

“Life-Changing”:

**A Qualitative Inquiry on the Influence of Autism Assistance Dogs on the
Wellbeing of Autistic Children and Their Families**

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Abstract

Autism Assistance Dogs (AADs) are specifically trained to perform tasks to increase the independence and quality of life of autistic people.¹ Despite rising interest in their potential usefulness in this population, the evidence base for AADs remains limited. Even rarer are studies on how AADs impact the wellbeing of autistic children and their families, including with the voices of groups other than parents, such as service-providers. Using a qualitative design with triangulation, this thesis explores how AADs might influence the wellbeing of autistic children who have been diagnosed with level-three autism spectrum disorder. It also explores how AADs might affect the wellbeing of the autistic child's family. Sixteen interviews in total were conducted across two groups to achieve these aims. Participants comprised nine parents who have a level-three autistic child with an AAD and seven service-providers. Thematic analysis identified six themes, with results suggesting that AADs might enhance the wellbeing of both autistic children and their families through improved sleep quality, decreased stress, augmented safety, easier and safer access to the community, and enhanced confidence and self-efficacy. The combined impact of these themes led to participants reporting that AADs are 'life-changing.' A significant finding in this thesis is that the influence of AADs upon the wellbeing of children and their families do not exist in a vacuum: the themes were interrelated, and the wellbeing of the children and their families was symbiotic. Findings of this thesis may lead to helpful practical implications for clinicians and families with an autistic child.

¹ Identity-first-language is respectfully used throughout this thesis, due to its preferred-use by autistic people (Botha, et al., 2021).

Conference presentations based on the data from this thesis

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Declaration

This thesis contains no material which has been accepted for the award of any other degree of diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made.

I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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September, 2022

Introduction

Background

We need light in the darkness and sound in the silence. We need bridges in place of walls, and we need to be encouraged to cross those bridges one step at a time from our own world to a shared world.

(Donna Williams, Australian author with autism (as cited in Gross, 2006, p. 3)).

In the mid-1990s, a group of organisations in the United States began purposefully training ‘service dogs’ (known as ‘assistance dogs’, in Australia) to meet the unique needs of autistic children (Fry-Johnson et al., 2009). Since then, the number of organisations dedicated to training assistance dogs for autistic children has proliferated internationally, including within Australia. In their advertisements, these organisations espouse the various benefits that autism assistance dogs (henceforth: AADs) can have upon reducing symptoms associated with autism spectrum disorder (henceforth: autism),² including improved physical safety, improved emotional regulation, and improved social functioning (e.g., Smart Pups, 2017). In Australia, media reports have documented individual cases of AADs dramatically improving the life of the child they have been paired with (e.g., Cooper, 2021; Whetham and Chave, 2022).³ Despite the purported benefits touted by AAD-providers and anecdotal recounts supporting the use of AADs for autistic children, there is insufficient evidence to support these claims. The limited existing research has typically found positive results for autistic children (e.g., Leung and Dickson, 2022), however there is still insufficient evidence-based

² The abbreviation ‘autism’ is often preferred over the abbreviation of ‘ASD’ by autistic people (Bury et al., 2020).

³ In Australia, AADs are trained to be paired with one autistic child exclusively.

literature to support these claims. There is even less evidence surrounding the impact of AADs on families.

Consequently, the aim of this exploratory study was to describe the influence of AADs upon the wellbeing of autistic children's families, including the autistic children themselves. It achieved this through the perspectives of parents who have a level-three autistic child with an AAD (henceforth: 'parents'), and service-providers who work with autistic children who have an AAD.

Terminology

Identity-First-Language: "Autistic Children"

Because autistic people are often marginalised and stigmatised, society—including academia—must acknowledge the perspectives of autistic people on discourse around the term 'autism.' The use of pathology-first, person-first, and identity-first-language in the world of autism has generated polarising debate (Dwyer, 2022), particularly on social-media (Shakes & Cashin, 2020). Even empirically, polarisation is high—for example, in Bury et al. (2020), Australian autistic adults were likely to rate the term 'autistic' among *least* offensive terms to describe themselves, yet also rated it as the *most* likely to be offensive, dependent upon its usage. This usage tended to turn on whether the term was pathologising or identifying (Bury et al., 2020). To pathologise the term 'autistic', is to use the term with a negative pathology or connotation. Identify-first language, on the other hand, encompasses the term 'autistic' as a positive part of someone's identity, which coexists along other identities (e.g., 'a French autistic man'). Because the term 'autistic' here is used as an adjective, the words 'autism' and 'autistic' will not be capitalised throughout this thesis (Bury et al., 2020). Chapman (2020) puts forward that autistic people can use identity-first language in this way, to take pride in their neurodivergence. Autistic people themselves have recently

agreed with this (Botha et al., 2021). As such, this thesis intentionally and respectfully uses identity-first-language to describe autistic children.

Use of the Terms “Family” and “Parents”

This research originally set out to examine the influence of AADs in ‘households’ in which autistic children and the AAD resides. The intention of this was to capture diverse living-arrangements between families. However, after interviews were completed, it became clear that participants (specifically parents) referred to their ‘family’ when discussing their ‘household’. This use of language by participants is therefore reflected throughout this thesis.

Likewise, this research invited ‘parents or carers’ of level-three autistic children to participate, however the term ‘parents’ is used for brevity.

Wellbeing

Psychological wellbeing is defined as a state in which individuals can cope with stressors, realise their potential, work productively, and contribute to their community (WHO, 2013).

Importantly, much of the existing literature on AADs focus on their biological and social benefits to autistic children primarily at an individual level (e.g., Viau et al., 2010). This thesis, however, will incorporate emotional and psychological wellbeing alongside biological and social factors which contribute to wellbeing, as well as considering benefits across multiple domains—ultimately utilising Engel’s biopsychosocial model (1977) and Bronfenbrenner’s social-ecological model (1979) in its interpretation of results in the Discussion.

Autism

Autism spectrum disorder (hereafter: autism) is a lifelong condition with diagnostic criteria set out in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed., text rev.; DSM-5-TR; American Psychiatric Association, 2022). The neurodevelopmental

disorder, typically diagnosed during early childhood, is characterised by deficits in social-emotional reciprocity; communication; and developing, maintaining and understanding relationships. It is also characterised by restricted, repetitive behaviours, including echolalia, repetitive motor movements, ritualised patterns, fixated interests and hyper- or hypo-activity to sensory input. For a diagnosis of autism, these symptoms must cause clinically significant impairments in functioning. For children specifically, these impairments in functioning can impact their ability to successfully navigate societal complexities, particularly once they enter school settings (Lester, 2015). Autism diagnosis levels are determined in the DSM-5-TR by the severity of an autistic individual's "social communication impairments and restricted, repetitive patterns of behaviour" (American Psychiatric Association, 2022, p. F84.0).

Individuals who are diagnosed with level-three autism require the highest levels of support in these domains, whilst level-one proportionately require the least. It is important to note that autistic people often have strengths due to their neurodivergence in the domains of analytic thinking, objective evaluation, systems design and extensive knowledge within their areas of special-interest (Nieforth et al., 2021).

The rates of autism diagnoses have been increasing worldwide, as demonstrated across population, incidence, and prevalence studies (Davidovitch et al., 2020; Jensen et al., 2014; Lyall et al., 2017). This includes Australia, where between the years 2015 and 2018, autism rates in Australia—of all levels—increased by 25.1% (ABS, 2019a). Debate continues as to whether increasing rates are due to a rise in the rate of autism itself (e.g., Raz et al., 2015), or a rise in diagnoses due to greater awareness, widening diagnostic criteria, diagnostic substitution, earlier identification, and improved service availability (e.g., Bent et al., 2017).

Wellbeing in Autistic Children

The enduring nature of autism, as well as the challenges that its symptoms can bring, can affect the wellbeing of individuals living with it (Lester, 2015). Wellbeing, particularly from a biopsychosocial standpoint, has been measured in autistic children with symptoms of varying severity. These findings demonstrate that autistic children are more stressed than their neurotypical counterparts based upon a range of criteria, including parental reports (Begeer et al., 2017), cortisol levels (Spratt et al., 2011), markers of oxidative stress (Essa et al., 2012), compromised sleep (Chua et al., 2022), and ‘meltdown’ behaviours (Montaque et al., 2018). Notably, measuring autistic children’s wellbeing through neurotypical behaviour indicators can be difficult, due to their idiosyncratic mood indicators (Ramey et al., 2022). Despite this, Mayes et al. (2011) found that autistic children had levels of anxiety and depression which were positively correlated with their severity of autism, as determined by parental perceptions. Findings from this study (Mayes et al., 2011), and further studies by the same team (Mayes et al., 2015), revealed that clinical levels of Generalised Anxiety Disorder were present in a vast majority of children studied, and clinical levels of Major Depressive Disorder were present in approximately half. In these studies, these symptoms were exacerbated by the child’s inability to recognise their own emotions, recognise other’s emotions, and communicate their feelings to others—all associated with their autism diagnosis. Interestingly, also in line with these findings, subjective wellbeing in autistic children—as reported by their parents—increased as the autistic child got older, when it correlated with their support needs decreasing (Begeer et al., 2016).

Autism and the Family

Families of autistic children are often negatively impacted by the abovementioned symptoms and behaviours associated with autism. For instance, of the approximate 136,000 carers for children living with a psychosocial disability in Australia—including autism—90%

reported a “profound or severe core activity limitation,” associated with their child’s disability (ABS, 2019b). This statistic echoes the findings of a qualitative study by Critchley et al. (2021), where one participant mentioned that “having a disabled child...disables the family as well” (p. 103884).

Overall, research on the systemic effects of autism on families has grown significantly in recent years. Much of this research concludes that having an autistic child within a family lead to increased stressors and decreased wellbeing for that family (e.g., Giallo et al., 2013; Neff & Fasso, 2015; Pepa et al., 2014). For example, Ekas and Whitman (2010) found that greater autism symptom severity was associated with poorer wellbeing and life-satisfaction in parents. Furthermore, parental wellbeing can be compromised through emotional overload, profound fatigue, and lack of social supports (Gomes et al., 2015); disintegrating family cohesion (Altiere & Von Kluge, 2009); heightened isolation, decreased happiness and lower levels of relationship satisfaction (Hoseinnejad et al., 2020), and decreased parental self-efficacy, coupled with greater parenting stress (Hamlyn-Wright et al., 2007). These broad-reaching impacts extend across cross-cultural boundaries: for example, from Israel (Raz et al., 2014), to Brazil (Gomes et al., 2015), to China (Su et al., 2013), to Australia (Giallo et al., 2013).

For siblings, especially those who are typically developing, having an autistic sibling can negatively affect their wellbeing (Critchley et al., 2021), through early-parentification, fear and anxiety surrounding their autistic sibling’s challenging behaviours, and feeling like their own needs are overlooked (Leedham et al., 2020; Pepa et al., 2014). On the other hand, there may be positive outcomes for siblings of an autistic person, including increased traits of empathy and compassion (Leedham et al., 2020). Siblings—particularly during childhood—can also benefit significantly from participating in their autistic sibling’s interventions, in instances where they feel motivated to do this (Ferraioli et al., 2012).

Autism Treatments and Interventions for Children

Treatments and interventions for autism are diverse, including many which are not empirically validated. As Chihon et al. (2020) put it in their evaluation of ‘fidget spinners’ as an autism intervention: “New, unsubstantiated therapies for individuals diagnosed with autism spectrum disorder (ASD) that lack empirical support for their effectiveness seem to be introduced almost daily” (p. 466). In an international sample, Hofer et al. (2017) found that between 28% and 95% of autistic children have been enrolled into non-empirically supported complementary treatments. Additionally, Goin-Kochel et al. (2007) asked 421 families with autistic children to list every type of treatment or intervention that they had used, or were using, for their autistic child. These families reported they had, on average, tried nine different forms of therapy for their child, with the average child being enrolled in six different types of therapy at the time of the study. In a study that also tried to capture the experiences of parents choosing treatments for their autistic children, Berquist and Charlop (2014) deduced that autism treatments and interventions can be divided into three categories: those that are scientifically supported, those that have not yet been scientifically supported, and those which have been shown to be ineffective—or even harmful. Therefore, building upon the body of literature that helps explore interventions and treatments for autism is important.

Large bodies of research highlight the efficacy of early behavioural interventions—such as Applied Behavioural Analysis—for autism (e.g., Spreckley & Boyd, 2009). However, emerging research demonstrates other evidence-based treatments for autism. These include, though are not limited to, symbolic play and joint attention interventions (Doernberg et al., 2021) and technology-mediated augmented-reality interventions (Pérez-Fuster et al., 2022). Ultimately, research often concludes that because autism is a ‘spectrum’ disorder, which presents differently from individual-to-individual—and presents differently over each autistic person’s lifetime—the efficacy of treatment is not universal (Volkmar et al., 2014). The

diversity of treatment options for autism is therefore warranted. Given the increasing rates of autism internationally, challenges that accompany the disorder, and evidence that suggests that early interventions often produce the most significant outcomes (Towle et al., 2020), the ongoing research of effective interventions for autism remains necessary. Further to this point, understanding novel and complementary therapies—such as animal assisted therapies, including AADs—should be given research consideration, due to the diverse presentations and personalities of autistic individuals.

Animal-Assisted Interventions for Autism in Children

Animal-assisted interventions (AAI)—including AADs—have become increasingly popular measures for supporting autistic children (Fine et al., 2019). Accordingly, empirical evidence on AAI have mounted.

Systematic reviews on AAI for autism have been conducted in recent years, including interventions with a range of animals (Hill et al., 2019; Lisk, et al., 2020; Nieforth et al., 2021; O’Haire, 2012). These reviews consistently found “unanimously positive” findings for AAI for autism, however all reviews emphasised that the studies-within lacked methodological rigour (O’Haire, 2012, p. 1606).

Beyond AADs, another example of AAI for autism are ‘therapy-dogs’: dogs who are brought into facilities (such as allied-health settings), by handlers who work or volunteer there to help calm *many* people (Gross, 2006). Importantly, therapy-dogs are different to assistance-dogs, who are trained to achieve specific tasks for *one* specific person. For example, London et al. (2020) undertook research on the impact of therapy-dogs with autistic children during occupational-therapy sessions, finding improvements in communication, emotional-regulation, and community participation. A qualitative study, which captured the perspectives of occupational-therapists, identified similar outcomes for autistic children with therapy-dogs during sessions (Hill et al., 2020).

Literature on AAI for autism often cites the significance of the human-animal bond as a unique contributing factor towards AAI efficacy for autism (e.g., McCardle, 2011). For some autistic children, this can extend to a ‘special connection’ that they feel with animals, as discussed at length in autistic author and animal-rights advocate, Temple Grandin’s, book *Animals in Translation* (Grandin & Johnson, 2006). As such, theories concerning the human-animal bond may go some way in explaining the impact of AAIs. However, given that the same benefits are not always found with pets or other animals without specific training, this theory is unlikely to fully explain the ways in which AAIs improve wellbeing for autistic children.

Autism Assistance Dogs and Wellbeing in Autistic Children

As part of the increasing literature on AAI for autism, there has been a contemporaneous increase in the amount of evidence surrounding the efficacy of AADs for autistic children they are paired with. Here, findings vary based on the outcomes considered in the studies, but most reported positive improvements across a range of symptoms and behaviours. For instance, Viau et al. (2010) studied the impact of AADs on cortisol excretion in 42 autistic children in a longitudinal, repeated-measures study, finding that the introduction of an AAD reduced cortisol excretion, which was matched with reported behavioural improvements by parents. Harris and Sholtis (2016) found that AADs have a positive impact on autistic children in school settings, via improving learning outcomes and emotional regulation. Other researchers have found that ‘meltdown’ and absconding type behaviours are reduced in children, thereby increasing children’s safety (e.g., Berry et al., 2013). Improved socialisation is another benefit of AADs for autistic children. For example, a South Australian study found that autistic children and their families left their homes significantly more (averaging 20.50km further from home) after the introduction of an AAD into their family, via occupational-mapping (Appleby et al., 2022).

Autism Assistance Dogs

Studies incorporating the impact of AADs on other members of an autistic child's family are also emerging. An exhaustive literature review on this topic found that a vast majority of these studies were quantitative in nature and exclusively captured the perspective of parents. For instance, Burgoyne et al. (2014) explored the impact of AADs in 134 Irish families, where parents rated their child as significantly safer from environmental dangers, perceived that the public acted more respectfully towards their autistic child, and felt more competent in managing their child, compared with waitlist parents. This study built upon prior qualitative research by Burrows et al. (2008), which found that parents worried less and slept more because of their child's AAD; and Smyth and Slevin (2010), which found that the presence of an AAD improved the entire family's quality of life due to decreased stress. Bibbo et al. (2019) further considered this topic, finding that AADs provided parental participants with less total family impact from the condition, and better emotional health compared to their waitlisted counterparts. Australian research has mirrored these findings, with a recent study by Leung and Dickson (2022) reporting that parents who had an AAD for their autistic child for longer, reported proportionately more positive outcomes on pro-social behaviours, adaptive functioning, and family wellbeing.

This thesis is—to the researcher's knowledge—the first study to examine the influence of AADs with triangulated data through service-providers; an important perspective since service-providers both have discipline specific expertise and see a broad range of families and can thus speak across a diversity of family circumstances in relation to AADs. It is also one of the first studies to elucidate how AADs impact family-units, rather than autistic individuals alone.

Aims

Due to autism's increasing prevalence, multiplicity of interventions, and lifelong impact on autistic individuals and their families, research that provides evidence on emerging interventions for autistic children is important. Given the dearth of literature on the topic of AADs' impact on wellbeing in both children and their families, this thesis therefore aims to explore this through the perspectives of parents with an AAD for their autistic child and service-providers (AAD-trainers and allied-health professionals) who work with AADs and their families. Accordingly, the research question for this thesis is:

How might Autism Assistance Dogs—i.e., dogs specifically trained to assist autistic people—affect the wellbeing of autistic children who they assist and their family-members?

Method

Research Design

This thesis was an inductive, qualitative inquiry, substantiated by Critland et al.'s research which found that qualitative research is a particularly effective method for research experiences related to families living with autism (2015). The study followed a critical realist epistemology—an approach midway along “the ontology continuum” between realism and relativism, which acknowledges that reality is experienced and interpreted through the prism of culture, language, and political interests (Braun & Clarke, 2013, p. 26).

Participants

Sixteen participants were interviewed for the study, across the two participant groups—parents and service-providers. Participants comprised of nine parents (see: Table 1), and seven service-providers (see: Table 2).

Table 1
Participant Characteristics for Parents

Participant Name*	Participant Relationship with Autistic Child with AAD	Participant Marital and Cohabitant Status	Neurodiversity of Parents	Name* of Autistic Child with AAD	Level of Autism in Child with AAD	Age and Sex of Autistic Child with AAD	Number of siblings, including their neurodiversity	Participant's AAD Name* and Breed	Number of months or years with AAD
Rachel	Mother (biological)	Cohabiting marriage with biological father	2 neurotypical	Ruby	2-3	10-year-old, Female	1 neurodiverse younger sister	Daisy, Poodle-crossbreed	2 years
Annabel	Mother (biological)	Cohabiting marriage with biological father	1 neurotypical 1 neurodiverse	Aaron	3	10-year-old, Male	1 neurodiverse older sister	Diego, Labrador	1 year, 3 months
Georgia	Mother (biological)	Cohabiting marriage with biological father	2 neurotypical	Grace	3	10-year-old, Female	1 neurodiverse older brother, 2 neurodiverse younger sisters	Daphne, Labrador	3 years
Maggie	Mother (biological)	Cohabiting marriage with biological father	2 neurotypical	Matthew	2-3	16-year-old, Male	1 neurotypical younger brother	Darcy, Golden Retriever (deceased), and Dash, Labrador	4 years (total)
Kate	Mother (biological)	Single	1 neurodiverse	Kelsey	3	11-year-old, Female	1 neurotypical older sister	Dixie, Labrador	2 years
Nina	Mother (biological)	Cohabiting marriage with biological father	2 neurotypical	Ned	3	8-year-old, Male	3 neurotypical older sisters	Dexter, Labrador	2 years
Laura	Mother (biological)	Cohabiting marriage with biological father	2 neurotypical	Liam	3	7-year-old, Male	1 neurotypical older sister, 1 neurodiverse older sister	Diesel, Labrador	2 years
Penelope	Mother (biological)	Cohabiting marriage with non-biological father	2 neurotypical	Poppy	2-3	13-year-old, Female	1 neurodiverse younger brother	Delilah, Labrador	5 years
Christina	Mother (biological)	Cohabiting marriage with biological father	1 neurotypical 1 neurodiverse	Chloe	2-3	8-year-old, Female	1 neurodiverse older sister	Dora, Poodle-crossbreed	6 months

*Denotes pseudonym

Table 2
Participant Characteristics for Service-providers

Participant Name*	Occupation	Years in Occupation	Estimated Number of Families with Autism Assistance Dog the Participant has Worked With
Hayley	Autism Assistance Dog AAD-trainer	17 years	40
Freya	Autism Assistance Dog AAD-trainer	14 years	30
Emily	Occupational-Therapist	9 years	20
Belinda	Autism Assistance Dog AAD-trainer	2 years	5
Jasmine	Occupational-Therapist	12 years	20
Olivia	Occupational-Therapist	6 years	25
Imogen	Occupational-Therapist	3 years	12

*Denotes pseudonym

All sixteen participants were female and came from across Australia, including capital-cities and regional-areas. All participants were associated with one of five Australian AAD-training organisations. For parents, this meant all AADs were trained through these organisations. For service-providers, this meant they were employed by one of these organisations. For participant anonymity, individual details regarding location and training organisation have not been provided (Saunders et al., 2015).

The average age of the parent's child with an AAD was 10 years and 11 months. Of the group of autistic children with AADs, five (55%) were female and four (45%) were male. The mode-average autism severity in these children was level-three, although children who had been diagnosed 'level-two and three' were also represented. Alongside their autism, 77% of children with an AAD had co-morbidities, including epilepsy, pica, Generalised Anxiety Disorder, Global Developmental Delay and Cri-du-Chat syndrome.

Six families (66%) had other neurodivergent children, including four families (44%) with a second or third autistic child. Other sibling neurodivergences included Attention-Deficit-Hyperactivity-Disorder, Generalised Anxiety Disorder and Global Developmental

Delay. Crucially, in these families, the AAD was only ‘paired’ with one child for the AAD’s welfare, as per policies of AAD-training organisations. Families had an AAD in their lives for between 6 months and 4 years ($M = 1$ year, 10 months).

Parents were aged between 33 and 54 years ($M = 41.5$ years), and were typically tertiary-educated (77%), and were mostly full-time-parents (66%). Three parents were culturally-and-linguistically-diverse.

Service-providers included three AAD-trainers and four occupational-therapists, who had been working with AAD families for between 2 and 17 years ($M = 9$ years; M (AAD-trainers) = 11 years; M (occupational-therapists) = 7.5 years). Service-providers were aged between 26 and 55 years ($M = 39$ years). Two service-providers were culturally-and-linguistically-diverse.

Procedure

Ethical approval was obtained by The University of Adelaide’s Human Research Ethics Committee and met the *National Statement on Ethical Conduct in Human Research 2007*. Ethical approval was also provided by Autism SA, who assisted with research promotion.

For inclusion, the first group of participants were required to be the parent or caregiver of a child who was diagnosed with level-three autism. Isolating level-three autistic children was intentional, in line with literature indicating that both children and parents with higher support-needs have lower wellbeing (Begeer et al., 2016). No age limit for children with the AAD was set. Parents must have had a trained AAD for their autistic child for more than six-months and able to speak conversational-English. AADs were required to be classified as an assistance dog under s. 9.2 of the *Disability Discrimination Act 1992* (Cth).

The second group of participants were required to be a service-provider who works with level-three autistic children who have an AAD, with at least two-years’ experience.

For recruitment, Australian organisations which specialise in working with autistic children were invited to disseminate flyer (Appendix A and B). Additionally, recruitment occurred through social-media and via snowball sampling.

If interested, participants contacted the student-researcher via email and were provided with the Information Sheet (Appendix C and D). The student-researcher determined whether participants met inclusion-criteria via email-exchange. Verbal consent was obtained from all participants before interviews commenced.

Interviews were solely conducted by the student-researcher. Thirteen took place over video-call due to location. The remaining three were conducted face-to-face. Length of interviews ranged from 52 minutes to 98 minutes ($M = 77$ minutes).

Interviews proceeded with a semi-structured approach, including a set of prescribed open-ended questions (Appendix E and F), developed based on existing literature (e.g., Burgoyne et al., 2008). The student-researcher invited participants to elaborate on key points. After each interview, the student-researcher used her audit-trail to reflect on the interview experience, including refining questions for future participants and noting potential codes or themes (Tracy, 2010).

All participants were verbally-debriefed at the end of each interview. A protocol for supporting research participants (Appendix G) was prepared in anticipation of participants requiring support, however no participants required this.

In line with Braun and Clarke (2006), interviews were transcribed verbatim. Participants were all provided with pseudonyms, and with the opportunity to 'member-check' (Lincoln & Guba, 1985), their de-identified transcript and comment on initial analysis. Nine of sixteen participants (56%) engaged in this process.

Data saturation was achieved by the eighth participant for parents; however, one further interview was undertaken to ensure this was reached (Guest et al., 2006). Data

saturation was achieved by the seventh participant for service-providers; however a further interview could not be completed due to time-constraints.

Data Analysis

Thematic analysis (TA) was utilised to analyse the data (Braun & Clarke, 2006). This involved familiarisation with interview-transcripts; generating codes; identifying themes; reviewing themes; refining and defining themes; and writing the analysis.

Initially, an inductive TA approach was used when analysing transcripts for coding purposes. A deductive approach was then used to examine the data against the research question. The academic-supervisor crosschecked codes and themes that were identified within the dataset (Braun & Clarke, 2006; 2013). This led to minor refinements.

Data from parents and service-providers are presented together because no major differences were apparent in their responses to the semi-structured interviews. However, specific instances of divergence—both within and between participant groups—are highlighted.

Reflexive Research

The student-researcher identifies as an ‘insider’ within the present study, which may have impacted the interviews and results (Berger, 2015). This is because the student-researcher has a younger brother—by three years—who has had a diagnosis of autism for twenty-two years (level-two). This undoubtedly shaped the way that the student-researcher spoke and asked questions to parents. She also used this as a source of connection with some participants. The student-researcher is European-Australian, heterosexual, and not a parent. She does, however, have pet dogs.

Accordingly, the student-researcher’s values and who she is generally have situated her within the interviews and data-analysis in a particular way. As such, she reflexively journaled in her audit-trail—where she actively reflected on how her own subjective

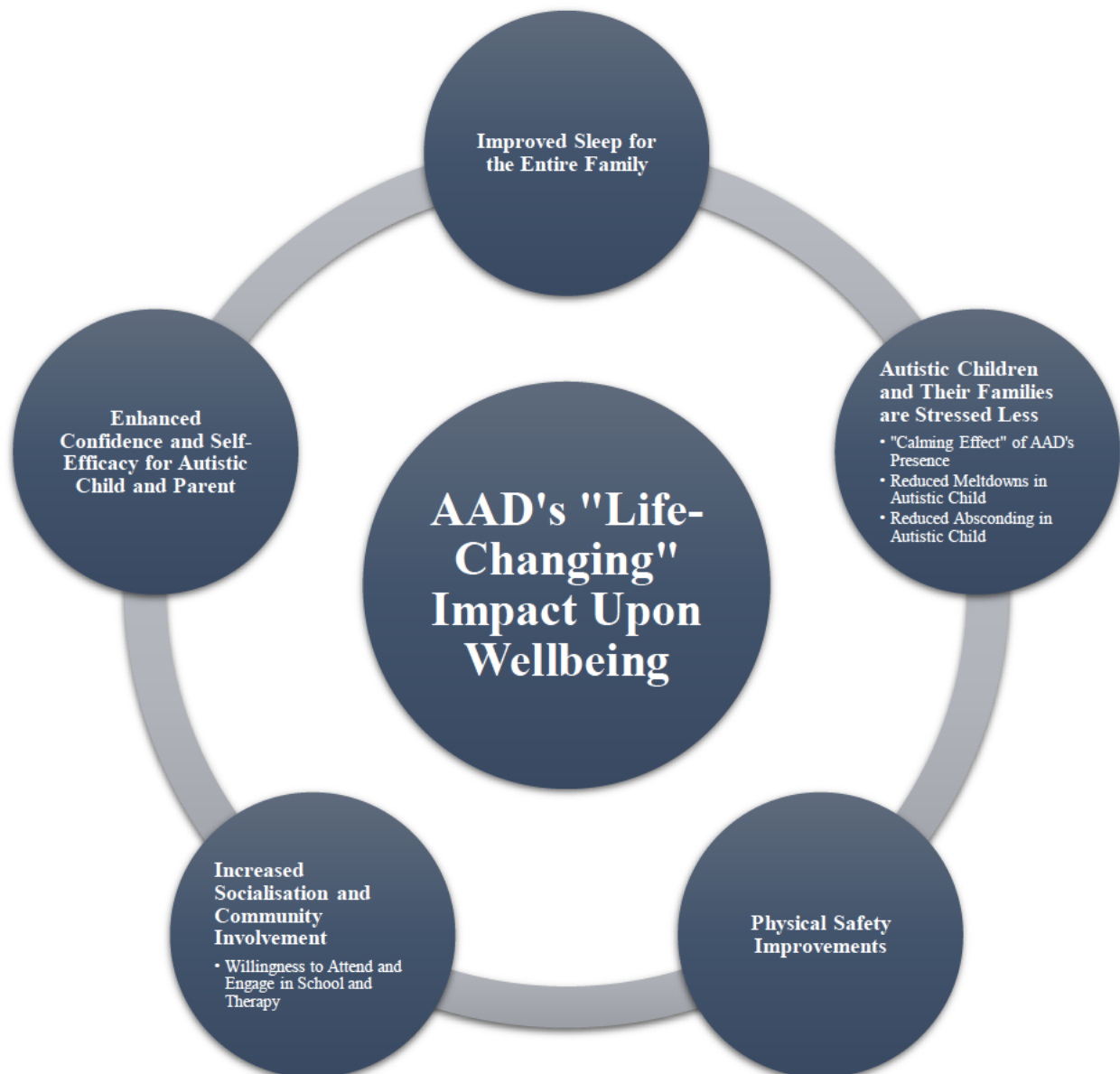
experiences might be shaping her research (Finlay, 2002)—and discussed this potential embeddedness in data-interpretations with her academic-supervisor (Tracy, 2010).

Results

Overview

The results are categorised into six themes arising from the TA. The first identified theme was that the AADs are ‘life-changing’ for autistic children with an AAD and their families’ wellbeing. The ‘life-changing’ theme was identified across all interviews and is seen as conceptually framing the remaining six themes, in that these are pathways through which ‘life-changing’ improvements were identified, resulting in improved wellbeing for families (see Figure 1 for a thematic map).

Figure 1
Thematic Map



AAD's "Life-Changing" Impact Upon Wellbeing

Across the sample, participants reflected that AADs improve wellbeing to the extent of it being 'life-changing.' This occurred without prompt across all participants from both groups. For instance, Annabel reflected, "I'm just truly blown away with just how much Diego [AAD] has changed our lives, like, as people say, it's life changing, but it is, it's truly life changing" (Annabel, parent). Expanding on the notion of the AAD impacting the entire family unit, Maggie remarked that, "it would be an understatement to say the dogs have changed our lives dramatically. Especially Matthew's [Autistic child] life. But all of our lives" (Maggie, parent). This use of language by parents emphasises the extent and scope of impact that the AAD has had on their autistic child's wellbeing and the wellbeing of their family.

Service-providers also indicated that they had observed the 'life-changing' impact of AADs on the wellbeing of family-members. This included allied-health professionals, such as Olivia, who said:

I think the benefits to the whole family with an assistance dog are substantial, to significant, to profound... And just, it's just like life changing in ways you maybe expected and also a lot of ways you didn't expect. Like, it's just completely transformative for the whole family. (Olivia, occupational-therapist)

Similarly, AAD-trainers of AADs also reported recounts of parents saying to them that their AAD had been 'life-changing' for their autistic child. For instance:

And they all just say, oh, gosh, it's been life-changing. Because I think they're not fighting a constant battle. Yes, there's still those hard moments during the day, but they're not fighting that constant battle with the child all day long, as well. (Hayley, AAD-trainer)

The remaining six themes demonstrate pathways towards how AADs might be ‘life-changing’ for an autistic-child and their family.

Improved Sleep for the Entire Family

Across the sample, participants described experiences of the AAD improving the sleep of the entire family, directly improving their wellbeing. Emily, for example, explained:

A lot of the kiddos really struggle with sleep and may have co-slept from day dot with their parent, or, you know, had night-terrors or frequent waking. And I definitely see that in both level two and level three kiddos. And I’ve definitely seen that the [AAD] dogs definitely help with that. (Emily, occupational-therapist)

Parents also reflected that now that the AAD sleeps with their child, their child mostly sleeps in their own bed, and sleeps for longer periods of time. For instance, Kate, parent of an 11-year-old girl, explained:

Kelsey [autistic child] was waking up a lot throughout the night and you know, coming into my room whilst I was asleep, or trying to sleep. But we’ve had like, none of that, since Dixie [AAD]. At all. Very rarely does she wake up during the night anymore. It’s amazing. (Kate, parent)

Parents also indicated that their autistic children seem to be less distressed when, or if, they do wake up in the night, meaning that they can get back to sleep in the company of the AAD, rather than in the company of their parents. Georgia, for instance, spoke of her autistic child, Grace, being, “not as scared with Daphne [AAD] there, you know, and also just, Daphne sleeps on her bed and having that ((pause)), it’s like having someone lie next to her, you know? Or cuddle her” (Georgia, parent). Here, Georgia implies that the AAD effectively *replaces* having the parent sleeping next to the autistic child—something other parents also expressed. Other parents expressed that their morning routines after waking up became much smoother with an AAD. For instance, Christina reflected:

Every morning I was being hit by Chloe [autistic child]. I constantly had bruises on my arm, it was ((pause))... it was the toughest part of every day. I would cry every day. She would hit me, kick me, say she wanted to kill me, at first thing, at seven o'clock in the morning, when I tried to get her out of her room to get organised for the day. So going from that to having Dora [AAD] licking her face and waking her up and having her wake up with the smiles. It's just priceless. (Christina, parent).

In line with these findings about multiple improvements to sleep, service-providers explained that training the AAD to sleep with the child was a task that they prioritised during their period working with the family after placing the AAD with an autistic child. Hayley, for instance, recounted that she worked with a child who had “never slept in his own bed,” and that she said to him:

[The AAD] needs your company tonight. He's feeling really lonely. Why don't you try and be with him? “Oh, I don't think that's gonna work,” he says. I say, “So come on, I say, I'll show you how it's gonna work,” And then I got there the next morning, and [the parents] are going, “Oh my god. You don't know how many people, over how many years, we have tried to get him in his own bed. Like, occupational-therapists, sleep therapists, behavioural therapists. but we just finally slept in bed by ourselves.” (Hayley, AAD-trainer)

Hayley went on to say: “Think of the lack of intimacy, even, of having a child in your bed for eight years”, explaining that many families she had worked with had found the lack of intimacy in their relationship a key challenge associated with their autistic child due to their autistic child, but that an AAD had resolved this (Hayley, AAD-trainer). Parents described the profound impact of their autistic child sleeping through the night and in their own bed as impacting their own wellbeing, because “it's improved Grace's [autistic child]

sleep dramatically, which has then improved our sleep,” as participant, Georgia, put it (Georgia, parent). Likewise, Penelope explained:

Daphne [AAD] has definitely improved my wellbeing. Especially for bedtime... because I love my sleep and I need, I want, eight hours. But when I’ve got Poppy [autistic child] coming in and waking and won’t settle back down, and is wanting me, you just don’t get that. Ever. But, then when Daphne [AAD] comes along and so Poppy stays in her bed, you know, it’s, it’s like ((gasps, laughs)), huge! (Penelope, parent).

Parents with an autistic child also spoke of their other children getting much better sleep during the night. For example, Kate expressed that her older daughter gets more sleep now that her autistic child, Kelsey, “sleeps all the way through... It’s good for everyone in the house, like she always woke up my older daughter too” (Kate, parent).

Across both participant groups, the impact of AADs on sleep for the entire family was identified as being an important way that AADs enhanced the wellbeing of families that they are placed within. Participants indicated that benefits—such as improved intimacy in parent relationships—also flowed from these sleep improvements.

Autistic Children and Their Families are Stressed Less

Decreased stress levels across autistic children and their families was also reflected as another wellbeing-enhancer of AADs, as described by both parents and service-providers. For autistic children, this became evident through reduced ‘meltdowns,’ ‘absconding’ and generally being ‘calmed’ by the AAD’s presence—all of which will be discussed as subthemes.

Parents described that their own stress levels had decreased since their autistic child received their AAD. For example, Kate said: “I definitely feel less stressed with Dixie

around. I feel like I definitely do have an extra set of paws ((laughs)) helping me” (Kate, parent).

Service-providers also discussed general and overarching reductions in stress for the broader families that they worked with. For example, Emily discussed the impact that lowering stress levels has on the wellbeing of entire families:

I think one of the main things that parents have always said is, is it reduces their stress level, and then they are in such a better position to, you know, have the energy to do things with the other siblings, and yeah, just be less stressed and more present and more calm and feel like a family. (Emily, occupational-therapist)

Service-providers also stated that they do not believe that the de-stressing benefits for families could come from a pet dog, because of the training AADs undergo around autistic behaviours. For example, Imogen said:

There’s a massive difference between an assistance dog and a pet... We’ve had a lot of families that have bought pets, including dogs. And like it... just the relationship hasn’t been there with other pets we find...I think because they’re trained very differently. They’re not dogs that are excitable jumping on them. They’re not barking at them, they’re calm, and they’re more predictable. (Imogen, occupational therapist)

Below, specific sub-themes in terms of AADs influence on stress-reduction are discussed.

‘Calming’ Influence of Dog’s Presence

Many participants used the term ‘calm’ or ‘calming’ to describe the influence of the AAD on either their autistic child, their household or their family when asked about the AAD’s impact on their wellbeing.

AAD-trainers explained this at-length. Freya, for instance, explained that the primary benefit of AADs for the autistic children she has worked with is due to the dog remaining

calm when the child enters ‘meltdown’ states or begin to abscond—in contrast to humans who may fret. Freya explained:

We also find that if a child is heightened, or changing their zones of regulation, they will come back up to the ‘Green Zone’ quicker with the dog than they would have before. I don’t know if that’s because the dog is consistent...like, the dog doesn’t have, it can’t show any emotion. Especially an Assistance Dog, because they’re calm. Whereas with the parents, the parents obviously can’t help showing emotions. We can’t really figure it out to be honest, because the dog is the dog...it doesn’t necessarily do anything in that moment. Sure, the dog may go do some deep-pressure or whatever, but I think the mere presence of a very calm dog is doing something too. (Freya, AAD-trainer)

Parents also reflected that their AADs were able to offer calming benefits that they themselves hadn’t. For example, Kate said:

I love that Dixie’s [AAD] able to [calm Kelsey [autistic child] when she’s heightened]. But then sometimes I think, oh, geez, you know, I feel bad. As a parent, why aren’t I giving her that? You know, why is the dog kind of fulfilling that kind of need? And not me? I kind of feel a bit like failure. But yeah, I’m just happy that Dixie’s able to kind of fill that need that obviously I can’t. Like, you know, one hundred of me would equal, like, one of Dixie. I just I wish I could do like everything for her, but I can’t. (Kate, parent)

Participants also spoke of the general de-stressing benefits of pet-ownership extending as benefits to the entire family, despite the ‘pet’ being an AAD. Olivia highlighted that “it might be ‘little Johnnie’s’ assistance dog, but it’s everyone [in the family’s] dog” (Olivia, occupational-therapist). Maggie explained, for example, that “the dogs have both

been a comfort to us, as well,” because “they know Matthew’s [autistic child] my person, but they know, this is my pack” (Maggie, AAD-parent).

Further to this point, many parents reflected that having the AAD in the home brought a source of comfort to their other children. For instance, Laura expressed that:

I don’t know that Lily [neurotypical child] would have coped in this house without this dog. Like she almost needs it with these two autistic siblings. She almost needed this warm, cuddly element. Like she can’t get that from...she doesn’t get it from her siblings. They’re like very cold to her, and all of the interactions that she has with her siblings are driven by her. There’s none of them that are driven from, from them, from the other way. So for her, just having this lovely dog that she can go and hug is important. (Laura, parent)

Hence, the ‘calming’ nature of the AAD has an impact on the wellbeing of autistic children and their families through increasing calmness and reducing stress.

Reduced ‘Meltdowns’

All parents reported that their autistic children experienced reduced duration, frequency, and intensity of ‘meltdowns’ through the presence of their AAD, to varying degrees. Parents directly attributed this to the AAD, but varied in how they thought their AAD achieved this for their child. Several participants speculated that, after getting an AAD, autistic children rarely get emotionally-heightened enough to trigger a ‘meltdown.’ For instance, Georgia reflected, “Grace [autistic child] was nearly always up here, you know ((gestures with hand above head))? Whereas now, she might be there for a bit, but then Daphne [AAD] quickly helps bring her out of it” (Georgia, parent). Others speculated reductions in meltdowns could be because AADs pick up on signals parents may miss about their autistic child’s distress. For instance, Annabel said, “those little micro movements or those hormones... Diego [AAD] just automatically senses them” and then “works” to “pre-

emptively calm him" (Annabel, parent). On the other hand, service-providers speculated that reduced meltdowns may be because of the way that the AAD is trained to provide pressure to help relieve stress. For example:

We learn that we can just go to our dog and lay down and our dog will lay on our lap, or they'll put their head on our belly while we lay on the floor, or whatever it is. So the time of recovery is less, because the dog helps. (Olivia, occupational-therapist)

Importantly, parents explained that they had tried other measures—including some that were like what the AAD provided, such as pressure—to reduce 'meltdown' behaviours in their autistic child without success. For example, Kate said:

We've tried like weighted blankets and things that, but it hasn't really worked. But Dixie's [AAD] able to kind of just... relax her a lot more. So we don't kind of have as many, kind of... I mean she'll still have a meltdown. But it's not full-on screaming and yeah, she's definitely able to come out of it a lot quicker than she was with anything else. (Kate, parent)

Parents explained that the reduction of their autistic child's meltdowns had a direct influence on their own wellbeing via reduced stress. For instance, Georgia explained that, "a major benefit [to my stress levels] are the meltdowns... like Daphne [AAD] supporting me with them" (Georgia, parent). Olivia further explained that for many parents with an AAD:

Life's still hard, a lot of the time, but the amount of that stress reduction is quantifiable. There is a profound reduction in those periods of like, extreme distress and meltdowns for the kiddos, ya know. So yeah, which I mean, has a huge impact on parents, to not see and deal with your child in that state. (Olivia, occupational-therapist)

Reduced Absconding

The type of stress-reduction that AADs afford autistic children can also lead to less absconding, as Nina said: “Ned [autistic child] just doesn’t bolt like he used to before Dexter [AAD]. Like he just doesn’t do it at all anymore really. But it was a big problem for him, for us, before” (Nina, parent).

Parents also reported that their child’s reduced absconding behaviours lead to reductions in stress for themselves and their families. For example, Kate expressed that for her this means that “I don’t kind of, worry as much” (Kate, parent). Laura explained that these types of “calmer” feelings about reduced absconding extended to her older neurotypical teenage daughters:

My other daughters are calmer because they also felt anxious. They had a lot of anxiety going out, because they knew they might have to chase after him with me, which is often what would happen. I’d be like, “Girls run,” and we’d all just run.
(Laura, parent)

Service-providers mirrored parents’ views on reductions in absconding. Freya reflected that, for all family-members, the AAD reducing absconding “obviously reduces their stress levels, because they feel safe walking out in the community, because they know their child’s safe with dog attached. So they’re definitely more relaxed” (Freya, AAD-Trainer)

Reduced absconding is a representation that autistic children are less distressed in the company of their AAD—indicating an improvement in their wellbeing. Children absconding less has a direct impact on familial stress reduction, also leading to improved wellbeing.

Physical Safety Improvements

Building on the previous themes of ‘Less Stressed’—though distinguished by participants enough to be identified as a distinct theme—participants indicated that autistic

children were physically safer towards themselves because of their AAD, directly influencing their child's wellbeing, and that of their family. Service-providers explained that this was the "primary purpose" of AADs, and that AADs were trained to achieve this through "physically preventing absconding and preventing self-harming and harming against others, particularly during the kids' meltdowns" (Belinda, AAD-trainer). Freya explained that the AADs might achieve this because:

They [the AADs] help with safety...especially with absconding. We find we don't really have to tether the dogs to the kids, but we can also train them for that. We also teach them [the AADs] to paw at the children when they begin self-harming, like if they are biting or hitting themselves or whatever. (Freya, AAD-trainer)

Parents also reflected that their child self-harmed less since receiving their AAD. For instance, Christina explained, "Chloe [autistic child] will try to hurt herself because she'll say she wants to die. So there's the self-harming which is—which was—a problem. Now, since we've got Dora [AAD], it has helped a lot" (Christina, parent).

Many related this improvement in safety to the child having fewer and less-intense meltdowns, as explored above, because during their meltdowns before receiving an AAD, the autistic child could harm both themselves and family-members. Annabel explained:

He'd [autistic child] go about punching his own head and pulling his eyelashes out. So Diego [AAD] is stopping that behaviour. He gives that deep pressure therapy...Whereas because Diego's stopping Aaron [autistic child] from punching his own head, by giving him deep pressure therapy, Aaron is slowly calming down without needing to get that frustration out another way—on himself and us. (Annabel, parent)

Participants often tied an increase in physical safety as being associated with reduced absconding, as described in ‘Reduced Absconding.’ For example, Annabel described that her 10-year-old son would:

...go and hide. He wouldn’t answer his name... so we live on a busy road so if he ever ran out of the house, there’s that fear of where is he going to go? Is he going to get hit by a car? He doesn’t have any sense of danger or any sense of awareness. And it was definitely becoming worse as he got older ((pause)). (Annabel, parent)

Nina added, “we haven’t had to call the police to find Ned [autistic child] since we got Dexter [AAD], actually! It was always so dangerous because we live by the highway,” (Nina, parent), after describing that it was something her family continued to struggle with before the arrival of their AAD.

Improving safety before the child “gets bigger” was also a source of motivation for seeking out an AAD for many of the parents (particularly parents with sons), adding that they felt “relieved” by the AAD being around for this reason (Annabel, parent).

The improved physical safety of the autistic child and their family also meant that parents felt safer and more confident in leaving the house with their autistic child, with benefits for themselves and other children. Laura explained, for instance, that before receiving an AAD for her son:

We just couldn’t, we actually just stopped going out because we just couldn’t, it was too unsafe...and it had become a problem, in that we were always having to do things separately as a family. So either myself or my husband would take our older girls out so that they could not miss out on everything. But they did start missing out on quite a few things, because, because of Liam [autistic child]. And because of just us saying, “Sorry, we, we just can’t do it. It’s just not safe.” So that was a big one, it started to affect the whole family. (Laura, parent)

Parents and service-providers reported that physical safety is an important enhancer to wellbeing offered by AADs to many autistic children and their families. Parents felt able to leave their house because of their child's improved physical safety, and autistic children and their families had fewer physical injuries since AAD acquisition. These improvements facilitated leaving the house, as explored in the next theme.

Increased Socialisation and Community Involvement

As elucidated in the themes above, participants perceived benefits of AADs to wellbeing including improved physical safety and decreased stress when leaving the home. These led to enhanced socialisation and community involvement for the autistic child and their family. As Belinda remarked, "For these kids with autism, most of the time, that's what they need...they need to be able to get out into the community without having meltdowns, without absconding, or whatever. It's what their parents need too." (Belinda, AAD-trainer). Whilst this theme is inextricably linked with the themes of 'Less Stressed' and 'Physical Safety Improvements', improved socialisation and community involvement—for the autistic child and their family—was identified as a theme directly and separately influencing wellbeing.

To demonstrate this, parents often told stories from times 'before' they got their AAD for their autistic child. Participants recounted these stories with considerable depth and nuance, emphasising the profound differences between "before [AAD] moments and after [AAD] moments," (Annabel, parent), and to demonstrate that the AAD "made what was previously impossible, possible" (Maggie, parent). For instance, Rachel described a moment where she faced the "exact same situation" at a shopping-centre with her daughter, Ruby, where she had previously had a "huge, uncontrollable meltdown" and absconded before getting her AAD:

Ruby screamed for maybe—at most—a couple of minutes until she calmed down [with Daisy] and then she just got up and walked again and she was happy. I was just like, holy crap, did you see that? Wow ((high pitch voice))! Like she was having a meltdown, but the meltdown just managed to dissolve into puppy fluff I guess and...wow...it's just meant we can get out and about, you know? (Rachel, parent)

Ultimately, being less 'housebound' had a profound impact on the wellbeing of the entire family because they were no longer socially isolated.

Participants also reflected that having an AAD enabled families to spend time together in what they often described as a 'normal' way. Hayley reflected on how many families that she's worked with have expressed this, and how this a motivation for her work:

I think just social inclusion would be the biggest thing [in my work], like just actually being able to do family things, you know ((pause)). Just having a normal life! I hate the word normal, but it just gives them a normal life, they can go and do what they want. (Hayley, AAD-trainer)

Laura similarly reflected that she used to feel "jaded" because she "hate[d] all the 'normals' and all their normal lives and you know" (Laura, parent). Laura then explained that now she has an AAD in her life that, "all this negative energy in the community that I just used to feel going out, it just dissipated. And it actually became like a positive energy" (Laura, parent).

Flowing on from this, parents also reflected that they felt better and less judged in public since their child's "invisible disability" was suddenly "visible" (Annabel, parent), because the AAD signals that the autistic child has a disability to members of the public:

I've heard this come from parents, you know, "Now when I go out they understand why we're having trouble, or why we're taking a bit longer, or why we've had to leave in a hurry halfway through and not finish the shopping." Because the dog's by

their side—and it doesn't have to say autism assistance dog—it can just say assistance dog. And people give them more time, give them more room. (Hayley, AAD-trainer)

Parents echoed this sentiment during interviews, usually anecdotally. For instance, Georgia explained:

We went out for breakfast the other day, and Grace [autistic child] was under the table with Daphne [AAD]. Now if she was just under the table, people would have probably been staring a lot more than with her being under the table with an assistance dog. Does that make sense? So sometimes, it can make me a little bit more comfortable even, because I feel like people maybe understand a bit more, because they can see Daphne and see what's going on, rather than just sort of being judgmental. (Georgia, parent)

Finally, because of their AAD, families could engage in shared experiences to strengthen their cohesion. Emily, for example, expressed:

They can go and do things as a family. Not one parent stays home with a child who is autistic because they're unsafe, and the other parent takes the other sibling out. So I think it's the cohesiveness of them feeling more connected with their partner and connected to their other kids. (Emily, occupational-therapist)

This was a source of grief for many parents before receiving their AAD. Laura for instance, expressed that, “We could never do things together as a family...Diesel [AAD] just gave us the confidence to be able to leave the house with Liam [autistic child], together” (Laura, parent).

From the perspective of both groups, improved family cohesion was ultimately an enhancer of wellbeing for all family-members with an AAD and was typically described by participants as the result of increased shared-experiences.

Enhanced socialisation and community involvement was therefore identified as a theme which led to improved wellbeing for both autistic children and their families, as expressed by both groups, due to the mental-health benefits of being less-housebound, particularly for parents and neurotypical siblings, and the sudden visibility of the autistic child's disability.

Willingness to Get to and Engage in School and Therapy

Parents and service-providers—particularly occupational-therapists—remarked on autistic children being more willing to go to and engage in school and therapy since their AAD arrived.

For instance, Maggie spoke of her son 16-year-old son Matthew's improvement in attending school both with and without his AADs over the past five years:

Both dogs [first AAD deceased] went to school with Matthew three days a week. And they [the school] noticed a difference too. So they noticed that Matthew was a lot calmer. It was a great way to have the other kids interact with Matthew too...and then it eventually generalised to not having Darcy and Dash there. (Maggie, parent)

Annabel added how much easier it was to get her son into his school, and to stay at school during the day. She explained her family had a 'restrictive practices procedure' for her son, which allowed school-staff to restrict the "rights or freedom of movement" of her son when he escalated (Queensland Government, 2022). Annabel explained that this:

Is very frowned upon ((pause)), and we had to get approval from the school and the [Queensland] Education Department. Before Diego [AAD], we were using that plan [the restrictive practices procedure] at least once a week. But with now over one year with Diego, we've only used that plan three times. (Annabel, parent)

Allied health professionals also spoke at length about the importance of AADs in both keeping children at school and in therapeutic settings. Olivia said, for example, that "the dogs

are minimising that anxiety and distress, which is otherwise preventing participation in things like therapy, or, I guess, school” (Olivia, occupational-therapist). Jasmine further added that, “in different sessions if the dogs not there, it’s been really, really tricky. So the dog really breaks down that barrier for the child when they come in the room” (Jasmine, occupational-therapist). Imogen, added to this remark that:

They like the dog to be right next to them. And lots of them will put their hand down and still be holding, just patting the dog while they’re doing the activity, you know, just that calm reassurance of that I’ve got the dog next to me, just patting, while we’re doing something else...And then in terms of yeah, like the regulation and being calm in a session, just having like time with the dog and pat the dog has been like really, really calming and regulating for lots of the kids, where parents have said like without or before the dog, they maybe haven’t stayed as long, or are not as eager to be involved. (Imogen, occupational-therapist)

Parents also spoke of the AAD helping their child both attend and engage with therapy. For instance, Georgia remarked that:

Daphne [AAD] helped a lot with things like even actually just getting to therapy...

Grace [autistic child] would refuse to go to speech therapy in the past, you know, so, yes. Daphne helps. She wouldn’t have done it without her, you know? (Georgia, AAD-parent).

Georgia, like many other parents, also spoke of using the AAD as a “tool” or “drawcard you can use” for therapy by saying that their autistic child could “show [the AAD] to the therapist and, you know, we can show her the cool trick she can do...just to kind of get her there,” adding that, “I feel like Grace [autistic child] felt safer in the room, with Daphne [AAD] there” Georgia (parent). Georgia also explained that her autistic daughter “actually” engaged in therapy with her AAD’s presence:

She's [autistic child] participating in therapy. Instead of NDIS paying for all this therapy, and she's just sitting there not talking half the time or having a meltdown. You know what I mean? Like, the outcomes are better. They actually do stuff in the therapy. (Georgia, parent)

In line with this, parents indicated that AADs were also useful in the context of telehealth appointments. Several parents expressed that their child did not enjoy telehealth appointments because they don't like "looking at [themselves] on [their] screen", but that the AAD helped their children in these scenarios via their mere presence: "just having Dexter [AAD] around when he's in the telehealth helps," said Nina (Nina, parent).

In addition, service-providers said that AADs could help autistic children have enhanced therapeutic outcomes outside of the therapeutic setting, because, "the dog [AAD] goes with them, you know? Which is then different to a therapy-dog or any other animal you might have in therapy otherwise. And I think that helps the outcome," (Imogen, occupational-therapist). Emily added that the AADs also allow for transferring skills from therapy into real-world scenarios:

Regardless of how much speech therapy you might do, you know, this mum said that now her little boy was comfortable, if a stranger came over, he would be so proud to talk about the dog. You know, and had the dog not been there, he wouldn't have said boo to that person. And he wouldn't have had a back-and-forth conversation. (Emily, occupational-therapist)

An ability for autistic children to socialise in their community was therefore a positive influence of AADs on wellbeing, which extended to enhanced wellbeing for parents. For children, this ability extended to their ability to engage in school and therapy and facilitated improved therapeutic outcomes beyond therapeutic settings.

Enhanced Confidence and Self-Efficacy for Autistic Child and Parent

Parents with an autistic child reported that their child seemed more ‘confident’ since receiving their AAD, which they also felt increased their autistic child’s wellbeing. For instance, Georgia reflected that “some of the best benefits have been the confidence Daphne [AAD] has given Grace [autistic child]” (Georgia, parent), whilst Kate related this to her autistic daughter’s ability to get into the community, by saying, “I really kind of want her to have that confidence in kind of doing everything and I think Dixie [AAD] really kind of brings that out for her. Because I don’t want her being cooped up in four walls” (Kate, parent).

AAD-trainers explained that they train AADs to improve children’s pro-social behaviours, which likely has an influence of either *directly* making the child more confident in social settings, or making the child *appear* more confident in social settings. For example, Freya explained that they teach the AAD and the autistic child a concept called “Food-Eye”:

Where the dog lies down with a treat on each paw. And then we encourage the child to... we train the dog to look in the child’s eyes. And then as soon as they do that, that child indicates which treat they want the dog to have, that encourages eye contact which the children usually struggle with. (Freya, AAD-trainer).

Hayley mused that the social skill development—and the ensuing confidence and self-efficacy—of children in social settings, is linked to the public access rights of the dog.

I think the confidence comes from the social skill development of those children. Like, we actually want them to be out there doing stuff. But if the parents aren’t taking them out, because they’re worried what the public are gonna think, because they’re worried they’re gonna have a meltdown, then that kid’s not getting that, oh, we go to the supermarket, we get the food, we go through the checkout line, all that stuff that other kids are just organically observationally learning ((pause)). And all

that happens with the dogs because of their access rights. So even though they [the autistic children] can't express to us what they're thinking, they're actually seeing it and learning it again. They understand those procedures. You know, and so "when we come here, we do this." It makes them more comfortable and confident; you know? (Hayley, AAD-trainer).

Service-providers expressed that increased parenting-confidence and parental-self-efficacy often occurs with an AAD. Olivia, for instance, remarked that:

Parents do seem to feel more competent, and more generally calm and in control [after the AAD comes into their lives]. So, the success of different parts of the day goes up. So yeah, it makes sense that parents' feelings of self-efficacy go up too. (Olivia, occupational-therapist).

Emily added:

Parents really feel like they can suddenly manage what for most families would be a regular thing with the assistance dog. So they'll say, like, I can actually do a normal mum thing with my kid on my side. So I think the satisfaction in being able to do normal things greatly improves with the support of the dog" (Emily, occupational-therapist).

Parents generally spoke less on this topic, and when they did, they were divided in their opinions (reasons of which will be elucidated within the Discussion). For instance, some parents also reported that they themselves feel "more confident in parenting" their autistic child since receiving their AAD, thereby increasing their own wellbeing (Kate, parent).

Parents often reported that feeling more confident in their parenting was directly associated with having greater parental-self-efficacy: being able to do what they are setting out to achieve, such as calming their autistic child. For instance, Annabel expressed that her and her

husband “are more confident in our abilities to help him [autistic child] to calm down” (Annabel, parent).

On the other hand, some parents reported that getting an AAD for their autistic child had *not* impacted their parenting-confidence or parental-self-efficacy. For instance, Rachel explained that, “we’ve got a clear idea of how we want to parent and how children should be raised. And I don’t think a dog is gonna change that,” (Rachel, parent).

Autistic children and their parents—notably, not siblings—were therefore often found to have improved confidence and self-efficacy associated with their AAD entering their lives. It was identified that this was also a source of improved wellbeing for autistic children and their families from the AAD.

Discussion

As illuminated at the beginning of this thesis, AADs can enhance wellbeing for autistic children, through acting as the “light in the darkness and sound in the silence” to cross from their “own world to a shared world” (Williams, D., 2006, as cited in Gross, 2006, p. 3). Furthermore, the findings of this thesis show that these benefits extend to family members. This is consistent with existing literature, where parents have described their experiences of having an AAD for a child in an overwhelmingly positive way (e.g., Burrows et al., 2008). It is also consistent with emerging literature that AADs are also positive for entire family units (e.g., Leung & Dickson, 2022). Whilst it became evident that benefits to wellbeing in autistic children from AADs extended to their families, it was also identified that benefits to wellbeing in the family contributed to the wellbeing of the autistic child. In other words, the relationship between these two phenomena were symbiotic, in line with findings from Tint and Weiss’ scoping review (2016).

Both the biopsychosocial model and socio-ecological model, as elucidated in the introduction of this thesis, can go some way in explaining the findings. In particular, Engel’s

biopsychosocial model (1977) has been demonstrated to be the most effective model for measuring the influence of canines upon wellbeing in humans, beyond those found in theories surrounding the human-animal bond (Gee et al., 2021). Additionally, the symbiosis between the autistic child and their family's wellbeing maps on to Bronfenbrenner's socio-ecological model (1979). The influence of AADs on family-wellbeing—including the wellbeing of the autistic child—will thus be explored through these prisms.

Influence of AADs on Individual and Family Wellbeing

Findings of this thesis suggest that AADs can influence autistic children and their families at an individual and family level in biological, psychological, and social ways (Engel, 1980).

First, AADs can improve wellbeing via reducing stress levels in autistic children and their family-members. This is in line with Bibbo et al. (2019), Smyth and Slevin's (2010) and Viau et al.'s (2010) studies on this topic. Findings in this study further identified that decreased stress is associated with reduced meltdown and absconding behaviours in autistic children. This is also supported by existing literature on AADs reducing these behaviours (e.g., Berry et al., 2013). Parents also reported less stress in themselves, largely because of improvements in their autistic child's wellbeing and behaviour, something also established in existing literature (Burrows et al., 2008). Additionally, the notion of parental stress reducing as an extension of their autistic child's stress reduction has been empirically demonstrated (Valicenti-McDermott et al., 2015). Also, parental stress exacerbating their autistic child's stress has also been empirically demonstrated (Hayes & Watson, 2012). Uniquely, however, this thesis found that sibling stress also decreased with an AADs' presence. Notwithstanding this, the stress of individuals with an autistic sibling has been established as being typically higher than those with neurotypical siblings (Athbah, 2021). The impact of this reduced stress not only influences each family-member individually, but the family-unit. This was

demonstrated by parents who reported that they were able to engage with their family-members beyond the autistic child more due to their 'calmer' homes. This aligns with existing literature on decreased stress leading to improved family-unit wellbeing in families with an autistic child (Giallo et al., 2013).

Decreased stress levels may have simply been associated with the AADs providing decreased loneliness, without reacting in the way that humans do to surprising or unnerving situations. Existing literature suggests that these effects can be found in pet dogs (e.g., Powell et al., 2019). However, findings of this thesis suggest that AADs are potentially able to reduce stress in family-members in ways beyond the capabilities of pets. For example, Imogen (occupational-therapist) reported that, "the relationship hasn't been there with other pets we find...I think because they're trained very differently." This is also empirically supported in studies which compare the positive effects of assistance-dogs (for all disabilities) beyond pets (Mengoli et al., 2021).

Individual and family level benefits were also seen in relation to improvements in physical safety, which can also be seen as an extension of the autistic child being less stressed; these improvements also resulted in individual family-members being less stressed. Improved physical safety has been empirically supported in studies on AADs for autistic children and their family-members (Burgoyne et al., 2014). These influences on wellbeing from the AAD extended to the family-unit beyond individual family-members, as they felt 'safer' to engage in shared family activities. The ability to engage in shared family activities in a physically safe way also aligned with findings of enhanced socialisation and community involvement. These findings mirror the recent findings of Appleby et al. (2022).

Improved sleep was also an important finding in this thesis at the individual level, not only for the autistic child, but for their family-members. AADs leading to improved sleep has been consistently found in studies on AADs (e.g., Burrows et al., 2008). Literature on other

form of AAI suggest that AADs are particularly good at achieving this for their paired autistic child (O’Haire, 2012). This is potentially impacted by the AAD-trainers’ role of integrating the AAD into the family, including training the AAD to sleep next to the child. This is unlike other forms of AAI, where the animal either cannot or would not sleep next to the autistic child all night (O’Haire, 2012). The impact of improved sleep is also potentially associated with improved wellbeing for family-members, including the autistic child—a phenomenon which has been widely empirically explored (specifically through families living with autism in Martin et al., 2020). In particular, for parents this included being able to regain “intimacy,” as Hayley (AAD-Trainer) put it, without the autistic child present.

AADs were also found to enhance the wellbeing of the autistic child themselves by improving their engagement with school and therapy. These findings are supported by existing literature, which have found that AADs support outcomes with school (Harris & Sholtis, 2016). However, the notion of children being more engaged in therapy with their AAD is a unique finding of this thesis. It is supported by general AAI literature, however, which has found that autistic children engage in therapy more with a therapy-dog more generally present (Hill et al., 2020).

Enhanced self-efficacy for the autistic child and their parents are also important findings from this thesis which demonstrate ways that AADs can influence wellbeing. Autistic children having increased functioning because of their AAD has been widely established (Berry et al., 2013). For parents that reported that the AAD had enhanced their own confidence, this tended to be associated with the parent being neurodivergent themselves; the autistic-child having co-morbidities; and single-parenting. Existing literature has demonstrated that parents can also have enhanced self-efficacy and self-confidence from the AAD (Leung & Dickson, 2022), however no studies have distinguished those who may experience this.

Influence of AADs on Social, Cultural and Community Wellbeing

In terms community benefits, results of this thesis suggest that AADs can enhance wellbeing via a child's reduced meltdowns and absconding. These findings extend to the AAD's ability to enhance the child and their family's wellbeing in community settings, because they can engage more easily and safely with their community. This echoes existing findings on AADs (e.g., Appleby et al., 2022; Berry et al., 2013). This ability for enhanced community engagement extends to improved family-cohesion, because they can have shared experiences together. This is reflected in existing literature on this topic, including Appleby et al. (2022).

This thesis also found that AADs can enhance wellbeing from a social and cultural perspective. Because of the AADs presence, the autistic child's 'invisible disability' became 'visible.' This meant that the autistic child and their family were treated with a greater level of consideration when the autistic child was behaving in a way that was surprising to onlookers—such as Georgia's example of her daughter sitting under a restaurant table. This extends existing literature suggesting that AADs can lead to the public acting more respectfully towards families with autistic children (Burgoyne et al., 2014). The notion of assistance dogs bringing attention to individual's 'invisible disabilities' broadly, however, have been associated with detriments for the individual living with a disability themselves (Mills, 2017), and thus this aspect of AADs requires more research particularly with autistic children and adults themselves.

The ability for the AAD to increase the confidence of the autistic child in public-settings was also a community level benefit found in this research. Because autistic children are increasingly able to leave their house due to their AAD, their ability to observationally learn social-norms increases. This can eventually lead to the autistic child feeling more included within the society of which they are a part. The notion of autistic children having a

greater ability to learn social-norms observationally alongside their AAD was a unique finding of this thesis, however it is implied within existing literature, which speaks of autistic children having greater abilities to engage within their communities because of AADs (Appleby et al., 2022).

The Biopsychosocial Model: Explaining the ‘Life-Changing’ Influence of AADs

Overall, and as seen in the first theme of this thesis, participants described AADs as ‘life-changing’. This is echoed in the multi-level benefits found in the other themes of this thesis, as described in the previous two sections. As such, the fact that AADs lead to benefits across individual, family, social, cultural and community levels (Bronfenbrenner, 1979; Engel, 1980), which goes some way to explaining this ‘life-changing’ effect. The notion of AADs having broad-reaching benefits that extend to other family-members was found in the qualitative studies of Burrows et al., (2008), Smyth and Slevin (2010) and Bibbo et al., (2019). Additionally, it is important to note that the themes and sub-themes identified for this thesis were largely all inter-connected. As just one example, it is possible that the impact of increased sleep led to decreased stress for family-members, as found in Valicenti-McDermott et al. (2015). On the other hand, it is possible that decreased stress in family-members facilitated increased sleep, as found in Martin et al. (2020). A study which can finely distinguish between these factors would be valuable, particularly in determining specific pathways through which AADs might be improving wellbeing for autistic children and their families.

Implications

Theoretical Contributions

The findings of this thesis provide further theoretical support for the beneficial impacts of AADs upon autistic children and their families. Contributing to this growing body of literature is important, particularly considering increasing autism rates (ABS, 2019a).

Furthermore, it adds to the mounting body of literature on novel interventions for autism. Finally, in line with the findings of Gee et al. (2021), this thesis provides theoretical support to continued use of the biopsychosocial model when considering the impact of human-canine relationships.

The impact of the AAD on any members of the family could potentially be viewed through the lens of the human-animal bond, and its well-established relationship with wellbeing, especially through the era of Covid-19 (Wells et al., 2022). However, this thesis suggests that the human-animal bond does not completely explain the benefits provided by AADs identified in this study. For example, participants indicated that they had not found similar improvements through pets, and many of the improvements to wellbeing found rely upon the training provided to AADs. For example, and as supported by long-standing existing literature, assistance dogs have a general ‘calming’ effect on people that they are around, which can go above and beyond the effect of companion dogs, which can be less predictable (Hart et al., 1987). Potentially the reason for this is that there are benefits associated with having a specifically-trained AAD with public-access rights. Or, perhaps it is something additional, such as reduced arousal and emotions in parents leading to accordingly-adjusted responses from autistic children. Understanding specific pathways through which AADs could improve wellbeing would therefore be valuable. For example, future research might consider family systems theory, which looks at the interconnected relationships within family units (Kerr & Bowen, 1988).

Practical Contributions

From a practical perspective, this research has helpful implications. It is important for service-providers, such as psychologists, to be cognisant of how any AAI may help autistic people (Black et al., 2011)—particularly the advantages of AADs. For instance, clinicians with a systemic approach (e.g., social workers or family therapists) can be aware of how

AADs might impact broader family wellbeing. Clinicians that work to enhance children's social skills (e.g., speech pathologists, schoolteachers, support-workers) could also consider how AADs may help the children that they work with. Occupational therapists, who are often tasked with enhancing autistic children's safety and socialisation, could also consider how AADs might help their clients achieve these goals beyond their sessions together. And finally, mental health clinicians who work with autistic children and their families may also consider the impact of AADs on the broader wellbeing of this demographic.

Practically, this research can also help inform policymakers. Rogge and Janssen's (2019) literature review on the economic cost of autism in Western countries found that most costs revolve around medical, therapeutic, education, accommodation and respite-care, and the cost of production-loss for the autistic person and their carer(s). In Australia, in 2014, this cost the Australian Government an estimated \$7.2 billion (Horlin et al., 2014). It is expected, given inflation and rising rates of autism (ABS, 2019a), that this number has grown significantly since this time. Given this expense—and the ultimate desire to provide effective, evidence-based interventions for autistic individuals and their families—the importance for research on this subject matter from a practical perspective becomes clear. This is particularly the case, given that AADs are presently not funded by Australia's National Disability Insurance Scheme—something which many participants spoke about as a challenge, and which has been documented in the Australian press (Cooper, 2021).

Limitations and Future Research

A key gap in this literature, and direction for future research, is to include the voices autistic children themselves, as well as siblings of autistic children. Incorporating these would help lead to Tracy's (2010) concept of 'crystallisation,'. Of value would be how autistic children themselves feel about their AADs, given no study has yet explored this. Research by Courchesne et al. (2022) has sought to explore how to engage the voice of

autistic youth in qualitative research—an approach which could be applied to their experiences with AADs. This is important, because the parents themselves in this research were not autistic, and thus this research runs the risk of being ‘capabilitarian,’ as elaborated by Robeyns (2016).

Moreover, incorporating children (or family-members of children) who also have a diagnosis of level-one or two autism may also provide interesting further data, especially considering studies which have found that lower support needs are associated with higher wellbeing (Mayes et al., 2011). This thesis limited its engagement to level-three children as a form of consistency between participants, and due to their increased support needs, however this limited representation means that these perspectives are not represented in this research.

A further limitation of this thesis—not through design, but by chance—was that all participants were female. Fathers and male service-providers may have provided different insights above and beyond their female counterparts (Runnels et al., 2014), and would be valuable to actively recruit in further research. Likewise, incorporating service-providers beyond AAD-Trainers and occupational-therapists in future research would be valuable.

Another important limitation of this thesis—and of any canine-AAI for children with autism—is related to cultural considerations. Whilst there was cultural diversity within this sample, cultures which hold dogs in different regard were not explicitly considered. A limitation of this thesis’ design was that participants were not asked about their religion or culture, only about their country-of-birth and language. However, specifically, dogs in Islamic and Rabbinic-Jewish religious-cultures are regarded as impure and should therefore not be kept inside (Fortuny, 2014). An interesting area of potential research, which has not yet been explored, would be investigating the impact of AADs (or canine-AAI in general) on autistic children from these religious-cultural backgrounds—and any families who simply do not ‘like’ dogs.

Finally, an area for future research includes including a focus on wellbeing for AADs themselves. Participants across groups expressed that this mattered to them. This is supported by recent Australian research findings that assistance dogs are generally ‘happier’ than pet dogs (Gibson & Oliva, 2022). Future research which considers this area – and relationships to human wellbeing – is important.

Conclusion

This thesis contributes to mounting literature on AAI for autism generally. Moreover, this thesis is an important supplement to research on the impact of AADs, specifically within the domain of their effect on wellbeing for autistic children and their families. Themes from this thesis suggest that AADs might enhance the wellbeing of both autistic children and their families in a symbiotic way through improved sleep quality, decreased stress, augmented safety, easier and safer access to the community, and enhanced confidence and self-efficacy (of autistic children and sometimes parents). The overall impact of this enhancement to wellbeing for autistic children and their families can be ‘life-changing’—as all parents in this thesis reported. Accordingly, this thesis has provided a foundation for future research, including exploring these findings through further triangulation with autistic children themselves. Ongoing research on the efficacy of AADs could carry potentially-important practical implications—particularly through acknowledging this thesis’ evidence that AADs are beneficial to wellbeing for the autistic child that they are paired with, as well as their family-members.

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Appendix A: Research Flyer for Parents

ETHICS APPROVAL: H-2022-066



Researchers from the University of Adelaide are conducting a study called:

The Influence of Autism Assistance and Therapy Dogs on Wellbeing for Children living with Level 3 Autism Spectrum Disorder and their Families



We would like to interview you if you:

- Are the parent or caregiver of a child who has (at some point) been diagnosed with Level 3 Autism Spectrum Disorder (i.e., high support needs); and
- Have had a trained Autism support dog (i.e. an 'Autism Service Dog' or an 'Autism Assistance Dog') for this child, living with you for more than six months; and
- Are over the age of 18; and
- Can speak conversational English

We will ask you about your understandings of the way that your dog has influenced your child's and your family's emotional and social wellbeing.

Interviews will take approximately 1 hour. Interviews will be conducted at a time and place convenient for you (including online).

A \$40 Coles-Myer Group voucher will be provided for your time.

If you would like further information or take part in the project, please

Appendix B: Research Flyer for Service-Providers

ETHICS APPROVAL: H-2022-066



Researchers from the University of Adelaide are conducting a study called:

***The Influence of Autism Assistance and Therapy Dogs
on Wellbeing for Children living with Level 3 Autism
Spectrum Disorder and their Families***



We would like to interview you if you:

- Are a trainer of Autism Service/Assistance Dogs or Therapy Dogs; **or**
- Are a service provider (e.g. teacher, occupational therapist, speech pathologist, psychologist, etc.) who works with children with Autism (who may or may not have access to an Autism Service or Assistance Dog); and
- Have worked in **any** of these roles for at least two years

We will ask you about your understandings of the way that Autism Service/Assistance Dogs have influenced the emotional and social wellbeing of the children with ASD that you have worked with, as well as their families.

Interviews will take approximately 1 hour. Interviews will be conducted at a time and place convenient for you (including online).

If you would like further information or take part in the project, please

Appendix C: Information Sheet for Parents

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: The Impact of Autism Assistance and Therapy Dogs for Wellbeing for Children with Level 3 (Severe) Autism Spectrum Disorder and their Families

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER:

[Academic Supervisor and Student Researcher]

STUDENT'S DEGREE: Psychology Honours

You are invited to participate in the research project explained below.

What is the project about?

This project focuses on the impact of dogs specifically trained to work with children on the Autism Spectrum. In particular, we are interested on the way that these dogs—Autism Assistance or Therapy Dogs—impact the social and emotional (“psychosocial”) wellbeing of children with severe (Level 3) Autism Spectrum Disorder and their families. We are interested in asking you about the way that your child’s Autism Assistance or Therapy dog has influenced your child, and your family, in this way.

Who is undertaking the project?

The researchers, [REDACTED]

[REDACTED] this project composes a large component of the research area for the degree of Psychology of Honours at the University of Adelaide.

Who is being invited to participate?

You are being invited to participate if you:

- Are the parent or guardian of a child who is, or has had, Severe (low- or non-verbal) Autism Spectrum Disorder; and
- Have had a trained Autism dog (i.e. a ‘Therapy Dog’ or an ‘Autism Assistance Dog’) for this child, living with you for more than six months; and
- Are over the age of 18; and
- Can speak conversational English

What will I be asked to do?

You will be asked to take part in an interview lasting about one hour. The interview can be done face to face, over the phone or via zoom—it is up to you. If you decide on a face to face interview, we can organise a convenient location for you, or we could do the interview in an office at the University of Adelaide. Participation is voluntary and you do not have to answer questions if you choose not to.

Are there any risks associated with participating in this project?

The project is unlikely to present any risks to you apart from the time to do an interview. There is a possibility that discussing your experiences of raising a child with severe Autism Spectrum Disorder may be upsetting. If that is the case we can follow up with you to ensure

that you are okay, and there are a range of other support organisations that we can facilitate your contact with.

What are the benefits of the research project?

We hope that the project will improve understandings of the impact of Autism Assistance Dogs (who have public access rights) upon children with severe Autism, which could potentially lead to improved access to these types of dogs for more people with severe Autism Spectrum Disorder.

You can also receive a \$40 voucher as a thank you for your time.

Can I withdraw from the project?

It is completely up to you if you would like to be a part of this project. If you would like to participate, you can still withdraw from the project at any time. We can remove your data if you choose up until the due date of this thesis (September 2022).

What will happen to my information?

Your interview will be audio recorded and we will transcribe this into a written interview. You will have an opportunity to review this transcript.

We will make sure we do not disclose your name or any other identifying information in the written interview or any publications. Only the researchers will be able to access the data from this project. This data will be kept for 7 years on a password protected computer then erased. We can send you a copy of the results of the project if you would like. The final results might be included in a journal.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2022-35664). If you have any questions or concerns in regard to your participation in the project or would like to voice a concern or complaint, please contact the Principal Investigator. Contact the Human Research Ethics Committee's Secretariat on phone +61 8 8313 6028 or email to hrec@adelaide.edu.au if you would like to discuss any concerns or complaints, or enquire about the University's policy on research with human participants or your rights as a participant. Any concern or complaint will be confidential and investigated completely. You will be informed of the result.

If I have questions or want to participate, what do I do?

If you are interested in participating, please contact **[Academic Supervisor and Student Researcher]** to ask questions or arrange a time for an interview.

Yours sincerely,

[Academic Supervisor and Student Researcher]

Appendix D: Information Sheet for Service Providers

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: The Impact of Autism Assistance and Therapy Dogs for Wellbeing for Children with Level 3 (Severe) Autism Spectrum Disorder and their Families

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER:

[Academic Supervisor and Student Researcher]

STUDENT'S DEGREE: Psychology Honours

You are invited to participate in the research project explained below.

What is the project about?

This project focuses on the impact of dogs specifically trained to work with children on the Autism Spectrum. In particular, we are interested on the way that these dogs—Autism Assistance or Therapy Dogs—impact the social and emotional (“psychosocial”) wellbeing of children with severe (Level 3) Autism Spectrum Disorder. We are interested in asking you about your understandings of the way these dogs influence the children and families that you work with, from an emotional, social and environmental standpoint.

Who is undertaking the project?

The researchers

[REDACTED], this project composes a large component of the research area for the degree of Psychology of Honours at the University of Adelaide.

Who is being invited to participate?

You are being invited to participate if you:

Are a trainer of Autism Therapy or Assistance Dogs; **or**

Are a service provider (e.g. teacher, occupational therapist, speech pathologist, psychologist, etc.) who works with children with Autism (who may or may not have access to an Autism Therapy or Assistance Dog); and

Have worked in **any** of these roles for at least two years; and

Are over the age of 18; and

Can speak conversational English

What will I be asked to do?

You will be asked to take part in an interview lasting about one hour. The interview can be done face to face, over the phone or via zoom – it is up to you. If you decide on a face to face interview, we can organise a convenient location for you, or we could do the interview in an office at the University of Adelaide. Participation is voluntary and you do not have to answer questions if you choose not to.

Are there any risks associated with participating in this project?

The project is unlikely to present any risks to you apart from the time to do an interview.

There is a possibility that discussing your experiences of working with children and families

impacted by severe Autism Spectrum Disorder may be upsetting. If that is the case we can follow up with you to ensure that you are okay, and there are a range of other support organisations that we can facilitate your contact with.

What are the benefits of the research project?

We hope that the project will improve understandings of the impact of Autism Assistance Dogs (who have public access rights) upon children with severe Autism, which could potentially lead to improved access to these types of dogs for more people with severe Autism Spectrum Disorder.

Can I withdraw from the project?

It is completely up to you if you would like to be a part of this project. If you would like to participate, you can still withdraw from the project at any time. We can remove your data if you choose up until the due date of this thesis (September 2022).

What will happen to my information?

Your interview will be audio recorded and we will transcribe this into a written interview. You will have an opportunity to review this transcript.

We will make sure we do not disclose your name or any other identifying information in the written interview or any publications. Only the researchers will be able to access the data from this project. This data will be kept for 7 years on a password protected computer then erased. We can send you a copy of the results of the project if you would like. The final results might be included in a journal.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2022-35664). If you have any questions or concerns in regard to your participation in the project or would like to voice a concern or complaint, please contact the Principal Investigator. Contact the Human Research Ethics Committee's Secretariat on phone +61 8 8313 6028 or email to hrec@adelaide.edu.au if you would like to discuss any concerns or complaints, or enquire about the University's policy on research with human participants or your rights as a participant. Any concern or complaint will be confidential and investigated completely. You will be informed of the result.

If I have questions or want to participate, what do I do?

If you are interested in participating, please contact **[Academic Supervisor and Student Researcher]** to ask questions or arrange a time for an interview.

Yours sincerely,

[Academic Supervisor and Student Researcher]

Appendix E: Semi-Structured Interview Questions for Parents

Main Prompts

Demographic questions (age, education, occupation, language, citizenship)

Tell me about your family structure.

Prompts: Children, support-networks, grandparents, schedules, dogs and other pets

Tell me about your relationship with the child with autism (i.e. are you their parent?)?

Tell me about the experience of having a dog for your child with autism.

Prompts: What sort of training has your dog had? What breed and size is it? Do they have public service access, like being able to go into schools, restaurants and on public transport? How long have you had the dog for?

Follow-Up Questions

Do you think having your dog has impacted your family functioning?

If so, in what ways? If not, why not?

Prompts for different types of family functioning (e.g., sibling relationships, parent-child relationships)

Prompts for demographic characteristics (e.g. age of child)

Do you think having your dog has affected your child(ren)'s functioning?

If so, in what ways? If not, why not?

Prompts for different types of social, emotional, behavioural, academic functioning

Prompts for demographic characteristics (e.g. age of child/ren)

Have you noticed any positive effects on your child/ren with Autism since the arrival of the dog?

Prompts for other children?

Have you noticed any negative effects on your child/ren with Autism since the arrival of the dog?

What are the benefits, if any, of having the dog?

What are the challenges, if any, of having the dog?

Describe the relationship between your child and the dog?

Are there any more supports you need to manage your dog?

Prompts for child relationship with dog?

Appendix F: Semi-Structured Interview Questions for Service-Providers

Main Prompt

Tell me about the kind of work that you do that involves working with Autistic Children who have access to Autism Therapy or Assistance Dogs

Prompts:

- What is your role?
- How many years have you been in the role and have you had other related roles?
- How many families would you estimate that you've had contact with that have had a child with Level 3 Severe Autism?
- How many of these children would you estimate have other comorbidities/what are they?
- How many of these children tend to come with a dog?
- How many dogs would you estimate are Autism Assistance Dogs, in comparison to Therapy Dogs and regular pet dogs?

Follow-Up Questions

- 1) Do you think AAT dogs impact your clients' family functioning?
 - a. If so, in what ways? If not, why not?
 - b. Prompts for different types of family functioning (e.g., sibling relationships, parent-child relationships)
 - c. Prompts for different types of dogs (Autism Assistance v therapy)
 - d. Prompts for demographic characteristics (e.g. age of child)
- 2) Do you think AAT dogs impact the Autistic child's functioning?
 - a. If so, in what ways? If not, why not?
 - b. Prompts for different types of social, emotional, behavioural, academic functioning
 - c. Prompts for different types of dogs (Autism Assistance v therapy)
 - d. Prompts for demographic characteristics (e.g. age of child)
- 3) Where you have known families and children before they had a dog, have you noticed any positive effects on children since the arrival of the dog?
 - a. Prompts for different types of dogs (Autism Assistance v therapy)
- 4) Where you have known families and children before they had a dog, have you noticed any negative effects on children since the arrival of the dog?
 - a. Prompts for different types of dogs (Autism Assistance v therapy)
- 5) Have families with Autism Therapy or Autism Assistance Dogs discussed benefits or challenges of having a dog with you?
 - a. If so, what are these?
 - b. Prompts for different types of dogs (Autism Assistance v therapy)
- 6) Can you tell me about the relationship between the child and the dog? What has this typically looked like to you?

Appendix G: Protocol for Supporting Research Participants

Providing Support to Participants at Interviews

It is possible that participants in the study may seek advice or support from researchers. Participants may also become upset at the time of an interview. In such a case, we will:

- Ensure that the participant is clear about the role of the researcher and that as a researcher, we are unable to provide direct advice but may provide some information about services or assist in finding further information or avenues for support.

If a participant becomes upset or seeks information, support or referral, the researcher will:

- Acknowledge the participant's concerns and/or distress
- Give them an opportunity to talk about what is upsetting them, and listen supportively and empathetically
- Remind the participant that they can stop participating at any time
- Ask the participant if they have support, how it is going and, if appropriate, talk about other ways they might get support – for example from family or friends
- Talk about how services might be able to support the participant and what services are available
- Refer to the support organisation sheet provided to all participants (e.g., a separate document provided to participants which lists available services such as Lifeline) and:
 - encourage the participant to seek further support if desired, and leave this information with participant
 - refer participants (with consent) to organisations that are available and with whom the research team have working relationships
 - encourage participants to contact their preferred primary care provider
- Emphasise that personal details will not be disclosed to anyone and will only be used by researchers to make contact again (e.g., to pass on information regarding services or to follow up, as appropriate, to see if they have been able to access a service) if necessary
- In cases of significant distress the student will speak with their supervisor about the participant's situation/problem – always seek the participant's permission to do so first
- At the earliest opportunity, the researcher will record details of concerns, course of action/exactly what happened and what support was offered and/or taken up. Record using participant ID stored separately from the participant's contact details.
- Ensure the researcher's supervisor and HREC are informed about this.