Lived experiences of assistance dogs for people with autism and their families: A systematic review and meta-aggregation of qualitative studies

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## Contents

[Lived experiences of assistance dogs for people with autism and their families: A systematic review and meta-aggregation of qualitative studies 1](#_Toc151539407)

[Contents i](#_Toc151539408)

[Disclaimer iv](#_Toc151539409)

[Acknowledgements iv](#_Toc151539410)

[Suggested citation iv](#_Toc151539411)

[Abbreviations v](#_Toc151539412)

[Glossary vi](#_Toc151539413)

[Executive summary 1](#_Toc151539414)

[1. Background and NDIS context 3](#_Toc151539415)

[2. What did we do? 4](#_Toc151539416)

[2.1 Objective 4](#_Toc151539417)

[How did we do it? 4](#_Toc151539418)

[3. What did we find? 6](#_Toc151539419)

[3.1 Summary of study participants 6](#_Toc151539420)

[3.2 Characteristics of studies 6](#_Toc151539421)

[Table 1: Characteristics of included studies 7](#_Toc151539422)

[3.3 Overview of results 10](#_Toc151539423)

[Meta-synthesis 1: Perceived benefits to the child and their family 10](#_Toc151539424)

[Synthesised finding 1: 10](#_Toc151539425)

[Meta-synthesis 2: Practical considerations of owning an assistance dog 11](#_Toc151539426)

[Synthesised finding 2: Parents described a range of challenges and practical considerations they were unprepared for. 11](#_Toc151539427)

[Meta-synthesis 3: Educating the community 11](#_Toc151539428)

[Synthesised finding 3: Taking the dog out in public can be a means to educate the broader community about autism and assistance dogs. 11](#_Toc151539429)

[3.4 Quality of the available evidence 12](#_Toc151539430)

[Table 2: Quality appraisal of included studies 13](#_Toc151539431)

[4. Discussion 15](#_Toc151539432)

[4.1 NDIS perspective 16](#_Toc151539433)

[Efficacy vs other autism supports. 16](#_Toc151539434)

[4.2 Limitations of this report 17](#_Toc151539435)

[4.3 Directions for future work 18](#_Toc151539436)

[References 19](#_Toc151539437)

[Appendix A. Detailed study methodology 21](#_Toc151539438)

[A1. Study objective 21](#_Toc151539439)

[A2. Electronic search strategy 21](#_Toc151539440)

[Table A1: Search Strategy 22](#_Toc151539441)

[A3. Study selection and eligibility criteria 22](#_Toc151539442)

[A3.1. Types of studies 22](#_Toc151539443)

[A3.2. Types of participants 23](#_Toc151539444)

[A3.3. Types of interventions/phenomena of interest 23](#_Toc151539445)

[A3.4. Types of studies 23](#_Toc151539446)

[A4. Data extraction 23](#_Toc151539447)

[A5. Study quality 24](#_Toc151539448)

[A6. Data analysis 24](#_Toc151539449)

[Appendix B. Detailed results 25](#_Toc151539450)

[B1. Study selection 25](#_Toc151539451)

[Table B1a: Identification of studies via databases and registries 26](#_Toc151539452)

[Table B1b: Identification of studies via other methods 26](#_Toc151539453)

[B2. Characteristics of studies 27](#_Toc151539454)

[B2.1. Summary of included studies 27](#_Toc151539455)

[B3. Study quality 30](#_Toc151539456)

[Table B1: Quality appraisal of included studies 31](#_Toc151539457)

[B4. Findings of the review 33](#_Toc151539458)

[B4.1. Meta-synthesis 1: Perceived benefits to the child with ASD and their family 34](#_Toc151539459)

[Synthesised finding 1: Parents perceive there to be a broad range of potential benefits of assistance dogs to children with autism, and their families. 34](#_Toc151539460)

[B4.2. Meta-synthesis 2: Practical considerations of owning an assistance dog 35](#_Toc151539461)

[Synthesised finding 2: Parents described a range of challenges and practical considerations they were unprepared for. There is a need for families to be provided with education about the practicalities of owning an assistance dog and an appropriate level of training to ensure the dogs are being adequately cared for. 35](#_Toc151539462)

[B4.3. Meta-synthesis 3: Educating the community 35](#_Toc151539463)

[Synthesised finding 3: Taking the dog out in public can be a means to educate the broader community about autism and assistance dogs. However, the reactions from the community are varied. 35](#_Toc151539464)

[Table B2: Results of the first meta-aggregation of qualitative research findings 36](#_Toc151539465)

[Table B3: Results of the second meta-aggregation of qualitative research findings 38](#_Toc151539466)

[Table B4: Results of the third meta-aggregation of qualitative research findings 39](#_Toc151539467)

[Table B5: Qualitative findings and exemplary supportive quotes 40](#_Toc151539468)

## 

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Views and recommendations of third parties in this report, do not necessarily reflect the views of the NDIA, or indicate a commitment to a particular course of action. However, this report may inform the implementation policies in the National Disability Insurance Scheme (NDIS).

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The NDIA acknowledges the Traditional Owners and Custodians throughout Australia and their continuing connection to the many lands, seas, and communities. The NDIA pays respect to Elders past and present and extends that respect to any Aboriginal and Torres Strait Islander people who may be reading this Report.

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## Abbreviations

AD Assistance Dog

C Credible

DD Developmental Delay

JBI Joanna Briggs Institute

NDIA National Disability Insurance Agency

NDIS National Disability Insurance Scheme

NS Not Supported

PRISMA Preferred Reporting Items for Systematic reviews and Meta-Analyses

RCT Randomised Controlled Trial

SD Standard Deviation

U Unequivocal

USA United States of America

## Glossary

| Term | Definition |
| --- | --- |
| Adaptive functioning | Adaptive functioning refers to an individual’s ability to effectively and appropriately navigate and interact with their environment. It encompasses a range of skills, behaviours, and capacities that allow a person to meet the demands of everyday life and to adapt to the challenges and expectations of their social, cultural, and personal context. |
| Animal-assisted interventions /supports | Animal-assisted interventions and supports are broad terms that capture any type of intervention or support that includes an animal. This may include assistance dogs (defined below) or any of the following:   * Visitation animals are those that belong to a volunteer who trains the animal to visit a facility to increase the wellbeing of the participants. * Therapy animals are similar to visitation animals in the type of training but are used by allied health professionals to support structured, goal-directed interventions. * Companion animals receive no specific training, and the term is interchangeable with pets. |
| Assistance dogs | Assistance dogs are dogs that have been trained to assist a person with a disability to alleviate the effect of the disability and meet standards of hygiene and behaviour that are appropriate for an animal in a public place.  The minimum standard for an assistance dog is that the dog must be trained to perform at least three tasks or behaviours which mitigate the effects of a person’s disability when required. These tasks will depend on the person’s specific disability and may occur with or without command. They must also be trained to a high level of obedience. |
| Autism | Autism (also referred to as “autism spectrum disorder”) is the collective term for a group of neurodevelopmental conditions affecting the brain’s growth and development. Autism is a life-long condition which can impact, to varying degrees, all areas of a person’s life, including social communication and social interaction.  The behavioural features of autism are often present before a person is three years of age but in others they may not be recognised until their school years or later in life. The developmental challenges, signs and/or symptoms can vary widely in nature and degree between individuals, and in the same individual over time – that is why the term “spectrum” is used.  We know that people prefer different terms to describe autism. We have used people on the autism spectrum (person-first language) to be consistent with how we refer to other target populations. |
| Autism characteristics | Autism characteristics include those used to diagnose autism such as difficulties with social communication (e.g., engagement in play, initiation in social interaction, joint attention), restricted, repetitive, and/or sensory behaviours, as well as challenging behaviours (e.g., noncompliance, aggressive and disruptive behaviour). |
| Meta-analysis | A meta-analysis uses statistics to combine the results from these studies to find out how much of an effect the intervention has on selected outcomes (which we call the effect size) and what factors can predict the size of the reported effects. |
| Parent | For clarity of writing, throughout this report we use the term ‘parent’ to refer to any individual who has parenting responsibilities for a child. |
| Systematic review | A systematic review summarises the evidence from research studies focused on the same topic. |

## Executive summary

This report is the second of two reports that have investigated the impacts of assistance dogs for people on the autism spectrum using systematic review methods. A systematic review is a method for collecting evidence from studies on a particular topic. The first report (Mulraney & Lampit, 2023) summarised the quantitative evidence from the systematic review to examine the magnitude of possible benefits associated with assistance dogs using statistical methods. This report summarises qualitative findings from a systematic review and meta-aggregation of existing research on this topic. Meta-aggregation is a method for synthesising this evidence to inform recommendations for practice (JBI, 2020). Using these methods, this research aimed to understand the lived experiences and perspectives of people with autism with assistance dogs, and their families.

There were eight eligible studies with a total of 134 participants with autism, from which three aggregated findings were synthesised:

* Parents perceived assistance dogs to be associated with a broad range of benefits to the child and family, including increased child sociability, improved child emotion regulation, and decreased parental stress. However, many of the identified benefits have also been described in the literature by parents of children with autism with a pet dog.
* Many parents were unprepared for the practicalities associated with owning an assistance dog and described challenges related to forming a bond between the child and dog, as well as caring for the dog’s wellbeing.
* There is a lack of awareness in the community about autism and the role of assistance dogs. This meant many parents were denied access to public places with the dog and were often required to educate members of the community on the role of an assistant dog.

The first report on the meta-analysis of quantitative studies (Mulraney & Lampit, 2023) found small to moderate benefits of assistance dogs on measures of autism characteristics, adaptive functioning, family outcomes, and child safety. However, the effects of assistance dogs were comparable to those of pet dogs.

The findings from this review, combined with the previous meta-analysis (Mulraney & Lampit, 2023), indicate there is currently limited evidence to suggest that assistance dogs confer unique benefits to people with autism. It is likely that some individuals will respond well to animal-assisted supports, but the current evidence does not suggest that assistance dogs would be more effective than pets. Given the lack of certainty about benefit, it may be prudent to consider assistance dogs only after more cost-effective and evidence-based supports have been tried and found ineffective for an individual participant. However, there is limited research on this topic and the quality of existing research varies, which can reduce confidence in the evidence.

## Background and NDIS context

As of March 2023, the total number of active NDIS participants with a primary diagnosis of autism was 199,367, which represents 35% of all participants in the scheme. During January to March 22/23, 19.3% of participants *entering* the NDIS had autism, making it the second largest disability group by entrants, after developmental delay. A major focus of the NDIS is to provide cost effective intervention to improve participant outcomes. This is also with the aim of reducing the intensity of specialist supports required later in life and to maximise functional outcomes throughout life.

Recently, there has been an increasing number of requests by participants with autism for assistance dogs. Between July 2021 and March 2022, there were 348 NDIS requests for assistance dogs. 151 of those requests (43%) were for participants with vision impairment, followed by autism (22%), and psychosocial disability including schizophrenia (7%).

The NDIS use the internationally recognised definition of assistance animals recommended by La Trobe University (Howell et al., 2019). An assistance animal is a dog or other animal which is trained to perform at least three tasks or behaviours which mitigate the effects of a person’s disability when required. These tasks will depend on the person’s specific disability and may occur with or without command. They must also be trained to a high level of obedience. Examples of assistance animals include dog guides, medical alert animals, hearing assistance animals, mobility assistance animals, psychiatric assistance animals, and assistance animals for developmental disorders (Howell et al., 2016).

This systematic review synthesises qualitative evidence in this area. A report of the data from quantitative studies (Mulraney & Lampit, 2023) complements this report and describes the results of a meta-analysis investigating the magnitude of benefits of assistance dogs for people with autism (hereafter referred to as the meta-analysis)..

## What did we do?

The following section provides an overview of the systematic review and meta-aggregation approach. A full description of the study methods is available in **Appendix A**.

### Objective

The objective of this systematic review and meta-aggregation was to synthesise the available evidence on people with autism and their family’s lived experiences of having an assistance dog.

#### How did we do it?

Findings included in this report were identified through a systematic review and meta-aggregation. A systematic review is a process to locate and summarise the results of all studies that ask a particular research question, usually by using different methods with a common underlying question (e.g., are assistance dogs associated with better outcomes in people with autism?). A meta-aggregation is a method of data synthesis that combines results from the qualitative studies identified in a systematic review (JBI, 2020). The primary level findings (e.g., themes) from each study are aggregated into categories and then those categories are further aggregated into lines of action that may be used to inform policy recommendations without losing the critical interpretive value of the qualitative findings. The detailed study methodology is provided in **Appendix A**.

We searched four academic literature databases to identify studies reporting qualitative data about participant experiences with assistance dogs. We also included studies that examined the efficacy or association of having an assistance dog, or pet dog, on any outcomes in people with autism at any age, which have been discussed separately in our quantitative report (Mulraney & Lampit, 2023).

We included studies with any design (e.g., cross-sectional, case studies, longitudinal) provided they reported qualitative data on the lived experiences of people with autism and an assistance dog.

Studies with comparison groups (i.e., people with autism who do not have an assistance dog) were included, but only data from the participants with an assistance dog were extracted. Studies including only visitation or therapy dogs (i.e., animals that visit a facility to increase enjoyment of participants, or those that take part in structured, goal-directed interventions with the guidance of an allied health professional) were excluded.

We included all studies that described the lived experiences and perspectives of persons living with autism or their family members of having an assistance dog.

Risk of bias and study quality was assessed using the Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research (Lockwood et al., 2015). Two independent reviewers appraised all the studies. Differences in the scoring were resolved via discussions between the independent reviewers and consensus was reached.

Qualitative research findings were pooled across studies. This involved the synthesis of findings to generate a set of statements (categories) that represent aggregation, through assembling the findings rated according to their quality, and categorising these findings based on similarity in meaning. These categories were then meta-synthesised to produce a comprehensive set of synthesised findings that can be used as a basis to make policy recommendations.

## What did we find?

The following section highlights the key findings from the review. A detailed description of results from the meta-aggregation is available in **Appendix B**.

### Summary of study participants

Eight primary studies, reported in 10 articles, comprising 134 participants with autism were included in the meta-aggregation. The characteristics of included studies are shown in **Table 1.** Most studies (n=7) included only children, with one study including both children and adults (Leung et al., 2022). Of the included studies, three were from Australia (Appleby et al., 2022; Hellings et al., 2022; Leung et al., 2022), one from Canada (Burrows & Adams, 2008; Burrows, Adams, & Millman, 2008; Burrows, Adams, & Spiers, 2008), one from Ireland (Burgoyne et al., 2014), and three from the USA (Brown, 2017; Solomon, 2010; Wild, 2012).

### Characteristics of studies

All studies included dogs living in the home, but the length of time that the dog had been in the home varied across studies. Very little information was provided about the type and duration of training received by dogs and families, with most studies not reporting any information about this. Four studies used semi-structured interviews (Appleby et al., 2022; Brown, 2017; Hellings et al., 2022; Leung et al., 2022), with one also including observations in the natural environment (Burrows & Adams, 2008; Burrows, Adams, & Millman, 2008; Burrows, Adams, & Spiers, 2008), two studies used open-ended survey questions (Burgoyne et al., 2014; Wild, 2012), and there was one case study (Solomon, 2010).

##### 

#### Table 1: Characteristics of included studies

Note: AD = Assistance Dog; ASD= Autism spectrum disorder.

| **Study name** | **Study design** | **Sample size;**  **Sex (% male);**  **Age (mean (range)** | **Method** | **Phenomena of interest** | **Length of dog placement** |
| --- | --- | --- | --- | --- | --- |
| **Appleby et al. (2022); Australia** | Cross-sectional | N = 8  Sex not reported; 7-12 years | Semi-structured interviews | Parent’s experiences and perceived benefits of owning an AD for ASD | At least 12 months and up to 8 years |
| **Brown (2017); USA** | Cross-sectional | N = 15  80.0%; 10.6 (8-18) years | Semi-structured interviews | Parent’s experiences of owning an AD for ASD | Three months to seven years (mean = 3.3 years) |
| **Burgoyne et al. (2014); Ireland** | Cross-sectional | N = 80  87.5%; Age categories only reported (0-6 n = 30, 7-9 years n = 50) | Open ended survey questions | Parental perceived benefits and constraints of having an AD for a child with ASD | Not specified |
| **Burrows et al. (2008a, 2008b, 2008c); Canada** | Longitudinal | N = 10  70%; 4-14 years | Semi-structured interviews and observations | Experiences of integrating an AD for ASD into the family home | 6 months |
| **Hellings et al. (2022); Australia** | Longitudinal | N = 4  100%; 5-13 years | Semi-structured interviews | Lived experiences of AD ownership for children with ASD and their families | 6 months |
| **Leung et al. (2022); Australia** | Cross-sectional | N = 6  83.3%; Age categories only reported (5-10 n=1; 10-16 n=2; 16-20 n=1; >20 n=2) | Semi-structured interviews | Perceived benefits of having an AD for ASD (parental perspective for children and self-perspective for adults) | <6 month (50%), 6-12 months (16.7%), >12 months (33.3%) |
| **Solomon (2010); USA** | Case study | N = 1  100%; 13 years | Case study | Understanding the importance of dog involvement in child participation in everyday activities and social relationships | Not specified |
| **Wild (2012); USA** | Longitudinal | N = 10  80%; 7.1 (4-16) years | Open ended survey questions | Parental perceived impact of AD for ASD on child safety and parent stress | 12 months |

### Overview of results

The current systematic review is based on data extracted from eight studies, which resulted in three synthesised findings. Synthesised finding 1 was supported by 7 categories from 37 findings **(Table B2)**. Synthesised finding 2 was supported by three categories from 15 findings **(Table B3)**. Synthesised finding 3 was supported by two categories from 7 findings **(Table B4)**.

The extracted findings were consistently supported by participant quotes that adequately informed and supported the finding **(Table B5)**. A total of 13 categories were created based upon similarity of meaning in the findings. The categories were then subjected to meta-synthesis to produce synthesised findings for the purpose of providing an evidence base on which to make recommendations for practice and policy. The synthesised findings, their categories, and findings are described below.

#### Meta-synthesis 1: Perceived benefits to the child and their family

Synthesised finding 1 was the result of the identification of seven categories from 37 findings **(Table B2)**. The findings were supported by illustrations taken directly from the papers that reflected the voices of parents of children with autism.

Synthesised finding 1: Parents perceive there to be a broad range of potential benefits of assistance dogs to children with autism, and their families.

Parents perceive a broad range of benefits for their child related to having an assistance dog, such as increased confidence, sociability, and support with emotion regulation and safety issues (e.g., running onto roads). Parents described flow on benefits to the family, such as reduced stress, as a result of the altered child behaviour.

#### Meta-synthesis 2: Practical considerations of owning an assistance dog

Synthesised finding 2 was the result of the identification of three categories from 15 findings **(Table B3)**. The findings were supported by illustrations taken directly from the papers that reflected the voices of parents of children with autism.

Synthesised finding 2: Parents described a range of challenges and practical considerations they were unprepared for. There is a need for families to be provided with education about the practicalities of owning an assistance dog and an appropriate level of training to ensure the dogs are being adequately cared for.

There are several challenges resulting from having an assistance dog for children with autism. The key challenge described by parents in the studies was the time, energy and dedication required to look after the dog's wellbeing and heath. Other issues include the financial costs associated with the dog's care, including food and veterinary services. Families also described struggling with how to best include the dog into the family routine, particularly when there are other children in the house. Finally, there is an adjustment period where parents sometimes found it difficult to help build a relationship between the dog and their child with autism. Parents described how the dogs over time learned how to interpret the child’s behaviour to avoid the child if they were going to be aggressive, or to provide companionship and comfort when it was safe to do so.

#### Meta-synthesis 3: Educating the community

Synthesised finding 3 was the result of the identification of two categories from seven findings **(Table B4)**. The findings were supported by illustrations taken directly from the papers that reflected the voices of parents of children with autism.

Synthesised finding 3: Taking the dog out in public can be a means to educate the broader community about autism and assistance dogs.

However, the reactions from the community are varied.

It is important to recognise both advantages and disadvantages of parents educating the community about the role of assistance dogs. Awareness of assistance dogs and autism can be raised and mediated through the dog. However, this comes with time and energy costs that could potentially interrupt the parent’s routine/schedule. Parents also described some significant issues with public accessibility as the dog can be denied entry into schools and restaurants, even in locations where local laws permit full access to assistance dogs. Access denial might be seen by the family as a rejection of the whole family unit and the rights of children with autism.

### Quality of the available evidence

The quality of the qualitative studies was assessed using the JBI Critical Appraisal Checklist for Qualitative Research, with all studies determined to be of poor quality (**Table 2**).

No studies met all ten quality criteria, with many studies either not meeting some criteria or it was unclear if the criteria had been met. For example, no studies provided a statement which positioned the researcher to provide transparency in how their background may have influenced interpretation of findings, and only one study had congruity between the stated philosophical perspective and the chosen research methodology.

#### Table 2: Quality appraisal of included studies

Note: N, no; U, unclear; Y, yes. JBI critical appraisal checklist for qualitative research: Q 1: Is there congruity between the stated philosophical perspective and the research methodology? Q 2: Is there congruity between the research methodology and the research question or objectives? Q 3: Is there congruity between the research methodology and the methods used to collect data? Q 4: Is there congruity between the research methodology and the representation and analysis of data? Q 5: Is there congruity between the research methodology and the interpretation of results? Q 6: Is there a statement locating the researcher culturally or theoretically? Q 7: Is the influence of the researcher on the research, and vice-versa, addressed? Q 8: Are participants, and their voices, adequately represented? Q 9: Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? Q 10: Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

| **Reference** | **Q1** | **Q2** | **Q3** | **Q4** | **Q5** | **Q6** | **Q7** | **Q8** | **Q9** | **Q10** |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Wild (2012) | Y | N | U | U | Y | N | Y | Y | Y | Y |
| Burgoyne et al. (2014) | N | U | U | N | U | N | N | Y | Y | U |
| Appleby et al. (2022) | N | Y | Y | Y | Y | N | N | Y | Y | Y |
| Brown (2017) | N | Y | Y | Y | N | N | Y | Y | Y | U |
| Leung et al. (2022) | N | N | Y | N | N | N | N | N | Y | N |
| Burrows and Adams (2008) | N | U | U | U | U | N | N | Y | Y | Y |
| Burrows, Adams and Millman (2008) | N | U | U | U | U | N | N | Y | Y | Y |
| Burrows, Adams and Spiers (2008) | N | U | U | U | U | N | N | Y | Y | Y |
| Hellings et al. (2022) | N | Y | Y | Y | Y | N | N | Y | Y | Y |
| Solomon (2010) | U | Y | Y | N | Y | N | N | Y | Y | Y |

## Discussion

To the best of our knowledge, this is the first systematic review and meta-aggregation which investigated the lived experiences and perspectives of people with autism and their families of having an assistance dog. By using systematic search and formal methods for synthesising qualitative data, we bring together the entirety of the published research findings on the lived experienced of people with autism and their families owning an assistance dog. This ensures that findings are examined objectively, and that diverse voices and views are represented.

The synthesised findings reveal many barriers, such as lack of community understanding of assistance dog ownership, or the efforts required to consider dog wellbeing. Perceived benefits include improved companionship, social functioning, emotional regulation, and positive behavioural changes, as well as reduced stress in the family. However, similar benefits were reported in qualitative studies that examined the perceived benefits of pet dogs in children with autism (Byström & Persson, 2015; Harwood et al., 2019; Lane, 2020). Therefore, while there are a range of potential benefits to assistance dogs for children with autism, these do not seem to substantially exceed the benefits that would be obtained from a pet dog, which is consistent with our findings from the meta-analysis.

The meta-analysis (Mulraney & Lampit, 2023) found that assistance dogs are associated with only modest benefits in autism across key clinical domains of autism characteristics, adaptive functioning, mental health, child safety, and family outcomes (parenting stress, parenting, family quality of life). There was inconclusive evidence to suggest that assistance dogs would achieve better outcomes compared with pet dogs.

The data from this qualitative review also extend our findings from the meta-analysis by providing information about the challenges families experience related to owning an assistance dog for a child with autism. If an assistance dog is deemed appropriate, families would need ongoing education and support around the practicalities of owning an assistance dog. Finally, the review has highlighted a general lack of understanding in the community about the varied roles of assistance dogs (beyond dogs guides) which at times leads to families being denied public access with the dog.

### NDIS perspective

While our results provide preliminary indications that assistance dogs may be associated with some benefits for children with autism, it is critical to interpret them in context, namely the overall quality of the evidence and the limited benefits of assistance dogs compared to pet dogs and other common supports for people with autism (Whitehouse et al., 2020). Further, it is important to consider that reporting across included studies, made it unclear whether the dogs owned by study participants would meet the definition and training requirements of an assistance animal under the NDIS.

Efficacy vs other autism supports.In keeping with the results of our quantitative synthesis (Mulraney & Lampit, 2023), the perceived benefits of assistance dogs described by parents are comparable to those described by families with pet dogs (Byström & Persson, 2015; Harwood et al., 2019; Lane, 2020). Although direct comparisons cannot be made between the two types of data, it should be noted that the effect size estimates found in our quantitative meta-analysis were no greater than those of pet dogs, substantially lower than those reported for canine-assisted therapy, and comparable to those estimated for common autism interventions such as behaviourally based interventions.

Therefore, there is currently little qualitative or quantitative evidence to suggest that assistance dogs confer unique benefits in people with autism. It is likely that some individuals will respond well to animal-assisted supports, but the current evidence does not support the notion that assistance dogs would be more effective than animal-assisted therapy, visitation animals or pets. Given the lack of certainty about benefit it may be prudent to consider assistance dogs only after more cost-effective and evidence-based supports have been tried and found ineffective for an individual.

### Limitations of this report

This report summarised and synthesised the qualitative evidence across the literature of the lived experiences of families who own an assistance dog for their child with autism. It was prepared by a panel of researchers with expertise in qualitative evidence synthesis who extracted, synthesised, and appraised studies independently in duplicate, and reviewed by internal experts in assistance dogs. While there were sufficient studies identified to conduct a meaningful meta-aggregation, several critical limitations mean that the results must be interpreted with caution.

There is a very high risk of bias in the reported findings as none of the studies described how researcher bias was managed. Further, many studies included leading questions about the benefits of assistance dogs (e.g., “What are your views of the benefits of having an assistance dog?”) rather than broad, open-ended questions about participant’s lived experiences (e.g., “tell me about the experience of having a service dog for your child with Autism).

The quality of reporting overall was quite limited; for example, 30% of the findings described in studies were not supported by participant quotes. Only a single study included adults with autism, and the majority of participants in that study were children. Although the assistance dogs were for the children with autism, children’s voices were notably absent from the reports with the data collected almost exclusively from parents. Therefore, the results may not apply to the participants themselves.

Only one study provided any information about the training provided to the dogs and families. No study provided any information about any other treatments or supports the participants may have been receiving. Thus, it is unclear how having a dog may interact with other supports and interventions the child may be receiving. Although, one study mentioned that the dog went with the child to therapy and was helpful in keeping the child engaged and focused.

### Directions for future work

Further primary or synthesis work may be required to understand who might benefit from assistance dogs and for what outcomes, particularly in the context of NDIS participants and providers. These may include qualitative and quantitative comparisons of the benefits and harms associated with assistance dogs versus therapy, visitation, or companion animals, as well as other evidence-based supports available for people with autism. We note a paucity of data regarding adults with autism, as well as little information regarding training and maintenance requirements to ensure meaningful benefits and animal wellbeing.

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## Appendix A. Detailed study methodology

This systematic review adheres to guidelines from the JBI Manual for Evidence Synthesis in relation to the conduct and reporting of systematic reviews of qualitative research (JBI, 2020). The protocol for the systematic review was registered with PROSPERO on 9th October 2022 (CRD42022363398). This report focuses on the synthesis of qualitative evidence identified in the systematic review.

### A1. Study objective

The objective of this systematic review and meta-aggregation was to synthesise the available evidence on the lived experiences of having an assistance dog of people with autism or their families.

### A2. Electronic search strategy

A single search of MEDLINE, EMBASE, CENTRAL and PsycINFO via OVID was conducted on 30 August 2022 for studies examining the benefits and harms of Assistance Dogs for individuals with autism. The search strategy is shown in **Table A1**. The search was not limited by time, location, or language. Articles written in a language other than English were translated using Google translate. Additional articles were identified by scanning the reference lists of existing reviews. One author conducted the initial search. Screening of title and abstracts was conducted by two reviewers and the review of full texts was conducted by three reviewers. Discrepancies were resolved by MM who also contacted corresponding authors for additional information when required.

#### Table A1: Search Strategy

| **MEDLINE search strategy** |
| --- |
| 1. Exp child developmental disorders, pervasive/ |
| 1. Developmental disabilities/ |
| 1. Autis\*.mp |
| 1. Asperger\*.mp |
| 1. (development\* adj3 delay\*).mp |
| 1. (ASD or ASDs or ASC).mp |
| 1. 1 or 2 or 3 or 4 or 5 or 6 or 7 |
| 1. Exp human-animal interaction/ |
| 1. Exp animal-assisted therapy/ |
| 1. Pets/ |
| 1. Exp animals, domestic/ |
| 1. Dogs/ |
| 1. (dog$1 or canine).mp |
| 1. ((therap\* or Assis\* or working or service or companion\* or support\* or visit\* or facilit\*) adj3 (animal or pet)).mp |
| 1. 8 or 9 or 10 or 11 or 12 or 13 or 14 |
| 1. 7 and 15 |

### A3. Study selection and eligibility criteria

#### A3.1. Types of studies

All study designs were eligible for inclusion in the review (e.g., randomised controlled trials, observational studies, cross-sectional studies, case-series, and qualitative studies). Eligible studies include peer-reviewed journal articles as well as published reports and policy papers. Unpublished data (e.g., obtained from study authors, reported in pre-prints, unpublished dissertations) were also eligible.

Eligible studies included in the meta-aggregation were any that reported qualitative data about the lived experiences of having an assistance dog of people with autism or their families.

#### A3.2. Types of participants

Studies were eligible if they included people, of any age, diagnosed with autism of any aetiology or Developmental Delay (DD). Autism/DD comorbid with other conditions (including established or evident intellectual disability) were eligible. Studies combining autism/DD with other conditions (e.g., vision impairment) were eligible for inclusion only if >50% of the sample have a diagnosed autism/DD or if data for participants with autism/DD was available separately from other conditions.

#### A3.3. Types of interventions/phenomena of interest

Eligible studies included data that described the participant (or their family’s) experience with an assistance dog. Non-assistance dogs may undergo specific training, but do not provide support that targets a person’s specific disability, and do not reside in the participant’s home. Studies including only non-assistance dogs were excluded. Examples of non-assistance dogs include visitation dogs and therapy dogs.

#### A3.4. Types of studies

The review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

### A4. Data extraction

Qualitative data were extracted from papers included in the review by two authors independently (MM, ORP). Discrepancies were discussed until consensus was achieved. The qualitative data extracted included all findings reported by the authors (i.e., themes and subthemes described), along with an illustration to support the theme. Illustrations are direct quotes from participants that have been included in the paper. Findings are then assigned a level of credibility based on the JBI levels of Credibility; the three levels of credibility are:

* Unequivocal (U) – evidence beyond a reasonable doubt
* Credible (C) – findings are accompanied by an illustration lacking a clear association, but it could be plausible
* Not supported (NS) – findings not supported by the data (including when no illustrations are provided)

In addition to the qualitative data, information on the study design and characteristics were extracted for each eligible article which included: author, publication year, country, study design, sample descriptive information (i.e., age, sex, etc.), and intervention description.

### A5. **Study quality**

Study quality was assessed using the JBI Critical Appraisal Checklist for Qualitative Research (Lockwood et al., 2015). Two independent reviewers (ORP & CB) appraised all the studies; differences in the scoring were resolved via discussions between the independent reviewers and MM until consensus was reached.

### A6. **Data analysis**

Qualitative research findings were pooled across studies. This involved the synthesis of findings to generate a set of statements (categories) that represent aggregation, through assembling the findings rated according to their quality, and categorising these findings based on similarity in meaning. These categories were then meta-synthesised to produce a comprehensive set of synthesised findings that can be used as a basis to make policy recommendations.

## Appendix B. Detailed results

### B1. Study selection

The initial search identified 2016 records, of which 564 were duplicates. A total of 1344 records were screened based on title and abstract (**Tables B1a and B1b**). The full text of 202 records were assessed, of which 33 were eligible. Authors from five studies were contacted for additional information, resulting in additional data for one study (Atherton et al., 2022) and identification of a follow-up publication (Moses Bélanger et al., 2022). Two records (Hall et al., 2019; Hall et al., 2016), reporting on the same study were excluded as the authors did not reply to the request for additional information. Three records (Burrows & Adams, 2008; Burrows, Adams, & Millman, 2008; Burrows, Adams, & Spiers, 2008) reported data from the same study and thus are considered as a single study. The final dataset for the meta-aggregation included eight independent studies comprising four cross-sectional (Appleby et al., 2022; Brown, 2017; Burgoyne et al., 2014; Leung et al., 2022), three longitudinal (Burrows & Adams, 2008; Burrows, Adams, & Millman, 2008; Burrows, Adams, & Spiers, 2008; Hellings et al., 2022; Wild, 2012), and one case study (Solomon, 2010).

As shown in **Tables B1a and B1b**, a total of 34 articles met inclusion criteria for the quantitative and qualitative reviews. For the current qualitative report, 10 articles, representing eight independent studies, were included in the meta-aggregation.

#### Table B1a: Identification of studies via databases and registries

| **Articles screened** | **Articles excluded** |
| --- | --- |
| 2016 records identified from database search | 672 duplicates removed |
| 1344 records after duplicates removed | 1142 excluded based on title and abstract |
| 202 full text articles assessed for eligibility | 169 articles excluded   * 75 no eligible outcomes * 47 wrong interventions * 35 reviews * 9 wrong population * 2 identical data already reported * 1 erratum |
| 33 articles met eligibility criteria |  |

#### Table B1b: Identification of studies via other methods

| **Articles screened** | **Articles excluded** |
| --- | --- |
| 1 record identified through contacting authors | 0 articles excluded |
| 1 record assessed for eligibility | 0 articles excluded |
| 1 record met eligibility criteria |  |

### B2. Characteristics of studies

Ten records representing eight studies were included in the meta-aggregation (N = 134). Participants ranged in age from 2 to 20+ years, however most studies (n = 7) included only children, with one study including both children and adults (Leung et al., 2022). Included studies were from Australia (Appleby et al., 2022; Hellings et al., 2022; Leung et al., 2022), Canada (Burrows & Adams, 2008; Burrows, Adams, & Millman, 2008; Burrows, Adams, & Spiers, 2008), Ireland (Burgoyne et al., 2014), and the USA (Brown, 2017; Solomon, 2010; Wild, 2012).

All studies included dogs living in the home, but the length of time that the dog had been in the home varied across studies. Very little information was provided about the type and duration of training received by dogs and families, only two studies reported any information about this. One study (Burrows & Adams, 2008; Burrows, Adams, & Millman, 2008; Burrows, Adams, & Spiers, 2008) reported that the dogs received National Service Dog training (Canada), and another study (Hellings et al., 2022) reported that the dogs underwent two years of training prior to placement. Neither study provided any further information about what the training programs entailed or how much training handlers received.

Four studies used semi-structured interviews (Appleby et al., 2022; Brown, 2017; Hellings et al., 2022; Leung et al., 2022), with one also including observations in the natural environment (Burrows & Adams, 2008; Burrows, Adams, & Millman, 2008; Burrows, Adams, & Spiers, 2008) alongside interviews, two studies used open-ended survey questions (Burgoyne et al., 2014; Wild, 2012), and there was one case study (Solomon, 2010).

#### B2.1. Summary of included studies

Appleby et al. (2022) conducted once off interviews about lived experiences of having an assistance dog with parents of children with autism aged 7 to 12 years. The study included families (n = 8) that had an assistance dog for at least 12 months, and up to eight years. Five main themes emerged through thematic analysis of the transcripts. These were: freedom through restraint; expanding our world; a calming/sensory tool; “at the end of the day, they're dogs”; and friendship and personal growth.

Brown (2017) reports a doctoral dissertation on semi structured interviews about parent’s (n = 15) experiences of owning an assistance dog for their child with autism (5-18 years). The length of dog service at the time of interview ranged from three months to seven years, with a mean of 3.3 years (SD=2.1). Participants reported overwhelmingly positive experiences of owning an assistance dog. Benefits included: increased physical safety, improved social and communication functioning, improved emotional and behavioural functioning, increased family freedom and decreased parental stress. Participants identified several challenging aspects of their experience, including the significant time and energy investment required, public and school access issues, and financial demands or concerns.

Burgoyne et al. (2014) conducted a cross-sectional survey of parents of children with autism aged between 0 to 9 years. The study included families who had an assistance dog (n = 80) for an unspecified length of time. The survey included open ended questions about the perceived benefits and constraints of owning an assistance dog. Three themes were identified under ‘benefits’. These were: physical factors, relationship factors, and family factors. Four themes emerged from the data on constraints. These were: 'change factors', 'relationship factors', 'limiting factors’, and ‘no constraints’.

The three articles by Burrows (Burrows & Adams, 2008; Burrows, Adams, & Millman, 2008; Burrows, Adams, & Spiers, 2008) report findings from a doctoral dissertation on the experiences of integrating an assistance dog into the home for families of a child with autism (5-13 years). In this study the researcher conducted semi structured interviews with 10 families and observed them in their natural environment one week after receiving the dog and again 3- and 6-months later. The results are published in three articles, each focusing on a different aspect of the lived experience. The first paper (Burrows & Adams, 2008) focused on the challenges of integrating the dog into the family home and community and identified seven themes related to community and environmental factors, public access issues, additional time requirements for dog training and maintenance, and concerns about dog behaviour and health. The second paper (Burrows, Adams, & Millman, 2008) investigated factors that influence the dog’s ability to work effectively with the child with autism and factors that influence dog welfare. Three key themes emerged related to: the service dog at work, physical factors (including physical stress, maintaining the dog’s health, rest/recovery time, and recreational activities), and social interactions (including companionship and social bonding). The final paper (Burrows, Adams, & Spiers, 2008) focused on the experiences of integrating the dog into the family home and three themes were identified. The themes were (a) the dog as a sentinel of safety, (b) gaining freedom through enhanced safety, facilitating public outings and family activities, and (c) improving social recognition and status, in which the presence of the dog promoted awareness of autism and effected social interaction.

Hellings et al. (2022) conducted semi-structured interviews with parents of four children with autism (5-13 years) prior to and 6 months after dog placement. The interviews focused on families lived experiences of assistance dog ownership and four themes emerged from the data: (1) Benefits to the child and the family/caregiver; (2) Dog ownership required adjustment and was not always as expected; (3) Community attention was sometimes but not always beneficial; and (4) Community education about the role of assistance dogs is needed.

Leung et al. (2022) conducted once off interviews with six families (n = 2 adult participants with autism and n = 4 parents of children with autism) who had an assistance dog. Families had the assistance dog for varying lengths of time (<6 month (50%), 6-12 months (16.7%), >12 months (33.3%)) prior to the interview. The semi-structured interviews focused on the benefits of owning an assistance dog and six themes were identified: provide companionship, increase independence, emotional regulation, increase confidence, improve communication and sociability, calmness, and harmony.

Solomon (2010) reports a case study of a 13-year-old boy with autism who received an assistance dog. The key theme that emerged from this case study was that the lives of every family member had been changed as a result of having the dog.

Wild (2012) reports a mixed-methods doctoral dissertation on families of children with autism aged between 4 and 16 years. Ten parents of children who received an assistance dog, completed open ended survey questions about the impact of the assistance dog on child safety and parental stress at three time points (prior to receipt of the dog and 6-months, and 12-months later). A single theme of concerns for child’s safety was identified from the responses with two subthemes: (a) lack of fear of danger, and (b) non-compliance.

### B3. Study quality

The quality of the qualitative studies was assessed using the JBI Critical Appraisal Checklist for Qualitative Research, with all studies determined to be of poor quality (**Table B1**).

The first five questions of the checklist focus on the dependability of the study, that is, the appropriateness of the methodology, methods, and implementation of the research methods. The concept of dependability in qualitative research is analogous to reliability in qualitative research, however the focus is on achieving consistent quality rather than repeatability. Across most studies insufficient information was provided to determine dependability. None of the studies addressed researcher bias and how this had been managed. All studies were conducted ethically, and all but one adequately represented participant voices. In 7/10 studies the conclusions logically flowed from the data, but in 2 studies this was unclear, and in one study the conclusions did not match the data.

#### Table B1: Quality appraisal of included studies

Note: N, no; U, unclear; Y, yes. JBI critical appraisal checklist for qualitative research: Q 1: Is there congruity between the stated philosophical perspective and the research methodology? Q 2: Is there congruity between the research methodology and the research question or objectives? Q 3: Is there congruity between the research methodology and the methods used to collect data? Q 4: Is there congruity between the research methodology and the representation and analysis of data? Q 5: Is there congruity between the research methodology and the interpretation of results? Q 6: Is there a statement locating the researcher culturally or theoretically? Q 7: Is the influence of the researcher on the research, and vice-versa, addressed? Q 8: Are participants, and their voices, adequately represented? Q 9: Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? Q 10: Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

| **Reference** | **Q1** | **Q2** | **Q3** | **Q4** | **Q5** | **Q6** | **Q7** | **Q8** | **Q9** | **Q10** |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Wild 2012 (Wild, 2012) | Y | N | U | U | Y | N | Y | Y | Y | Y |
| Burgoyne et al. 2014 (Burgoyne et al., 2014) | N | U | U | N | U | N | N | Y | Y | U |
| Appleby et al. 2022 (Appleby et al., 2022) | N | Y | Y | Y | Y | N | N | Y | Y | Y |
| Brown 2019 (Brown, 2017) | N | Y | Y | Y | N | N | Y | Y | Y | U |
| Leung et al. 2022 (Leung et al., 2022) | N | N | Y | N | N | N | N | N | Y | N |
| Burrows et al. 2008a (Burrows & Adams, 2008) | N | U | U | U | U | N | N | Y | Y | Y |
| Burrows et al. 2008b (Burrows, Adams, & Millman, 2008) | N | U | U | U | U | N | N | Y | Y | Y |
| Burrows et al. 2008c (Burrows, Adams, & Spiers, 2008) | N | U | U | U | U | N | N | Y | Y | Y |
| Hellings et al. 2022 (Hellings et al., 2022) | N | Y | Y | Y | Y | N | N | Y | Y | Y |
| Solomon 2010 (Solomon, 2010) | U | Y | Y | N | Y | N | N | Y | Y | Y |

### B4. Findings of the review

The current systematic review is based on data extracted from eight studies, which resulted in three synthesised findings. Synthesised finding 1 was supported by 7 categories from 37 findings **(Table B2)**. Synthesised finding 2 was supported by three categories from 15 findings **(Table B3)**. Synthesised finding 3 was supported by two categories from 7 findings **(Table B4)**. All findings were informed by illustrations (i.e., quotes) from the included studies **(Table B5).**

Each finding had an assigned level of credibility based upon the Joanna Briggs Institute levels of Credibility. The three levels or degrees of credibility are: Unequivocal (U), Credible (C), and Not Supported (NS). There were 25 NS findings across the papers included in the systematic review **(Table B5)**, these findings were not included in the meta-aggregation.

The total number of findings from this review was 59, with 16 being credible and 43 being unequivocal. Specifically, synthesised finding 1 had 11 credible findings and 26 unequivocal findings, synthesised finding 2 had 5 credible findings and 10 unequivocal findings, and synthesised finding 3 had 1 credible finding and 6 unequivocal findings.

The extracted findings were consistently supported by participant quotes that adequately informed and supported the finding **(Table B5)**. Following assignment of a level of credibility, each of the findings was then categorised into statements that represented the findings based on similarity of meaning. A total of 13 categories were created based upon similarity of meaning in the findings. The categories were then subjected to meta-synthesis to produce synthesised findings for the purpose of providing an evidence base on which to make recommendations for practice and policy. The synthesise findings, their categories, and findings are reported below.

#### B4.1. Meta-synthesis 1: Perceived benefits to the child with ASD and their family

Synthesised finding 1 was the result of the identification of seven categories from 37 findings **(Table B2)**. The findings were supported by illustrations taken directly from the papers that reflected the voices of parents of children with autism.

#### Synthesised finding 1: Parents perceive there to be a broad range of potential benefits of assistance dogs to children with autism, and their families.

Parents perceived a broad range of benefits for their child with autism related to having an assistance dog, such as increased confidence, sociability, and support with emotion regulation and safety issues (e.g., running onto roads). Parents described flow on benefits to the family as a result of the altered child behaviour including reduced stress. Synthesised finding 1 indicated that parents perceived increased child safety to be a critical benefit of having an assistance dog. Many parents described tethering their child to the dog when out in public which prevented the child from running away or ‘bolting onto a busy road’. Additionally, some parents described scenarios where the dog barked to alert parents of potential dangers such as the child leaving the house unattended. Closely related to this, parents described many benefits to the family including being able to leave the house more freely. Parents described reduced stress and a sense of freedom as they did not have to worry about their child’s safety outside of the home and there was a reduction in negative feelings such as embarrassment in public settings due to the dog being a visible indicator of the child’s disability. Many of the other perceived benefits of assistance dogs described by parents are similar to what one would expect from a pet dog. The dog provided companionship to the child, with some parents describing the dog as the child’s only friend. Parents also described their child as having increased confidence and independence, particularly in social settings, with their child feeling more comfortable talking to other people about their dog. The dogs assisted children with emotion regulation, providing a calming presence and a sensory tool. Lastly, parents described how the dog positively impacted their child’s behaviour including how the child took on the responsibility of caring for the dog.

#### B4.2. Meta-synthesis 2: Practical considerations of owning an assistance dog

Synthesised finding 2 was the result of the identification of three categories from 15 findings **(Table B3)**. The findings were supported by illustrations taken directly from the papers that reflected the voices of parents of children with autism.

#### Synthesised finding 2: Parents described a range of challenges and practical considerations they were unprepared for. There is a need for families to be provided with education about the practicalities of owning an assistance dog and an appropriate level of training to ensure the dogs are being adequately cared for.

There are several challenges resulting from having an assistance dog for children with autism. The key challenge described by parents in the studies was the time, energy and dedication required to look after the dog's wellbeing and heath. Other issues include the financial costs associated with the dog's care, including food and veterinary services. Families also described struggling with how to best integrate the dog into the family routine particularly when there are other children in the house. Finally, there is an adjustment period where parents sometimes found it difficult to build a relationship between the dog and the child with autism. Parents described how the dogs over time learned how to interpret the child’s behaviour to avoid the child if they were going to be aggressive or provide companionship and comfort when it was safe to do so.

#### B4.3. Meta-synthesis 3: Educating the community

Synthesised finding 3 was the result of the identification of two categories from seven findings **(Table B4)**. The findings were supported by illustrations taken directly from the papers that reflected the voices of parents of children with autism.

#### Synthesised finding 3: Taking the dog out in public can be a means to educate the broader community about autism and assistance dogs. However, the reactions from the community are varied.

It is important to recognise both advantages and disadvantages of educating the community about the role of assistance dogs. Awareness of assistance dogs and autism can be raised and mediated through the dog. However, this comes with time and energy costs that could potentially interrupt the parent's routine/schedule. Parents also described some significant issues with public accessibility as the dog can be rejected from schools and restaurants even in locations where current laws permit full access to assistance dogs. Access denial might be seen by the family as a rejection of the whole family unit and the rights of children with autism.

##### Table B2: Results of the first meta-aggregation of qualitative research findings

**Synthesised finding 1: Perceived benefits to the child with autism and the family.** Parents perceive there to be a broad range of potential benefits of assistance dogs to children with ASD, and their families.

| **Findings** | **Category** |
| --- | --- |
| * Benefits > physical factors > safety & security (U) * Benefits > safety (U) * Sentinel of Safety (U) * Concerns for child's safety > Lack of fear of danger (U) * Concerns for child's safety > non-compliance (C) | Increased safety of the child with autism |
| * Increase confidence (U) * Benefits > confidence (U) * Increase independence (U) | Increased confidence of the child with autism |
| * Benefits > physical factors > no bolt (U) * Benefits > improved sleep (U) * Benefits > attention and learning (C) * Benefits > adjunct to clinical therapy (U) * Benefits > care for another (U) * Benefits > responsibility (U) | Behavioural changes in the child with autism including improved sleep and taking responsibility for the care of the dog |
| * Benefits > social and communication (U) * Improve communication and sociability (C) | Increased sociability of the child with autism, the dog provides a conversation starter |
| * A calming/sensory tool (U) * Benefits > emotional and behavioural (U) * Emotional regulation (U) | The dogs support children with autism in regulating their emotions |
| * Provide companionship (U) * Benefits > companionship (C) * Social interactions > companionship (C) * Benefits > constant presence (C) * Benefits > relationship factors > friend (U) * Friendship and personal growth (U) | Assistance dog is a companion for children with autism |
| * Impacts on the family > increased family cohesiveness (C) * Lives of every member of the family had been changed (U) * Benefits to the child and the family/caregiver (U) * Constraints > no constraints (U) * Freedom through restraint (U) * Impacts on the family > increased freedom (U) * Expanding our world (U) * Public perceptions and reactions > Feeling less embarrassed by their child’s behaviours and self-conscious about how they are perceived as a parent (U) * Social interactions > social bonding (C) * Impacts on the family > decreased stress (C) * Calmness and harmony (C) * Individual Respite, Relaxation, and Family Recreation (C) | Family benefits related to reduced parental stress about being in public with the child with autism |

##### Table B3: Results of the second meta-aggregation of qualitative research findings

**Synthesised finding 2:** **Practical considerations of owning an assistance dog.** Parents described a range of challenges and practical considerations they were unprepared for. There is a need for families to be provided with education about the practicalities of owning an assistance dog and an appropriate level of training to ensure the dogs are being adequately cared for.

| **Findings** | **Category** |
| --- | --- |
| * Dog ownership required adjustment and was not always as expected (C) * Maintaining a Service Dog (U) * Challenges > time & energy (U) * ‘‘Finding the Time’’ and Extra Work (U) * Considering Family Factors (U) * “At the end of the day, they're dogs” (U) * Constraints > relationship factors > life (C) * Interpreting Dog (C) * Seasonality of Service Dog Placement (C) | Practical implications and challenges of assistance dog ownership |
| * Constraints > limiting factors > cost (C) * Challenges > financial responsibility (U) | The financial burden of assistance dogs |
| * Physical factors > the dogs developed an ability to interpret the child’s behaviour (U) * Performance: The Service Dog at Work (U) * Physical factors > The dogs did not object (U) * Physical Factors > physical stress (U) | Assistance dog's role and skillset |

##### Table B4: Results of the third meta-aggregation of qualitative research findings

**Synthesised finding 3:** **Educating the community.** Taking the dog out in public can be a means to educate the broader community about autism and assistance dogs. However, the reactions from the community are varied.

| **Findings** | **Category** |
| --- | --- |
| * Facilitating Awareness and Education About Autism (U) * Community education about the role of assistance dogs is needed (U) * Community attention was sometimes but not always beneficial (U) * Shifting the Focus from Autistic Child to Service-Dog Companion (C) | Educating others about the role of assistance dogs |
| * Challenges > public and school access (U) * Public Access Issues: Pioneering for Access Rights (U) * Community Factors: Testing Cultural Diversity (U) | Public access challenges of assistance dog ownership |

##### Table B5: Qualitative findings and exemplary supportive quotes

Note: This table is based on the format suggested by the Joanna Briggs Institute for reporting of meta-aggregation analysis. The Joanna Briggs Institute proposes 3 categories to assess findings/illustrations: U: Unequivocal, C: Credible, or NS: Not Supported).

| **Finding** | **Illustration** | **Credibility** |
| --- | --- | --- |
| Benefits > physical factors > safety & security | ‘A sense of security & protection for our daughter especially walking in local environments’ | U |
| Benefits > physical factors > no bolt | ‘(Dog) will stop child from bolting from home’ | U |
| Benefits > physical factors > Physiological |  | NS |
| Benefits > physical factors > management |  | NS |
| Benefits > relationship factors > friend | ‘She is his very best friend’ | U |
| Benefits > relationship factors > calm & comfort | Only illustration given was from the control group | NS |
| Benefits > family factors > visibility |  | NS |
| Benefits > family factors > emotion & stress |  | NS |
| Benefits > family factors > fun & play |  | NS |
| Benefits > family factors > social | ‘a sense of responsibility, for example he can feed the dog’ | NS |
| Benefits > family factors > freedom | Only illustration given was from the control group | NS |
| Constraints > change factors > dedication | “It’s like an additional child in the family” | NS |
| Constraints > change factors > attention |  | NS |
| Constraints > change factors > walks |  | NS |
| Constraints > relationship factors > acceptance |  | NS |
| Constraints > relationship factors > dogs’ life | ‘concern is when the dog has to retire, how will my child cope?’ | C |
| Constraints > limiting factors > cost | ‘Extra expense for food, vet bills etc’ | U |
| Constraints > limiting factors > holidays |  | NS |
| Constraints > limiting factors > clean |  | NS |
| Constraints > limiting factors > restrictions |  | NS |
| Constraints > no constraints | ‘There are none, the dog is a valuable and much-loved addition to the family’ | U |
| Provide companionship | ‘The dog loves him unconditionally … he’s got that constant companionship’. | U |
| Increase independence | ‘Sleep is much improved; he is willing to stay in a room by himself with [the assistance dog]’. | U |
| Emotional regulation | ‘When he has a panic attack, [the dog] will lay on top of him and give him deep body pressure and it will calm him’. | U |
| Increase confidence | ‘[He] knows that despite who else is up there or who’s looking at him … he can look at [the dog] instead of the 14000 people … it has given him a bit more confidence’. | U |
| Improve communication and sociability | ‘[He] would express his emotions and feelings through [the dog] … like “[the dog] is not liking the music, it’s too loud and scary.” … he is able to tell [mum] something through the dog’. | C |
| Calmness and harmony | ‘Getting dressed, ready and out of the house is a lot easier because [the dog] has her routine’. | C |
| Concerns for child's safety > Lack of fear of danger | “Safety concerns at the moment are Aaron taking off, but since we got Radar (our service dog), that has pretty much gone away. Noah is tethered to Radar anytime we leave the house. So that has helped. But I do worry about him opening the front and side doors at our house. We have trained Radar to bark when Noah goes to either door, which is a great help. But it’s just the scary thought of my son who has no fear, no language, and doesn’t respond to his name...it’s scary to think of him getting out or away from us. Aaron likes to run, especially if he’s not tethered to Radar which is not often. When he is tethered, we can put Radar in a down which helps prevent Aaron from running. He may scream but that’s safer for him. He does like to wander away from us, however, since we got Radar, our service dog, that issue has been mostly resolved. Since getting our service dog, our public life is a bit easier. We can still have meltdowns when out in public, but we are able to walk through stores now. Before our dog this was not an option.” | U |
| Concerns for child's safety > non-compliance | “His focus is on the dog...helps him to focus more on task then move on.” | C |
| Freedom through restraint | He couldn’t believe he was walking up and down the footpath and was looking around. It was the first time that he’d been out walking by himself. Otherwise, he would be in a pusher… it was like the world opened up for him. It was amazing… He was restrained in a way, but it wasn’t a big strap over him in a pusher… he was more free | U |
| Expanding our world | He’s enabling for Bradley. Like we can go places that we would never be able to go without the dog, like a concert for example. He would have been stressed, and still is if I don’t take the dog for whatever reason | U |
| A calming/sensory tool | And every time it got a little bit too much for he would just come back and snuggle into Oscar and stick his head into Oscar’s side and then you could just see, he would just calm down | U |
| “At the end of the day, they're dogs” | Avi likes to eat rocks. He got cut open twice. That was unexpected but it could happen with any dog. At the end of the day, they're dogs | U |
| Friendship and personal growth | He’s her friend, I’ll say her friend because she really only has one. It’s him. She’s had friends that come and go… Whereas Avi doesn’t care less. He’s just her friend. He’s the one that—we’ll come home and find her, curled up in bed, cuddling him | U |
| Benefits > safety | “I know he’s not going to break away from my hand and run out in front of a car. It’s just not possible.” | U |
| Benefits > social and communication | “It’s a good bridge to social interaction with other kids and people in our community.” | U |
| Benefits > emotional and behavioural | “When he is frustrated or needs a break, he can go to her for the emotional support.” | U |
| Benefits > companionship | “love with her is sitting on the couch playing iPad and just petting her head or laying against her.” | C |
| Benefits > constant presence | “kind of like an anchor, [the child’s] routine is built around the dog’s, so she’s always kind of needing to know where he is and he’s always with her.” | C |
| Benefits > attention and learning | “he’s able to be more attentive to everything around him because he’s forced to slow down. He’s paying attention and is able to observe the world around him instead of just trying to go.” | C |
| Benefits > responsibility | “has instilled in [the child] a responsibility for something that he never had before.” | U |
| Benefits > care for another | If [the dog] wants [the child’s] pillow or blanket, [the child] will give it to [the dog]. And he would not give it to me, but he will give it to her. He would provide everything she needs and he would give up anything she wants. | U |
| Benefits > adjunct to clinical therapy | “we have been able to use [the dog] in a few different areas in therapy to kind of help motivate [the child].” | U |
| Benefits > improved sleep | “has been sleeping through the night since day 3 of having [the dog].” | U |
| Benefits > confidence | “self-confidence is the biggest [positive effect]” and “it covers so many things, so many areas of his life.” | U |
| Benefits > involvement in extracurricular activities |  | NS |
| Challenges > time & energy | “having a dog is a big commitment, it’s not a wheelchair, it’s not crutches…we have a living thing that we are taking responsibility for as well.” | U |
| Challenges > public and school access | “It has complicated our school life because it’s pretty new in the school.” | U |
| Challenges > financial responsibility | “It’s actually something I never even imagined doing to be honest, because I thought it’s too expensive, it will take too long.” | U |
| Challenges > dog behavioural issues |  | NS |
| Challenges > sibling jealousy |  | NS |
| Impacts on the family > increased freedom | “we did holidays last summer, a full road trip in a camper. Unheard of before [having the dog], and it was an awesome trip.” | U |
| Impacts on the family > decreased stress | When I take him to the doctor’s office for blood work, he would scream and it was very difficult to do every doctor visit. But if I have [the dog] and she’s sitting there really calmly, she doesn’t mind if [the child] screams or whatever, and that is a reminder to me like, it’s okay if he screams, it is okay, don’t worry about it. | C |
| Impacts on the family > increased family cohesiveness | “kind of embraced autism more easily because of [the dog].” | C |
| Public perceptions and reactions > Feeling less embarrassed by their child’s behaviours and self-conscious about how they are perceived as a parent | When [the child] does have some kind of meltdown in public or any kind of behaviour that would seem abnormal or would normally embarrass me because people are thinking you’re a bad parent or something like that, now it’s like they know there is something more going on, and we get a lot more sympathetic looks rather than annoyed looks. So even that’s made a big difference for me just in my day to day life. | U |
| Public Access Issues: Pioneering for Access Rights | . . .We went into the <restaurant> . . . and I placed an order. <The employee> said, ‘‘Are you going to be taking this to go?,’’ and I said ‘‘No, I’m staying.’’ He said, ‘‘Well you have a dog with you, you know. That might be an issue.’’ I said, ‘‘No, it’s not an issue . . . this is a service dog . . . he’s guaranteed full public access’’ . . . <The employee> tried to cite some issues about the Health Department and I said, ‘‘I appreciate your concerns, but . . . it’s no issue.’’ But that bothered me, you know? In one of the e-mails [from NSD], it said don’t take it personally, but it was the first real issue that I had had and I thought to myself . . . I’m not leaving but I scarfed down my lunch. It was the most unenjoyable lunch I’ve ever had . . . I didn’t look up at the counter, but I’m sure that there were a lot of stares directed my way . . . | U |
| Public Access Issues: Overbearing Social Acknowledgements |  | NS |
| Community Factors: Testing Cultural Diversity | You know we’ve had some pretty serious challenges getting people to accept the dog in public in <this city>. [This city] is very ethnic based, and that’s been a huge obstacle for us . . . Some ethnic backgrounds are terrified of dogs . . . various [groups of people] . . . are terrified. They’re not just a little upset that there’s a dog, I mean the sheer panic. | U |
| Community Factors: Testing the Public School System |  | NS |
| ‘‘Finding the Time’’ and Extra Work | . . It’s the stupid things—it’s the realizing I have to brush him for an hour every day to get this 400 lb of hair off him, so he’s not shedding in clumps in the mall . . . | U |
| Seasonality of Service Dog Placement | The winter time is tough because you can’t do any outdoor work really, especially, I mean, my daughter would much rather just flop to the ground and not participate and you know, you’re out in the snow, and she doesn’t like to be outside to start with unless she’s running in her own backyard, so walking up the street is like, it’s not going to happen. | C |
| Interpreting Dog Behaviour | [The dog] discovered there was a pound of butter on the counter . . . And he promptly ate it . . . It took a while to get that smell out of the carpet. | C |
| Maintaining a Service Dog | I was noticing the other day that he smelt like a dog . . . I gotta do this demonstration with him at the school . . . when am I going to have the time to bath and dry this dog, you know? And not having the money to run him off to a groomer . . .’ cause you know if you spend 50 bucks grooming the dog, it’s 50 bucks I’m not spending on the kids, so . . . I guess I’m bathing and grooming my own dog. So you just, I mean, you don’t mind doing it . . . but you know, not everybody is able to pull this off. | U |
| Considering Family Factors | But this walking with another child . . . with autism, and the service dog you’re still trying to . . . get this relationship working with one son and [the service dog], and yeah, it would be nice to have just the leash and concentrate on that, but I also have to keep my other son walking, so this hand, you know, so uh, you know, so it’s the corrections maybe aren’t coming when they should, because I’m, you know, just [concentrating on other things]. | U |
| Performance: The Service Dog at Work | In harness, he is as proud as proud as could be. His whole stance changes…out of harness, he’s just a dog. | U |
| Physical Factors > physical stress | [Our child] would go 2 days before he would sleep…the poor dog,…he was up constantly…[our child would] be in and out of there every ten minutes and the poor dog was right there beside him because he knows he has to follow him and in and out and in and out, and the poor dog would get exhausted too.…He did a good job…but you could see the look on his face like when am I going to get some sleep too?! | U |
| Physical Factors > maintaining the dog's health |  | NS |
| Physical Factors > rest/recovery time |  | NS |
| Physical factors > The dogs did not object | … [service dog] is so, so tolerant. And [my child] will…sometimes sit on him…and he just, he puts up with it all—it’s quite amazing | U |
| Physical factors > the dogs developed an ability to interpret the child’s behaviour | [The service dog] knows the difference between [her] cries … one, to go away because he’s about to get thumped because she’s angry…when she starts to really cry, he kind of looks at us for direction. Like do I go or do I stay? He just cowers and hides and waits until she stops…but absolutely zero aggression. When [service dog] thinks she’s being too rough on him…he leaves. He somehow knows the different between like a cry of being upset and frustrated…versus [being] …angry about something. He knows when he’s gonna get hit and he should get out of there, and he knows when he should stick around. | U |
| Physical Factors > recreational activities |  | NS |
| Social interactions > companionship | [The other kids in the family] touch [the service dog]. The whole point was that the [other] kids like [the service dog] as well because if it was just, well, it’s [autistic child]’s dog, that would be a lot harder trying to tell the other kids also that you can’t touch the dog, you can’t play with the dog | C |
| Social interactions > social bonding | … in the morning, because he sleeps in [my child]’s room, when I’d go to get him, he’d start jumping, like literally jumping up at me and you know, I’d walk in the door after being out for groceries or whatever and he’d be jumping. I kept thinking, what are you doing? And I couldn’t get him to stop jumping and I didn’t like it. | C |
| Sentinel of Safety | Definitely [the dog]’s there as the bed buddy, you know, and to alert us of issues though the night rather than us lie there with one eye open, both ears . . . and I can get a sounder sleep and that’s helped out immeasurably. I remember the first time we brought the dog home, it was the first time in nine years our son slept through the night. | U |
| Child Companionship and Learning New Skills |  | NS |
| Shifting the Focus from Autistic Child to Service-Dog Companion | This is the first time that something’s been for me. The dog is for the child, but the benefits benefit me, not the child . . . the pressure that’s off me because of the dog outweighs far more than anything else out there. | C |
| Individual Respite, Relaxation, and Family Recreation | For me he relieves a lot of stress. . . . Because I have to walk him, and that time is, you know, exercise is a good down time, right? So that’s really been worth its while. | C |
| Enhancing the Family’s Social Status |  | NS |
| Facilitating Awareness and Education About Autism | The biggest benefit has been that when you’re out in public, the dog generates empathy and support. I never expected that. It’s sort of like standing, you stand up and say, “Yes, yes, I have special needs,” and so you’re really making yourself stand out much more than almost anything else that you could do externally. But, because it’s a dog, people react positively . . . people are drawn to animals, and to see that an animal could help somebody who could benefit from it, it really draws on the heartstrings. And, therefore, the people are much more open to my daughter. They are much more different. They will stand aside and let us move past. It’s quite rare that somebody is annoyed because we are in their way . . . people are more comfortable, more accepting. | U |
| Benefits to the child and the family/caregiver | “I didn’t think I could get Ethan back to school but I think Max has actually given Ethan an element of confidence.” | U |
| Dog ownership required adjustment and was not always as expected | “struggled to develop a really strong bond between Michael and the dog.” | C |
| Community attention was sometimes but not always beneficial | It’s not something you want to be discussing with complete strangers, but everybody asks: Is he your dog? Are you training him? Why have you got him? Who’s he for?” | U |
| Community education about the role of assistance dogs is needed | “You’re trying to stay quite chilled and happy because you are representing assistance dogs and everything like that and trying to educate everyone on it but you definitely get a lot of attention.” | U |
| Lives of every member of the family had been changed | I’m so sorry for the long delay in updating you on Child two and Simon. I can now report on their first month together . . . where to begin! The pictures attached are from the first day of school. Child two objected at first that Simon wasn’t coming to school (and Simon consistently tried to board the bus), but now he accepts that Simon stays home. So here’s a typical day for the two boys: Child two wakes up, showers and dresses, then gets Simon out of the crate at 6:30am. Child two gets Simon fresh water, takes him to the trees, and runs him around the cul-de-sac 3 times, some point at which Simon will poop and Child two will show Dad where to pick up. Child two gets Simon breakfast, and then they eat together. Child two walks Simon out to the bus, where he hands Daddy the leash. When Child two gets home, he comes straight in and checks on Simon. Simon is always on his pillow in the kitchen, and he always barks ‘‘hello.’’ Every afternoon, they head off on a 2.5 mile walk to Juice Zone (one of his afternoon therapists takes them - they understand the rules for curbs and also how to behave in the Juice store). When they get back Simon pillows next to Child two in the play room, and Child two does homework. Then at dinner time, Child two brings Simon down and gives him dinner, and he eats in the kitchen while we’re eating then pillows down. After dinner, Child two, Dad, and sometimes the girls go with Simon outside and do retrieving. Then Child two takes Simon with him to the computer, then to his room to watch TV. At 9:30pm, about half the time Child two will bring Simon out of his room and indicate it’s time for ‘‘Simon sleepy time’’- which means Child two is falling asleep, and he knows the routine is Simon in the crate. The other half the time, they both fall asleep. On the weekend, Simon goes everywhere with Child two, including church, breakfast after church, Home Depot, Costco, girls’ soccer games, dinner out on Saturday, wherever we go - Child two insists on it, no exceptions. | U |