to succeed as guide dogs. During a test with a toy, dogs that dropped the toy more quickly and jumped less often during the game were more likely to succeed at training. This study also determined that 14 months of age is the most accurate time to assess a dog for suitability as a guide dog [16]. Finally, one study examined the cost-effectiveness of guide dogs, by statistically analysing survey data [17]. These details are presented in the health economics analysis (Section 5) of this report.

While the benefits of AAs for individuals with a vision or hearing impairment are considerable, there are common limitations of the studies providing this evidence base. Typically, the sample sizes are reasonably large for guide and hearing dog studies, likely because these uses of AAs are well established and the pool of people who could potentially take part in the study is large. For instance, three of the studies used approximately 50 individuals [9, 11, 14], and one study included 831 survey respondents [10]. However, many studies relied heavily on self-reports to the exclusion of physiological or behavioural measures. Furthermore, while some of the studies do include controls for comparison with AA owners, such as prospective owners [12, 14] or the AA owners themselves before they obtain the dog [6, 9], others had inadequate controls [10], or no controls of any kind [8, 11]. Finally, there is a lack of standardised measures used in these studies.

# 2.2 MOBILITY IMPAIRMENTS DUE TO PHYSICAL DISABILITY

There were more articles relating to AA effects on individuals with a mobility impairment (n = 21) than any other type of impairment. These included behavioural observations [18], as well as surveys or interviews [19-21], some of which were longitudinal [22] or at least collected data before and after the respondents obtained an AA [6], and one randomised controlled trial [23]. There were also two reviews [7, 24].

The outcome measures for all studies typically related to quality of life, independence, self-esteem, social interactions, and community participation. Overall, results suggest that the presence of an AA improves all of these outcomes. Survey and interview results indicate that AAs provide a considerable improvement in independence, quality of life, social interactions, and community participation for their owners with disability [6, 8, 21, 22, 25-28]. A series of ethnographic interviews, for example, showed that AA owners felt more independent, and were able to engage in employment roles that may have otherwise been impossible due to their disability [20]. Similar effects were observed in all interview and survey studies obtained, except for one study which did not show any overall psychosocial benefits for AA owners compared to individuals with a mobility impairment without an AA [29]. However, in this study, positive affect scores were higher in AA owners who had a progressive impairment or clinical depression than they were in non-owners [29].

A randomised controlled trial of 48 individuals showed increased levels of self-esteem, internal locus of control, and well-being among 24 AA owners compared to 24 wait-listed controls [23]. The researchers also reported increased community integration and attendance at school or work, and a decreased reliance on human assistance.

The authors of this study suggested that the benefits they identified could result in cost offsets of up to US \$60,000 per person over 8 years [23]. However, this contradicts two other studies. One study examining AA effects on various outcome measures related to mobility-impaired or hearing-impaired owners suggested that there was reduced dependence on others, but that most of the cost offsets, especially for hearing-impaired owners, were for relatively inexpensive equipment, such as blinking lights for telephones [6]. Another study found that, while AA owners were more independent in completing daily tasks than they were before they obtained their AA, they were not completely independent, and still needed human assistance, including formal, paid help and informal, unpaid help [22].

In two studies, self-report results were confirmed through behavioural measures, such as the amount of time taken to complete functional tasks [30] or to navigate with a wheelchair [18] when the owners were with versus without the dog; both studies showed improvements in these areas. A third study observed that children with an AA received more friendly glances and more interactions that led to long conservations with others, both in a school playground and in another public setting [31]. Yet another observational study with 11 individuals showed that, after 7 months of owning an AA, the owner's physical endurance was lower. In this study, more effort was required to complete tasks when the owners were without their dog, than had been necessary before they obtained the dog [32]. This suggests that some owners may rely so heavily on their AA that they become more impaired after owning the dog than they were beforehand, although whether this should be perceived as problematic or not is questionable.

A different study asked a large sample of people with a mobility impairment (N = 1074), none of whom were assisted by an AA, for information about their perceptions of AAs and whether they would like to have an AA [33]. Obstacles to obtaining an AA included perceived undesirable dog attributes and cumbersome government and provider organisation requirements. However, young women were more likely than older women to express a desire to own an AA [33]. This study was conducted in Japan. Cultural differences make it unclear whether the findings would be replicated in Australia.

Key limitations of the existing literature are small sample sizes, poor controls, and a reliance on self-report measures. For one study, just three individuals were included [30], while several others included between five and 10 individuals [19, 20, 27, 31, 34]. Furthermore, although some studies included controls, such as people on a wait-list for an AA [22, 23], people with no AA [22, 27], people with a pet dog [28], or within-subjects measures of the owner with and without the dog [6, 18, 25, 32], several studies had no control group of any kind [8, 19-21, 26, 30, 31]. Also, most of the studies relied solely on self-reported outcome measures, such as perceived well-being, self-esteem, and independence [6, 8, 19-22, 25-28]. While many of these outcomes are difficult to measure in any other way, it is possible that AAs produce a strong placebo effect in owners, who then overestimate their improvements. Indeed, as authors of one behavioural study suggested, the emotional support provided by the dog appears to significantly improve owner quality of life, and is difficult to separate from any observed physical improvements [32]. This emotional support may, therefore, be an indirect benefit which is responsible for many of the measured benefits.

The results of the above studies accord with a 2002 review which included 14 studies [7], and a later review of 12 studies from 2011 [24]. The results suggest that AAs can provide a considerable measure

of improvement for their mobility-impaired owners on a variety of outcome measures related to independence, quality of life, and well-being. However, the small number of studies, and serious methodological constraints, make it difficult to draw broad conclusions about their effectiveness. One recent study, published in 2015, developed and implemented an outcome measure for an AA's 'impact on participation and autonomy' [35]. This is a positive sign, as it indicates an awareness by the field of the need for standardised measures. Future research will hopefully involve more standardised scale development for use in this area.

#### 2.3 EPILEPSY & DIABETES

Epilepsy and diabetes were combined for the purposes of this review for two reasons. First, the AAs function similarly for both conditions, by reportedly alerting the owner of an impending seizure or that their blood sugar levels are out of normal range, and then by taking steps to help the owner manage the situation. For seizure alert dogs, this may mean keeping the owner still so that s/he is not physically injured during a seizure. Diabetes alert dogs, meanwhile, may bring a blood sugar test kit and insulin to the owner. Second, these conditions may not always qualify as a disability. If the individual is functioning well and the condition does not impact on their normal community participation, then this condition would not be considered a disability. If, however, the condition is so disruptive to the person's daily life that s/he cannot go about normal activities, engage in social interactions, or participate in work or school, then perhaps it would meet the definition of a disability according to the Disability Discrimination Act (DDA) [5] for that specific individual.

We found 11 studies examining the effectiveness of seizure alert dogs, and eight for diabetes alert dogs. The results of these studies generally suggest that these animals can be effective at alerting or response behaviours. As with the mobility impairment research, most of the studies on seizure and diabetes AAs are based on surveys or interviews. In one survey, 9 out of 20 *pet* dog-owners who had seizures indicated that their dog responded to the seizures, and all reported that they found comfort in that response [36]. For that study, companionship was the primary benefit mentioned. In the same study, the research team visited four training centres for seizure response dogs, and spoke to 15 clients about their dogs. These clients reported that the trained dogs tend to alert approximately 30 to 45 seconds before seizure onset, and are accurate at least 70% of the time. This is similar to results from other research studies, which generally find a high level of reliability in alerting/responding [37-39], although there may be some exceptions at night or in very noisy places [39]. Interestingly, alerting behaviours can spontaneously occur in pet dogs [37, 40-44], which could mean that it would be relatively inexpensive to train a motivated pet dog for this type of work.

Although some studies suggest a high level of accuracy in alerts by AAs trained for epilepsy and diabetes, there are exceptions. For instance, in one study three dogs trained to alert to hypoglycaemia were tested on skin swabs, some of which were taken during a low blood sugar episode [45]. The results suggest that the dogs were not able to accurately detect low blood sugar samples using this method, which may be a function of the use of skin swabs instead of breath samples, or reflect the fact that the swabs were not taken from the dog's usual owner. Also, a review of five seizure detection studies showed mixed results [46]. Two of the studies reported that dogs were efficient at detection, which coincided with a reduced level of intensity and frequency of observed seizures. However, the other three studies were less promising: two showed no effect, while the results of the final study suggested that the AA actually induced seizure-like activity. This same review also examined seven diabetes alert studies, and concluded that dogs are effective in that role [46]. Finally, a study reporting two cases of individuals presenting to a hospital with a seizure alert dog showed no benefit of the dog in the clinical setting [47]. It is unclear whether these dogs were sourced from a provider organisation.

Indeed, another short review of seizure alert dogs cautions against the use of improperly trained animals for this sort of work [48].

While some of these studies focused primarily on the effectiveness of the AA in detecting the hypoglycaemia or responding to the seizure, others examined the effect of the animal on other outcomes of these conditions. A 2002 study of 10 dogs and owners over 48 weeks showed that nearly all owners experienced a reduced frequency of seizures, and 4 out of the 10 experienced a reduction of more than 50% after they obtained their dog, compared to before obtaining the dog [49]. Only one owner showed no improvement. In a different survey of 22 owners, nearly half suggested that their seizures occurred less frequently, were less intense, and/or were shorter in duration after obtaining an AA [39]. Several studies have suggested an improved quality of life for the owners and/or their family members [38, 39, 41, 50-52]. In two studies, owners reported fewer paramedic callouts, unconscious episodes, accidents or near-misses while driving, and hospitalisations due to their condition after obtaining their AA [38, 41]. If accurate, these outcomes could indicate considerable medical savings associated with having an assistance dog.

The limitations of research in this area are similar to those for the mobility-impairment AA research. The sample sizes tend to be small; in fact, there were four case studies in the 19 articles we found [40, 43, 44, 51], and several other studies with 10 or fewer individuals [45, 49, 52, 53]. There is also a heavy reliance on owner reports [36-44, 50, 51] instead of objective measures.

#### 2.4 AUTISM SPECTRUM DISORDER AND OTHER DEVELOPMENTAL DISORDERS

We found eight research articles relating to the effectiveness of AAs for children with autism spectrum disorder (ASD) and one for developmental disorders. Of these, three were reviews. All suggest that the key benefits for children with ASD and their families relate to increased physical safety, decreased aggression and anxiety, increased calmness, decreased behavioural problems/outbursts, and more manageable bedtimes [54-56].

Three of the studies were qualitative, involving interviews with parents of children with ASD or developmental disorders to examine the effects of an AA on the child and the family. In one study of 10 families over 1.5 years, interviews with parents showed that parents believed the child was physically safer at home and in public, and both when a family member was present and when the child was separated from the family [57]. They also reported an improvement in motor control, decreased anxiety and stress, decreased dissociation, and improved bedtime routines. Importantly, this study also described benefits to the parents, who experienced a reduced level of strain and stress because the dog took on some parenting responsibilities, a finding replicated in another interview study with similar results [58].

A case report highlighted the changes in a 13 year old boy's life after he obtained an assistance dog named Simon to assist with management of his ASD [59]. The boy's mother indicated that the entire family engaged in more community interactions since Simon came to live with them. Also, Simon's importance to the child was illustrated in a school assignment in which children were prompted to write a story starting with "I like to..." The boy's story (reproduced verbatim) was almost entirely about Simon:

I like to named Simon. I like to play with Simon. I like to feed with Simon. I like to Simon sleep in her kennel. I like to Simon a boy. I like to Simon play with ball. I like to Simon swimming pool. I like to eat Simon food. I like to walk Simon. I like to black and white dog. I like to puppy. He has a tail, ears, nose, mouth, ears and paws. I like to sleep in bed with Simon. I like to play with the catch the ball with Simon. I like to living a house.

I like to Simon with bath outside. I like to go outside. I like to go in the car with Simon. Mom go in the car. I like to sister play with Simon. I like to eat dog food. I like to dog drink water. Mom buy with dog food. I like to dog food in your kitchen. Mom feed Simon. I like to Simon big. I like to brown eyes. I like to black nose. [59, p.160]

We located one study of AA providers, examining their assessments to measure improvements in children with ASD once a dog is placed in their home [60]. All five providers who participated expected to see improvements in attention span, language skills, and increased familial cohesion. However, not all desired outcomes were routinely assessed. Assessments included interviews, intake conversations, child social diaries filled in by parents, and pre-placement and post-placement surveys [60]. While this study did not specifically measure outcomes for the clients themselves, it does highlight the need for more standardised assessments of AA effectiveness by providers.

There were no studies with objective behavioural measures available in the literature, but one study did measure cortisol levels when children with ASD woke in the morning, 30 minutes after waking, and at bedtime [61]. Before the AA entered the home, children experienced a 58% increase in salivary cortisol, a stress hormone, when waking up in the morning, compared with other times when cortisol was measured. After the dog came into the home, this increase dropped to 10% when waking up compared to other times of the day. When the dog was subsequently removed from the household, the levels bounced back to a 48% increase when waking up. However, no effect on cortisol levels taken during the day (i.e. several hours after waking) was observed [61].

Undesirable behaviour on the part of the dog was sometimes cited by parents of children with ASD. This may indicate training deficits, confirming that it will be important to have basic standards and guidelines for training AAs in place, for use by any organisation or individual who intends to provide dogs to people with disability. In order to better understand AA selection, training, and maintenance practices by organisations working in this space, it will be important to work closely with providers. However, this finding also highlights the importance of managing expectations concerning AAs. While it is reasonable to expect a certain level of training and ability in AAs coming from provider organisations, animals cannot be expected to perform to mechanistic perfection. Further research is required to demonstrate the limitations of AAs and to identify the characteristics of individual and family circumstances in which inflated and unrealistic expectations may render deployment of a dog inappropriate.

As with other disabilities, the main limitations of the research on AA effectiveness with children who have developmental disorders or ASD are small sample sizes and methodological constraints, such as relying almost exclusively on interviews and self-reports. In fact, only one available study used physiological data, and none used behavioural measures [61]. Sample sizes ranged from four [58] or five [60] to 10 [57] individuals, although the physiological study had a larger sample size of 42 children [61].

The strength of qualitative research is that it shows very clearly whether the intervention is positive for that particular person or group of persons, and it also provides in-depth information about those people's perspectives of the intervention. A limitation is that qualitative results may not always generalise to others. Future research should incorporate more quantitative measures into AA studies in conjunction with qualitative methods currently used, using the knowledge gained from the qualitative studies to develop quantitative measures for use in a larger group of people. For instance, the experience of Simon the dog's family may or may not reflect the experiences of most families who have an AA to support a child with ASD. Based on the information provided by the mother, and by the child's own description of life with Simon, behavioural measures (e.g. bedtime routines, getting ready

for school, social interactions, engaging in activities to care for the dog) could be developed to determine whether their experiences reflect those of other families.

Additionally, only a few studies could be found on this topic. Indeed, the reviews cited in this report were only able to summarise between two [56] and four [54] studies specifically related to AAs, all of which were also included in this report. The other studies cited in those reviews investigated therapy animal effectiveness. Additionally, the existing evidence is focused on AAs for children with ASD. However, adults with ASD can also have AAs; indeed, one such individual participated in the AA owner consultations described in Section 4 of this report. These adults are not represented in existing peer-reviewed literature, so there is no evidence to report about the effectiveness of AAs for them. Finally, as the authors of the AA provider study note, there is a lack of standardised outcome measures for providers to use for assessing the value of AAs for their clients [60]. Collaboration with skilled research staff would result in production of more convincing evidence.

#### 2.5 POST-TRAUMATIC STRESS DISORDER

Only three articles were found which investigated the effects of AAs on people with post-traumatic stress disorder (PTSD), all of which were qualitative in nature [62-64] and showed positive results. In one study, five owners were assessed over eight weeks, including four weeks before the dog arrived, and four weeks after it came into the household [64]. While none of the results were statistically significant, due partly to the small sample size, improvements at the group level were reported on three mental health domains: vitality, emotional health, and partnership. At the individual level, all but one of the five people reported an increase in vitality, social functioning, and emotional health, and three reported an increase in overall mental health [64].

A second study interviewed seven couples about their experiences with an AA [63]. In this study, the dog was credited with reducing symptoms of PTSD and increasing overall functioning. Some individuals reported an improvement of up to 50-60%. The third study analysed media reports on 19 veterans, and the results suggested lower levels of hypervigilance and anger, a reduced number of flashbacks, and lowered levels of general anxiety, depression, and avoidance behaviours once the veterans received an AA [62].

Although there are only three studies related to PTSD and AAs, the results are promising. However, as with the previous disabilities, sample sizes are small and all studies are qualitative, with no attempts as yet to incorporate more objective physiological and behavioural measures. Furthermore, the couples study did not interview people who took part in the study before obtaining the dog; rather, they were asked to describe their experiences retrospectively [63]. The study with 19 veterans relied on owner accounts as published in media reports, rather than firsthand reports [62].

#### **2.6 OTHER**

We found five studies, including two reviews, which examined the effectiveness of a broad range of AAs [65-69]. The results follow similar patterns to those observed elsewhere. Benefits of AA ownership include assistance in functional tasks, emotional support, mental health improvements, a sense of physical safety, increased social functioning, and reduced physical assistance required from other people [65, 68].

One study reported a reduction of 2 hours per week in paid human assistance, and 6 hours in unpaid human assistance [65]. A review of 9 studies indicated a reduction in the number of human assistant hours, and an increase in the amount of time spent in paid employment, social acknowledgement, and perceived health and happiness [67].

These studies also discussed some of the disadvantages of AA ownership. For instance, some owners found it difficult to maintain the dog and they struggled with the public's lack of awareness about the animal's working role [65]. In interviews with parents of children with an AA to help them manage their disability, the financial and time costs of caring for the animal were considered a burden by about one-quarter of respondents [68]. Allergies were also a problem in five owners, and over half of the respondents reported that their dog behaved inappropriately (e.g. panting that disturbed the child, barking, stealing food, jumping, guarding objects, running away, chasing cats, and refusing to obey some commands). Additionally, 65% of owners indicated that they had experienced accessibility problems at least once per month after receiving their AA [68]. Education could help reduce the incidence of some of these problems, but prospective owners should be forewarned about the substantial costs involved in AA ownership. They should also be taught that they cannot expect to obtain an animal that is trained to robotic perfection: a highly trained animal is still an animal, and it cannot be expected to behave like a machine. Also, it will be important to continue to educate the community about the valuable role of AAs for individuals with impairments, in order to improve access for people with AAs.

One way to manage the access issue was highlighted in a 2013 study investigating concerns around AAs in the workplace [66]. After consultations with a diverse group of stakeholders, including people with AAs, trainers, vocational rehabilitation counsellors, and other healthcare professionals, the authors formed a framework that can be used in the development of interventions for integrating AAs at the owner's place of work. The six categories included in the framework are: dog preparation, monitoring (i.e. ensuring that the dog behaves appropriately and does not disturb or distract other employees), employee competence, legal knowledge, information and education, and co-worker preparation [66]. While this study focused specifically on places of employment, some of these categories, such as dog preparation, monitoring, legal knowledge, and information and education, may also apply to other public areas.

As in previous sections, a key limitation of studies reviewed in this section is the self-report nature of most of the research. While sample sizes are generally larger in these studies, with the smallest sample size being 17 individuals [68], and the largest being 202 [65], they also failed to include objective measures of physiological changes or behaviours. As reported in the review [67], only three of nine included studies had a control group, and most were descriptive in nature.

## 2.7 GENERAL LIMITATIONS OF ASSISTANCE ANIMAL RESEARCH

One of the most important findings to come out of our review of the peer-reviewed scientific literature is that the existing evidence base is weak, but generally positive. While nearly all available studies report that AAs are beneficial, serious methodological limitations abound. These include: lack of controls; generally small sample sizes, with case studies over-represented; and heavy reliance on subjective outcome measures, particularly self-report methods.

Many studies do not include controls of any kind. This is problematic because it might mean that any positive benefits observed are due to a factor other than the presence of the AA, such as the simple passing of time. To address this possibility, it will be important in future studies to include preplacement and post-placement measures, or to include a control group of individuals with a similar disability, but without an AA. Ideally, people taking part in a study would be randomly assigned to AA and non-AA conditions. This is unlikely to be feasible given ethical constraints on randomly assigning animals to people who may not be motivated or able to care for them appropriately. Waiting list controls, however, are an established methodology that would support stronger conclusions. These have been effectively utilised in only a small number of relevant studies.

Small sample sizes are difficult to counter, given that there simply are not many owners of AAs except for guide dogs for the hearing- and vision-impaired. However, small sample sizes are particularly problematic in this context because there are likely to be large individual differences among people with disabilities within a given group, among assistance dogs, and among specific person-dog combinations, and there is likely to be a selection bias inherent in work of this kind. As one author states [68], because many people, including healthcare professionals, are not aware of AAs other than guide dogs, the people who approach an AA organisation to enquire about obtaining an AA may be particularly predisposed to seek innovative solutions to manage their disability. This could mean that they are more tenacious and better able to cope with adversity than the wider population of people with disability [68] and these factors may influence the outcomes. One can imagine a situation in which AAs are very useful for some, perhaps highly motivated, people with disabilities, but would not assist the broader population of people with a similar disability in any measurable way. It is very important, therefore, for future research to incorporate as many people and as many controls as possible, in order to establish not only general effectiveness of AAs, but also the type of person and circumstance for which an AA is likely to be effective.

A general reliance on self-reported and entirely subjective outcome measures is also problematic. These measures are informative and it is difficult to measure well-being and quality of life in any way other than by asking the respondent, and some of these are well-validated quantitative measures [70]. However, perceived improvements could be the result of a placebo effect or a self-fulfilling prophesy – people who have high expectations regarding the impact of an AA become more likely to experience such benefits. Such measures should not be used exclusively, therefore, and objective outcome measures should be incorporated whenever possible to increase the validity of results. For instance, physiological measures of cortisol or  $\alpha$ -amylase would provide evidence for a reduction in short-term or long-term stress levels, respectively. Additionally, behavioural measures of daily activities and social interactions would provide stronger evidence for improved independence and community participation.

A summary of the limitations to existing research, and ways to improve the quality of future research in this area, is provided in Table 2.

Table 2: Summary of limitations to existing research, and suggestions for the future

# The main limitations to existing AA research are:

- ❖ Inadequate or no controls
- Small sample sizes
  - case studies are over-represented
  - possible inherent selection bias in that people approaching AA organisations may be more resourceful in managing their disability than the general community of people with disability.
- Over-reliance on subjective and self-report measures

# Future research should incorporate:

- Control groups
  - (e.g. people on a waiting list for an AA, people with no AA, pre- and post-placement measures)
- Larger and more diverse samples where possible
- Behavioural observations and physiological measures in addition to selfreports

#### 2.8 HOW THERAPY ANIMAL RESEARCH MIGHT HELP

Therapy animal research is a related field which may provide a positive example for the types of controls that could be included in future AA research. While early therapy animal research was subject to the same sorts of limitations that can be observed in AA literature, more recent studies have made a concerted attempt to address these limitations. For instance, two research studies from Queensland have provided high-quality evidence in support of guinea pigs in animal-assisted interventions for children with ASD [71, 72].

In one study with 114 children, skin conductance, as a measure of arousal, was measured in children with ASD and typically developing children across four different conditions [71]. When reading silently, reading aloud, and playing with children in the presence of toys, arousal levels were higher for children with ASD than typically developing children. However, when guinea pigs were in the room with the children, there was no difference in arousal levels between the two groups. Children with ASD showed a 43% decrease in arousal when they were playing with other children in the presence of the animals, compared with the presence of toys.

The second study, which included 99 individuals over the course of one year, measured social behaviours of children with ASD when in the presence of guinea pigs [72]. When the animals were present, children with ASD demonstrated increased social approach behaviours towards adults and their peers, than when toys were in the room instead of the animals. They also displayed more prosocial behaviours, and smiled and laughed more. They engaged in self-focused activities less frequently when the animal was present. This was observed even though the children engaged in more overall interactions with the toys than the guinea pig, including looking at the toys and touching the toys. However, they talked to the animal more than they talked to the toy, although this did not reach statistical significance [72].

These two studies are well designed for three reasons. First, they include a large number of individuals, drawn from a classroom setting rather than being self-selected. Second, they rely not on subjective

reports of perceived improvements, but instead measure behaviours or physiological changes. Third, they instituted quality controls, such as a control group of typically developing children, and control conditions, such as the presence of a toy instead of the animal. These permit comparisons between groups and/or conditions, and provide stronger evidence that the observed effect is, in fact, due to the presence of the animal and not a spurious variable. In a 2015 report from the National Autism Center in the USA, animal-assisted therapies for ASD were considered 'unestablished interventions', in which the evidence base was not strong enough to assume that these therapies were effective [73]. Over time, future research studies that are as well-controlled as these two studies may help change that outcome.

These sorts of studies should be used as examples for AA research in the future, where incorporating larger and more diverse samples into well-designed, well-controlled studies that obtain behavioural and physiological measures in addition to self-reports, should be the goal. This will be necessary to improve the evidence base for AAs of all kinds, although it is important to keep in mind that current weaknesses in the evidence base do not imply that AAs are ineffective – but only that their efficacy or lack thereof is yet to be conclusively demonstrated.

#### 2.9 SUMMARY OF EXISTING LITERATURE

In sum, the existing evidence base for AA effectiveness across many types of disabilities or impairments is relatively weak, but generally suggestive of positive outcomes. Only a small number of studies have examined this topic and many of the existing studies have serious limitations, but this appears to reflect the immature nature of the field rather than a systematic failure of AA's to provide benefits. If so, the evidence base will undoubtedly improve as more, and better quality, research is funded. At present, it appears that assistance animals, or at least assistance dogs, may provide considerable benefits for many of the individuals they are trained to support. Many of the specific results need to be empirically validated using objective measures, and further research is needed to understand exactly how and why AAs provide positive outcomes for their owners, whether there are some people for whom an AA is not advisable and, by extension, whether alternative types of supports could be adequate substitutes for a well-trained AA. The trend, however, seems that people's lives are typically improved by the presence of an AA.

A summary of the advantages and disadvantages of AA ownership according to existing scientific literature is provided in Table 3. Overall results are summarised, since there was little variation between impairment categories regarding the perceived benefits or disadvantages of AAs.

Table 3: Summary of advantages and disadvantages of owning an assistance animal

# Key benefits for AA owners include improvements in:

- Quality of life
- Independence (including reduced dependence on formal and informal carers)
- Self-esteem
- Social interactions
- Mental health
- Community participation
- Economic engagement
- Perceived physical safety
- Family relationships (for PTSD and ASD)

Owners also cited the **emotional support and companionship** that the AA provided them, as an important benefit of AA ownership.

# Potential disadvantages of AA ownership were:

- Financial and time costs of caring for the AA
- Lack of public awareness about AAs
- Undesirable animal behaviour (especially for ASD)

### 3. PROVIDER ORGANISATION SURVEY

If persons with disabilities are to receive benefits from an AA, processes and procedures for procurement require careful management. Due to a lack of information regarding AA selection and training practices available in published documents or on provider organisation websites, we created a survey in order to request further details from providers. This enabled acquisition of standardised information. The aim of the survey was to understand the roles that AAs are currently being trained for, the species used by different organisations, selection/training practices, and their associated costs. Ethics approval was obtained for this part of the project from the La Trobe University College of Science, Health and Engineering Human Ethics Committee (Approval Number: S16-21).

#### 3.1 METHODS

#### 3.1.1 Respondents

A list of AA provider organisations worldwide, which had websites in English, was compiled. In total, 216 organisations were included on the list, including 26 organisations from within Australia. Of these, 176 listed a contact email address on their website; these were emailed a link enabling them to access an online copy of the survey. Potential respondents were asked to inform anyone else who may be interested in participating that they could also receive an invitation to complete the survey by contacting the research team. A total of 42 respondents had completed the survey before the deadline of 1<sup>st</sup> June, 2016. In order to participate in the survey, respondents were asked to confirm that they were at least 18 years of age, able to read and write in English, and were employed by or volunteered for an organisation that provided AAs to people with disabilities.

A majority of respondents indicated that their role in their organisation was Manager/Director (67%), while 24% indicated that they were the owner. Three respondents (7%) were trainers, and the other respondent (4%) was an office worker/receptionist.

#### 3.1.2 Materials

A survey was created with five key themes and 38 total items. Each theme, and the number of questions contained within it, is shown in Table 4. There was also an informed consent item at the beginning of the survey; anyone who did not provide informed consent was unable to participate. Eight of the items required text-based responses, in which respondents were asked to describe certain policies or practices (e.g. selection practices, how they ensure the animal's welfare). A copy of the survey in its entirety is available in Appendix A.

Table 4: Major themes of the provider organisation survey, and number of survey items within each theme

Theme	Number of items
Organisation headquarters and service locations	6
Animals – species and number	6
Clients – selection criteria and referral sources	2
Training practices and associated costs	6
Accreditation and associated costs (incl. innovations and research)	14
Animal welfare	3

### 3.1.3 Procedure

Assistance animal provider organisations were emailed directly through Qualtrics, the online software platform which hosted the survey, inviting them to complete the survey. We emailed potential respondents directly, rather than circulating recruitment materials on social media and other internet sites, in order to ensure that only eligible employees/volunteers of an AA organisation could access the survey. It was expected to take 15 to 30 minutes per respondent to finish the survey. Data collection proceeded for approximately six weeks in April and May, 2016.

### 3.1.4 Analysis

Frequency data and descriptive statistics established patterns in the data, and were analysed using IBM SPSS Statistics 22. For text-based, descriptive responses, main themes were extracted using QSR International NVIVO 11.

### 3.2 RESULTS

# 3.2.1 Organisation headquarters and service locations

Sixteen respondents (39%) reported that their organisation was based in Australia, while the remaining respondents worked in organisations overseas, including the USA (54%), Canada (4%), and New Zealand (2%). When asked to report how many personnel were employed by or volunteer for the organisation, the most commonly selected option, at 22% of respondents, was 6 to 10. Results for all respondents are presented in Table 5.

Table 5: Number of personnel working in assistance animal organisations represented in the provider survey

Number of personnel	Number of respondents	Percentage of respondents
5 or fewer	3	7
6-10	9	22
11-20	5	12
21-50	7	17
51-100	5	12
101-200	5	12
201 – 250	3	7
250-1000	2	5
1000-5000	2	5

#### 3.2.2 Animals – species and number

All 42 respondents indicated that their organisation worked exclusively with dogs, except for one organisation which had trialled a donkey in addition to the dogs it typically used. No organisations reported that they worked with horses or monkeys. Respondents were also asked to report how many animals the organisation was currently responsible for, and results are reported in Table 6.

Table 6: Number of animals that assistance animal organisations are currently responsible for

Number of animals	Number of respondents	Percentage of respondents
None	1	2
1-5	1	2
6-10	2	5
11-20	3	7
21-50	13	32
51-100	1	2
101-200	8	20
201-299	5	12
300-499	3	7
500-1,000	2	5
Over 1,000	2	5

Respondents were asked to report where they sourced their animals. They were able to select more than one option, so percentages reported exceed 100%. The most popular option, selected by 55% of respondents, was the organisation's own breeding program. Half (50%) reported that they purchased animals from breeders, 31% indicated that breeders donated animals to the organisation, and 28% purchased or adopted them from animal shelters. Some organisations (13%) used the client's own animal, and just one (2%) respondent reported that they sometimes sourced their animals from other AA organisations.

Respondents reported the roles that they trained their AAs to perform for clients. As above, respondents could select more than one option, so results exceed 100%. The most common types of impairments that AA organisations trained for were mobility and autism spectrum disorders. A large percentage also trained mental health service animals, and diabetes alert and/or response. Relatively few organisations trained for vision or hearing impairments, most likely because large organisations such as Guide Dogs Australia (and its state-based members) and Seeing-Eye Dogs Australia are well established throughout Australia. Results are reported in Table 7.

Table 7: Percentage of respondents who trained assistance animals for various impairments

Type of impairment	Number of respondents	Percentage of respondents
Vision	13	31
Mobility	30	71
Hearing	9	21
Autism spectrum/developmental disorders	29	69
Diabetes alert/response	21	50
Epilepsy alert/response	15	36
Post-traumatic stress/mental health impairments	25	60
Other*	7	17

<sup>\*</sup>Respondents were able to write in impairments that were not listed. These write-in responses included: dementia, cardiac alert, narcolepsy, and traumatic brain injury.

### 3.2.3 Animal selection practices

Respondents provided free text descriptions of their selection practices for the animals they trained as AAs. Some respondents mentioned the physical traits that they found desirable in their potential AAs, such as dogs being of an appropriate size. This may vary depending on the type of work or the specific needs of the clients; however, many organisations reported having a breed preference (e.g. Labrador retrievers, Great Danes, Newfoundlands) or they looked for dogs within a specific weight range. Other physical factors included general physical health, as determined by genetic background, hip and/or eye health scores, and some respondents mentioned the importance of an appropriate gait. Of respondents who mentioned the age of the dog at the commencement of training, the preferred age ranged from 6 months to 2 years. One respondent mentioned the importance of a coat that was compatible with the climate where the client lived and the client's ability to maintain the coat, and another respondent indicated that hypoallergenic, non-shedding coats were necessary. A final respondent mentioned that they looked for 'friendly physical traits'.

For temperament traits, the most commonly cited desirable traits were confidence and a calm demeanour. Eagerness to be with people and intelligence were also important for many respondents. Some respondents indicated that dogs should be food motivated, as they used reward-based clicker training, with food as the reward. Clicker training involves the use of a device that makes a short, sharp 'click' noise, which the trainer uses to indicate that the animal has performed a desired behaviour [74]. The animal first learns that the click noise precedes a reward, and then it learns to perform behaviours which elicit the click. This training method is believed to reduce training times because the noise made by the clicker is precise: the animal learns that the behaviour it was performing at the exact moment of the click is the desired behaviour, rather than what it was doing several seconds later when it

received a treat [74]. Since a willingness to work is necessary for success, according to some respondents, a dog that is strongly motivated by the reward makes it easier for the trainer to instil a strong work ethic in the dog.

Respondents described the methods that they used to determine whether a dog possessed the physical and temperament traits desired by their organisation. To assess physical traits, veterinary checks, elbow/hip x-rays, and DNA tests were used. For temperament traits, many respondents reported that they ran a series of temperament tests; however, most did not go into detail about what these entailed. One respondent reported that they put different harnesses on a dog to see which one was tolerated, and another indicated that their behavioural evaluation measured 'interest in people, body handling comfort, play response, food guarding behaviours, startle response, and treat motivation for training'. A few respondents explained that they used existing temperament tests, adapted for their own needs, such as the Volhard Temperament Test [75] or Suzanne Clothier's CARAT assessment [76]. Both of these tests measure sociability and social tolerance, reactivity to different types of stimuli, impulse control, and willingness to obey commands. Most respondents indicated that these formal and informal assessments were ongoing throughout the training process, rather than being a one-off test performed only at the beginning of the selection process.

A summary of the criteria used by respondents in selecting appropriate animals for assistance work is provided in Table 8.

Table 8: Summary of animal selection criteria

# Physical traits that many AA provider organisations found desirable were:

- ❖ Appropriate size/weight for impairment they are helping to manage
- Healthy genetic background
- ❖ Hip and eye health scores indicating good health
- ❖ Hypoallergenic coat or coat that is suitable for climate of client
- Some respondents reported breed preferences

# Temperament traits desirable to AA provider organisations were:

- Confidence
- Calm demeanour
- Intelligence
- Eagerness to be with people

**Some respondents also preferred food-motivated AAs**; since they used food rewards in training, a food-motivated animal should be easier to train.

Respondents used veterinary tests to confirm physical health. Ongoing temperament tests were used to measure temperament over time, to ensure reliability.

#### 3.2.4 Clients – referral sources and criteria for provision of an assistance animal

Respondents were asked to report the source of their client referrals, with the opportunity to select more than one response option. Nearly all respondents (95%) reported that their clients were self-referred, but 75% also indicated that they could be referred by doctors or other health professionals.

We asked respondents to write in the selection criteria that they used to ensure that a prospective client would be a suitable candidate for an AA. The main themes described were impairment-specific requirements, age requirements, and the ability to manage the dog.

Some of the requirements that were specific to the particular impairment serviced by the organisation were: being declared legally blind, severe to profound hearing loss, being a current or past military service person with PTSD or a traumatic brain injury, or having a diagnosis of diabetes. Many respondents indicated that a referral from a physician or specialist was required to confirm the diagnosis. One organisation, which provided autism assistance dogs to children, required that clients be less than 80kg and inclined to wander from places of safety. Another organisation providing autism assistance dogs also required that the child be inclined to abscond, but added that they must also be severely deficient in communication skills (verbal and non-verbal), with very little ability to engage in social interactions, and regularly engaging in severely repetitive behaviours. Finally, an organisation providing dogs for people with a vision impairment required that the clients had a functional orientation on the routes that they would be using regularly, that they planned to use those routes regularly enough to maintain the dog's skills, and that they had the ability to safely cross the road with appropriate assistance.

Some organisations had no age limit for clients, but most indicated some age requirement. Some autism assistance dog provider organisations provided ASD AAs to families with children as young as 2 or 3 years of age, but most respondents who indicated an age limit reported that clients should be at least 10 years old, with some respondents requiring that clients be 'of independent living age' or at least 18 years of age. One respondent did not indicate a specific age limit, but did explain that very young or very old clients needed appropriate support.

The level of support needed by individual clients, as indicated by respondents responding to this item, related primarily to the client's ability to care for the dog. Many respondents reported that the client must be able to engage with, train, and exercise the dog, or have a support system in place that would ensure that the dogs' needs were met. Several respondents reported that clients should be able to communicate verbally or through hand signals. Some respondents also mentioned that the client should have the financial ability to provide for the dog, and others mentioned that clients should have a suitable environment with secure fencing, no other dogs in the home, and lead an active lifestyle.

Some respondents indicated selection criteria which were unrelated to the specific impairment, age limit, or ability to care for the dog. For instance, some respondents reported that the clients should be at least one or two years post-diagnosis. Others mentioned that clients should have the desire to become more independent, which could be fulfilled through provision of an AA. Finally, one respondent reported that 'high IQ and a sense of humour would be helpful'.

A summary of the criteria used to select clients, based on respondent responses, is presented in Table 9.

Table 9: Summary of client selection criteria

Nearly all provider organisations accepted client self-referrals, but most had also accepted referrals from a health provider.

Many organisations cited **impairment-specific requirements**, such as legal blindness but a functional orientation to navigate common routes.

Most organisations had some **age requirement**, with clients typically required to be at least 10 years old. Some required clients to be of independent living age.

Many respondents mentioned that the client, or their support network, must be able to provide appropriate care and management of the AA.

## 3.2.5 Funding sources

Respondents indicated the percentage and amount of funding obtained from various sources. Government funding represented very little of the total amount received per year, which consisted mostly of donations from the public. Results are shown in Table 10. The total amount (mean and median) that respondents reported receiving from each source per year, along with standard deviation and range, are also presented.

Table 10: Percentage of funding received from various sources, reported by respondents representing different organisations.

Percentage of funding	Donations from public	Government	Client	rporate undation ants	Program fees, events, and breeding
0%	7	87	10	- Co for gra	10
1-10%	10	7	27	25	40
11-20%	7	7	3	38	20
21-30%	7	-	10	13	30
31-40%	-	-	3	13	-
41-50%	7	-	3	-	-
51-60%	7	-	3	-	-
61-70%	10	-	3	13	-
71-80%	17	-	-	-	-
81-90%	14	-	7	-	-
91-100%	14	-	30	-	-
Amount received p.a. (Mean)	\$613,969	\$11,538	\$161,590	*\$165,011	(combined with grants)
Standard deviation	\$1,000,204	\$33,627	\$299,505	*\$247,940	(combined with grants)
Median	\$262,750	\$0	\$65,000	*\$68,000	(combined with grants)
Range	\$0-\$4,000,000	\$0-\$120,000	\$0-\$1,170,000	*\$0- \$1,000,000	(combined with grants)

<sup>\*</sup>Mean amounts, standard deviation, and range for corporate and foundation grants also includes program fees, events, and breeding program. In the survey, these items were write-in options that some respondents completed after selecting 'other'.

Respondents were asked to indicate how much they charged the client for AAs in various roles. The most expensive role for AAs, on average, was autism spectrum disorder, followed by diabetes alert and/or response. Vision and hearing AAs cost less for clients than other working roles. The reason for the disparity in costs is unclear from available data. The large standard deviation and range reflect a wide range of actual prices charged, although even the top of the range for vision and hearing AAs was lower than for other roles. Results are presented in Table 11.

Table 11: Mean, standard deviation, and range for amounts charged to the client for assistance animals in various working roles.

Type of impairment	Mean amount charged	Standard Deviation	Median	Range
Vision	\$3,364	\$6,990	\$0	\$0-\$18,200
Mobility	\$7,677	\$9,972	\$1,300	\$0-\$29,000
Hearing	\$2,719	\$5,981	\$0	\$0-\$18,200
Autism spectrum/developmental disorders	\$11,178	\$11,563	\$11,700	\$0-\$35,000
Diabetes alert/response	\$9,954	\$11,943	\$2,725	\$0-\$35,000
Epilepsy alert/response	\$8,469	\$11,266	\$1,300	\$0-\$32,500
Post-traumatic stress/mental health impairments	\$7,823	\$10,916	\$628	\$0-\$35,000

# 3.2.6 Training – length of time and number of animals placed

Respondents were asked to report how long it took them to complete the training process for the animals in their organisation. The majority of organisations indicated that it took between 1 and 2 years to fully train their AAs, but one respondent reported that it took less than 3 months. Results are reported in Table 12.

Table 12: Length of time taken to train animals for placement by assistance animal organisations

Length of time	Number of respondents	Percentage of respondents
Less than 3 months	1	2
3 to 6 months	2	5
7 to 9 months	7	17
10 to 12 months	5	12
13 to 18 months	8	19
19 to 24 months	16	38
2 to 3 years	2	5
Highly variable	1	2

Respondents reported the number of AAs that began training, completed training, and were placed with a client, within the past 12 months. The raw data showed that three of the respondents reported that they had placed more animals than the number that had completed training. We are unsure where these extra animals came from, and this merits further investigation in future research, but it is likely that they completed training the year prior to being placed. Results are presented in Table 13.

Table 13: Percentage of organisations that reported different ranges for animals that began training, completed training, and were placed with a client

Number of animals	Began training	Began training	Completed training	Completed training	Placed with client	Placed with client
aiiiiiais	Number	Percentage	Number	Percentage	Number	Percentage
None	-	-	-	-	1	2
1	-	-	-	-	-	-
2-5	2	5	4	10	4	10
6-10	8	19	7	17	9	21
11-20	10	24	12	29	13	31
21-40	7	17	11	26	8	19
41-60	5	12	2	5	3	7
61-80	3	7	2	5	1	2
81-100	3	7	-	-	-	-
More than 100	4	10	2	5	2	5

### 3.2.7 Training practices

Respondents described the training practices used in their organisation in free-text responses. According to respondents, there were two main types of training provided to AAs: general obedience/socialisation training needed for public access rights, and impairment-specific training. Most respondents indicated that they started with socialisation of puppies, often when they were still with the breeder. Socialisation is the process of exposing an animal to everything it is likely to encounter over the course of its life, including different types of people, objects, places, and animals [77]. The practice of extensive, early socialisation accords with a large body of literature identifying the importance of socialisation for puppies in their first months of life, to help them develop into adult dogs that are well-integrated into modern western human society [for reviews, see 77, 78]. For some organisations, this practice was outsourced to puppy raisers or foster homes, who helped teach the dog what life would be like in a human home. A few organisations indicated that they used prison programs to raise puppies, in order to help the inmates learn life skills through dog training that may be useful when they were released from incarceration. Other organisations provided the puppy to the client, so that the puppy grew up in the client's home.

There was some disagreement among respondents regarding the use of puppy raisers or placement in the client's home. One respondent wrote a free-text comment about the pitfalls of puppy raising: 'I do not approve of puppy raising. From the puppy's standpoint it is too much of shifting loyalty. I have seen a dog in service for 5 years be thrilled to find their puppy raiser, and then clearly not wanting to go back to work'. However, another respondent wrote a comment expressing concerns about placing a puppy with a client too early on: 'I think it is unfair to put pups or young dogs in homes with recipient families. I would recommend fully trained assistance dogs only so that we don't have a lot of throw away pups because they were sent in early to do the job they were not adequately prepared to handle'. Future research should examine whether some approaches to puppy raising are more effective than others in producing successful long-term outcomes.

During the early socialisation period, or immediately afterwards, most organisations began obedience training the dogs. This included house training, crate training, leash and recall training in the early stages, and typically progressed onto training for public access rights. Among respondents who described the amount of time it took to complete training for public access, all reported that it took at least one year to complete the socialisation and obedience component of training.

Impairment-specific tasks were often taught after the socialisation/obedience training was complete, although the training sometimes took place simultaneously. For instance, one organisation that trained dogs for individuals with a hearing impairment indicated that the dogs began learning to respond to auditory stimuli while they were also learning about obedience. The organisations training dogs for scent work, as alert dogs for diabetes or epilepsy, also indicated that they started alert training when the dogs were young puppies; 'the younger the better to pick the right pup for the individual client'.

The types of tasks that the AAs learned, varied depending on the needs of the client. An organisation which trained autism assistance dogs reported that they trained dogs to accept behaviours such as being stroked with firm pressure, having their hair, lips, ears and tail pulled or played with, and being manipulated accidentally or on purpose. Trainers also reported that they 'imitate the tantrums and unique behaviour of children with autism, training the dog to remain calm...' An organisation training mobility assistance dogs indicated that they may be taught to retrieve specific items on command, open drawers and doors, turn light switches on and off, etc. Organisations that provided more than one type of AA trained dogs for different types of tasks. The same organisation training mobility assistance dogs also trained guide dogs for the vision-impaired, and for that cohort they taught dogs to walk in a straight line, watch for obstacles and overhangs, and identify different types of crosswalks.

The total length of time to train dogs for any type of assistance work was reported to be typically approximately two years if the training and socialisation began when the dog was a young puppy, with some individual variation. One notable exception was cited by a respondent whose organisation trained dogs from 8 weeks of age with the owner, who did most of the training. This meant that dogs could be accredited from 13 months of age, rather than 18-24 months. However, it is unlikely that all potential AA recipients would be capable of managing the needs of a puppy, so whether this should be adopted by all provider organisations as a matter of course is unclear. According to Assistance Dogs International standards, it takes approximately 120 hours of training over six months, including at least 30 hours in public, to train a service dog [79]. Most respondents indicated that the training process was long and intensive.

Part of the training process for AAs involves training the handlers. This requires teaching the handler how to work with their individual dog, but some organisations may also teach their clients about learning theory and how to read a dog's body language. One organisation reported that their clients were required to read three books: Karen Pryor's *Don't Shoot the Dog* [74], Jean Donaldson's *The Culture Clash* [80], and Patricia McConnell's *The Other End of the Leash* [81]. All of these books focus on the theory and techniques of reward-based training to achieve positive outcomes. Other organisations reported that they taught clients about their public access rights based on the disability laws of their respective jurisdictions.

### 3.2.8 Ongoing maintenance training

All respondents indicated that their organisation offered ongoing maintenance training after the dog was placed with the client. This was typically required by the organisations, and was often fairly intensive immediately after placement (e.g. weekly training sessions for at least eight weeks, monthly reports for the first year, an in-home visit after 60 days). Required training became less frequent over time. Most respondents indicated that they re-certified teams for public access once per year. A few respondents reported that certification was only required every two years.

All respondents reported that they offered training assistance as needed to clients over the course of the dog's working life. These sometimes involved in-person training sessions, but respondents indicated that they were also available via Skype or phone, and one respondent reported that they offered a private Facebook forum. A private Facebook forum is a good idea, as it would permit clients to interact with each other, sharing experiences and tips that worked for them. This may help clients obtain useful information more quickly than waiting on a trainer to reply to a phone call or email if the trainer is unavailable at that particular moment.

Based on the information provided by respondents in the provider organisation survey, recommended good AA training practices are presented in Table 14.

Table 14: Recommended good assistance animal training practice

The two main types of training undertaken by provider organisations were for general public access and aiding with impairment-specific tasks.

# **General public access:**

- Should take at least one year
- Includes socialisation and obedience training of puppies
  - ❖ May involve foster homes, puppy raisers, prison programs, or the client
  - May include crate training, house training, leash and recall work, moving on to more advanced training for public access

# **Impairment-specific tasks:**

- Should typically take at least one year
- Are often taught after public access obedience is complete
  - ❖ Exception: medical alert dogs were often taught simultaneously
- Varies depending on impairment. May include:
  - ❖ Turn on/off lights and retrieve objects for mobility impairments
  - ❖ Accept hair pulling, tail tugging, and tantrums for ASD
  - Walk in a straight line for vision impairments

**Total time taken to train is typically at least two years**. In cases where the client is also the trainer and obtains the AA as a puppy, this time can be reduced to as little as one year. This is not likely to be feasible for all clients.

To maintain the AA's training post-placement, service providers should offer intensive maintenance training immediately after placement. This may be reduced in frequency over time. For example, weekly training sessions for at least eight weeks, an in-home visit after 60 days, and monthly reports for the first year were cited by respondents. Recertifying the team annually was recommended by many organisations, although this could potentially be extended to every two years after the owner has worked successfully with the AA for a few years.

Trainers should be available in person, but also by phone, Skype, and social media. Private social media forums are a good way to connect clients with each other, to share advice and offer support.

# 3.2.9 Cost-saving innovations

Respondents were asked to provide free-text responses describing any innovations that they had adopted in their organisation over the past five years, which had subsequently saved the organisation money. The main themes were client screening and careful client and AA matching. Client screening was thought important in order to (as one respondent put it), 'make sure the person is ready for the dog...when exceptions are made to the acceptance policy, it costs the organization more money in the long term for client follow-up'. Providing the client with pre-instructions reduced the amount of time taken to place the dog for one organisation, thus saving money. Matching the right client with the

right dog was deemed necessary 'to better pair a client's needs and wants with the dog's personality and abilities'.

Another innovation undertaken by some organisations was improved client services. This could be in the form of extra visits and additional support for clients, and monitoring whether this additional support improved long-term outcomes for the team, as indicated by one respondent. One organisation hired a part-time development director whose role was to source large sponsorship or donations; this organisation provided each client with five hours of the director's time to generate funding ideas in the client's own community. Another respondent reported that their organisation offered both boarding school training and a combination of group classes, private instruction, and training in the client's home. The boarding school cost between \$12,000 and \$22,000, but the group classes/private instruction/in-home training cost just \$2,000 to \$5,000. This was a considerable cost saving for the organisation, but the respondent acknowledged that not all clients were well-suited for this less expensive training. Some clients lived too far from the organisation's base to benefit from the group instruction, and others needed the sort of intensive training that the boarding school could provide, due to limited prior experience with training and managing dogs.

Several respondents indicated that their organisation used its own breeding program, which helped ensure that suitable breeding stock were used, increasing the likelihood of success in the progeny. Other respondents reported that their organisation worked with specific breeders who had supplied successful dogs in the past. Some of these breeders worked closely with the organisation to begin a socialisation program while puppies were still in the litter. Puppy raising programs through community volunteers or prison programs were cited by some respondents as helping to ensure that the dogs were adequately socialised and trained in a consistent way. These programs also helped increase community awareness of the roles these dogs play in society, according to one respondent:

We have begun a breeder host program and a puppy raiser program to not only increase awareness about service dogs and their use in coping with invisible disabilities like diabetes, autism, seizure disorder and PTSD, but also to help reduce costs for kennelling and staff time associated with caring for the over 100 dogs that are consistently in training at our facility. These programs not only engage the public, they also provide wonderful socialization experiences for our puppies in training.

One respondent who trained dogs for medical alert work (e.g. epilepsy, diabetes) mentioned that the client owned the dog, and the client did most of the training. The benefits of this method are that the bond between the dog and owner is already established, and costs are reduced because there is no need to board dogs or pay for extensive training with a trainer. Furthermore, most of the dogs in the program were already spontaneously alerting to changes in the owner's physiology. This would mean that dog training would need to focus primarily on obedience for public access rights, and motivating the dog to continue alerting appropriately.

Use of volunteers to cut down on the costs to run the organisation was cited by several respondents. Volunteers could reduce the organisation's need for support staff, help test the dogs and also train basic skills that the dogs would need in their working life. At least one organisation provided *all* post-placement support on a voluntary basis. According to one respondent, '90% of the work done with clients post-placement is provided on a volunteer basis, so no-one is being paid wages to help support the further training of their dogs'.

Two respondents noted that positive reinforcement training reduced costs for them, by reducing the training times and 'producing better outcomes for dogs'. Two other respondents indicated that they

regularly attended international conferences for AA organisations, allowing them to share information about what worked for them and learn from others.

Finally, some respondents indicated that they were incorporating newer technologies into their programs, in order to increase efficiency. For instance, one respondent reported that their staff used mobile technologies, which permitted them to 'spend more time with the dogs and clients, and less time in the office undertaking administrative work'. Another respondent indicated that they used Facebook to 'encourage current clients and potential clients to communicate about before and after having an [AA], fund raising ideas, and generating a sympathetic base of parents dealing with autism...'

A summary of the types of innovations providing cost savings to organisations is presented in Table 15.

Table 15: Summary of cost-saving innovations

# Provider organisations improved client services through:

- Improved systems for client selection
- Matching the client to an appropriate AA
- Offering additional support post placement
- Hiring additional personnel or volunteers

# For AA selection, to ensure reliable breeding stock, organisations:

- Had their own breeding program
- Worked with certain breeders, to help ensure that the breeding stock was reliable

# For AA training, organisations used:

- Puppy raising programs
- Clients who owned their AA from puppyhood (when feasible)
- Positive reinforcement training
- ❖ Mobile technologies (to enable trainers to spend more time working with clients)

#### 3.2.10 Accreditation

Respondents were asked to provide information about their accreditation practices, including which organisations, if any, provided independent accreditation for their animals. Respondents were able to select more than one response option. A large majority (90%) reported that they accredited their AAs in-house by their own organisation, but 41% also indicated that their AAs were accredited by Assistance Dogs International, and one respondent (2%) reported that the Government of Queensland accredited their animals. Just one respondent (2%) indicated that their animals were not accredited at all. When asked to explain why, they wrote, 'I model my program off of Service Dog International, [the] AKC and [the] Assistance Dog United Campaign...the USA laws in our state do not require certification'. This suggests that, while there was no official accreditation by this particular organisation, they nonetheless appeared to expect that their dogs would meet a certain standard of training, as set by different organisations.

Respondents reported how long it took for their animals to be accredited for work, and over one-third (35%) indicated that it took between 13 and 18 months. Several others reported that it took between 19 and 24 months. Results are reported in Table 16.

Table 16: Length of time taken for assistance animals to become accredited for their working role

Time taken to accredit	Number of respondents	Percentage of respondents
Less than 3 months	-	-
3 to 6 months	2	5
7 to 9 months	4	10
10 to 12 months	5	13
13 to 18 months	14	35
19 to 24 months	8	20
2 to 3 years	4	10
Highly variable	2	5
Not applicable	1	3

Respondents also reported how long the accreditation for each of their animals lasted, and results are reported in Table 17. For most organisations represented, accreditation lasted between 1 and 3 years, although for some it lasted less than 12 months. Nearly one in five respondents indicated that the accreditation lasted for the life of the animal.

Table 17: Duration of accreditation once assistance animal has obtained accreditation

Duration of accreditation	Number of respondents	Percentage of respondents
1 to 3 months	1	3
7 to 12 months	9	23
1 to 3 years	21	53
More than 3 years	2	5
For the life of the animal	7	18

Respondents were asked to write in the costs to initially train and accredit animals, as well as the costs to maintain accreditation. We had intended for respondents to provide the amount that it cost the organisation (e.g. \$30,000), however at least one quarter of the respondents appeared to misunderstand the question and wrote an amount less than \$5,000. These respondents may have thought we were asking them to report the amount paid to the organisation by the client (e.g. \$0 or \$300). Since the data reflected in the responses appeared not to truly represent the costs to the organisation, these results are not presented here.

Respondents indicated the organisation's requirements to maintain an animal's accreditation, and they were able to select more than one response option. The majority of respondents (72%) reported that they provided ad-hoc training if the client requested help, and 28% provided ongoing assessments over the course of the AA's working life. Respondents also indicated that they had formal maintenance training with their clients and AAs once per year (42%), every six months (8%), every three months (8%), or once per month (3%).

A few respondents wrote free-text comments about the training and accreditation process. According to one respondent, 'It is imperative to ensure that any accreditation process considers not just the capacity of the provider to train the assistance animal, but their expertise (or lack thereof) in working with the specific disability they seek to address'. Most organisations reported accrediting their AAs inhouse; however, if there is ever an independent body overseeing the accreditation of AAs in Australia, the trainer's knowledge of disability should perhaps be a consideration.

Another respondent wrote about the need for closer cooperation between large and small AA provider organisations:

[I] would love to have access to the research after completion to learn more as... our industry is not very good about sharing, and the large organisations try and avoid working with us as much as possible. They'd rather sell a failed dog to the public than us, with a client of ours benefiting from the training/investment already made. As our needs are tailored to the clients, a rejected dog may well be what we need. Sad, short sighted and poor vision!

Closer coordination and cooperation between organisations may benefit all parties if there is ever an independent body accrediting AAs, as working together to share knowledge could improve outcomes for clients. Indeed, one respondent wrote that they would like to develop a training cadet program for adoption by provider organisations:

"...that will certify trainers and instructors in a way that every school taking on new trainers would know what they are getting in base knowledge of understanding at least... The biggest advantage to this process that I see is that the trainers also receive some understanding of the differences in training and expectations when they are training a dog, not for themselves or another dog training enthusiast, but for a client who has or is living with a child [with] disability who needs assistance: not a hobby, distraction, another disadvantage or a hassle'.

A standardised training course for individuals who are interested in becoming dog trainers for AA provider organisations would be desirable, either as a stand-alone program or part of a graduate diploma or TAFE certification. Any course of this kind should be based on the best available evidence for dog management and training. Furthermore, if other species become more popular as AAs over time (e.g. horses, donkeys), the training course should be flexible enough to accommodate training for animal species other than dogs. Behaviour theory, which is the basis of many popular training methods in dogs [e.g. 74, 80], applies to other animal species as well [82]. However, the motivations and emotions represented by certain behaviours may vary by species, and this should be accounted for in any AA training course.

# 3.2.10.1 Perceptions of accreditation requirements and organisational research

Respondents were asked to rate the extent to which they agreed or disagreed with a series of statements related to accreditation by government bodies and public access tests. Respondents were typically in agreement about the importance of requiring that all AA's pass a Public Access Test, but responses to other items were variable; the means did not stray very far from the mid-point of 3.0 on a scale of 1 (strongly disagree) to 5 (strongly agree), but the standard deviations were large. Responses are reported in Table 18.

Table 18: Percentage of respondents who agreed or disagreed with statements about accreditation and government certification of assistance animals, including means (M) and standard deviations (SD)

Item	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	M	SD
Every assistance animal should be required to be registered with an official government body.	15	12	29	10	34	3.4	1.4
Assistance animals should only need to be accredited by their organisation.	22	2	29	17	-	3.2	1.4
Assistance animal organisations should be accredited by an official government body.	10	26	17	17	31	3.3	1.4
Assistance animals should be able to be trained by individuals who are not affiliated with an AA organisation.	46	5	10	29	10	2.5	1.6
All assistance animals should pass the Public Access Test	5	-	5	10	81	4.6	1.0
There are some people with disabilities who need an AA which has not passed the Public Access Test.	71	14	7	2	5	1.6	1.1

Respondents reported whether they had undertaken any research within their organisation, which had subsequently been made available for people outside the organisation, and 76% indicated that they had not. Of the remaining 24% of respondents who reported that they had made the information available, all indicated that they had published results in peer-reviewed academic journals, and two-thirds of these respondents (67%) had published in academic conference proceedings. One respondent (11% of respondents who have published) indicated that they had published the results in publications for the assistance animal community, and another respondent published on websites.

Among respondents who indicated that they had not published any of their organisation's research, 44% reported that all of their research was kept only for their use, 33% reported that they had not done any research, and 22% reported that they did intend to publish their research in the future.

Respondents provided free-text descriptions of the type of research that their organisation had undertaken. For most organisations, this involved regular interactions with the clients throughout the working life of the AA, and evaluations both pre- and post-placement. Many respondents also noted that they were constantly updating their training practices, based on their own experiences of what worked as well as conference attendance and further education for staff, in order to learn about best practice from others.

A few respondents mentioned having worked with local university researchers to examine dog cognition in general and, in the case of medical alert dogs, accuracy of alerting behaviours. For these types of AAs, some respondents indicated that they asked clients to keep thorough alert logs. One of these respondents indicated that, according to research undertaken in collaboration with a highly ranked university in the USA, the accuracy ratings for their diabetes and seizure alert dogs varied between 92% and 97%.

Two respondents whose organisations worked with prisons, reported that they had examined the impact of the AA training program on these individuals. One of these respondents indicated that recidivism for prisoners in the training program was lower than for the general prison population (17% vs 55%).

A summary of accreditation practices and research being undertaken by AA organisations is visible in Table 19.

Table 19: Summary of accreditation practices and organisational research

Nearly all respondents agreed that all AAs should pass a public access test.

**Most organisations accredited their AAs in house**, but nearly half also had the AAs accredited by Assistance Dogs International.

# Accreditation typically:

- ❖ Took 1 to 2 years to complete (for initial accreditation)
- ❖ Lasted between 1 and 3 years
- ❖ Was maintained through ongoing ad-hoc or formal training sessions

# Respondents mentioned the desire for:

- Trainer education in the disability(ies) of their clients
- Closer cooperation between different provider organisations to meet client needs
- ❖ A standardised training course for AA trainers

# Research undertaken by organisations included:

- Regular interactions with clients
- Pre-/post-placement evaluations to measure benefits of AAs
- \* Recidivism of prisoners in a puppy program was much lower than the general prison population, based on research completed by one organisation.

#### 3.2.11 Animal welfare

Respondents were asked to detail ways in which they ensured the welfare of the animals in their organisation. They were also asked to indicate the typical working life of their animals, and results are presented in Table 20. The mean duration of the AA's working life was 9.3 years (standard deviation = 1.5 years).

Table 20: Typical working life of dogs working in assistance animal organisations

Working life	Number of respondents	Percentage of respondents
5 years or less	-	-
6 years	-	-
7 years	2	5
8 years	14	35
9 years	6	15
10 years	14	35
11 years	2	5
12 years	-	-
13 years	-	-
14 years	2	5
15 years or more	-	-

Respondents also provided free-text responses indicating how they ensured the AA's welfare over the course of its working life. Nearly all respondents reported that their organisation required the client to provide regular veterinary reports confirming that the dog was in continued good health. Early in the training and shortly after placement, the organisations often kept in frequent contact with clients, and these observations and conversations helped organisation staff understand whether the dog was experiencing good welfare with the owner. Two respondents indicated that their clients were required to obtain pet insurance for their AA, and one reported that there was a special fund to help cover the cost of any necessary medical care that the client could not afford.

While nearly all respondents noted the importance of veterinary care to ensure dogs' physical health, some respondents also mentioned the impact of diet, training practices, and stress levels on the AA's welfare. For instance, several respondents indicated that they required their clients to feed their AA's appropriate amounts of a species-appropriate diet and to maintain the dogs at a healthy weight. One respondent reported that their organisation required their clients to provide monthly receipts of dog food purchased for the AA.

Some respondents indicated that they used only positive reinforcement-based training with their dogs, and one respondent reported that their clients must also agree to only use positive training methods. Other respondents mentioned the importance of regular, continuing education and regular program evaluation to ensure that optimum training methods were being used by the organisation.

Only a few respondents mentioned the importance of downtime for play to reduce stress on the AA. One respondent indicated that this was accomplished through education of their clients, and others cited that clients were expected to balance the dog's work and play time.

All AA's eventually stop working, and retirement has potential welfare implications for both AA and owner. Some respondents reported that their organisation worked with the client to determine the best outcome for both, such as the dog remaining with the client or family member, being adopted by a friend of the family, or being returned to the organisation for rehoming. Since the results of one study suggested that having agency in the outcome of the rehoming process may help reduce distress levels in guide dog owners [15], we support the implementation of this practice by AA provider organisations, whenever possible.

Nearly all respondents reported that they retained ownership of the AA throughout its working life, and the contract that clients signed typically allowed the organisation to take the AA back if there were concerns for its well-being. One respondent noted that, despite working in a large organisation, this was rare: 'We have placed 500 service dogs. To date, we have only had to recover 5 dogs'. One respondent indicated that the dog was owned by the client, and was therefore the client's responsibility, and another respondent noted that the organisation owned the AA until its second accreditation, at which point ownership was transferred to the client. However, this organisation was willing to recover dogs for rehoming if they could not remain with the client.

A summary of the ways in which provider organisations worked to ensure the welfare of the animals in their care is presented in Table 21.

Table 21: Summary of ways that organisations ensure the welfare of their assistance animals

The typical working life of an AA (for dogs only) was between 8 and 10 years. Most organisations retained ownership of the AA and could recover it due to welfare concerns, but this was rare.

Most respondents relied heavily on veterinary statements to ensure animal welfare.

Other important factors relating to AA welfare were:

- Diet
- Training practices
- Stress levels, including balancing work with non-work time

At retirement, some organisations worked with the client to determine the best outcome for AA and client, including:

- Remaining with the client as a pet
- Being adopted by friends or family of the client
- ❖ Being returned for rehoming through the organisation

#### 4. ASSISTANCE ANIMAL OWNER CONSULTATIONS

To begin to understand the perspective of clients who rely on the services provided by AAs, we devised a series of questions related to the advantages and disadvantages of AAs for individuals who own one, including the economic impacts of having an AA. We facilitated a total of five focus group meetings, including a total of 20 individuals. These attended one face-to-face meeting in Adelaide (n = 9), one in Sydney (n = 4), or they logged on to one of three meetings which proceeded online (n = 5 across three meetings). Two children with ASD provided written responses to the focus group questions. One owner later requested that their data be excluded from analysis, so information from 19 owners is presented. All owners owned an assistance dog; no other species was represented. A list of the number of owners with specific impairments is provided in Table 22. Since some owners had more than one impairment, the total number exceeds 19. Ethics approval was obtained for this part of the project from the La Trobe University Human Ethics Committee (Approval Number: 16-028).

Table 22: Types of impairments represented in focus group meetings, and number of AA owners with each impairment

Impairment	Number of owners
Vision	3 adults
ASD/Developmental disorders	1 adult with ASD 7 parents of children with ASD 3 children with ASD
Generalised anxiety/psychiatric disorders	2 adults
Epilepsy	1 adult
Diabetes	1 adult
Mobility	2 adults

More parents of children with autism spectrum disorder or other developmental disorders took part than AA owners with any other type of impairment, and this is reflected in the data. A summary of the main themes extracted during the conversations is presented below.

# 4.1 EXPECTATIONS OF, AND REASONS FOR, OBTAINING AN ASSISTANCE ANIMAL

We asked AA owners to describe their reasons for obtaining an AA, and their expectations prior to obtaining their AA.

# 4.1.1 Reasons for obtaining an assistance animal

Most owners obtained an AA to help them manage the specific needs of their disability, or to improve their overall quality of life. One adult with a vision impairment and diabetes explained:

The main [reasons] were to increase my independence with getting out and about safely and independently in the community and also to help with managing my diabetes.

An owner with a mobility impairment had similar motivations.

I was having a lot of falls, and my mom wanted me [to] get a Medivac alert and I really didn't want to do that... The idea of having a dog that could be my friend 24/7 and help

me in that respect was a much better idea than having the Medivac alert...I guess the idea of having a companion to look after me and be my friend was ... a double bonus.

#### 4.1.2 Expectations of assistance animals

Owner expectations of their AA prior to obtaining the animal varied depending on their level of previous experience with AAs. Owners who were currently living with their 2<sup>nd</sup> or 3<sup>rd</sup> AA generally had clearer and more realistic expectations of their AA's contribution to their disability management than people who were living with their first AA. This was confirmed by those owners, who explained that their expectations of their first AA were probably unrealistic. An owner with a vision impairment explained:

I guess I had pretty unrealistic expectations about what a dog was capable of.

However, a child with ASD was expecting companionship.

I'd have a good friend in the house.

One parent of a child with ASD explained that she had no real expectations at all.

You know what? I honestly didn't know. If somebody had asked me that same question when I was looking, I would have said I really don't know. I was clutching at straws... I was really a mom reaching out... I wanted to normalize things for him.

Another child with ASD was unsure about the potential benefits of having an AA.

I couldn't see how exactly a dog could help.

Whether this experience is typical is unclear based on the information provided by other owners in the focus groups. However, if unrealistic expectations are common, it will be important for provider organisations to be careful in managing these expectations as much as possible prior to placement. This will be easier to accomplish reliably once results of well-designed studies on the effectiveness of AAs are available.

#### 4.2 ADVANTAGES OF ASSISTANCE ANIMALS

There was a time prior to having [my child's AA] that I just thought, I just can't keep doing this...I just can't keep being the pillar, the post. It was all just kind of crumbling on top of me.

We asked owners to describe the benefits that their AA provided. These benefits included general positive outcomes in addition to everyday improvements in owners' ability to manage their disability. Some owners also mentioned unexpected benefits that they had not anticipated before the AA came into their lives.

#### 4.2.1 General benefits

The main benefits of owning an AA were increased confidence, perceptions of safety and independence, and improved social interactions with the community. For instance, one owner who had a mobility impairment due to dizzy spells explained that her dog, contrary to her commands, once refused to let her move when she was in a public place; he stood in front of her chair and refused to move when she commanded him to. A few moments later, she had a debilitating dizzy spell. She believed that the dog anticipated this, and that he was behaving disobediently in order to keep her

safe. As a result, she was subsequently more confident when accessing public places with her dog, as she trusted him to care for her.

A child with ASD indicated that her AA kept her company when she was upset.

When I get upset...she gives me company...when I'm on the floor, she'll lick me...I like how she does that.

This owner also reported that taking the dog to training helped encourage social interactions with others.

I've got dog training we do on Thursday, with the dog, and there are other kids...I take her there and I train her...there's other kids there and loads of dogs...she's also making friends.

Another child with ASD also expressed enjoyment about dog training.

I do dog training with [my AA] and that is actually kind of fun...[my AA] is really good at doing tricks so I feel happy I have taught him.

This child appears to have learned life lessons from training his AA.

We are both afraid of heights but face our fears. We will respond to them. In dog obedience, that is.

An owner with a son with ASD explained that he (the son) became willing to engage with the community.

What it's done for me is to increase our inclusion in community so that we can actually take our son with us rather than leave him home because ... his anxiety is so bad that he hides under the table. He doesn't want people looking at him. The dog's helped with all that sort of stuff.

This owner then went on to describe the types of interactions her child had with others in the community when accompanied by the AA.

He's confidently showing his dog off because everybody wants to see the dog...and people talk to [my child] through the dog. Every now and then, [my child] will actually participate in that conversation, and that's increased his dialogues, so it's increased the opportunity for him to engage with people in the community through the dog...Everybody in [my town] knows the dog, and they always ask [my child's] permission, "Can I pet [your dog] today?"... It gives him a sense of empowerment really when he's the one saying, "Yes, you can," or, "No, you can't."... He feels he has got some control over something in his life ...[otherwise] he feels a lot of the time out of control.

Social inclusion was cited by several other owners as well. One owner with a mobility impairment described the types of interactions that she had with other community members because of the AA.

I was in the shopping centre one day and everyone was smiling as they went past me. My support worker...[said] that that's what happens, that [the dog] was making everyone else happy in the shop.

People see me more when I have a dog and want to know all about the dog [rather than] seeing me as the girl in a chair. After I lost...my first dog I was back to being the girl in the

chair, I wasn't the girl with the dog. The way people saw me was different, and the way I saw myself. It took a little bit of an adjustment to be that person again without the dog.

A child with ASD explained that his friends enjoy talking with him about the AA.

My old friends...loved [my AA]. He was good and kind and gentle and not too rough. They liked to ask me questions...My friends also all want to pat him and ask questions about him, and I simply answer the questions for him, like how we got [the AA].

An owner with a visual impairment mentioned that she would be unlikely to go out alone.

I never went out unless somebody was available to go with me. Living on my own, that opportunity didn't come up very often, so I was completely socially isolated. I didn't have the confidence to go out myself... I'd wait for somebody to come along and help, which is far from satisfactory. A dog allows me to live a more normal life and walk confidently.

One owner with a mobility impairment said that, if she did not have her AA, she would probably still be able to accomplish her daily tasks, but it would take a lot longer. She then went on to explain that the responsibility of caring for her AA gave her a reason to spend time outside, when she otherwise might not bother.

I think just the fact that I get out every day. With MS it's very easy, you don't have the energy to go out and it's just easier to stay inside. Because I've got him, it gives me a purpose to get out and walk him which then gets me out in the sunshine. I'm always glad that I've gone out. From that point alone, I think he's definitely opened my world because of that responsibility.

Similarly, a child with ASD stated that the key advantages were related to confidence rather than specific practical benefits.

On a physical level, no, my dogs don't help me with anything much; however, I do feel that they have the capacity to increase my overall happiness and confidence... and [my AA] has significantly lowered my anxiety levels.

An adult with ASD explained that she was fully independent because of her AA.

I can do everything I need to do to be an independent adult.

Finally, another parent of a child with ASD described the dog's role as a confidante for an individual who had struggled to make friends.

He doesn't have a buddy he can get on the phone with and be like, 'my life sucks', so he does it with the dog.

The general theme of having a companion or confidente was also cited by other owners.

...probably one of the biggest side benefits for me with having a dog is the constant companionship. I mean she's more of a constant companion than my husband is. She's just always with me.

#### 4.2.2 Specific improvements

In additional to general improvements in quality of life, there were specific benefits that helped owners engage in their daily tasks more effectively than they could before they had an AA. For instance, one owner with a mobility impairment described the types of practical tasks that the dog assisted with.

We've got a tugger on the fridge, so he will open the fridge for me, and pull my socks off. If I've finished exercising and I've got no energy, he will pull my socks tight and well, push my shoes off and he can pull my socks off... He pulls stuff out of the washing machine for me as well which is good.

Another owner described the way that her previous AA helped her manage getting to and from work.

I've had three dogs in my time at work...Once he learned how to do everything that was expected it was great being out, just getting in and out the building by myself. It was an old building... I used to just wait by the door until someone came through. With the dog, I could get in myself which was so better... I felt a little bit safer being out and about in that area with my dog on the way home.

A parent of a child with ASD explained that her child had developed verbal skills to give the AA commands, and social skills to facilitate interactions around the AA. The child had been given scripts for when people asked questions such as 'what kind of dog is that?' Using these scripts had enhanced the child's communication skills in other contexts. Another parent of a child with ASD explained that they were able to go out, knowing that the child could not run away because he was anchored by the AA.

[Before the AA], you try to get him out and walk around for a little while but yeah, he'd just try and run straight away so then you're sort of forced to put him back in the pram and it seemed to just take the fun out of everything.

Other parents of children with ASD described using the responsibilities inherent in managing a dog's needs, to help the children develop empathy and a sense of responsibility.

'Has the dog got water? Has the dog been out to the toilet? Have you made sure the dog is okay? This is your dog'. This is what we have been able to teach our kids, 'this is your dog'.

[My child] grooms the dog. [He] brushes his dog. He feeds the dog. It's given him an element of responsibility, which is really good because, yes, he's got to blow the whistle and that dog comes to wait...

There was also some mention of specific skills that individuals with disability acquired, such as dexterity through grooming the AA, and motor control through throwing objects when playing with the AA. One child with an AA for ASD explained that he learned to speak in order to communicate with the AA, and that the AA permits him to go outdoors.

I probably wouldn't talk without [my AA] and would be that lonely...I never thought I could go walking with a dog before outside.. I don't run away when [my AA] is around.

## 4.2.3 Unexpected benefits

Several owners also described ways in which their AA had gone above and beyond its original training, and learned how to respond to the owner's specific needs without training by the owner. For instance, one guide dog owner who was also diabetic noticed that her guide dog was making alerting behaviours when she was having a low blood sugar episode, even though the dog had not been trained for that purpose. She worked with a trainer to strengthen the dog's natural tendency to alert, and the dog subsequently functioned in dual roles.

For parents of children with ASD or other developmental disorders, a commonly cited theme throughout the conversations was the impact of the AA on the entire family dynamic. The parents found it very useful that the AA would prevent a child with ASD from bolting, but they were particularly impressed by the calming influence that the animal had on all members of the family.

Look, my son like normally won't get into other people's cars and even our friends, so I've always been the driver. I take him everywhere... The other day, he [asked to take the school bus]. He stands outside the front gate. I'm not even allowed to go out there now. I've got to stay inside. [The dog] is on the other side of the gate, and they're just sort of playing with each other through the gate until that bus arrives, and then [my child] gets on the bus. [The dog] turns around and comes inside.... Just that half an hour in the morning ...just to sit and have a cup of tea and just reflect on the morning and having me time, that to me is the most valuable of all.

It has given me more time to spend with my other two daughters who also have special needs. I guess, holistically all around, the dog has had a complete calming effect on the whole of the house, the entire household... the expectation was I didn't think I was going to get anything out of this. I thought this dog was purely going to be for [my child] and to help him, engage him and be less isolated and all the rest, but it's had a whole of the household effect. We've all benefited from the dog, which is something I hadn't really thought of, to be honest, because I wasn't looking for quick fixes for the rest of us.

Another parent of a child with ASD indicated that the child's sibling viewed the AA as a positive outcome of her sister's disability.

In some ways I can see more of a benefit for the family at the moment and the benefit for my daughter who's on the spectrum is going to realise itself over time.

Finally, a different parent of a child with ASD explained that her child's AA actually had a profound impact on one of her other children, reducing the self-harm that this child engaged in prior to the AA's arrival. The AA had interrupted numerous suicide attempts by the child through alerting the parents, who were then able to stop the behaviour.

[This] was a result of the bond they formed, which is ironic as our first dog was meant for our youngest child; [it] worked with my youngest but bond was with my eldest.

#### 4.3 DISADVANTAGES OF ASSISTANCE ANIMALS

It's the person handling the dog in the community that has to face those day-to-day rejections [of public access].

The most notable problem with AA ownership was public access. Most owners expressed some dismay over the fact that, even though they were legally permitted to go virtually anywhere with their AA, some people tried to refuse them access to places they could rightfully go.

In the beginning, I would walk in to a new environment and kind of go, 'Okay, so how is this going to go?' All of a sudden, someone looks at you, 'Excuse me, madam, you've got to tie your dog up outside'.

This particular owner, the parent of a child with ASD, explained that educating shop owners about their dog's public access rights was typically enough for them to permit the AA public access. However, one psychiatric AA owner indicated that these interactions require a higher level of assertiveness than many people with an AA for an anxiety disorder possess. Therefore, either these individuals leave the situation because they cannot engage with the person lacking awareness about public access rights, or their anxiety is exacerbated by being forced to stand up for themselves.

Using taxis was a problem for several owners. Taxi drivers had sometimes refused to pick them up if they had their AA with them, even if they were clear when booking the taxi that a dog would be travelling with them. This was particularly problematic for guide dog owners, many of whom preferred to take a taxi rather than relying on public transport and travelling on foot, especially when going to an unfamiliar location.

I'll have to say the only disadvantage for me with a dog on public transport is when it comes to catching a taxi. So many ...drivers will refuse to take a dog even though they're protected under the law. They, for personal or religious reasons or whatever, won't take a dog and I've been left standing on the curb, which is just not right.

When I have to ring a taxi, I say I have an assistance dog as a passenger as well, and time and time again I'd have somebody turn up as you have and go, 'Oh, you've got a dog?' Yeah, that's what I said when I booked the taxi... they need to feed that information through.

These are issues that further education for shop owners and taxi companies could address. However, as one owner mentioned, this is a problem that people with disability are encountering *now*, and future educational efforts do little to alleviate the day-to-day disruptions that they currently encounter.

It doesn't matter what amount of public education is on it...To be left standing on the curb because a taxi driver won't take a dog is a really distressing situation. That's also unlawful, and no amount of public education is going to change it whether it be from the assistance dog schools or from the assistance dog handlers.

While increased social interactions were listed as an important advantage of AA ownership for many owners, the nature of the interactions were not always desirable.

Yeah, it's a pain that everybody wants to come up and pet the dog and ask questions about why I'm in a wheelchair or why my hands are that way and all those personal questions that you shouldn't really tell a stranger. You have to just talk about the dog.

For individuals with an 'invisible' disability, this could mean that the disability was no longer invisible. One owner with a psychiatric service dog reported that her partner and family members sometimes felt embarrassed when approached by strangers asking what role the AA served.

One child with an AA explained that his AA did not always respect his wish to be alone.

...there are times when you want to be left completely alone, something an animal can't quite understand.

Finally, cleaning up after the dog was cited as a disadvantage for some owners. The dog hair generated by many of the breeds that are commonly used for these roles was a source of some frustration.

The main issue has probably been my cleaner just left and she has a real problem with his hair... He's got a winter coat and he's just losing the hair everywhere. That's probably the only real hassle for me.

I have to sweep my floors every day and I get bucket-loads of hair, and that was a job that I never had to do, but I wouldn't trade it for not having to sweep up...but to get these bucket-loads of hair just reminds me, yeah, I've got a dog...

#### 4.4 TRAINING AND RELATIONSHIP WITH PROVIDER ORGANISATION

### A bad dog is better than no dog at all. He's still a great help to me at home.

Two owners reported that they had not felt adequately supported by their AA provider organisation. One owner explained that her dog became ill very quickly. She asked the provider organisation for advice on how to manage the illness, but nobody in the organisation responded to her phone calls. Eventually she euthanased the dog on advice from a veterinarian, without consultation from the organisation. This experience left her feeling very resentful.

Another owner with a mobility impairment indicated that she had obtained three different AAs from two different organisations, and none of the dogs was suitably trained.

In January he also started reacting to cars as well. That happened in the middle of the road while I was crossing at the light which was a real danger because he put me off course and I was kind of off the road. The trainers then decided, 'well let's just send him back'. It had already been like five months. Why would I change then?

The organisation was unable to help her solve these problems. She kept the dogs anyway because she had grown attached to them and they did provide support in other ways, but none of them reached a level of training that should reasonably be expected in an AA.

I like my dog, I rely on him so much as any normal person would... I [would not] just take it back and demand a refund or a replacement. It was a living, breathing thing. You can't just do that... I prefer to work through these problems and get help for these problems than change dogs but it's been really tough to get that [support].

She and another owner with a mobility AA both indicated that their dogs lost public access rights due to behavioural problems, but they were so helpful at home that they were still worth keeping.

Other owners typically described more positive relationships with their organisation.

When I got [my AA], he pretty much came with the instruction kit, a couple of pieces of paper with all the commands.

We asked owners about the difference between an AA and a well-trained pet dog, and whether it might be feasible for AA owners to train their own animals for some roles. Most owners indicated that the level of training required to become an AA would be unrealistic for most individuals with a disability or their families to accomplish. A few said that they would possibly be able to train their own AA once they had had experience with one, although acquiring the correct breeding lines would still be an issue and would likely require continued collaboration with the AA provider organisations.

As a busy mum with two kids on the spectrum 18 months apart, I didn't have the time to train a nice pet dog. However, now, given my kids are older and I've more time, I would be capable of getting a dog and training it.

There are certain lines you can't get from a rescue dog or just any puppy – there's a reason Labs are good, they are bred from certain lines in guide dogs. So we'd look for organisations to get the dog but we would be capable to train because we've done it for 10 years.

To ask a special needs family who are already going through so much to train a dog at the same time is hard. The dog needs a level of knowledge before it goes to those people – maybe their next dog they can do themselves.

There are people who can raise and train a dog for public access with a little bit of support and those who cannot. No different from any other decision of the NDIS, it's got to be tailored to the family involved.

In general, owners appeared to be satisfied with their relationships with the provider organisations, although there were some legitimate concerns around training maintenance and health emergencies. Provider organisations should work to ensure that their clients feel supported in difficult times, even if they are interstate or live in a rural area that is not located close to the organisation's headquarters.

#### 4.5 ANIMAL WELFARE CONSIDERATIONS

We have lots of playtime and free runs in the backyard and interacting with other dogs and things like that... they definitely do get downtime.

We asked owners to describe ways in which they ensured that the welfare needs of their AA were met. Most owners reported that the dog had plenty of downtime and opportunities for play.

My dog has free run of the house. He can sleep on the couch. He can sleep in my bed, he can sleep on anybody's bed.... If he wants his downtime and just wants to be left alone, he can just go into his crate. With the door open, he can just come out whenever he wants.

It would not be fair to the dog to have them working 24 hours a day. They work, they rest and they play like any other animal.

In homes with a child that had a developmental disability, there could be special considerations around the child's behaviour. In those situations, parents described the AA's option to leave the area when the child was having a meltdown, as well as the need to discipline the child when s/he mishandled the AA.

It hasn't really come up as a problem for us because [the dog] has the choice in the home to be there or not.

It's also just not underestimating our kids as well, just because they're non-verbal doesn't mean they don't have a say and they don't understand. So it's...being firm as a parent.

This parent explained that, when they obtained their first AA, their youngest child was violent and hit the dog once. The parents removed the dog from the child's presence. The child's meltdown escalated but the mother was firm, and the child had not behaved that way since. Another parent reported a different problem: now that her son was older, managing his behaviour toward the AA was more difficult.

He's never kicked or punched or done anything like that but has he yanked on the leash too hard and over corrected? Absolutely he has, and that's a work in progress.

Finally, a child with ASD confirmed that managing an AA's needs can be challenging, but worthwhile.

While my current dog can be a bit too pushy at times, along with of course requiring a fair amount of effort to take care of properly, I cannot see my life without him as I do love him very much.

#### 4.6 SPECIES OTHER THAN DOGS IN ASSISTANCE ANIMAL ROLES

It's a hard one because I don't want to deny a person with a disability having assistance from any other animal that can fulfil that role, but it's just harder to accept.

Although not common in Australia, there are species other than dogs being used in some AA capacities overseas. We asked owners their opinions about using other species, such as horses or monkeys, in these types of roles. In general, the owners did not support their use, because they considered dogs to be more socially acceptable.

Monkeys? I don't know. Pigs? Cats? Snakes? I don't know. To me, they're just not as sort of acceptable in a social or public situation as a dog would be... The fact that [dogs] can be toilet trained, that they can have obedience training to make them quiet, clean and obedient in all situations is a big advantage.

Owners did appreciate that dogs are not for everyone, so there was some discussion about situations in which another species might be more suitable.

Horses would be good for people past the 8 year old cut-off [for autism assistance dogs] who are heavier.

## 4.7 DEATH OF ASSISTANCE ANIMAL / TRANSITION TO A NEW ASSISTANCE ANIMAL

I know they can be replaced, but you go on a waiting list and you have to go through the whole process of training with the new dog, which is probably physically, mentally and emotionally one of the most stressful times of my life.

The death of an AA, and/or the transition to a new AA, was cited by several owners as an area for which far more support was needed.

There is no support certainly in the guide dog circles or any other assistance dog circles that I know helping you deal with the grief of the loss of either retiring or losing a dog and having to train with a new one... My first dog did a full working life and then got cancer and passed away pretty soon after he retired. You really need more than family and friend support at that time... I would say maybe peer support, somebody that is professionally trained who has a disability and uses a dog and can have that true understanding of what it's like to work with a dog, be reliant on a dog to help with the disability and then to retire or lose a dog... The strain of having to train with a new dog, I think that's an area that's really neglected.

One parent of a child with ASD whose AA died, waited six months before obtaining a new AA and, during that time, her children simply did not attend school. She became emotional when describing the effect on the household during that period.

My kids didn't go to school, my eldest had three suicide attempts, absolute hell in a madhouse. My youngest lost 7kgs, stopped eating. There's no way to tell you how life shattering it is... There's nothing like watching your 12 year old [child with ASD] who apparently has no empathy, laying on the floor with the dog's coat and howling and there's no support for that. None.

A child with ASD explained that he felt very saddened over the loss of his first AA, but that the second AA has helped him move past that grief.

[My first AA] passed away and we were very very very sad...[my first AA] was a very good friend and he is in heaven....[without my second AA I would] still be heartbroken when [my first AA] passed away...my dogs...will always be in my heart.

Provider organisations or other relevant service providers may need to consider creating support groups to help people cope with loss of their AA. The impact on the individual and the household is clearly profound, and more people will be affected if the use of AAs becomes more widespread.

#### 4.8 ECONOMIC IMPACT OF ASSISTANCE ANIMALS

This dog has done more for my child than speech [therapy], occupational therapy, and psychology all wrapped into one.

There appeared to be considerable economic benefits for some clients after obtaining an AA, so these dogs could potentially help release some of the pressure on public resources. For example, an owner with a guide dog who was trained for diabetes alert work reported that she previously called the paramedics for assistance approximately once per week due to low blood sugar complications. The last time she had to call, she spent 10 days in hospital. After training her dog for low blood sugar alert work, which she had completed 18 months previously, she had not had to call paramedics or go to

hospital at all. Her need for medications to manage the diabetes was also reduced because her diabetes was much better controlled due to her AA.

For managing my diabetes, there's all sorts of technology and equipment out there available to help you monitor your diabetes, but I can't seem to use it... [it is] not accessible to people who are blind.

Another owner with diabetes indicated that she had lost her driving license due to two fainting episodes resulting from hypoglycaemia. However, she had since been able to regain her license because she had a diabetes alert dog. This, in turn, enabled her to be employed, because having a licence meant she could travel to and from her workplace. Two other owners mentioned that they were also able to work because of support provided by their AA.

if I had not had my dog to help me get to work, I wouldn't have been working... she basically enabled me to hold down a job and contributed to my economy because I wouldn't have done it without her. I just couldn't have physically gotten myself to work with her.

I've been able to work – I now own a business since we've got this second dog.

The comment about owning a business was made by the parent of a child with a developmental disorder. This parent reported being no longer sleep deprived due to the presence of the AA, and the calming influence this had on her child. Other parents of children with ASD/developmental disorders also indicated that they were able to sleep for more than two unbroken hours per night after obtaining an AA, which improved their functioning and their ability to care for their families. One parent explained that their child slept through the night for the very first time, the first night that an AA came into the home. Once the child calmed down enough to sleep, his speech began to develop, even after years of speech therapy, which had proven ineffective. This child could now speak well enough to get his message across, and the parent credited the dog with motivating development of that ability.

A child with ASD confirmed that he is verbal because of his AA.

Usually when I tell [my AA] commands it could help me talk.

Children who were previously unable to attend school became able to attend because of their AA's presence in their lives.

The last 12 months, I actually had to home school him because he found school, mainstream schooling, just far too stimulating and he just wasn't coping. Only this year and this term I've been able to integrate [my child] back into school only for the mornings. We started off 2 hours in the morning and, now, he's going for half a day...

One adult owner with ASD reported being able to live alone and hold down a job because of her AA. When she started to feel overwhelmed and anxious, the dog comforted her by pushing her against a wall until she calmed down and could continue working. As her mother (who also took part in the consultations) explained:

The dog is aware of what's going on that nobody else picks up...Also very aware that that behaviour from the dog comes across to other people who don't know as being bad behaviour and it's not, it's the dog doing its job.

For individuals with a vision or mobility impairment, a heavy reliance on taxis could be extremely costly.

Before I got my dog, I would have called a taxi and had to pay for a taxi to get me from A to B. The dog has saved a huge amount of money, given me confidence and safety to get out independently and walk and use public transport. It reduces my travel expenses hugely.

These stories are fascinating, and it is clear that these animals profoundly impacted the lives of their owners and the owners' families. However, the mechanism by which the animals provide these types of benefits is unclear. By extension, it is also unclear whether a non-sentient, less expensive replacement could ever be sufficient to meet some or all of these needs.

# 4.9 DO OWNERS BELIEVE THERE SHOULD BE GOVERNMENT FUNDING FOR ASSISTANCE ANIMALS?

# It's not just a fashion accessory. It's not a pet.

Owners were asked whether they believed that the NDIA should fund AAs for individuals with a disability. Not surprisingly, there was universal agreement that it should.

I think it is mandatory. It doesn't matter what disability the dog is fulfilling. Whether it be sight impaired, hearing impaired or medical alert or supporting somebody with autism, they're fulfilling an individual and vital role for that person and they are working dogs with the same public access testing, the same obedience, the same needs to be with that personal time. I think it's absolutely mandatory that all assistance dogs are fully funded under the NDIS.

Owners mentioned the cost of keeping an AA, particularly veterinary bills. However, some owners argued that these would be expected of any pet owner, so they are not unreasonable and should not necessarily be funded by the NDIA.

What I want compensation for is the costs on top of that for having a reasonable family with a reasonable dog. Like checking in with a trainer every month, harnesses, costs of extra testing like [public access testing]...But not regular costs of having a dog as that's a normal cost for a dog.

Others noted that many people with disability have limited income, and may need help to maintain the animal properly. One owner highlighted that some provider organisations required clients to use special, and expensive, diets for their AAs.

Food is one – some companies say these are the five foods you are allowed to use to ensure a healthy dog. [The organisation] highly recommend [clients] use one food – you can't just buy the cheapest one and most people wouldn't spend \$150 on a bag of dog food.

One owner suggested that a national veterinary group or pet insurance group should be contracted to offer some sort of discount or assistance for AA owners when their AAs need veterinary care.

A few owners indicated that lack of funding within provider organisations may impact the level of support that could be provided after placement.

For me, the benefit of those medical alert dogs being funded under the NDIS, the trainers would then have the financial means to say, 'Okay, I need to see, you know, I've got a client in Perth, in Darwin and in Sydney, all having trouble, they need support, so I have the

financial means, you know, to get on the plane instead of driving my car from one end of Australia to the other to see these clients and help them'.

You just don't get the support that you need because everybody's a volunteer and they just don't have the finances available to get the support that they need, especially when you're doing it across Australia.

# 4.10 SUMMARY OF CONSULTATIONS WITH ASSISTANCE ANIMAL OWNERS

A summary of the main themes and concerns highlighted across all focus groups are presented in Table 23.

Table 23: A summary of the main themes and concerns raised in the AA owner consultations

The main themes discussed in the consultations with AA owners were the advantages and disadvantage of AA ownership, owner relationships with provider organisations, the use of species other than dogs, support for transition to a new animal or following death of a current animal, animal welfare, economic benefits, and whether the NDIA should fund AAs.

# The main advantages of AA's were identified as:

- Increased independence
- Improved social interactions
- Companionship
- ❖ Assistance with specific, impairment-related, tasks

The main disadvantage was inconvenience due to a lack of education around public access rights. This meant that owners sometimes faced rejection, such as a refusal to be picked up by taxi drivers. Cleaning up dog hair and unwanted attention from strangers were mentioned by a few owners.

Most owners described **positive relationships with their provider organisation**, with a few exceptions. A few owners had lost public access rights for their AA due to behavioural problems. **Others expressed concern about a general lack of support**, **particularly in the context of the retirement or death of their AA and transition to a new AA**. Most owners did not support the use of animals other than dogs as AAs, although they acknowledged that it is a complex issue.

Owners generally appeared to understand the importance of **meeting their AA's** welfare needs, through downtime and playtime. Parents of children with ASD explained that the AA can choose to leave the area when their child is behaving in a way that could harm the animal.

# Potential economic benefits of AAs identified included:

- Children who could not attend school becoming able to attend
- Individuals who were unable to work becoming employed
- ❖ Large reductions in paramedic call-outs and hospital visits due to better management of medical conditions such as diabetes
- \* Reduced reliance on taxis for people with a vision impairment

Owners agreed that the NDIA should fund AAs, but some disagreed that costs associated with pet ownership (e.g. food, regular veterinary visits) should be covered. Others cited the high costs of premium dog food required by provider organisations as a cost that should be borne by the NDIA, as most dog owners would not spend \$150 per month on dog food.

#### 5. HEALTH ECONOMICS ANALYSIS

Notwithstanding the rights of people with disability to participate as equals in society, the NDIA must use the resources at its disposal efficiently to ensure it gets maximum value from its limited budget. Economic evaluation can help in this process by identifying the most efficient means of meeting specified needs.

Economic evaluation is defined as 'the comparison of two or more courses of action in terms of both their costs and consequences' [83]. A typical economic evaluation will endeavour to find which course of action minimises the cost of meeting a given need, or it will identify the option that maximises the benefits we get from a given amount of resources. This is the aim of cost-effectiveness analysis. Economic evaluation can also be used to consider whether providing any sort of service or support is worthwhile (i.e., whether the social benefits exceed the social costs). This is the aim of cost-benefit analysis.

Limited as we are by time and resource constraints, we have not set out to evaluate the cost-effectiveness or the cost-benefit of assistance animals in this report. Our aim is rather more modest. First, we report on what is known about the cost-effectiveness of assistance animal programs, drawing primarily on published research. Second, we consider what ought to be included within an economic evaluation.

#### 5.1 WHAT DOES THE RESEARCH LITERATURE SAY?

Unfortunately, there is very little published evidence on the cost-effectiveness of assistance animals. Our searches revealed only one economic evaluation of relevance. This was a study by Wirth and Rein [17] that purports to evaluate the costs and benefits associated with guide dogs for the vision-impaired. However, the study is more limited in scope than this, reporting only the net costs of the intervention, comprising the cost of training and keeping the dog, less the cost-offsets associated with a reduced need for formal and informal care.

Over the eight year working life of the dog, the authors estimate the gross costs of the program to be US \$40,600. This is made up of \$35,000 in dog acquisition and training costs plus \$700 per year in annual maintenance costs including dog food and veterinary costs. Partially offsetting this cost is a reduction in both formal and informal care leading to 'savings' worth around \$21,500 in total (\$16,300 in formal care costs and \$5,200 in informal care costs). Thus, the net cost of the program was around \$19,000, which needs to be considered alongside the benefits that a guide dog confers to the person with visual impairment, if we are to judge cost-effectiveness. The authors point to benefits such as increased confidence, self-esteem, mobility and independence, which is consistent with the evidence presented in earlier sections of this report; however, the authors make no effort to measure or value them these benefits.

Allen and Blascovich [84] do provide quantified estimates of the benefits of assistance animals in the USA, albeit in the context of people with severe and chronic ambulatory disabilities such as muscular dystrophy, multiple sclerosis and traumatic brain injury. In a randomised trial of an AA program, people in the intervention group scored significantly better than people in a wait-list comparison group in terms of self-esteem, psychological well-being, and community integration. They were also more likely to be attending school or participating in the paid workforce.

This study also quantified the impact on the need for care services, both formal and informal. Having an assistance animal reduced the need for paid carer support by 70% and for unpaid carer support by 60%: a savings of approximately 30 hours and 15 hours of carer time per week respectively [23].

In the absence of economic evaluations of assistance animals, we examined studies of the costs of living with disability to see if they might point towards the potential for cost-saving offsets of the sorts seen in both the study by Wirth and Rein [64] and that by Allen and Blascovitch [11]. Studies have examined the costs of intellectual disability and autism spectrum disorder (ASD) [85, 86], ambulatory disability [87, 88], diabetes [89-93], and post-traumatic stress disorder [94, 95].

The contexts vary among these studies, as do the methods employed and the range of factors considered, so comparisons of cost across types of disability are not possible. The evidence points to the high costs of disability associated with aspects that may be partially amenable to change with the help of an AA. This includes the need for care and social support as well as the lost opportunity to participate in paid labour, which affects both the person with the disability and their family members or carers. The economic impact can be especially significant. Horlin and colleagues [86], for example, found that lost income cost families with children with ASD in Western Australia close to \$30,000 per year, which was 90% of the total cost incurred by families. This would go some considerable way to off-setting the costs of an AA program.

As the evidence from AA owner consultations (Section 4 of this report) indicates, an AA may also help reduce the costs associated with the medical consequences of disability, by detecting the early signs of hypoglycaemic attack or an epileptic seizure, for example. Hypoglycaemia is associated with both increased health care costs (US \$1200 per episode in 2015 in the USA [87]) and with time off work or reduced productivity whilst at work worth up to five hours per week [93]. The published evidence also points to the potential for AAs to reduce the costs associated with post-traumatic stress disorder by reducing the incidence of depression [90]. Medical costs associated with PTSD were found to be three times higher in patients with PTSD and depression compared with patients who had just PTSD.

In summary, there is little definitive evidence of the cost-effectiveness of AA programs. What evidence there is confirms the potential for such programs to impact greatly on several aspects of well-being and to reduce some of the costs associated with disability that may, at least partially, offset the costs of the program itself. The cost offsets could be quite significant, and they benefit both the person with disability and his or her family by improving the opportunity to undertake paid employment and by reducing the burden of informal care, and the health system by reducing the need for medical care and formal support.

After weighing up what is known about the likely costs of AA programs and the potential for cost offsets, it is unlikely that any AA program will be cost-saving. It is important therefore that any evaluation of economic efficiency consider the value of the benefits that the AA program brings to the user and sets this against the net cost of the program and the value that could be obtained by using the resources in some other way. The challenge in this respect lies less in identifying and measuring the benefits but in assigning them value.

# 5.2 INFORMATION NEEDED TO ASSESS THE ECONOMIC VALUE OF ASSISTANCE ANIMAL PROGRAMS

In the absence of published evidence on cost-effectiveness, we consider here what sort of information needs to be gathered to enable one to assess the cost-effectiveness of AA programs. Economic evaluation is a very structured exercise (see Table 24) and we can use this structure to describe the evidence gaps.

Table 24: Steps to be taken in an economic evaluation

# Steps to be taken in an economic evaluation:

- 1. Specify the question to be addressed and the perspective from which costs and benefits will be evaluated
- 2. Describe the alternative options that will be compared
- 3. Identify, measure and value where possible all significant costs (or inputs) required by each intervention being compared
- 4. Identify, measure and value where possible all important benefits (or consequences) of each intervention being compared
- 5. Adjust costs and benefits for different timing and explore the impact of uncertainty on estimates of cost and effect
- 6. Formulate a decision rule (e.g., a cost-effectiveness ratio or net benefit or cost-benefit ratio) and interpret the results in light of other important factors such as affordability, feasibility and concerns with equity

# Step 1: Specify the question and the perspective from which costs and effects will be evaluated

As indicated above, cost-effectiveness analysis endeavours to find which course of action minimises the cost of meeting a given need or which option maximises the benefits we get from a given amount of resources. In both cases, it is assumed that something will be done to meet a specified need, and the question is what should be done to make best use of available resources. In contrast, cost-benefit analysis is used to consider whether providing any sort of service or support is worthwhile (i.e., whether the social benefits exceed the social costs). Strictly speaking, cost-effectiveness requires there to be only one outcome of interest so that an assessment can be made of the difference in cost to achieve that outcome. Cost-benefit can include multiple outcomes but collapses them into a single dimension – denominated in money terms – to facilitate comparison with costs.

A key aspect at this stage of the evaluation is to specify the perspective from which costs and benefits will be evaluated. The perspective defines whose costs and benefits should count. Ideally, one adopts a *societal perspective* in which all costs and benefits are included, irrespective of who incurs the former and who enjoys the latter. This ensures that society's resources are allocated to the most valued uses. In some instances, a narrower organisational perspective is warranted, looking, for example, just at the costs and benefits relevant to the NDIA. This would cover outcomes of importance to the agency (including social and economic participation of people covered by the Scheme), but would exclude costs and benefits that fall outside of the agency's remit (costs falling on health agencies, perhaps).

In practice one can cover the narrow perspective within a broader societal evaluation by including in the latter information on the distribution of costs and benefits.

#### Step 2: Describe the options to be compared

Economic evaluation is always a comparative exercise. In this instance, where the object of the evaluation might be to assess the cost-effectiveness of an AA program, one might use 'usual care' as the comparison. The evaluation would then look at the extra costs associated with adding an AA to the package of services that a person currently receives, and tracing its impact on service use, economic and social participation, and health and well-being. Alternatively, if one were concerned

about shortcomings in the existing package of services, then the comparison could be made with an ideal configuration of services short of receiving an AA.

An issue raised in the body of the report was - what benefits would an AA offer over and above just having a family pet? So this too could be one of the comparator options. The economic evaluation would then look at the additional costs of the AA program (primarily training and acquisition costs as one might expect the costs of upkeep to be similar across the two options), and the additional benefits of the AA program over and above those derived from the companionship provided by the pet. In this way, the evaluation focuses on costs and consequences due to the animal's special training.

Such a comparison raises issues that extend beyond economic efficiency, however. There are financial costs associated with keeping a family pet and also time costs to train and socialise a young dog. If the NDIA covers the costs associated with an AA but not the costs of a family pet, this shifts costs on to the person with disability and his or her family, which may place a family pet beyond their means. Thus, there may be a case for NDIA support of companion animals on the grounds of equity or fairness, even if an AA is not cost-effective.

### Step 3: Identify, measure and value all significant costs

The costs that we are interested in relate to *physical resources* such as time and space, and not just those associated with a financial expense. Costs are best thought of as the ingredients required by each of the options being compared.

*Identifying* the costs involves listing the ingredients of each intervention. For the AA program this includes the costs of acquiring the animal, the costs of training it and the costs of keeping it (primarily food and vet bills). Even with an AA, the person with disability may still require formal and informal care, medical visits, and aids for everyday living such as mobility and self-care supports, and these should all be included.

Measuring refers to the physical quantities of these resources required by each person (e.g., for someone on the program this might include one AA, 12 months of dog food, 4 vet visits, 20 hours of formal care per week, 20 hours of informal care per week, etc.)

Valuing involves assigning a dollar value to each resource input, typically using market rates such as the price paid per visit to the vet and salary rates for formal care hours. Informal care, provided by friends and family, is an example of an important resource input or cost that has no obvious financial value. In these circumstances, one can and should impute a value for time input that is provided freely by family. One common approach is to ask how much it would cost to replace this input if it were not provided freely. That is - what would the financial cost be if the informal care were to be replaced by a professional care assistant?

Each of these three steps is completed for each of the alternatives being considered. However, as the economic evaluation is a comparative exercise we will eventually net out of the costs of the intervention, costs associated with the comparator option. The evidence reported previously suggests that someone with an AA may require less formal and informal care than someone with an equivalent disability who does not have an AA. Therefore, an alternative way of looking at things is to compute the total costs of the AA program and subtract from this the potential savings that arise because of the reduced need for care and support. Thus, some part of the costs of the comparison program become *cost-offsets* associated with the AA intervention.

## Step 4: Identify, measure and value all benefits

The same three-step process is now applied on the outcome side. By *identifying* all benefits of interest, including those that may subsequently prove difficult to measure or value, we ensure that nothing substantial is overlooked.

The research literature and the interviews conducted as part of this study identify a wide array of benefits including:

- ❖ Improvements in social engagement and economic engagement
  - Increases in social interaction and community integration
  - Increases in school participation
  - Increases in economic participation (production)
- Improvements in confidence, self-esteem, independence
- Improvements in physical mobility and reduced reliance on aids
- Improvements in physical and mental health
  - Reductions in depression
  - Increased control of chronic disease
  - Increased motor control

A variety of scales and instruments are available to *measure* changes in these outcomes. With one exception, the problem for the economic evaluation lies in establishing the value of these changes. The exception is the value of changes in economic participation. This is measured by changes in the percentage of people active in the labour market and the number of hours per week they each work, and it is valued relatively easily by using the person's salary scale or wage rate.

The challenge lies in trying to assign value to changes in well-being associated with improved support for people with disability. In the health field, economists have used two approaches to value changes in health and health related quality of life. Unfortunately neither is especially well-suited to capture the value of services for people with a disability. The first approach, contingent valuation, essentially asks people how much they would be willing to pay for the benefits of interest, or for an intervention likely to bring those benefits about. The approach is prone to various sorts of bias, though careful study design can overcome some of these challenges. One sizeable problem remains, however: willingness to pay is conditional on ability to pay, and people with a disability are also likely to have lower incomes on average. This does not rule out using willingness to pay methods but does suggest that caution is warranted and imaginative study design is needed.

The second approach collapses the different dimensions of health and well-being into a single index, often referred to as a quality-adjusted life-year, or QALY. This uses subjective preferences to weight (or value) the different dimensions of well-being, which allows the index to be computed, but falls short of valuing the outcomes *per se*. As a consequence it enables cost-effectiveness analysis to be used despite there being multiple dimensions of health benefit. Depending on the particular scale that is used to assess quality of life, QALYs can include relevant dimensions of well-being including self-care and mobility, as well as self-esteem and confidence. They suffer from one major problem in this context, however, which is that a person's disability places an upper limit on the improvement that anyone can experience, and this may have implications for consequent estimates of cost-effectiveness.

This seemed to be apparent in recent work completed by the Deakin Health Economics Group who set out to evaluate the cost-effectiveness of alternative support packages for a small number of people with disability [96]. Their results suggested that improved packages of care would not generally be deemed cost-effective by current standards. Of course, it may be the case that the additional support

services did not represent good value for money, but the suspicion remains that this result owes more to problems in the valuation techniques rather than to any inherent shortcoming in the assistive technologies.

# **Step 5: Adjust for timing and uncertainty**

This step is primarily a technical exercise but one that can be critically important in this context.

The bulk of the costs of an AA program occur 'up-front' in relation to the acquisition and training of the animal. The benefits – be they improvements in quality of life or reductions in the future costs of usual care - are spread over time. To render the two programs comparable, one needs to 'discount' the alternative flows of costs and benefits. Discounting is just an arithmetic process, but one that reflects an important value judgement; namely that as a society we prefer to enjoy our benefits today but to defer costs to the future. As a consequence, a cost incurred now does not have the same real value as an otherwise equivalent cost incurred in the future.

A discussion the merits or the status of the value judgement is beyond the scope of the current report. It is important to note, however, that discounting reduces the current value of interventions such as the AA program because the up-front costs are weighted more heavily than the distant future benefits, and the higher the discount rate that is used, the more severe the consequences. It is quite possible that at one (low) discount rate, the AA program appears relatively more cost-effective than usual care, and for this advantage to be reversed as the discount rate is increased.

For health economic evaluations, the Pharmaceutical Benefits Scheme recommends a rate of 5%. Good practice uses this rate in the base case appraisal, and explores the consequences of discounting by reworking the results of the evaluation in a sensitivity analysis substituting a range of alternative discount rates, possibly zero, 3%, 7% and 10%. If the same option comes out better at each of these rates, then the analysis is robust and one can act on the results with more confidence. More care needs to be taken if the results of the evaluation are sensitive to the choice of discount rate.

Sensitivity analysis is also used to explore the impact of other assumptions on the results of the evaluation. The costs of the AA program increase if poor selection of animals means that a greater proportion do not complete the training program or are otherwise unable to be placed with clients. Sensitivity analysis is used to explore the impact on costs of differences in success and retention rates. It can also be used to explore the consequences of different estimates of the value of the benefits of an AA, which is important given the concerns raised about the inadequacies of our current methods for valuing benefits.

# Step 6: Formulate a decision rule and interpret the results in light of other important considerations

The final stages of the evaluation involve deciphering the results to identify which of the options is more cost-effective or more cost-beneficial.

If all outcomes of importance have been valued in monetary terms, then the decision rule is to adopt the new intervention if the net benefit (\$Benefits minus \$Costs) or if the benefit to cost ratio (\$B/\$C) is greater than 1. Such metrics need to be interpreted cautiously, however, not least because of the difficulties we have discussed already in relation to valuation and because there are concerns other than economic efficiency that need to be taken into account (affordability, acceptability and equity, to name just a few).

If outcomes are not valued in monetary terms, then interpreting the results of the evaluation needs a little more care. One of four outcomes is possible (see Figure 1). In quadrant 1, the AA program is more expensive than usual care and is less effective. In quadrant 2, the AA program is more effective than

usual care and more expensive despite the potential for cost-offsets. In quadrant 3, the AA program is more effective than usual care and it is less expensive. In quadrant 4, the AA program is less costly, but it is also less effective (perhaps such an outcome is unlikely in this instance).

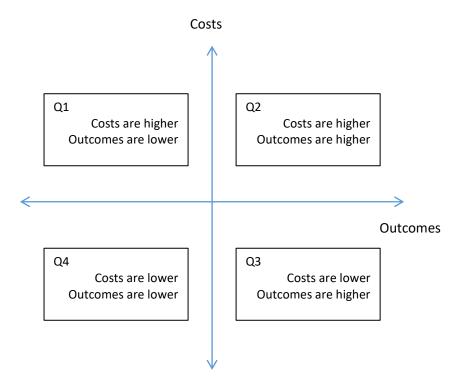


Figure 1: The cost-effectiveness plane

In two of these cases, a decision is easy. In Q1 and Q3, either the AA program is unambiguously worse than usual care (Q1) or it is unambiguously better than usual care (Q3).

Things are more challenging in Q2 (and by symmetry Q4 also) where the AA program comes at a net cost, but it also improves well-being. Here a value judgement needs to be made to decide whether or not the additional benefits are worth the extra cost.

If outcomes have been denominated in terms of QALYs, then a simple rule of thumb can be applied to ascertain whether or not the program is cost-effective. If the incremental cost per QALY is less than \$20,000, then the program can be regarded as highly cost-effective. If the cost/QALY falls in the range of \$20,000 to \$50,000 then, generally speaking, this would be regarded as cost-effective. At costs/QALY in excess of \$50,000 the intervention begins to look less cost-effective, and at rates above \$100,000/QALY, there would need to be substantial non-economic benefits to warrant investing in this program.

If the multiple outcomes that one expects to see from the AA program have been left measured but unvalued, then the best the economic evaluation can do is to set out the differences in cost between the two programs and the differences in each dimension of value in what is called a *cost-consequence* analysis, leaving it to the decision maker to decide whether the array of benefits warrants the investment in the program.

As has been stressed throughout, there are other considerations beyond cost-effectiveness that may influence the decision on whether or not to invest in the program; equity being one of them. In the Deakin study cited earlier [96], the assistive technologies being evaluated came in at costs/QALY in excess of \$150,000. These would not be considered cost-effective by the usual rules of thumb.

However, the authors pointed out that in the interests of equity it is quite possible that we, as a society, would assign greater weight to a quality-adjusted life-year experienced by someone with disability than we would to someone without a disability. If that weight exceeds 3, then the interventions become cost-effective. Of course, such weights are highly subjective, and highly contestable. The approach adopted by the Deakin team does, however, make the value judgements explicit, which renders the decision-making transparent.

#### **5.3 SUMMARY OF HEALTH ECONOMICS ANALYSIS**

In this section, we have reviewed what little economic evidence there is that relates to AA programs. Scant though it is, the evidence points to the potential of AA programs to promote quality of life and social and economic participation, and also to offset some of the costs of the program through reductions in the need for formal and informal care. From the evidence available to us, we have not been able to quantify the costs of the program, the extent of any cost-offsets or the benefits of the program.

In the absence of this evidence, we have described in some detail the sorts of information that need to go into an economic evaluation of an AA program and the sorts of consideration that should influence one's interpretation of the results.

Quantifying the net-cost of an AA program is logistically challenging but not complicated conceptually. Effort needs to be invested in specifying and measuring the resource inputs (the ingredients), ideally in a study design that captures the counter-factual so that cost-offsets can be determined.

Measuring the benefits of the program presents similar logistic challenges in data collection but is also not conceptually complicated. The likely outcomes of an AA program have been identified in this report and in the research literature, and there are scales and instruments available to measure changes in health-related quality of life, social and economic participation, independence, etc.

The biggest challenge for any economic evaluation in this field is how to reflect adequately the value of these changes first to someone with a disability and second to society at large. Question marks hang over the approaches currently available to economists. This does not rule out their use, as the Deakin work [96] shows the valuable insights that the sensitive application of economic methods brings. Nonetheless, there is work to be done to interrogate the valuation techniques to get a better understanding of their strengths, weaknesses and relevance to the evaluation of disability supports.

In the meantime, economic evaluation can, and should, strive to set out the net costs of AA programs and the full array of the benefits they bring people with a disability to enable a fully informed and transparent discussion of their value and the role they may play in the NDIS.

#### 6. DISCUSSION

Existing evidence from a literature review of peer-reviewed evidence about AA effectiveness, an AA provider organisation survey, and consultations with AA owners, would suggest that AAs may provide considerable benefits to their owners, although there are limitations to existing research. This section provides further details about the participant cohorts that are most likely to benefit from an AA, recommended training and assessment standards, and animal welfare considerations for AAs.

#### **6.1 PARTICIPANT COHORTS LIKELY TO BENEFIT**

To date, the evidence base surrounding the use of AAs for disability management has clustered around the following groups: mobility impairments, epilepsy and diabetes alerts, children with autism spectrum disorders and other developmental disorders, psychiatric disorders (e.g. post-traumatic stress), and vision/hearing impairments. The existing evidence for all of these cohorts suggests that AAs can provide substantial benefits to their owners. However, the limitations of existing research, such as small sample sizes, selection bias, and an over-reliance on exclusively self-report measures, makes it difficult to draw firm conclusions about their efficacy.

The consultations with AA owners undertaken for this project included individuals from all of the impairment categories listed above, and also included one adult with ASD, a cohort that appears to be entirely missing from existing research. This lack of research may be due to the focus on the physical benefits that these dogs can provide (e.g. preventing bolting, stopping repetitive behaviours) and the fact that some providers only supply AAs to children under a certain age. Since the existing literature suggests that these AAs may be beneficial for other reasons as well, such as reducing anxiety, perhaps provision of AAs for adults deserves more attention than it has previously received. These conversations highlighted similar advantages and disadvantages to those already documented in existing literature. However, as with previous studies, the sample size was small and data consisted solely of self-reported outcomes.

Taking into account the results of existing studies, the outcomes of the AA owner consultations, and the limitations of the field to date, we recommend that AAs be considered for funding as part of the NDIS for all cohorts listed above, but with the qualifier that cases must continue to be evaluated at an individual level. There is insufficient evidence available to determine the mechanisms behind the effectiveness of AAs, so knowing under what circumstances they will be effective remains difficult to predict. What we do know is that there can be quite profound positive outcomes, including increased independence, increased social interactions, improved quality of life, and improved functioning on the whole. There is a critical need for future research to help strengthen the evidence base around the use of AA's. Future research should aim to determine when AAs are likely and unlikely to be effective, to ascertain whether there are circumstances in which the benefits associated with their use might be insufficient to justify the cost of provision, and to understand whether these benefits are able to be met by some other (non-sentient) means. In the absence of this evidence, there is no clear rationale for excluding people from acquisition of an AA on the basis of their disability or personal circumstances.

Qualitative reports from our AA owner consultations suggest that the improvements they have experienced are due to the presence of the AA itself. A non-sentient substitute would not suffice, because 'real' animals fill a triple role as companion, disability management tool, and social lubricant in interactions with family and the community. Furthermore, a well-trained pet dog would also not suffice in many circumstances, because of the level of training required, which is simply not feasible for most people to achieve. The specific tasks that need to be trained for disability management, and

for public access, are two key training needs for AAs. Most individuals, with or without disability, probably lack the understanding of animal behaviour/learning and ability to effectively train an animal to the level required to meet this extremely high standard. Some owners in the consultations did mention that they might be capable of training their own AA once they had extensive experience in owning and training one. In situations where clients feel confident to train their own AA, provider organisations should be on hand to provide any necessary support and assistance, and also to provide the independent assessment required for accreditation. This will reduce costs to the provider organisation, and may also increase the number of individuals with disability who are able to benefit from an AA.

There may be individual circumstances in which a pet dog can provide considerable benefits to a person with a disability, provided that the dog is appropriate selected and trained. One study from the United Kingdom asked 40 parents of children with ASD who either owned a pet dog (20 parents) or did not own a dog (20 parents) about the expected and actual benefits of the pet dog for the child. The results of this study suggest that even a pet dog can provide considerable improvements for children with ASD, such as social skills, increased calmness and cooperation, and improved attention and language skills [97]. However, the parents who took part in this study were recruited through a program run by a provider organisation called Dogs for the Disabled. The program consists of a workshop which teaches parents of children with ASD about dog behaviour and welfare, as well as how to select a suitable pet dog for their family [97]. Therefore, even in this study showing a benefit of pet dogs for children with ASD, an AA provider organisation was involved in educating parents about how to find the right dog and manage it appropriately.

The specific role of AAs for children with ASD merits further investigation due to laws in most Australian states and territories which do not permit the use of tethering as a behaviour management tool, as a matter of course. One study examining the animal welfare impacts of working in this capacity on the AAs, stated that the primary function of AAs for ASD is to keep the child safe, and this is accomplished by tethering the dog to the child so that the child is unable to bolt [98]. This would not be permitted in many parts of Australia without meeting specific guidelines for that individual. Based on existing literature, many parents of ASD do appreciate the perceived security that the dog provides (section 2.3). However, there are other reasons why parents opt to obtain an AA for their child with ASD, as highlighted in the consultations with AA owners (section 4). It is likely that, even if tethering were not available to keep a child with ASD from absconding, many parents would consider an AA worthwhile due to the improvements in functioning that AAs appear to enable in children with ASD. Indeed, the adult with ASD who took part in the consultations mentioned that the AA helped her live an independent life, and preventing absconding was not part of her AA's working role. It is likely that AAs could improve the lives of many adults with ASD, even though they do not require tethering.

# 6.2 RECOMMENDED STANDARDS FOR ASSISTANCE ANIMAL TRAINING AND ASSESSMENT

Based on the results of the provider organisation survey, we recommend that training and assessment for all AAs cover general public access requirements as well as tasks specific to the needs of the individual client. These recommendations relate most clearly to dogs at present, as all provider organisations reported working almost exclusively with dogs. If other species become more commonly used as AAs in the future, the basic categories of public access and specific tasks will still apply, although the actual standards may need to be adapted somewhat. In particular, the working life of an assistance horse may be three or four times that of an assistance dog [3]; the recertification process may not be necessary every year after the first several years of a team working together.

# 6.2.1 Training

For most AAs, training should be expected to take approximately two years. The first year should focus primarily on adequate socialisation and obedience training, in order to prepare the AA for the public access test. As a juvenile, the animal should be exposed to everything that it is likely to experience over the course of its life, in a safe and fun way, in order to reduce its likelihood of becoming fearful of novelty in the future [77]. It should also be house trained and crate trained during this time, and obedience training should progress until the animal's behaviour is controlled and reliable enough to pass the public access test (PAT).

Early socialisation is important for animals, but genetic factors are also likely to play a large role in adult animal temperament. Therefore, selection for AAs with desirable temperament traits is crucial for improving the odds that a larger proportion of AAs will ultimately be successful in their training. Even with extensive training, not all animals would be suitable AAs. The role of a strong genetic predisposition toward confidence, willingness to cooperate with humans, calmness, and other commonly reported traits desired by AA provider organisations, should not be underestimated.

The second year should focus on training the animal for specific tasks that it will need to assist its owner in managing the owner's disability. The Assistance Dogs International (ADI) minimum standards state that AAs must be able to perform at least three tasks that directly and clearly mitigate the impact of the owner's disability [99]. The types of tasks that AAs will need to perform should be individualised to the needs of the client, and therefore it is impossible to list all potential tasks here. However, the International Association of Assistance Dog Partners provides examples of the types of tasks that a psychiatric AA might perform for his or her owner, including, but not limited to: bringing medication to alleviate symptoms and a beverage to take the medication, calling a suicide hotline, alerting a sedated owner to a smoke alarm or doorbell, and providing an excuse for the owner to leave a distressing situation [100]. The same organisation provides information about the types of tasks that a guide dog for the vision impaired may perform, including navigating around obstacles, informing the owner of changes in elevation, and locating dropped objects [101].

It may be possible in some cases to reduce the amount of time taken to complete training. Because this will influence cost, further research is needed with respect to specific training requirements. Many organisations represented in our survey focused on obedience and socialisation for the first year of the dog's life, and then trained the animal for specific tasks needed by the client. However, some medical alert AA providers began training their puppies to alert to the blood sugar change or oncoming seizure as early as possible. This is because, according to these respondents, the motivation to alert could be affected by the bond with the owner, so creating an early, strong bond between dog and owner will improve alerting outcomes over the course of the animal's life. Whether this is true merits further study. Nonetheless, if an AA can be trained to reliably perform the necessary tasks and be certified for public access in under two years, then this should of course be encouraged.

## 6.2.2. Assessment

Many survey respondents reported that their AAs are certified by Assistance Dogs International (ADI). The public access test (PAT) for these dogs is available on the ADI website [102]. The test covers the dog's behaviour in the following situations:

- Unloading from a vehicle
- ❖ Approaching a building
- Entering a building through a doorway
- Navigating through a building
- In a restaurant
- When taken by another person

- Exiting a building
- Loading into a vehicle

The ADI PAT also covers whether the dog is able to reliably:

- Recall at a distance of 2m in a large open area
- Sit on command
- Lie down on command
- Stay focused on the owner during noise distractions

Finally, the test measures whether the owner is able to maintain control of the dog and recover a dropped lead, and whether the quality of the owner-dog relationship is positive and close.

We recommend that a PAT like that of the ADI be the standard of assessment for public access rights. This should be completed on initial accreditation, and the team should be recertified annually throughout the AA's working life. While the ADI test is specifically designed for use in dogs, the same basic requirements should be relevant for any animal species intended for assistance work in the future. Some of the specific behaviours measured may need to be adapted by species, but the general theme of sufficient owner control over the AA should apply.

This raises an issue in placing dogs with children who are too young to legally control them. AAs that help children manage ASD and other developmental disorders are currently legally controlled by the parents, creating a three-member 'team' of AA, child, and parent. However, if these AAs are ever invited to attend school with the child, who becomes responsible for the AA? The school administrators? The teacher? It may be possible, and even desirable, for a classroom to have one AA belonging to one child. However, in a special needs school, if several children in the same class have an AA and expect to be able to bring it to school, this is likely to have a large impact on the way the school functions and the supports it will need to manage all of these animals. Furthermore, if older (e.g. teenaged) children are ever provided with an AA for another type of impairment, such as guide dog or a mobility dog, who will be responsible for the animal when children are not with their parents? Two key benefits of AAs are increased independence and social interactions with the community. These benefits are to be lauded and encouraged. However, if these animals become more commonly used by children in the future, even when they are not with their parents, the community at large will need to come to an agreement about responsibility and management of the AAs.

It is possible that some clients' specific needs dictate that their AA not pass the PAT, because they need to wilfully disobey the owner when it is in the owner's best interest. However, this 'intelligent disobedience' is already taught by some of the provider organisations, based on responses to the survey. It is therefore likely that passing the public access test does not preclude a willingness to disobey when necessary.

In addition to the PAT, the AA should be tested to confirm whether it can reliably complete at least three tasks which assist the owner in managing their disability. The ADI provides minimum standards for certification of AAs, and this is one component of that certification process. Additionally, owners must be able to demonstrate a clear knowledge of dog behaviour, training, and welfare, an ability to continue training with the dog and learn new tasks, and an understanding of local laws around disability access rights [103]. We support these requirements and recommend that they be incorporated as minimum standards for assessment under the NDIS. We also recommend that an independent accreditation body be established for all potential AAs in Australia, in order to ensure that minimum standards are being met by any organisation or individual who is training AAs.

#### **6.3 IMPLICATIONS FOR ANIMAL WELFARE**

One important consideration that is under-researched in peer-reviewed literature is the welfare of the animals themselves. Whenever a sentient creature is used to provide a benefit for a human, it is necessary to consider whether they will experience a negative welfare impact, and, if so, whether the benefits that they will provide to the human(s) outweigh that negative impact [104, 105].

#### 6.3.1 What is animal welfare?

Good animal welfare typically means the absence of negative feelings (i.e. suffering) and the presence of positive feelings (i.e. pleasure) [106]. The paradox of animal welfare measurement is that animal welfare is actually impossible to measure directly, precisely because it relates to subjective feelings such as suffering and pleasure [106]. Therefore, measures of behaviour, physical health, and physiological indicators of stress, such as cortisol and  $\alpha$ -amylase, are often used to try to infer whether an individual animal has a positive welfare state [107]. A combination of these measures should ideally be used, because it may be possible for an animal to have good physical health without experiencing good welfare [106]. For example, selective breeding over many generations has enabled livestock animals to survive and reproduce in conditions which, according to behavioural or physiological stress measures, may not be optimal for meeting their welfare needs, although these types of results are open to interpretation [107].

The Farm Animal Welfare Council has a basic standard for livestock animal welfare [108] which can theoretically be applied to any animal. According to this standard, which is called the Five Freedoms, in order to experience good welfare, an animal must have [108]:

- 1. Freedom from hunger and thirst by ready access to fresh water and a diet to maintain full health and vigour;
- 2. **Freedom from discomfort** by providing an appropriate environment including shelter and a comfortable resting area;
- 3. Freedom from pain, injury, or disease by prevention or rapid diagnosis and treatment;
- 4. Freedom to express normal behaviours by providing sufficient space, proper facilities and company of the animal's own kind;
- 5. **Freedom from fear and distress** by ensuring conditions and treatment which avoid mental suffering.

A team of veterinary researchers have proposed that quality of life, which is synonymous with animal welfare, in pet dogs should be measured using virtually the same considerations as the Five Freedoms [109]. We agree that these guidelines should be used for pet animals, as well as for AAs.

## 6.3.2 Assistance animal welfare considerations

We found just two published studies which focused on the welfare of AAs. Authors of one study proposed that the most important factors affecting an AA's welfare are probably the owner's general satisfaction with it and benefits derived from it, so they asked owners of mobility-assistance dogs about these topics [26]. Most owners indicated that their AA was a valued member of the family and a provider of comfort, and that they relaxed more when having the dog. The authors therefore concluded that the welfare of the dogs is likely to be a primary consideration for the owner. While this makes intuitive sense, it is based on the authors' assumptions, rather than evidence. It would be useful to run behavioural studies which correlate positive welfare outcomes (e.g. regular veterinary visits, down-time from the working role) with satisfaction levels and perception of benefits derived from the animal.

The study most relevant to the current project investigated specific welfare considerations for AAs working in ASD assistance roles [98]. In this study, 11 parents of children with an autism assistance dog were interviewed when they obtained the dog, and then every three months over a period of one year. During these interviews, the researcher also made casual observations of note (e.g. one dog had gained so much weight within six months that it no longer fit into its jacket). According to the results of these interviews and observations [98], the key factors that could impact on the AA's welfare, and which of the Five Freedoms may be impacted, are shown in Table 25.

Table 25: Factors that negatively impact assistance animals working in autism assistance, and the Five Freedoms affected

Factors affecting animal welfare	Five Freedoms impacted
Inadequate rest or recovery time after working	Freedom from discomfort Freedom from pain, injury, or disease
Unintentional mistreatment by the child	Freedom from pain, injury, or disease Freedom from fear and distress
Lack of predictability in the daily routine	Freedom to express normal behaviours Freedom from fear and distress
Not enough recreational activities for the AA	Freedom to express normal behaviours Freedom from fear and distress
Over-feeding (one owner)	Freedom from hunger and thirst Freedom from discomfort

At first glance, over-feeding does not appear to negatively impact 'freedom from hunger and thirst'. However, the owner who allowed their dog to gain so much weight that it could no longer fit into its jacket was arguably not meeting that guideline, which states that animals must be given 'a diet to maintain full health and vigour' [108]. That particular dog also appeared to experience discomfort when wearing the jacket because it was too small, which the authors believe affected its motivation to work [98].

Most animals will have some negative experiences throughout the course of their lives. However, situations that have the potential to cause ongoing suffering for the animal should be modified if at all possible, in order to mitigate these negative outcomes. For instance, a lack of sufficient rest or recovery time after working was most commonly seen in AAs who attended their child's school. In a situation such as this, it is important that the dog has plenty of time to rest when the child returns home from school. This may mean that the AA is physically removed from the presence of the child for a few hours. Furthermore, some children experienced 'meltdowns' and slapped or kicked the dog [98]. There is no simple solution to this problem. Fortunately, most dogs quickly learned what signs to look for when the child was approaching this state, and they were either able to redirect the child's behaviour to avoid the meltdown altogether, or at least remove themselves from the child's presence during the event [98]. A list of proposed steps that owners can take to reduce the impact on the animal's welfare for each of these situations is provided in Table 26. This study did not highlight the potential animal welfare impact of tethering the dog to the child with ASD as a major consideration, but the authors did mention that it may be stressful for the dog to have to prevent the child from absconding.

Table 26: Proposed steps to alleviate negative welfare impacts of commonly reported factors affecting assistance animal welfare

Factors affecting animal welfare	Proposed steps to alleviate impact
Inadequate rest or recovery time after working	Ensure that the dog is not expected to work for several hours after attending school with the child
Unintentional mistreatment by the child	Dog is taught to redirect child's attention elsewhere, or to remove itself from the child's presence
Lack of predictability in the daily routine	Attempt to enforce a daily routine for the dog, even if not possible for the rest of the family: clear times when the AA is working, and clear times when it is not.
Not enough recreational activities for the AA	Incorporate additional play time at home and non-work outings: visit parks or beaches without the jacket
Over-feeding	Provide species-appropriate foods in amounts adequate to maintain a healthy weight

A final study reported in a book chapter examined physiological stress in 18 dogs participating in animal-assisted therapy, by measuring cortisol levels [110]. Dogs participating in these activities attended sessions with individuals who may receive some therapeutic benefit from interactions with the dog. These sessions do not usually occur every day, and dogs in animal-assisted therapy activities may engage with more than one person per session. This is therefore different from AAs who live with an owner with a disability and provide specific services for that person, so the results may not apply to AAs. Nonetheless, cortisol levels were higher in dogs after attending a therapy session compared to before; they were also higher on days when there was a therapy session, compared with days when there was no session [110]. Sessions longer than 3 hours were also associated with higher cortisol levels in dogs.

These results indicate that dogs may find these activities stressful; however, cortisol does not differentiate between 'good' and 'bad' stress, so whether the dogs found these experiences unpleasant cannot be determined based on this measure alone. For AAs, who are working with their owners on a daily basis, a measure of stress such as  $\alpha$ -amylase may be more appropriate; there is some evidence that  $\alpha$ -amylase is an indicator of chronic stress [111], which may be more likely in animals who do not have much respite from their working role.

Perhaps the best, and most easily observable, indicators of stress are behavioural. Indeed, a lack of motivation or ability to work effectively was regularly observed in Burrows et al.'s study of autism assistance dog welfare, after the dogs had spent a long time working, were overfed to the point where the jacket no longer fit comfortably, or the dog's daily routine was unpredictable [98].

Other symptoms of stress in dogs could include [110]:

- changes in eating habits
- gastrointestinal problems (e.g. vomiting or diarrhoea)
- shivering and shaking
- restlessness
- hair standing up
- stereotypies (i.e. repetitive behaviours that serve no obvious function, like tail-chasing)
- skin problems or allergies
- blood-shot eyes
- any other unexpected behavioural changes

Symptoms such as these first warrant a trip to the veterinarian to confirm that there is no underlying physical cause, and then to a behaviourist or trainer to help the owner manage the dog's stress. Many organisations provide ongoing training and assistance to owners. Owners should therefore express any concerns about the dog's stress levels to the provider organisation, who can work with the owner to reduce negative impacts on the animal's welfare and, by extension, increase its ability to work effectively.

### **6.4 SUGGESTIONS FOR FUTURE RESEARCH**

As highlighted throughout this report, the existing evidence for AAs is limited, and further research is recommended to strengthen the evidence base. For instance, we recommend long-term studies of AA effectiveness which include:

- Large sample sizes
- Objective measures of impact (social, economic, behavioural and/or physiological)
- Pre- and post-placement designs
- Control groups consisting of people without an AA (preferably wait list controls)

The lack of evidence surrounding the cost-effectiveness of AAs relative to other disability supports indicates the need for future research examining this aspect. In addition to the benefits mentioned above, this would include the costs of AA programs (that is the costs of animal training, acquisition and upkeep), and the possible cost off-sets of these programs in the form of changes in the need for formal and informal care. A further evidence gap lies in the value that people with disability and society at large assign to the benefits of intervention. Current methods for valuing outcomes may not adequately capture the impact of service provision and support. Even if AA programs are more expensive than other types of support, perhaps the additional benefits they bring in increased social and economic engagement, increased confidence and improved health, when suitably valued, would outweigh the extra costs. However, this is also unclear, and merits further examination.

A rigorous analysis of training and selection practices could help provider organisations improve their success rates over time. Currently, many provider organisations do research in-house, or do not do any research at all. Collaborating with experienced scientific researchers would help these organisations develop studies aimed at understanding which of their practices are efficient and which are not. For instance, some provider organisation survey respondents suggested the puppy raisers were not an effective way to raise AAs, while others indicated that placing an AA-in-training with their owner could jeopardize the training outcomes. This deserves investigation.

While the effectiveness of animal-assisted therapy (AAT) was beyond the scope of this report, the therapeutic benefits of AAT merit further study. While AAs were defined for this report as 'animals that live with, and provide specific support for, an individual with an impairment', AAT has the potential to reach a much larger proportion of people with disability. AAT involves the use of animals in therapeutic interventions designed to improve functioning of clients, facilitated by professionals working in health, education, or human services. It does not require that the animal live with the person they are benefitting, so individuals who lack the inclination, or adequate support systems, for AA ownership, could still experience therapeutic benefits from interactions with an animal. Like AAs, the evidence base for AAT is still small, but it is becoming stronger due to recent, well-designed studies, which support their use in children with ASD. We recommend a large-scale study of AAT effectiveness, in order to measure the ongoing therapeutic benefits that could be provided to individuals who are unable to have an AA. For example, since the upper age limit for some organisations provided AAs to

children with ASD is 8 years, it is possible that AAT would provide a therapeutic benefit for children who are no longer eligible for an ASD AA.

Finally, existing recommendations for meeting a companion animal species' welfare needs are based largely on expert opinion. There is relatively little behavioural, evidence-based research devoted to understanding what companion animals need to experience optimum welfare. Since most (if not all) AAs in Australia are dogs, dog behaviour and welfare research should be encouraged, not just in clinical populations such as dogs with separation anxiety, but in all dogs. This type of research could result in advances that would improve welfare for AAs beyond simply ensuring that they are physically healthy.

### 7. CONCLUSIONS

In this project a review of existing literature was undertaken to determine the effectiveness of assistance animals (AAs). This review was supplemented by a survey of AA provider organisations worldwide, including 16 in Australia, and consultations with 19 individuals who currently have an AA to help them manage a disability. Impairment types represented in the review and consultations included people with an AA for autism assistance/developmental disabilities, psychiatric disabilities, medical alert (diabetes or epilepsy), mobility impairments, and vision/hearing impairments. Results of the literature review and AA owner consultations indicate that a broad range of improvements may be provided by the AA. However, limitations of existing research make it difficult to draw clear conclusions about their effectiveness.

Provider organisations almost exclusively train dogs for AA roles, rather than other species. They currently vary in their selection and training practices for AAs and clients, but typically training lasts approximately two years. Dogs are often accredited in-house and several are accredited by Assistance Dogs International, which provides minimum standards for training and accreditation of assistance dogs. We recommend that these standards be adopted for use by the NDIA, should they provide AAs on the Scheme.

Animal welfare considerations are largely overlooked in existing literature, but provider organisations and AA owners who took part in our consultations suggest that AA welfare is a priority. This is measured most often by veterinary checks; however, owners should also be required to give their AA plenty of downtime and free play when they are not working. It must be made clear to all individuals that even a highly trained AA is not a machine, and that no animal can be expected to work all the time.

The AA owner consultations suggest that there may be large economic benefits to AA ownership, including the ability to work or attend school in cases where this has previously not been possible, or in services no longer needed, such as speech therapy for a non-verbal child with ASD who now speaks. However, the evidence base for AA cost effectiveness is limited, and future research should focus on understanding the economic impact of these benefits.

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# **APPENDIX A: PROVIDER SURVEY**

1.	I confirm that I am employed by or volunteer for an organisation providing assistance animals to people with disabilities, I am at least 18 years of age, and am able to read and write in English. I have read the Participant Information Statement and give my informed consent to complete the survey.  □ Yes □ No (If no, skip to end of survey).
2.	What position do you currently hold in your organisation?  Owner  Manager/Director  Trainer  Office/Reception worker  Volunteer  Other (please write)
First w	e will ask you some questions about your organisation.
3.	Where is your organisation based?  □ Australia □ Outside Australia (please write country)
4.	(If based in Australia) In which state or territory is your organisation's head office based?
	□ Victoria □ New South Wales □ Tasmania □ Western Australia □ South Australia □ Queensland □ Australian Capital Territory □ Northern Territory □ Other (e.g. if your organisation has offices in each state) (please specify)
5.	(if based in Australia) Where does your organisation operate? Please select all that apply.    Victoria   New South Wales   Tasmania   Western Australia   South Australia   Queensland   Australian Capital Territory   Northern Territory   Overseas (please write country/ies)
6.	(If based overseas) In which countries does your organisation operate? (please write)

7.	n total, how many personnel currently work/volunteer in your organisation (including management, trainers, foster carers, volunteers, etc.)?  □ 5 or less □ 6 - 10 □ 11 - 20 □ 21 - 50 □ 51 - 100 □ 101 - 200 □ 201 or more (please estimate)
Now we	will ask you a few questions about the animals that your organisation works with.
8.	What animal species does your organisation work with? Please select all that apply.  □ Dogs □ Horses □ Monkeys □ Other (please write)
9.	How many animals is your organisation <b>currently</b> responsible for? This includes those that have not yet begun assistance roles and those that have.    5 or less   6 - 10   11 - 20   21 - 50   51 - 100   101 - 200   201 or more (please estimate)
10.	Where do these animals come from? Please select all that apply.  Organisation's own breeding program Purchased from breeders Donated from breeders Purchased/adopted from animal shelters Use client's own animals Other (please write)
11.	Please provide a brief overview of your animal selection practices. What do you look for in an assistance animal, and how do you know when you have found an animal that possesses those traits? Remember, your responses will be completely anonymous. (please write)
12.	What sort of training are the animals provided with?  □ No training beyond what a typical companion animal would receive  □ Minimal additional training (e.g. advanced obedience)  □ Animals are trained to perform specific tasks to assist the needs of the client

13. What assistance role(s) have you trained your animals for <b>to date</b> ?  □ Vision impairments □ Mobility impairments (including clients in wheelchairs, clients with spinal cord injuries, fine motor control related tasks, etc.) □ Hearing impairments □ Autism spectrum disorder or other developmental disabilities □ Diabetes alert and/or response □ Seizure alert and/or response □ Post-traumatic stress impairment or other mental health disabilities (e.g.
generalised anxiety disorder, panic disorder)   Other (please write)
Next we will ask you some questions about your clients
<ul> <li>14. How do clients who wish to receive one of your animals normally contact you? Please select all that apply.</li> <li>□ Referred from doctor or other health professional</li> <li>□ Clients are self-referred</li> <li>□ Other (please write)</li> </ul>
15. What selection criteria must applicants fulfil in order to be considered for your animal assistance program (e.g. a particular age, verbally communicative, able to move at least one limb)? (please write)
Now we will ask you some questions about your organisation's training practices and their associated costs. If you are unsure of specific details, please estimate as best you can.
16. How long does it normally take to train an animal, from the very beginning of the training process once the animal is initially selected, until it is handed over to live with the client? This does not include any ongoing maintenance training once the animal is living with the client.  □ Less than 3 months □ 3 to 6 months □ 7 to 9 months □ 10 to 12 months □ 13 to 18 months □ 19 to 24 months □ 2 to 3 years □ More than 3 years (please write)

17.	How many animals did your organisation begin training for assistance roles in the last 12
	months? If you work with more than one animal species, please specify number of animals per
	species.

	Dogs	Horses	Monkeys	Other (please write)
				<del></del>
None				
1				
2-5				
6-10				
11-20				
21-40				
41-60				
61-80				
81-100				
More than 100 (please estimate)				

18. How many animals did your organisation **complete training** for assistance roles in the last 12 months, **whether or not they were eventually accredited**? If you work with more than one animal species, please specify number of animals per species.

	Dogs	Horses	Monkeys	Other (please write)
None				
1				
2-5				
6-10				
11-20				
21-40				
41-60				
61-80				
81-100				
More than 100 (please estimate)				

					Dogs	Horses	Monkeys	Other (please write)
	None							
	1							
	2-5							
	6-10							
	11-20							
	21-40							
	41-60							
	61-80							
	81-100							
	More the estimate)			(please				
1.	More the estimate)  Please provincluding a animal has animal's life	vide any inicipal section with the secti	brief tial tra matc ease v	overview aining before the with write)	of your to ore the a the clien	raining pract nimal is mat nt, and ongoi	tices for both t ched with a clic ing maintenanc	he animals and the client ent, early training once th ce training throughout th al is placed with a client
1.	More the estimate)  Please provincluding a animal has animal's life.  What train ensure its o	vide a ny ini s beer fe. (pla ing (it	brief tial tra mate ease v f any)	overview aining before the with write)does your effectivene	of your tore the athe clienter organisates? (please	raining pract nimal is mat at, and ongoi ation provide ase write)	tices for both t ched with a clic ing maintenanc	he animals and the client ent, early training once th ce training throughout th al is placed with a client
1. <u>ov</u> 2.	More the estimate)  Please provincluding a animal has animal's life.  What train ensure its of we will as a series and a s	vide any inition of the conting (if the conting contin	brief tial tra n matce ease v f any) nued e nabou ls acc that a nimals	overview aining before the with write) does your effectivened to accredit.	of your to ore the althe client organisates? (pleasess? (pleases) y your organisated inedited by	eraining practinimal is mat and ongoination provide ase write) your organise preamination whouse by my an externa	tices for both to ched with a clice and an indepersormants or an indepersormants of the companies of the com	he animals and the clien ent, early training once to ce training throughout to al is placed with a client

24.	it has been obtained, before it must be renewed?  □ Less than one month  □ One to three months	w long does this accreditation last after
	<ul> <li>□ Four to six months</li> <li>□ Seven to 12 months</li> <li>□ One to three years</li> <li>□ More than three years</li> <li>□ For the life of the animal</li> </ul>	
25.	(if accredited by in-house or by external body) What in Please select all that apply.  □ Formal maintenance training with the organ □ Ad-hoc maintenance training with the organ □ Annual dues/membership fee □ Other (please write)	nisation at least once per month nisation at least every three months nisation at least every six months nisation at least once per year
26.	(if accredited by in-house or by external body) How lo accredited, from selection to training completion?   Less than 3 months  3 to 6 months  7 to 9 months  10 to 12 months  13 to 18 months  19 to 24 months  2 to 3 years  More than 3 years (please write)  Not applicable	_
27.	(if accredited by in-house or by external body) Please animal, excluding training costs. Please write numer relevant for you. AUD\$/US\$/€/£	
28.	(if accredited by in-house or by external body) Pleatraining and accreditation for the animal. Please write most relevant for you. AUD\$/US\$/€/£	
29.	We are interested in where you obtain funding to acquanimals you provide to clients. What proportion of th last 12 months comes from the following sources?	
	Donations from the public	% of total income (dropdown 0 – 100%)
	Government funding	% of total income (dropdown 0 – 100%)
	Clients payments/donations	% of total income (dropdown 0 – 100%)
	Other sources (please describe)	% of total income (dropdown 0 – 100%)

30. Approximately how much funding did you receive in the last 12 months from each of the following sources? Please write numerals only and select the currency most appropriate for you.

Donations from the public	AUD\$/US\$/€/£
Government funding	AUD\$/US\$/€/£
Clients payments/donations	AUD\$/US\$/€/£
Other sources (please describe)	AUD\$/US\$/€/£

31. We are aware that different organisations charge different amounts for an assistance animal. Please outline **how much in total** a client or their sponsor must pay/donate to receive an assistance animal from your organisation. **Remember, your responses will be completely anonymous.** Please write numerals only and select the currency most appropriate for you.

Vision impairments	AUD\$/US\$/€/£
Mobility impairments	AUD\$/US\$/€/£
Hearing impairments	AUD\$/US\$/€/£
Autism spectrum or other developmental	AUD\$/US\$/€/£
disabilities	
Diabetes alert and/or response	AUD\$/US\$/€/£
Seizure alert and/or response	AUD\$/US\$/€/£
Post-traumatic stress/anxiety disorders	AUD\$/US\$/€/£
Other (please write)	AUD\$/US\$/€/£

- 32. Please rate the extent to which you agree with the following statements: Strongly disagree (1) → Strongly agree (5)
  - a. Every assistance animal should be required to be registered with an official government body.
  - b. Assistance animals should only need to be accredited by their organisation.
  - c. Assistance animal organisations should be accredited by an official government body.
  - d. Assistance animals should be able to be trained by individuals who are not affiliated with an assistance animal organisation.
  - e. All assistance animals should pass the public access test (definition from Assistance Dogs International: 'stable, well-behaved, and unobtrusive to the public; the client has control over the [animal], and the team is not a public hazard').
  - f. There are some people with disabilities whose specific needs require them to have an assistance animal which has not passed the public access test.

33.	Please outline any innovative strategies you have introduced in the last five years to reduce
	the costs and/or achieve better outcomes in selecting and preparing animals for their
	assistance role, and matching them with their client. (please write)

	completely anonymous. (please write)
	methodology improvement or assistance animal effectiveness? Again, your responses will be
34.	What in-house research or evaluation (if any) is conducted by your organisation on training

35. Has any of this research been published for people outside the organisation to access?  ☐ Yes ☐ No
(If yes) In which types of publications have you published this research?
<ul> <li>□ Academic conference proceedings</li> <li>□ Academic edited books</li> </ul>
<ul> <li>□ Publications for the assistance animal community</li> <li>□ Publications for the animal training community</li> </ul>
☐ Another type of publication ( <i>please write</i> ) (If no) Why did you decide not to publish this research for people outside the organisation to
access?
<ul><li>□ All of our research is kept only for our use</li><li>□ We intend to publish our research in the future, but we haven't yet</li><li>□ We have not done any research</li></ul>
Finally, we will ask you some questions about how you promote the welfare of your animals
36. What is the typical working life of your animals? Please select the appropriate number from the dropdown menu, then select 'months' or 'years'.  □ Dropdown 1 − 20 □ months or □ years
37. How do you ensure the welfare of your animals during training, working life and beyond (please write)
38. Thank you very much for participating in our survey. Is there anything else that we haven' mentioned which might be useful to know? (please write)