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Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study

Corresponding Author: Louise Burgoyne,

Institution: Department of Epidemiology & Public Health, University College Cork (UCC).

Contact: l.burgoyne@ucc.ie, ph.: 00-353-4205517, fax: 00-353-214205469.

Co-authors

Lisa Dowling, Final Year Medical Student, School of Medicine, UCC

Anthony Fitzgerald, Biostatistician, Department of Epidemiology & Public Health, UCC

Micaela Connolly, Psychologist, Brothers of Charity, Cork.

John Browne, Professor, Department of Epidemiology & Public Health, UCC

Ivan J Perry, Professor & Head of Department of Epidemiology & Public Health, UCC.

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Abstract.

Background: Whilst there is an emerging literature on the usefulness of assistance dogs for children with Autism Spectrum Disorder (ASD), there is a dearth of quantitative data on the value of assistance dogs programmes for the family unit and family functioning.

Objectives: Using previously validated scales and scales developed specifically for this study, we measured parents/guardians perceptions of having an assistance dog on (a) child safety from environmental dangers, (b) public reception of ASD, (c) levels of caregiver strain and sense of competence. We also obtained open ended response data from parents/guardians on benefits and constraints of having an assistance dog.

Primary and Secondary Outcome Measures: The primary outcome measures were scores on environmental hazards and public reception scales. Secondary outcome measures were scores on caregiver strain and competence scales.

Setting: This study was based in the primary care setting, within the context of a specific national assistance dog's programme in the Republic of Ireland.

Participants: A total of 134 parents/guardians with an assistance dog, and 87 from a waiting list control group were surveyed.

Results: Parents/guardians of children who have ASD and an assistance dog rate their child as significantly safer from environmental dangers ($p<0.001$), perceive that the public act more respectfully and responsibly towards their child ($p<0.001$), and feel more competent about managing their child ($p=0.023$) compared to controls. There was an intensity of positive feeling towards assistance dogs programmes. Safety and comfort for children, and a sense of freedom from family restrictions associated with ASD were regarded as the most important benefits of having an assistance dog. The amount of dedication and commitment

required to care for a dog were viewed as the primary constraints. **Conclusions:** Our findings indicate that the assistance dog programmes can be a valuable intervention for families with children who have ASD.

Main Strengths and Limitations of this study

- This study is the first to capture the views of a large group of parents/guardians on an assistance dog's intervention.
- Findings indicate the high value of dogs in promoting safety, security and positive public reception for children with ASD.
- This study assessed the perceptions of waiting list controls as opposed to using a stronger RCT design, where controls are randomly assigned to another intervention.

Introduction

The presence of animals as an intervention tool was first studied by psychotherapist Boris Levinson via a series of case studies. [1] At the time animals were seen as inferior replacements for human social interactions. [2] Since the 1970's animals have been used as a means of improving human physical, emotional, cognitive and social functioning. Animal interventions are classified into three groupings; animal assisted activities (AAA), animal assisted therapies (AAT) and service animal programmes (SAP). [3]

Animal assisted activities are delivered by trained personnel in environments such as hospitals and educational settings with an emphasis on quality of life enhancement via recreation and education e.g., therapeutic horse riding to treat populations with physical and mental disabilities. [4-5] Animal assisted therapies are practiced by professionals with individualised therapy goals. [6] The emphasis is on improvements in physical, social and cognitive functioning. A meta-analysis of the literature on AAT has shown that they are associated with moderate effect sizes in improving outcomes in four areas: autism spectrum symptoms, medical difficulties, behavioural problems, and emotional well-being. [7]

Service animal programmes (SAP) use dogs to assist people with a disability in performing daily activities. Service dogs live in-house with the people they work with. Of late assistance dogs have received growing attention as a means of aiding children with ASD. The presence of a dog has been shown to improve quality of life in children. [8] Social and cognitive benefits in addition to physical and medical benefits have been found. [9-10] Assistance dogs complete a unique triad between parent/guardian and child. Typically the child is attached to the dog via a lead (leash) and belt. The dog walks with the child but

takes commands from the parent (handler). [11] If the child tries to step off a footpath or attempts to bolt, the dog will use all his/her power to slow the child down. Assistance dogs prohibit dangerous behaviour such as elopement (bolting) and provide a calming presence.

Elopement or the tendency to 'bolt' is characteristic of ASD. Such behaviour can result in a child's exposure to dangerous traffic situations or encounters with strangers. [12] Despite reports of higher mortality rates in ASD populations owing to accidents such as suffocation, drowning and injuries, research on elopement behaviour is sparse. [13-15] If left untreated elopement may result in the need for a child to be moved to a restrictive setting. [16] In a systematic review of the literature on current elopement treatments such as function based interventions, Lang and colleagues conveyed that just two of ten studies examined reported complete elimination of elopement. [17] Treatments that effectively eliminate elopement behaviours are warranted.

Social, emotional and behavioural challenges at home and in public mean that parents/guardians of children with ASD experience stress in most areas of their lives. [18-21] In addition to behaviours such as elopement, public tantrums and the reaction from others are regarded as being some of the more difficult aspects of a child with ASD's behaviour. Situations can leave parents/guardians feeling judged as 'bad' parents, or feeling like a failure. [22] In this context assistance dogs can provide a unique support by facilitating child safety and promoting positive public reception.

Currently there are 188 service animal programmes registered with the governing body Assistance Dogs International (ADI). These programmes include guide dogs for the blind,

hearing dogs for the hard of hearing, and service dogs for people with other disabilities including autism. In this study we measured parents/guardians ratings on: (a) the impact of having an assistance dog on child safety from environmental hazards, (b) public acceptance and awareness of autism, (c) sense of competence with managing a child with autism and (d) levels of caregiver strain. We also obtained parents/guardians views on the primary benefits and constraints of having an assistance dog.

Methods

Study Design and Participants

Our study was based in the primary care setting, within the context of a specific national assistance dog's programme in the Republic of Ireland. Parents/guardians with an assistance dog (N=205) and parents/guardians on the waiting list for an assistance dog (N=107) were eligible to take part. Expedited ethical approval was granted from the Clinical Research Ethics Committee of the Cork Teaching Hospitals. Data were gathered between October 2012 and March 2013.

Measures

Parents/guardians were asked to complete a four part questionnaire (Table 1). Part one examined child demographics. Part two measured parents/guardians sense of competence for managing a child with autism using Perceived Competence Scales (PCS) [24] ($\alpha = 0.876$, 7 point scales: low-high competence). It also assessed levels of strain using the Caregiver Strain Questionnaire CGSQ [25] ($\alpha = 0.940$, 5 point scales: low-high strain), which has been validated to assess burden among caregivers of children with autism. [26] Part three examined perceptions of child safety from environmental hazards such as traffic, dangerous materials

and outdoor spaces (α=0.928, 7 point scales: low-high safety/security). Additionally it assessed parents/guardians ratings on the general publics' acceptance of their child (α=0.940, 7 point scales: low-high acceptance). Scales for part three were developed with reference to the format and structure of the Neighbourhood Environment Walkability Scale – Youth [27] , and via consultation with parents and author MC, who is a psychologist specialising in children with autism. Part four asked participants to give their views of the main benefits/constraints of having an assistance dog. Those on the waiting list were asked to give the benefits/constraints that they feel a dog will bring.

Pilot

We piloted the questionnaire with eight parents/guardians, four of which have an assistance dog and four who are on the waiting list. Minor modifications were made to the final questionnaire on the basis of their responses.

Procedures

The primary caregiver from each family with an assistance dog, and each family on the waiting list received a postal questionnaire from the contact person at the assistance dog's centre. In the interests of confidentiality, the researchers at University College Cork did not have access to names and addresses of participants. The assistance dog's centre did not have access to the completed questionnaires. Each questionnaire pack contained a consent form with study details, a questionnaire, a stamped addressed envelope, and an envelope marked 'Research'. Participants were requested to place completed questionnaires in the envelope marked 'Research' and to seal it. They were asked to place the sealed envelope with the signed consent form in the stamped addressed envelope, and to post back to the

assistance dog's centre. Participants were assured that participation in the study would have no impact on their status with the centre.

Data Analysis

Descriptive statistics are reported using frequencies tables. T-tests were used to test for differences within the data on competence, caregiver strain (CGSQ), environmental hazards and public awareness. We adjusted for age, gender, location and type of school attended using a linear regression model. Qualitative data were analysed thematically, coded and cross checked by authors LB and LD.

Results

Demographics

A total of 134 parents/guardians with an assistance dog (65% response), and 87 parents/guardians from the waiting list controls (81% response) completed the questionnaire. A large proportion of participants with a dog have children over the age of ten (40%) compared to just three participants from the waiting list. For this reason we eliminated the 'over tens' from further analysis in this paper.

A breakdown of the demographic characteristics of participants' children is in Table 2. A majority are male (87.5% with dog; 91.7% waiting list) and similar percentages have other medical conditions in addition to ASD (35% with dog; 32.1% waiting list). The largest group live in suburban areas (41.3% with dog; 57% waiting list) followed by the countryside (45% with dog; 34% waiting list). Over half of the children with a dog are verbal (52.5%) and under half of the waiting list controls are verbal (42%). There are differences in types of

school attended between participants whose children have an assistance dog and controls. These are reflective of the remaining age differences between the two groups post removal of the over tens from the total sample. The main difference is that 61.3% of children with a dog attend a special school for ASD compared to 35.7% of waiting list controls. Conversely 34.5% of controls are in a special class in primary school compared to 21.3% who have a dog.

With regard to conventional interventions received there are some descriptive differences between participants whose children have an assistance dog and waiting list controls (Table 2). There is a less than 10% difference between the groups for regular speech and language therapy (47.5% with dog; 38.1% waiting list) and regular occupational therapy (46.3% with dog; 38.1% waiting list). Similar percentages from both groups have a resource teacher (25% with dog; 26.2% waiting list), and there is a 12% difference with regard to special needs assistants (80% with dog; 67.9% waiting list)

There are significant differences between profiles of children who have a dog and waiting list controls with respect to gender, age and schooling. There are no significant differences between the groups for other conditions in addition to ASD, whether a child is verbal or nonverbal, conventional interventions and home location.

Environmental Hazards & Public Awareness

The environmental hazards scales are summarized in Table 4. Ratings are from low perceived safety to high safety. Mean ratings are higher for parents/guardians whose children have a dog (32.43) than for those on the waiting list (22.97). These differences

remain significant after adjustment for gender, age, home location and school type ($p<0.001$). We did however find a significant interaction between school types and whether children have a dog. Although there are significant differences between the rating of parents/guardians with a dog and those on the waiting list for children attending a special school for autism (mean difference=6.62: 95%CI 0.639, 12.61), the effect is not as large as it is for children attending a primary school (mean difference=12.53: 95%CI 4.16, 20.90) or a special class in a primary school (mean difference=19.49: 5%CI 13.171, 25.821).

The range of scores from the public perception scales (Table 3) are from low to high, with higher scores indicating a perception from parents/guardians that people act more respectfully and responsibly towards children with ASD when in public settings. Parents/guardians mean ratings are higher for those whose children have an assistance dog (15.87) than for controls (10.67). For the most part these differences remain significant after adjusting for gender, age, home location and education level ($p<0.001$). However, there was a significant interaction between type of school attended and whether children have an assistance dog. Although there are significant differences between the ratings of parents/guardians with a dog and waiting list controls where their children attend a special school for autism (mean difference=6.65: 95%CI 3.79, 9.51), and a special class in primary school (mean difference=7.01: 95%CI 2.88, 11.13), there is no significant difference in the ratings of parents/guardians who have a child in a main stream primary school ($p=0.09$).

Perceived Competence and Caregiver Strain

A summary of results from parents/guardians perceived competencies with regard to caring for and managing their child with ASD are in Table 3. Mean scores for parents/guardians

whose children have an assistance dog (19.75) show higher perceived competencies than waiting list controls (17.91). This difference remained significant after adjusting for gender, age, home location and education level (p=0.02). Results from the Caregiver Strain Questionnaire (CGSQ) (Table 3) show that parents/guardians rated the questionnaire items similarly. We found no significant differences between the groups with regard to any of the individual items on the scales, or the summarized scores for 'objective strain', 'subjective internalized strain', and 'subjective externalized strain'.

Benefits and Constraints

Qualitative data were analysed using a thematic approach and constant comparison techniques by authors LB and LD. The initial qualitative analysis was performed by LB, and these results were cross-checked and refined by LD. We analysed the first and second listed benefits and constraints of having an assistance dog. Data beyond the first two benefits and constraints are sparse and not reported.

Three themes were identified under 'benefits'. These were; physical factors, relationship factors and family factors (Figure 1). 'Physical factors' is divided into four categories and focuses on how assistance dogs can keep a child safe whilst facilitating parents' ability to manage: *"A sense of security & protection for our daughter especially walking in local environments" (parent of girl 7-9yo with a dog)*, *"(Dog) will stop child from bolting from home" (parent of boy 4-6yo on waiting list)*. For 3 out of 4 categories, this theme is evenly dispersed between parents who have a dog and waiting list controls. For the fourth category 'no bolt', more parents/guardians from the waiting list state the benefit of the dog being able to stop the child from eloping. 'Relationship factors' is grouped into two

categories and centres on the direct positive relationship between the child with ASD and his/her assistance dog: *"She is his very best friend" (parent of boy 4-6yo with a dog), "It might calm him down instead of him head banging the windows" (parent of boy 4-6yo on waiting list).* The categories making up this theme are almost evenly dispersed between parents/guardians who have a dog and waiting list controls. 'Family factors' is split into five categories and is about how day to day family and social life is affected by the introduction of an assistance dog: *"Ability to do maybe ordinary things and go to ordinary places" (parent of boy 7-9yo on waiting list)*, *"a sense of responsibility, for example he can feed the dog" (parent of boy 4-6yo with a dog).* There were differences in the dispersal of this theme among parents/guardians with a dog and those on the waiting list. For example benefits listed by those with a dog formed more of the category 'visibility', which is about public reception and awareness of ASD. Benefits listed by parents/guardians on the waiting list formed more of the categories 'social' and 'emotion and stress'. 'Social' is about a child with ASD's sociability with family and outside the home. 'Emotion and stress' is about levels of emotion/stress in the family, and to a lesser extent the ability of the child to express emotion.

Four themes emerged from the data on constraints. These were; 'change factors', 'relationship factors', 'limiting factors' and 'no constraints' (Figure 2). Change factors has three categories and focuses on life style challenges that parents/guardians experience or anticipate experiencing when they have an assistance dog: *"Its' like an additional child in the family"(parent of boy 4-6yo with a dog), "To make time to go for walks everyday" (parent of boy 7-9yo on waiting list).* The categories comprising this theme are quite evenly dispersed between parents/guardians of children with a dog and those on the waiting list. Slightly

more parents/guardians waiting for a dog list 'dedication', which is the time and effort given to care for the dog as a main constraint. As with the benefits themes, 'relationship factors' is about the direct relationship between the child with ASD and the dog: *"My son may not connect with the dog" (parent of boy 4-6yo on waiting list), "my concern is when the dog has to retire, how will my child cope?" (parent of boy 7-9yo with a dog).* More parents/guardians on the waiting list make up the category 'acceptance', which is concerned about how the dog will be accepted by the child and other family members. The third theme 'limiting factors' has four associated categories and centres on day to day constraints of having a dog on family life; *"Extra expense for food, vet bills etc" (parent of boy 7-9yo with a dog), "it will be a bit difficult to travel" (parent of boy 4-6yo on waiting list).* There are large differences in the dispersal of two of the categories within this theme. In particular, more parents/guardians whose children have a dog contributed to the category 'clean' , which is about day to day hygiene activities related to the dog e.g., dog hair in the house and dealing with dog toileting. More parents/guardians on the waiting list contributed to a category on 'holidays', which expressed concerns about going on holidays with the dog. The final theme 'no constraints' has just one category. This was a category in which parents/guardians stated no issues for concern or anticipated drawbacks; *"There are none….our dog is a valuable and much loved addition to the family" (parent of boy 7-9yo with a dog), "don't anticipate any, feeling very positive about it" (parent of boy 4-6yo on waiting list).* This category was almost evenly dispersed between parents whose children have a dog and those on the waiting list.

Discussion

Our study is the first to capture the views of a large group of parents/guardians on an assistance dog's intervention. Quantitative findings indicate the value of dogs in promoting safety, security and positive public reception for children with ASD. They also suggest that the presence of an assistance dog can make parents/guardians feel more competent with managing their child. Qualitative findings indicate the role assistance dogs play in promoting child safety, calmness and provision of friendship. They also highlight the role the dog has in facilitating 'normal' family functioning, such as being able to visit a shopping centre. Constraints associated with having a dog relate to specific lifestyle changes experienced by parents/guardians and the larger family group, such as dedicated care of the dog.

There are several study limitations. Firstly, our findings are based on self-reports and are subject to participant overestimation and recall bias. Secondly, there were considerable differences in children's ages and type of schools attended between our two sample groups which resulted in removal of the over tens from our analyses and a reduction in sample size. Thirdly we did not assess the views of parents/guardians who do not want an assistance dog for their child. The fourth and main limitation of the study is that we assessed the perceptions of waiting list controls as opposed to using a RCT design, where controls are randomly assigned to another intervention. Such a design was not feasible however and the current data do provide insights.

Recognition of the value animal interventions play in promoting human health is gaining momentum. Animal interventions have been shown to produce increases in self-efficacy and coping in psychiatric patients [28-29] promote recovery from ill health [30, 2, 31], and improve

academic performance, adaptive functioning and behavioural/emotional problems with special education adolescents. [32] Autism spectrum disorder is one of the areas within which animal interventions have had most success. [7] This is particularly the case for assistance dog programmes, since dogs not only provide a possible mechanism for promoting improvements in social and behavioural functioning, they also play a part in control of elopement and promotion of child safety. Once a child is attached to a dog they cannot 'bolt'. In this study parents/guardians with a dog rated their child as considerably more safe from environmental hazards than did waiting list controls. We did find a reportable interaction between having an assistance dog, type of school attended and parents/guardians ratings. This interaction indicated a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for ASD. The smaller effect may be due to the specific care that children and families receive from ASD schools. Currently there are no other interventions that can successfully eliminate elopement among children with ASD. [17] Our quantitative findings authenticate the role of assistance dogs in providing this service. Our qualitative findings provide additional validation with safety and security being the most frequently stated benefit of having a dog.

Behavioural, social and emotional difficulties that encompass the lives of children with ASD can impact on parents/guardians wellbeing. [18-19] Our findings suggest that assistance dogs can provide parents/guardians with a higher sense of competency with regard to managing their child than waiting list controls. This result may reflect added supports dogs provide in public settings. Indeed public tantrums and reactions from the public are regarded as one of the more difficult aspects of a child with ASD's behaviour. [22] Qualitative results from this study highlight the role that an assistance dog has in promoting public awareness and

acceptance of ASD. Quantitative results suggest that parents/guardians whose children have assistance dogs rate the public's perception of their child as more positive. Our regression analysis did show an interaction between having an assistance dog and type of school attended. On examination we found that whilst the ratings of parents/guardians remained significantly different where their children attend a special school for autism or a special class in primary school, they were not significantly so where children attend a main stream primary school. Such a result may reflect a lack of awareness/acceptance of ASD in main stream schools.

Our findings from the caregiver strain questionnaire (CSGQ) show no significant differences between parents/guardians who have a child with a dog and waiting list controls. There are three sub scales within the CGSQ. 'Objective strain' deals with the caregiver burden on day to day tasks related to care, 'subjective internalized strain' deals with negative feelings internal to the caregiver, and 'subjective externalized strain' deals with negative feelings by the caregiver towards the child. We considered two reasons which may explain the lack of any real differences between the groups with regard to caregiver strain. Firstly parents/guardians expressed that the dedication required to care for a dog is a main constraint which may have affected responses on the objective strain scale. Secondly, we noticed that our sample scores on the CSGQ were generally less positive than scores from parents/guardians who took part in the most recent CSGQ validation study. [26] This may reflect a lower provision of services for families of children with autism in the Republic of Ireland. The ability of assistance dogs to provide a sense of calm and comfort for children with ASD is documented. [8, 10] Qualitative results from this study lend support to this view. Parents/guardians with an assistance dog frequently mentioned the dogs' ability to promote

calmness in their child. Those on the waiting list anticipated ways in which the dog would aid their child in times of distress. Previous research has recognised the role that dogs have in facilitating social development in children with ASD. [9, 33- 34] Our qualitative findings point to the idea that assistance dogs can act as a 'bridge' between children and the physical and social environment. However, more parents/guardians on the waiting list for a dog wrote about the anticipated ability of a dog to promote social development in their children than those with a dog. Those with a dog wrote more about the increased public awareness and acceptance of their child as a main benefit. That dogs may facilitate social interaction in children with ASD is not in dispute, but perhaps this role is more suited to the therapy dog (AAT) than the service dog. Parents/guardians listed constraints of having an assistance dog were centred on the lifestyle changes. Such changes include the care and costs required to ensure a dogs' health and wellbeing in addition to the restrictions associated with the dogs' requirements for exercise and companionship. It is important to recognise that each parent/guardian has a different level of tolerance for specific canine behaviours. [35] Whilst many of the parents/guardians in our study discounted the constraints of having a dog, some were explicit about their concerns. More of those with a dog expressed concern about the increase in housekeeping tasks associated with having a dog in house. Parents/guardians with children on the waiting list were more concerned about what to do with the dog during family holiday time.

Conclusions

Our findings indicate that assistance dog programmes are a valuable intervention in the treatment of ASD, particularly in relation to the control of elopement. Dogs help to promote calmness and provide a source of comfort for children. Further research with

stronger designs is required to support the case that assistance dogs can act as facilitators of social and emotional development in children.

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Contributorship Statement

Louise Burgoyne was the lead researcher and was involved in the design, implementation, analysis and reporting of the study.

Lisa Dowling took part of the project as her final year medical project. She was involved in the qualitative analysis and interpretation together with the overall reporting of the study and approval of the manuscript.

Anthony (Tony) Fitzgerald is the study statistician responsible for interpretation of the quantitative data and final approval of the manuscript.

Micaela Connolly is a psychologist specializing in children with autism. She was involved in the study design and was clinical adviser to the group throughout the course of research. She was also involved in the study reporting and approval of the manuscript.

John Browne is a psychologist and health services researcher. He was involved in the study analysis critical review and approval of the manuscript.

Ivan J Perry was the main project supervisor. He was responsible for overseeing the project from start to finish and approved the final manuscript.

Data Sharing Statement

Technical appendix, statistical code, and dataset available from the corresponding author at University College Cork, who will provide a permanent, citable and open access home for the dataset.

Technical appendix, statistical code, and dataset available from the corresponding author at University College Cork, who will provide a permanent, citable and open access home for the dataset.

Competing Interests: None

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Table 1 Questionnaire subsections, details and measures.

Section	Details	Measure
Part 1. Demographics	1. Gender, age, other medical conditions, age of diagnosis, home location. 2. Education, learning level, verbal/non verbal Interventions and therapies received	Tick boxes, yes/no options, free text.
Part 2. Parenting & Autism	1. Perceived competence 2. Caregiver strain questionnaire *Objective strain* *Subjective internalised strain* *Subjective externalised strain*	Four items on a 7-point scale. 21 items on a 5 point scale. *11 items* *6 items* *4 items*
Part 3. Environment & Public	1. Environment safety and security 2. Public Perception	Eight items on a 7-point scale. Four items on a 7-point scale.
Part 4. Benefits & constraints	1. Benefits of having an assistance dog 2. Constraints of having an assistance dog	Free text.

Table 2 Participant Characteristics (With Dog n=80, Waiting list for Dog n=84)

Characteristics		*With Dog N (%)*	*Waiting for Dog N (%)*	*P-value*
Gender	Male	70 (87.5)	77 (91.7)	<0.001
Age	0-6 years	30 (37.5)	60 (71.4)	<0.001
	7-9 years	50 (62.5)	24 (28.6)	
Location	Town/city centre	11 (13.8)	8 (9.0)	0.217
	Suburb	33 (41.3)	47 (57.0)	
	Countryside	36 (45.0)	28 (34.0)	
Other conditions	Yes	47 (35.0)	27 (32.1)	0.767
Verbal	Yes	42 (52.5)	35 (42.0)	0.165
Education	Preschool	0	10 (11.9)	<0.001
	Home tuition	1 (1.0)	4 (5.0)	
	Primary	13 (16.3)	11 (31.1)	
	Special class (Primary)	17 (21.3)	29 (34.5)	
	Special school (ASD)	49 (61.3)	30 (35.7)	
Interventions	Speech and Language	38 (47.5)	32 (38.1)	0.224
	Occupational Therapy	37 (46.3)	32 (38.1)	0.290
	Resource Teacher	20 (25.0)	22 (26.2)	0.861
	Special Needs Assistant	64 (80.0)	57 (67.9)	0.077

Table 3. Summary of results from Environmental Hazards, Public Awareness, Competence and Caregiver Strain scales.

Item	Description	Mean (95%CI)			P-value
		With Dog (n=80)	Waiting Dog (n=84)	Diff* (95% CI)	
HAZ	Environmental Hazards (range 8 -56)	32.43 (29.47: 35.39)	22.97 (20.83: 25.11)	10.9 (6.97, 14.89)	<0.001[1]
PUBLIC	Public Acceptance(range 4 –28)	15.87 (14.23: 17.50)	10.67 (9.56:11.77)	5.80 (3.69, 7.90)	<0.001[2]
SD	Competence (range 4 – 28)	19.75 (18.74:20.77)	17.91 (16.52: 18.92)	1.97 (0.273, 3.68)	0.023
OS	Objective strain (range 11-55)	35.03 (32.81: 37.20)	35.91 (34.08:38.01)	-0.54 (-3.78, 2.70)	0.744
SIS	Subjective Internalised strain (range 6-35)	22.47 (21.21:23.60)	23.63 (22.89:25.03)	-0.81 (-2.63, 1.00)	0.380
SES	Subjective Externalised strain (range 4-20)	7.74 (7.01: 8.46)	7.88 (7.28:8.49)	-0.34 (-1.37, .69)	0.522

*Adjusted for gender, age, location, education

1. There was a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for children with ASD
2. There is no significant difference in ratings of parents/guardians who have a child in a main stream primary school (p=0.09)

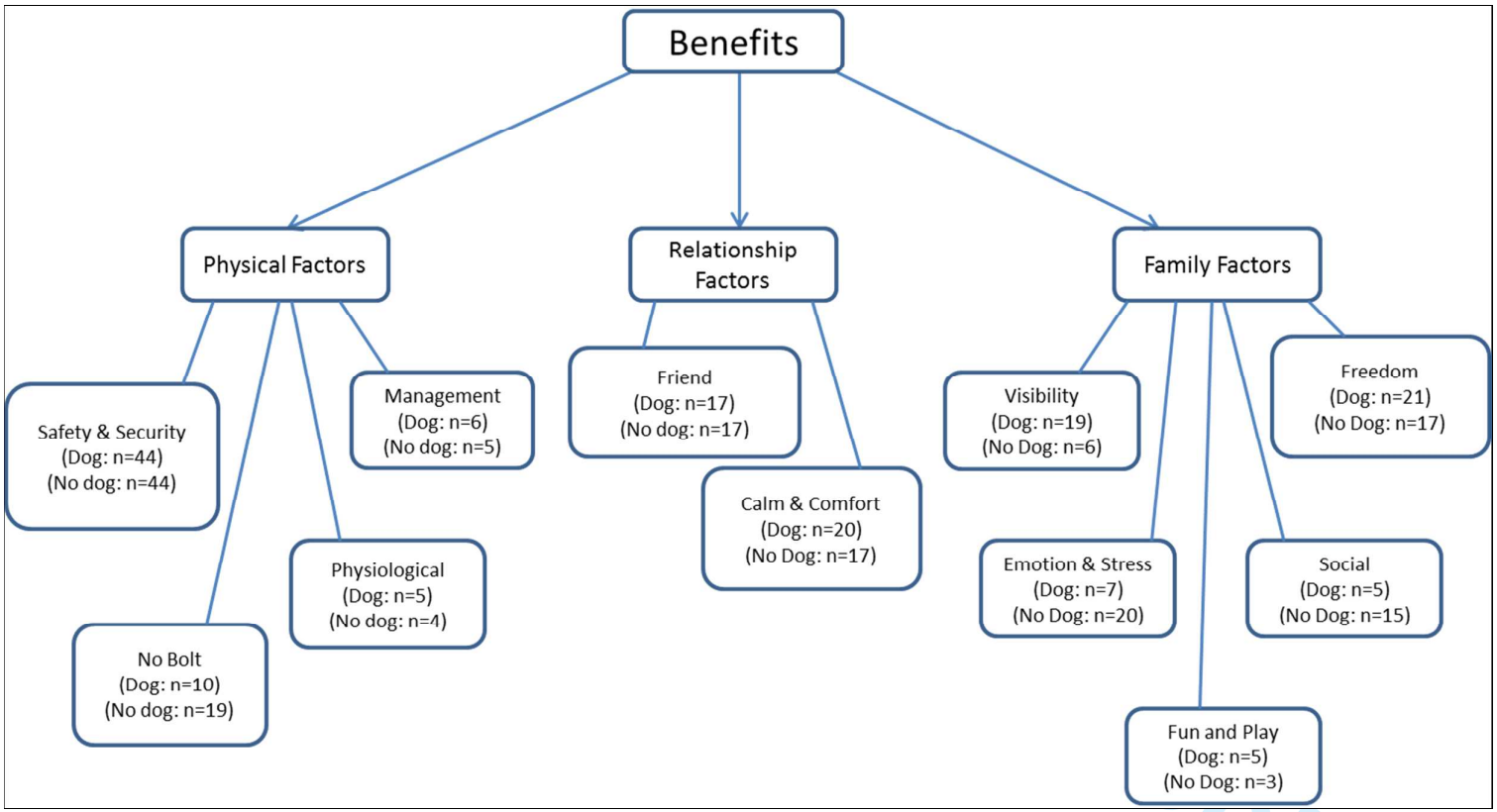

Figure 1 – Benefits of having an assistance dog (themes and categories)

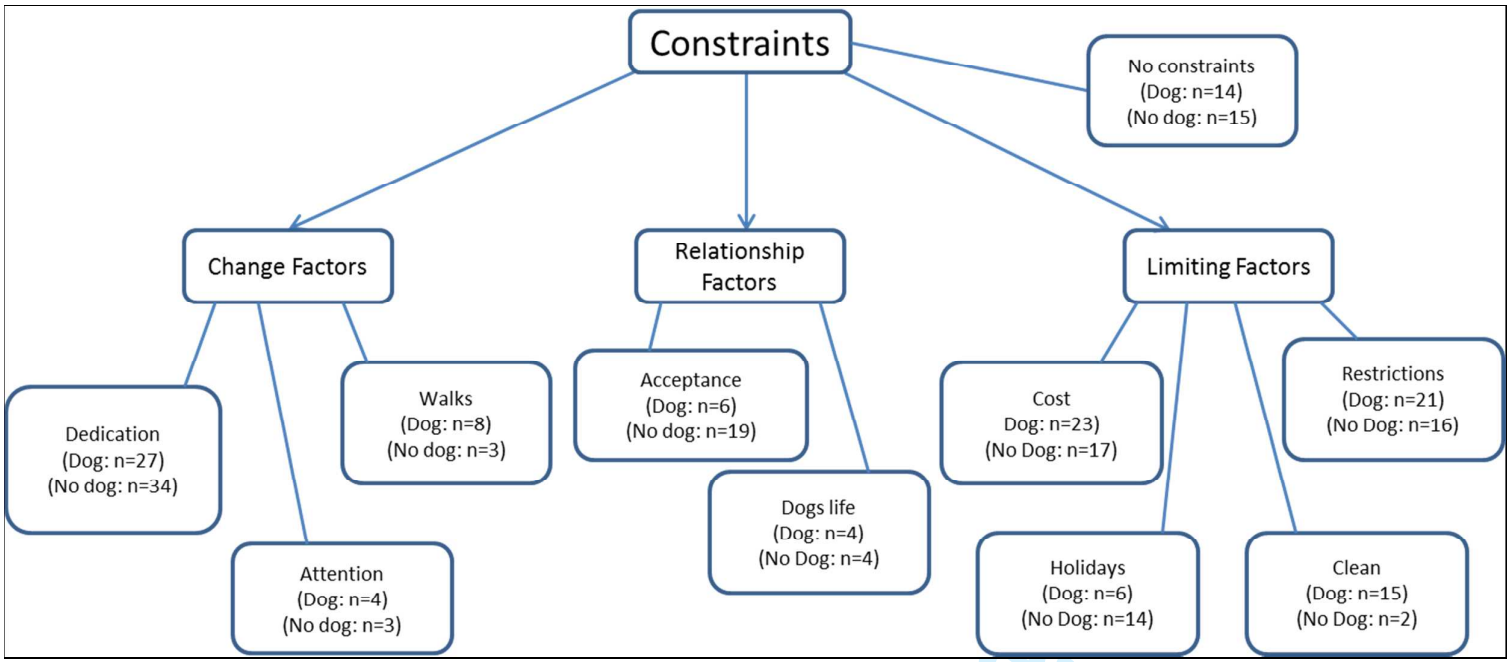

Figure 2 – Constraints of having an assistance dog (themes and categories)

STROBE Statement—parents perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study.

	Item No	Recommendation
Title and abstract	1	(*a*) We have indicated the study's design with a commonly used term in the title
		(*b*) We have provided in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	We have explained the scientific background and rationale for the investigation being reported
Objectives	3	Specific objectives, including any prespecified hypotheses are stated at end of the introduction
Methods		
Study design	4	We have presented key elements of study design early in the paper – details given in Methods section and at end of Introduction.
Setting	5	We have described the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	*Cross-sectional study*—We have given the eligibility criteria, and the sources and methods of selection of participants
Variables	7	We have clearly defined all outcomes, exposures, predictors, potential confounders, and effect modifiers.
Data sources/ measurement	8*	We have provided full descriptions of our measures and assessments in the methods section
Bias	9	We have addressed biases in our procedures section and in our regression analysis - adjusting for key demographic variables.
Study size	10	We sampled the total population of users of a national assistance dog's organisation. Explained in Methods section.
Quantitative variables	11	Data management techniques are described in the data analysis section at end of the Methods.
Statistical methods	12	(*a*) We have described all statistical methods, including those used to control for confounding – in the Methods section.
		(*b*) We have described methods used to examine subgroups and interactions in the Results section.
		(*c*) We had minimal missing data.
		Cross-sectional study—we used data analysis techniques appropriate for comparing two independent groups.
		(*e*) Describe any sensitivity analyses – we did not do a sensitivity analysis.

Continued on next page

Results		
Participants	13*	(a) We have reported numbers of individuals in our cross sectional study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, and analysed
		(b) We omitted the over tens from our analysis for this study – described in Results section.
		(c) We have the maximum of 5 tables and figures included – these were considered essential and so we do not have space for a flow diagram. We are happy to provide one if requested.
Descriptive data	14*	(a) We have given characteristics of the study participants (eg demographic, clinical, social) and information on exposures and potential confounders (start of Results section)
		(b) We had minimal missing data.
Outcome data	15*	
		Cross-sectional study—We have reported the numbers of outcome events or summary measures in the Results section.
Main results	16	(*a*) We have given unadjusted and adjusted means and 95% confidence intervals. We have explained the reasons for adjustment in the results section.
		(*b*) We did not categorise continuous variables.
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period – this was not relevant.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions – main interactions are reported in the Results section and in the Discussion.
Discussion		
Key results	18	We have summarised key results with reference to study objectives
Limitations	19	We have discussed limitations of the study, taking into account sources of potential bias or imprecision.
Interpretation	20	We have given a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	We have discussed the generalisability (external validity) of the study results at the end of the Discussion.
Other information		
Funding	22	This study was not funded from any particular source. It was done at University College Cork and by kind permission of the Irish Guide Dogs for the Blind. They assisted us in contacting their service users. We did not have access to their service users lists. They did not have access to the study data.

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study

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Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study

Corresponding Author: Louise Burgoyne,

Institution: Department of Epidemiology & Public Health, University College Cork (UCC).

Contact: l.burgoyne@ucc.ie, ph.: 00-353-4205517, fax: 00-353-214205469.

Co-authors

Lisa Dowling, Final Year Medical Student, School of Medicine, UCC

Anthony Fitzgerald, Biostatistician, Department of Epidemiology & Public Health, UCC

Micaela Connolly, Psychologist, Brothers of Charity, Cork.

John Browne, Professor, Department of Epidemiology & Public Health, UCC

Ivan J Perry, Professor & Head of Department of Epidemiology & Public Health, UCC.

Key Words

Public Health, Epidemiology, Autism Spectrum Disorders, Assistance Dogs, animal assisted interventions.

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Main Strengths and Limitations of this study

- This study is the first to capture the views of a large group of parents/guardians on an assistance dog intervention.
- Findings suggest that parents perceive a high value in dogs for promoting safety, security and positive public reception for children with ASD.
- This study assessed the perceptions of parents/guardians on the wait list for a dog as opposed to using a stronger randomised control trial (RCT) design, where controls are randomly assigned to another intervention.

Introduction

There is an expanding literature indicating the human mental and physical health benefits derived from interaction with companion animals. [1] The presence of animals as an intervention tool was first studied by psychotherapist Boris Levinson via a series of case studies. [2] At the time animals were seen as inferior replacements for human social interactions. [3] Since the 1970's animals have been used as a means of improving human physical, emotional, cognitive and social functioning. Animal assisted interventions (AAI) are classified into three groupings; animal assisted activities (AAA), animal assisted therapies (AAT) and service animal programmes (SAP). [4]

Animal assisted activities are delivered by trained personnel in environments such as hospitals and educational settings with an emphasis on quality of life enhancement via recreation and education e.g., therapeutic horse riding to treat populations with physical and mental disabilities. [5-6] Animal assisted therapies are practiced by professionals with

individualised therapy goals. [7] The emphasis is on improvements in physical, social and cognitive functioning e.g., an occupational therapist working to facilitate fine motor skills development in a child via a series of structured tasks such as grooming and feeding a cat. A meta-analysis of the literature on AAT has shown that they are associated with moderate effect sizes in improving outcomes in four areas: autism spectrum symptoms, medical difficulties, behavioural problems, and emotional well-being. [8] A recent systematic review of the literature on AAI for ASD has indicated preliminary 'proof of concept', but highlights the needs for more rigorous research to establish a convincing evidence base.[9] This view is upheld by another recent review pointing to the need for better research designs and larger sample sizes. [10]

Service animal interventions (SAP) use dogs to assist people with a disability in performing daily activities. Service dogs live in-house with the people they work with. Of late assistance dogs have received growing attention as a means of aiding children with Autism Spectrum Disorder (ASD) . Qualitative inquiry on the integration of assistance dogs into ten families with a child who has ASD, showed that the presence of a dog can improve quality of life for children and parents. [11] A study examining risks and benefits of assistance dogs using a series of structured interviews with 17 families, reported social and cognitive benefits in addition to physical and medical benefits. [12] An experimental study which assessed the effects of assistance dogs on basal salivary cortisol secretion of 42 children with ASD, demonstrated a reduction in the cortisol awakening response and the number of disruptive behavioural incidents post introduction of the dog. [13] Assistance dogs complete a unique triad between parent/guardian and child. Typically the child is attached to the dog via a lead (leash) and belt. The dog walks with the child but takes commands from the parent

(handler). [14] If the child tries to step off a footpath or attempts to bolt, the dog will use all his/her power to slow the child down. Assistance dogs prohibit dangerous behaviour such as elopement (bolting) and provide a calming presence.

Elopement or the tendency to 'bolt' is characteristic of ASD. Such behaviour can result in a child's exposure to dangerous traffic situations or encounters with strangers. [15] Despite reports of higher mortality rates in ASD populations owing to accidents such as suffocation, drowning and injuries, research on elopement behaviour is sparse. [16-18] If left untreated elopement may result in the need for a child to be moved to a restrictive setting. [19] In a systematic review of the literature on current elopement treatments such as function based interventions, Lang and colleagues conveyed that just two of ten studies examined reported complete elimination of elopement. [20] Treatments that effectively eliminate elopement behaviours are warranted.

Social, emotional and behavioural challenges at home and in public mean that parents/guardians of children with ASD experience stress in most areas of their lives. [21-24] In addition to behaviours such as elopement, public tantrums and the reaction from others are regarded as being some of the more difficult aspects of a child with ASD's behaviour. Situations can leave parents/guardians feeling judged as 'bad' parents, or feeling like a failure. [25] In this context assistance dogs can provide a unique support by facilitating child safety and promoting positive public reception. Outings to public places can become less stressful and families can enjoy greater freedom and mobility. Given the resource implications of assistance dog interventions for ASD, there is a need to assess the value of acceptability and likely uptake of services.

Currently there are 188 service animal interventions registered with the standards body Assistance Dogs International (ADI). These interventions include guide dogs for the blind, hearing dogs for the hard of hearing, and service dogs for people with other disabilities including ASD. In this study we measured parents/guardians ratings on: (a) the impact of having an assistance dog on child safety from environmental hazards, (b) public acceptance and awareness of ASD, (c) sense of competence with managing a child with ASD and (d) levels of caregiver strain. We also obtained parents/guardians views on the primary benefits and constraints of having an assistance dog.

Methods

Study Design and Participants

Our study was based in the primary care setting, within the context of a specific national assistance dog intervention in the Republic of Ireland. All children who receive an assistance dog from this centre have been formally diagnosed with ASD via the Irish Health Services Executive (HSE) using standard tools such as the ADOS (Autism Diagnostic Observation Schedule), the ADI-R (Autism Diagnostic Interview) and the DISCO (Diagnostic Interview for Social Communication). Parents/guardians with an assistance dog (N=205) and parents/guardians on the waiting list for an assistance dog (N=107) were eligible to take part in the study. Expedited ethical approval was granted from the Clinical Research Ethics Committee of the Cork Teaching Hospitals. Data were gathered between October 2012 and March 2013.

Measures

Parents/guardians were asked to complete a four part questionnaire (Table 1). Part one examined child demographics. Part two measured parents/guardians sense of competence for managing a child with ASD using Perceived Competence Scales (PCS) [26] (α = 0.876, 7 point scales: low-high competence). The PCS is a measure of one of three fundamental psychological needs within Self Determination Theory. [27-28] Like other measures within behavioural change theory, items on the PCS are typically written to be specific to the relevant behaviour or domain being examined. A sample item from the PCS we used for this study is 'I am able to do my own routine caring for my child with autism'. Part two also assessed levels of strain using the Caregiver Strain Questionnaire CGSQ [29] (α = 0.940, 5 point scales: low-high strain), which has been validated to assess burden among caregivers of children with autism. [30] The CGSQ asked participants to consider the past 6 months in terms of the problems presented by items such as: 'interruption of personal time resulting from your child's emotional or behavioural problem (Objective Strain)', 'how embarrassed did you feel about your child's emotional or behavioural problem (Subjective Externalised Strain)' and 'How worried did you feel about your child's future (Subjective Internalised Strain)'.

Part three of the questionnaire examined perceptions of child safety from environmental hazards such as traffic, dangerous materials and outdoor spaces (α=0.928, 7 point scales: low-high safety/security). Participants were asked to rate how strongly they agreed or disagreed with respect to their child's safety and security over the past 3 months e.g., 'I am confident that my child with autism is secure from environmental hazards when we go on walks in our neighbourhood.' Part three also assessed parents/guardians ratings on the general publics' acceptance of their child (α=0.940, 7 point scales: low-high acceptance). In

this case participants were asked to rate the public's perception of their child over the past three months on items such as 'I am sure that people make allowances for my child with autism when we are in a restaurant'. Scales for part three were developed with reference to the format and structure of the Neighbourhood Environment Walkability Scale – Youth, [31] and via consultation with parents and author MC, who is a psychologist specialising in children with ASD. Part four asked participants to list their views of the main benefits/constraints of having an assistance dog via 'free text'. Those on the waiting list were asked to give the benefits/constraints that they feel a dog will bring.

Pilot

We piloted the questionnaire with eight parents/guardians, four of which have an assistance dog and four who are on the waiting list. Minor modifications were made to the final questionnaire on the basis of their responses.

Procedures

The primary caregiver from each family with an assistance dog, and each family on the waiting list received a postal questionnaire from the contact person at the assistance dog centre. In the interests of confidentiality, the researchers at University College Cork did not have access to names and addresses of participants. The assistance dog's centre did not have access to the completed questionnaires. Each questionnaire pack contained a consent form with study details, a questionnaire, a stamped addressed envelope, and an envelope marked 'Research'. Participants were requested to place completed questionnaires in the envelope marked 'Research' and to seal it. They were asked to place the sealed envelope together with the signed consent form in the stamped addressed envelope, and to post

back to the assistance dog centre. Participants were assured that participation in the study would have no impact on their status with the centre, and that staff at the centre would have no access to the survey data.

Data Analysis

Descriptive statistics are reported using frequencies tables. Chi Square tests were used to test for differences between the categorical demographic variables. T-tests were used to examine differences between parents of children with an assistance dog and those waiting to receive one, within the data on competence, caregiver strain (CGSQ), environmental hazards and public awareness. We then fitted a linear regression that included having a dog or being on the wait list as a dichotomous variable and each of gender, age, home location and education as factors.

Qualitative data were analysed via open coding, followed by a process of categorisation which facilitated the emergence of themes. Author LB analysed the qualitative data initially and author LD completed a second analysis and cross check.

Results

Demographics

A total of 134 parents/guardians with an assistance dog (65% response), and 87 parents/guardians from the wait list (81% response) completed the questionnaire. A large proportion of participants with a dog have children over the age of ten (40%) compared to

just three participants from the wait list. For this reason we eliminated the 'over tens' from further analysis in this paper.

A breakdown of the demographic characteristics of participants' children is in Table 2. A majority are male (87.5% with dog; 91.7% waiting list) and similar percentages have other medical conditions in addition to ASD (35% with dog; 32.1% wait list). Other conditions include mild to moderate learning difficulties, ADHD, asthma and epilepsy. The largest group live in suburban areas (41.3% with dog; 57% wait list) followed by the countryside (45% with dog; 34% wait list). Over half of the children with a dog are verbal (52.5%) and under half of those waiting for a dog are verbal (42%). There are differences in types of school attended between participants whose children have an assistance dog and those who do not yet have a dog. These are reflective of the remaining age differences between the two groups post removal of the over tens from the total sample. The main difference is that 61.3% of children with a dog attend a special school for ASD compared to 35.7% of the wait list. Conversely 34.5% of children on the wait list are in a special class in primary school compared to 21.3% who have a dog.

With regard to conventional interventions received there are some descriptive differences between participants whose children have an assistance dog and those on the wait list for a dog (Table 2). There is a less than 10% difference between the groups for regular speech and language therapy (47.5% with dog; 38.1% wait list) and regular occupational therapy (46.3% with dog; 38.1% wait list). Similar percentages from both groups have a resource teacher (25% with dog; 26.2% wait list), and there is a 12% difference with regard to special needs assistants (80% with dog; 67.9% wait list)

There are significant differences between profiles of children who have a dog and children waiting for a dog with respect to age and schooling. There are no significant differences between the groups for other conditions in addition to ASD, whether a child is verbal or nonverbal, conventional interventions and home location.

Environmental Hazards & Public Awareness

The environmental hazards scales are summarized in Table 3. Ratings are from low perceived safety to high safety. T-test results showed that mean ratings are significantly higher ($p<0.001$) for parents/guardians whose children have a dog (32.43) than for those on the waiting list (22.97). These differences remain significant after adjusting for gender, age, home location and school type ($p<0.001$). We did however find a significant interaction between school types and whether children have a dog. Although there are significant differences between the rating of parents/guardians with a dog and those on the waiting list for children attending a special school for autism (mean difference=6.62: 95%CI 0.639, 12.61), the effect is not as large as it is for children attending a primary school (mean difference=12.53: 95%CI 4.16, 20.90) or a special class in a primary school (mean difference=19.49: 5%CI 13.171, 25.821).

The range of scores from the public perception scales (Table 3) are from low to high, with higher scores indicating a perception from parents/guardians that people act more respectfully and responsibly towards children with ASD when in public settings. T test results showed that parents/guardians mean ratings are significantly higher ($p<0.001$) for those whose children have an assistance dog (15.87) than for the wait list (10.67). For the

most part these differences remain significant after adjusting for gender, age, home location and education level ($p<0.001$). However, there was a significant interaction between type of school attended and whether children have an assistance dog. Although there are significant differences between the ratings of parents/guardians with a dog and those on the waiting list where their children attend a special school for autism (mean difference=6.65: 95%CI 3.79, 9.51), and a special class in primary school (mean difference=7.01: 95%CI 2.88, 11.13), there is no significant difference in the ratings of parents/guardians who have a child in a main stream primary school ($p=0.09$).

Perceived Competence and Caregiver Strain

A summary of results from parents/guardians perceived competencies with regard to caring for and managing their child with ASD are in Table 3. T-test results show that mean scores for parents/guardians whose children have an assistance dog (19.75), are significantly higher ($p=0.02$) in terms of perceived competencies than those on the waiting list (17.91). This difference remained significant after adjusting for gender, age, home location and education level ($p=0.02$). Results from the Caregiver Strain Questionnaire (CGSQ) (Table 3) show that parents/guardians who have a dog rated slightly lower levels of strain than those on the wait list. However we found no significant differences between the groups with regard to any of the individual items on the scales, or the summarized scores for 'objective strain', 'subjective internalized strain', and 'subjective externalized strain'.

Benefits and Constraints

Qualitative data were analysed using a thematic approach and constant comparison techniques by authors LB and LD. Each participant response was reviewed and codes were assigned to each 'segment of meaning'. Open codes were assigned to representative categories. The process of coding and categorisation facilitated the emergence of themes from within the data. Initial qualitative analysis was performed by LB, and these results were cross-checked and refined by LD. We analysed the first and second listed benefits and constraints of having an assistance dog. Data beyond the first two benefits and constraints are sparse and not reported.

Three themes were identified under 'benefits'. These were; physical factors, relationship factors and family factors (Figure 1). 'Physical factors' is divided into four categories and focuses on how assistance dogs can keep a child safe whilst facilitating parents' ability to manage: *"A sense of security & protection for our daughter especially walking in local environments" (parent of girl 7-9yo with a dog)*, *"(Dog) will stop child from bolting from home" (parent of boy 4-6yo on waiting list)*. For 3 out of 4 categories, this theme is evenly dispersed between parents who have a dog and waiting list controls. For the fourth category 'no bolt', more parents/guardians from the waiting list state the benefit of the dog being able to stop the child from eloping. 'Relationship factors' is grouped into two categories and centres on the direct positive relationship between the child with ASD and his/her assistance dog: *"She is his very best friend" (parent of boy 4-6yo with a dog), "It might calm him down instead of him head banging the windows" (parent of boy 4-6yo on waiting list).* The categories making up this theme are almost evenly dispersed between parents/guardians who have a dog and waiting list controls. 'Family factors' is split into five categories and is about how day to day family and social life is affected by the introduction

of an assistance dog: *"Ability to do maybe ordinary things and go to ordinary places" (parent of boy 7-9yo on waiting list)*, *"a sense of responsibility, for example he can feed the dog" (parent of boy 4-6yo with a dog).* There were differences in the dispersal of this theme among parents/guardians with a dog and those on the waiting list. For example benefits listed by those with a dog formed more of the category 'visibility', which is about public reception and awareness of ASD. Benefits listed by parents/guardians on the waiting list formed more of the categories 'social' and 'emotion and stress'. 'Social' is about a child with ASD's sociability with family and outside the home. 'Emotion and stress' is about levels of emotion/stress in the family, and to a lesser extent the ability of the child to express emotion.

Four themes emerged from the data on constraints. These were; 'change factors', 'relationship factors', 'limiting factors' and 'no constraints' (Figure 2). Change factors has three categories and focuses on life style challenges that parents/guardians experience or anticipate experiencing when they have an assistance dog: *"Its' like an additional child in the family"(parent of boy 4-6yo with a dog), "To make time to go for walks everyday" (parent of boy 7-9yo on waiting list).* The categories comprising this theme are quite evenly dispersed between parents/guardians of children with a dog and those on the waiting list. Slightly more parents/guardians waiting for a dog list 'dedication', which is the time and effort given to care for the dog as a main constraint. As with the benefits themes, 'relationship factors' is about the direct relationship between the child with ASD and the dog: *"My son may not connect with the dog" (parent of boy 4-6yo on waiting list), "my concern is when the dog has to retire, how will my child cope?" (parent of boy 7-9yo with a dog).* More parents/guardians on the waiting list make up the category 'acceptance', which is

concerned about how the dog will be accepted by the child and other family members. The third theme 'limiting factors' has four associated categories and centres on day to day constraints of having a dog on family life; *"Extra expense for food, vet bills etc" (parent of boy 7-9yo with a dog), "it will be a bit difficult to travel" (parent of boy 4-6yo on waiting list).* There are large differences in the dispersal of two of the categories within this theme. In particular, more parents/guardians whose children have a dog contributed to the category 'clean' , which is about day to day hygiene activities related to the dog e.g., dog hair in the house and dealing with dog toileting. More parents/guardians on the waiting list contributed to a category on 'holidays', which expressed concerns about going on holidays with the dog. The final theme 'no constraints' has just one category. This was a category in which parents/guardians stated no issues for concern or anticipated drawbacks; *"There are none….our dog is a valuable and much loved addition to the family" (parent of boy 7-9yo with a dog), "don't anticipate any, feeling very positive about it" (parent of boy 4-6yo on waiting list).* This category was almost evenly dispersed between parents whose children have a dog and those on the waiting list.

Discussion

Our study is the first to capture the views of a large group of parents/guardians on an assistance dog intervention. Quantitative findings indicate the value of dogs in promoting safety, security and positive public reception for children with ASD. They also suggest that the presence of an assistance dog may make parents/guardians feel more competent with managing their child. Qualitative findings indicate the role assistance dogs play in promoting child safety, calmness and provision of friendship. They also highlight the role the dog has in facilitating 'normal' family functioning, such as being able to visit a shopping

centre. Constraints associated with having a dog relate to specific lifestyle changes experienced by parents/guardians and the larger family group, such as dedicated care of the dog.

There are several study limitations. Firstly, our findings are based on self-reports and parents/guardians personal perceptions and are thus subject to participant overestimation, recall bias and possible subject expectancy effects. Also since we did not include any objective measures, we cannot know if parents perceptions reflect reality e.g., were children actually safer and did the public actually view them more positively when accompanied by an assistance dog. Secondly, there were differences in children's ages and type of schools attended between our two sample groups which resulted in removal of the over tens from our analyses and a reduction in sample size. Thirdly we did not assess the views of parents/guardians who are not registered with the assistance dog centre. Our results therefore can only be relevant to parents who are open to the possibility of having an assistance dog. A fourth limitation of the study is that we assessed the perceptions of waiting list controls as opposed to using a RCT design, where controls are randomly assigned to another intervention. Ideally we would employ a planned activity, another animal such as a cat, or a robotic dog as a control. Such a design was not feasible however and the current data do provide insights.

Recognition of the value animal interventions play in promoting human health is gaining momentum. Animal interventions have been shown to produce increases in self-efficacy and coping in psychiatric patients [32-33] promote recovery from ill health [34, 3, 35], and improve academic performance, adaptive functioning and behavioural/emotional problems with

special education adolescents. [36] Autism spectrum disorder is one of the areas within which animal interventions have had most success. [8] This is particularly the case for assistance dog interventions, since dogs not only provide a possible mechanism for promoting improvements in social and behavioural functioning, they also play a part in control of elopement and promotion of child safety. Once a child is attached to a dog via the leash and belt system they cannot 'bolt'. In this study parents/guardians with a dog rated their child as considerably more safe from environmental hazards than did waiting list controls. We did find a reportable interaction between having an assistance dog, type of school attended and parents/guardians ratings. This interaction indicated a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for ASD. The smaller effect may be due to the specific care that children and families receive from ASD schools. Currently there are no interventions that can successfully eliminate elopement among children with ASD. [20] Our quantitative findings support the role of assistance dogs in providing this service. Our qualitative findings provide additional validation with safety and security being the most frequently stated benefit of having a dog.

Behavioural, social and emotional difficulties that encompass the lives of children with ASD can impact on parents/guardians wellbeing. [21-22] Our findings suggest that assistance dogs can provide parents/guardians with a higher sense of competency with regard to managing their child than waiting list controls. This result may reflect added supports dogs provide in public settings. Indeed public tantrums and reactions from the public are regarded as one of the more difficult aspects of a child with ASD's behaviour. [25] Qualitative results from this study highlight the role that an assistance dog has in promoting public awareness and acceptance of ASD. Quantitative results suggest that parents/guardians whose children

have assistance dogs rate the public's perception of their child as more positive. Our regression analysis did show an interaction between having an assistance dog and type of school attended. On examination we found that whilst the ratings of parents/guardians remained significantly different where their children attend a special school for autism or a special class in primary school, they were not significantly so where children attend a main stream primary school. Such a result may reflect a lack of awareness/acceptance of ASD in main stream schools.

Our findings from the caregiver strain questionnaire (CSGQ) show no significant differences between parents/guardians who have a child with a dog, and those waiting to receive a dog. There are three sub scales within the CGSQ. 'Objective strain' deals with the caregiver burden on day to day tasks related to care, 'subjective internalized strain' deals with negative feelings internal to the caregiver, and 'subjective externalized strain' deals with negative feelings by the caregiver towards the child. We considered two reasons which may explain the lack of any real differences between the groups with regard to caregiver strain. Firstly, it is known that being a parent/guardian of a child with ASD can affect quality of life with respect to levels of care and support required, and the resulting impacts on family finance and family time. [37-38] In our study parents/guardians expressed that the dedication required to care for a dog is a main constraint. Assistance dogs require feeding, exercise, affection, grooming, regular company and financial expenditure. The added tasks of looking after an assistance dog may not therefore impact positively upon levels of caregiver strain. Secondly, we noticed that our sample scores on the CSGQ were generally less positive than scores from parents/guardians who took part in the most recent CSGQ validation study. [30] This may reflect a lower provision of services for families of children with autism in the

Republic of Ireland. It is interesting to note that although there were no significant differences between parents/guardians who have a dog and those on the wait list for a dog with respect to caregiver strain, there were significant differences with respect to perceived competence. Why do parents/guardians with a dog feel more competent but no less strained? A possible explanation is that the process and actual event of getting an assistance dog, and the specific procedures followed with respect to working with the dog, may make parents/guardians feel more competent. Having a dog may add more structure to parent's management technique without necessarily reducing levels of strain associated with having a child with ASD.

The ability of assistance dogs to provide a sense of calm and comfort for children with ASD is documented. [11, 13] Qualitative results from this study lend support to this view. Parents/guardians with an assistance dog frequently mentioned the dogs' ability to promote calmness in their child. Those on the waiting list anticipated ways in which the dog would aid their child in times of distress. Previous research has recognised the role that dogs have in facilitating social development in children with ASD. [12, 36 & 39] Our qualitative findings point to the idea that assistance dogs can act as a 'bridge' between children and the physical and social environment. However, more parents/guardians on the waiting list for a dog wrote about the anticipated ability of a dog to promote social development in their children than those with a dog. Those with a dog wrote more about the increased public awareness and acceptance of their child as a main benefit. It may be that although parents waiting for a dog anticipate changes in social interaction, this does not emerge as the most important benefit once they actually get a dog. That assistance dogs may facilitate social interaction in children with ASD is not in dispute. However, this role may be more suited to animal

assisted therapy (AAT), where a trained therapist may work with a dog to reach specific cognitive or behavioural goals for a child. Parents/guardians listed constraints of having an assistance dog were centred on the lifestyle changes. Such changes include the care and costs required to ensure a dogs' health and wellbeing in addition to the restrictions associated with the dogs' requirements for exercise and companionship. It is important to recognise that each parent/guardian has a different level of tolerance for specific canine behaviours. [40] Whilst many of the parents/guardians in our study discounted the constraints of having a dog, some were explicit about their concerns. More of those with an assistance dog expressed concern about the increase in housekeeping tasks, and specific hygiene activities associated with having a dog in the family home. Parents/guardians with children on the wait list were more concerned about whether the dog will be accepted by the child and family, and logistics during family holiday time. Our results suggest that some of the anticipated constraints do not necessarily emerge as the most important constraints once a dog is placed in the home.

Conclusions

Our findings indicate that parents/guardians perceive assistance dog interventions are valuable in the treatment of ASD, particularly in relation to the control of elopement. They also perceive that assistance dogs help to promote calmness and provide a source of comfort for children.

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Table 1 Questionnaire subsections, details and measures.

Section	Details	Measure
Part 1. Demographics	1. Gender, age, other medical conditions, age of diagnosis, home location. 2. Education, learning level, verbal/non verbal Interventions and therapies received	Tick boxes, yes/no options, free text.
Part 2. Parenting & Autism	1. Perceived competence From: Self Determination Theory *Deci & Ryan (1985 & 2000)* 2. Caregiver strain questionnaire *From: Brannan et al (1997) & Khanna et al., (2011)* *Objective strain* *Subjective internalised strain* *Subjective externalised strain*	Four items on a 7-point scale 21 items on a 5 point scale. *11 items* *6 items* *4 items*
Part 3. Environment & Public	1. Environment safety and security Adapted from scale structures: *Rosenberg et al., (2009)* 2. Public Perception	Eight items on a 7-point scale. Four items on a 7-point scale.
Part 4. Benefits & constraints	1. Benefits of having an assistance dog 2. Constraints of having an assistance dog	Free text.

Table 2 Participant Characteristics (With Dog n=80, Waiting list for Dog n=84)

Characteristics		*With Dog N (%)*	*Waiting for Dog N (%)*	*P-value*
Gender	Male	70 (87.5)	77 (91.7)	*
Age	0-6 years	30 (37.5)	60 (71.4)	<0.001
	7-9 years	50 (62.5)	24 (28.6)	
Location	Town/city centre	11 (13.8)	8 (9.0)	0.217
	Suburb	33 (41.3)	47 (57.0)	
	Countryside	36 (45.0)	28 (34.0)	
Other conditions	Yes	24 (30.0)	27 (32.1)	0.767
Verbal	Yes	42 (52.5)	35 (42.0)	0.165
Education	Preschool	0	10 (11.9)	*
	Home tuition	1 (1.0)	4 (5.0)	*
	Primary	13 (16.3)	11 (31.1)	0.025
	Special class (Primary)	17 (21.3)	29 (34.5)	
	Special school (ASD)	49 (61.3)	30 (35.7)	
Interventions	Speech and Language	38 (47.5)	32 (38.1)	0.224
	Occupational Therapy	37 (46.3)	32 (38.1)	0.290
	Resource Teacher	20 (25.0)	22 (26.2)	0.861
	Special Needs Assistant	64 (80.0)	57 (67.9)	0.077

P-values are from valid chi-square tests. *not included in chi-square analysis – numbers do not meet minimum expected count.

Table 3. Summary of results from Environmental Hazards, Public Awareness, Competence and Caregiver Strain scales.

Item	Description	Mean (95%CI)			P-value
		With Dog (n=80)	Waiting Dog (n=84)	Diff* (95% CI)	
HAZ	Environmental Hazards (range 8 -56)	32.43 (29.47: 35.39)	22.97 (20.83: 25.11)	10.9 (6.97, 14.89)	<0.001[1]
PUBLIC	Public Acceptance(range 4 –28)	15.87 (14.23: 17.50)	10.67 (9.56:11.77)	5.80 (3.69, 7.90)	<0.001[2]
SD	Competence (range 4 – 28)	19.75 (18.74:20.77)	17.91 (16.52: 18.92)	1.97 (0.273, 3.68)	0.023
OS	Objective strain (range 11-55)	35.03 (32.81: 37.20)	35.91 (34.08:38.01)	-0.54 (-3.78, 2.70)	0.744
SIS	Subjective Internalised strain (range 6-35)	22.47 (21.21:23.60)	23.63 (22.89:25.03)	-0.81 (-2.63, 1.00)	0.380
SES	Subjective Externalised strain (range 4-20)	7.74 (7.01: 8.46)	7.88 (7.28:8.49)	-0.34 (-1.37, .69)	0.522

*Adjusted for gender, age, location, education

1. There was a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for children with ASD
2. There is no significant difference in ratings of parents/guardians who have a child in a main stream primary school (p=0.09)

Figure 1 – Parents/Guardians perceived benefits of having an assistance dog (themes and categories)

99% of parents/guardians with a dog listed at least two benefits.
99% of parents/guardians on the wait list for a dog listed at least two benefits.
Category 'Physiological' refers to how assistance dogs can facilitate a child with respect to mobility and ambulation.
Category 'Management' refers to how assistance dogs can facilitate day to day management of their child.

Figure 2 – Parents/Guardians perceived constraints of having assistance dog (themes and categories)

66% of parents/guardians with a dog listed at least two constraints.
64% of parents/guardians on the wait list for a dog listed at least two constraints.
*Please note that one category 'other' from the waiting list group second constraint is not included in the figure.
Category 'Dogs life' refers to concerns about what happens when an assistance dog retires/dies.
Category 'Acceptance' refers to challenges around family and children's acceptance of an assistance dog.

Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study

Corresponding Author: Louise Burgoyne,

Institution: Department of Epidemiology & Public Health, University College Cork (UCC).

Contact: l.burgoyne@ucc.ie, ph.: 00-353-4205517, fax: 00-353-214205469.

Co-authors

Lisa Dowling, Final Year Medical Student, School of Medicine, UCC

Anthony Fitzgerald, Biostatistician, Department of Epidemiology & Public Health, UCC

Micaela Connolly, Psychologist, Brothers of Charity, Cork.

John Browne, Professor, Department of Epidemiology & Public Health, UCC

Ivan J Perry, Professor & Head of Department of Epidemiology & Public Health, UCC.

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Abstract.

Background: Whilst there is an emerging literature on the usefulness of assistance dogs for children with Autism Spectrum Disorder (ASD), there is a dearth of quantitative data on the value of assistance dog interventions for the family unit and family functioning. **Objectives:** Using previously validated scales and scales developed specifically for this study, we measured parents/guardians perceptions of having an assistance dog on (a) child safety from environmental dangers, (b) public reception of ASD, (c) levels of caregiver strain and sense of competence. We also obtained open ended response data from parents/guardians on benefits and constraints of having an assistance dog. **Primary and Secondary Outcome Measures:** The primary outcome measures were scores on environmental hazards and public reception scales. Secondary outcome measures were scores on caregiver strain and competence scales. **Setting:** This study was based in the primary care setting, within the context of a specific accredited assistance dog intervention in Ireland. **Participants:** A total of 134 parents/guardians with an assistance dog, and 87 parents of children on the wait list were surveyed. **Results:** Parents/guardians of children who have ASD and an assistance dog rate their child as significantly safer from environmental dangers ($p<0.001$), perceive that the public act more respectfully and responsibly towards their child ($p<0.001$), and feel more competent about managing their child ($p=0.023$) compared to parents on the wait list. There was an intensity of positive feeling towards assistance dog interventions with particular focus on safety and comfort for children, and a sense of freedom from family restrictions associated with ASD. The amount of dedication and commitment required to care for a dog were viewed as the primary constraints. **Conclusions:** Our findings indicate that parents perceive that assistance dog interventions can be a valuable intervention for families with children who have ASD.

Main Strengths and Limitations of this study

- This study is the first to capture the views of a large group of parents/guardians on an assistance dog intervention.
- Findings suggest that parents perceive a high value in dogs for promoting safety, security and positive public reception for children with ASD.
- This study assessed the perceptions of parents/guardians on the wait list for a dog as opposed to using a stronger randomised control trial (RCT) design, where controls are randomly assigned to another intervention.

Introduction

There is an expanding literature indicating the human mental and physical health benefits derived from interaction with companion animals. [1] The presence of animals as an intervention tool was first studied by psychotherapist Boris Levinson via a series of case studies. [2] At the time animals were seen as inferior replacements for human social interactions. [3] Since the 1970's animals have been used as a means of improving human physical, emotional, cognitive and social functioning. Animal assisted interventions (AAI) are classified into three groupings; animal assisted activities (AAA), animal assisted therapies (AAT) and service animal programmes (SAP). [4]

Animal assisted activities are delivered by trained personnel in environments such as hospitals and educational settings with an emphasis on quality of life enhancement via recreation and education e.g., therapeutic horse riding to treat populations with physical and mental disabilities. [5-6] Animal assisted therapies are practiced by professionals with

individualised therapy goals. [7] The emphasis is on improvements in physical, social and cognitive functioning e.g., an occupational therapist working to facilitate fine motor skills development in a child via a series of structured tasks such as grooming and feeding a cat. A meta-analysis of the literature on AAT has shown that they are associated with moderate effect sizes in improving outcomes in four areas: autism spectrum symptoms, medical difficulties, behavioural problems, and emotional well-being. [8] A recent systematic review of the literature on AAI for ASD has indicated preliminary 'proof of concept', but highlights the needs for more rigorous research to establish a convincing evidence base.[9] This view is upheld by another recent review pointing to the need for better research designs and larger sample sizes. [10]

Service animal interventions (SAP) use dogs to assist people with a disability in performing daily activities. Service dogs live in-house with the people they work with. Of late assistance dogs have received growing attention as a means of aiding children with Autism Spectrum Disorder (ASD) . Qualitative inquiry on the integration of assistance dogs into ten families with a child who has ASD, showed that the presence of a dog can improve quality of life for children and parents. [11] A study examining risks and benefits of assistance dogs using a series of structured interviews with 17 families, reported social and cognitive benefits in addition to physical and medical benefits. [12] An experimental study which assessed the effects of assistance dogs on basal salivary cortisol secretion of 42 children with ASD, demonstrated a reduction in the cortisol awakening response and the number of disruptive behavioural incidents post introduction of the dog. [13] Assistance dogs complete a unique triad between parent/guardian and child. Typically the child is attached to the dog via a lead (leash) and belt. The dog walks with the child but takes commands from the parent

(handler). [14] If the child tries to step off a footpath or attempts to bolt, the dog will use all his/her power to slow the child down. Assistance dogs prohibit dangerous behaviour such as elopement (bolting) and provide a calming presence.

Elopement or the tendency to 'bolt' is characteristic of ASD. Such behaviour can result in a child's exposure to dangerous traffic situations or encounters with strangers. [15] Despite reports of higher mortality rates in ASD populations owing to accidents such as suffocation, drowning and injuries, research on elopement behaviour is sparse. [16-18] If left untreated elopement may result in the need for a child to be moved to a restrictive setting. [19] In a systematic review of the literature on current elopement treatments such as function based interventions, Lang and colleagues conveyed that just two of ten studies examined reported complete elimination of elopement. [20] Treatments that effectively eliminate elopement behaviours are warranted.

Social, emotional and behavioural challenges at home and in public mean that parents/guardians of children with ASD experience stress in most areas of their lives. [21-24] In addition to behaviours such as elopement, public tantrums and the reaction from others are regarded as being some of the more difficult aspects of a child with ASD's behaviour. Situations can leave parents/guardians feeling judged as 'bad' parents, or feeling like a failure. [25] In this context assistance dogs can provide a unique support by facilitating child safety and promoting positive public reception. Outings to public places can become less stressful and families can enjoy greater freedom and mobility. Given the resource implications of assistance dog interventions for ASD, there is a need to assess the value of acceptability and likely uptake of services.

Currently there are 188 service animal interventions registered with the standards body Assistance Dogs International (ADI). These interventions include guide dogs for the blind, hearing dogs for the hard of hearing, and service dogs for people with other disabilities including ASD. In this study we measured parents/guardians ratings on: (a) the impact of having an assistance dog on child safety from environmental hazards, (b) public acceptance and awareness of ASD, (c) sense of competence with managing a child with ASD and (d) levels of caregiver strain. We also obtained parents/guardians views on the primary benefits and constraints of having an assistance dog.

Methods

Study Design and Participants

Our study was based in the primary care setting, within the context of a specific national assistance dog intervention in the Republic of Ireland. All children who receive an assistance dog from this centre have been formally diagnosed with ASD via the Irish Health Services Executive (HSE) using standard tools such as the ADOS (Autism Diagnostic Observation Schedule), the ADI-R (Autism Diagnostic Interview) and the DISCO (Diagnostic Interview for Social Communication). Parents/guardians with an assistance dog (N=205) and parents/guardians on the waiting list for an assistance dog (N=107) were eligible to take part in the study. Expedited ethical approval was granted from the Clinical Research Ethics Committee of the Cork Teaching Hospitals. Data were gathered between October 2012 and March 2013.

Measures

Parents/guardians were asked to complete a four part questionnaire (Table 1). Part one examined child demographics. Part two measured parents/guardians sense of competence for managing a child with ASD using Perceived Competence Scales (PCS) [26] (α = 0.876, 7 point scales: low-high competence). The PCS is a measure of one of three fundamental psychological needs within Self Determination Theory. [27-28] Like other measures within behavioural change theory, items on the PCS are typically written to be specific to the relevant behaviour or domain being examined. A sample item from the PCS we used for this study is 'I am able to do my own routine caring for my child with autism'. Part two also assessed levels of strain using the Caregiver Strain Questionnaire CGSQ [29] (α = 0.940, 5 point scales: low-high strain), which has been validated to assess burden among caregivers of children with autism. [30] The CGSQ asked participants to consider the past 6 months in terms of the problems presented by items such as: 'interruption of personal time resulting from your child's emotional or behavioural problem (Objective Strain)', 'how embarrassed did you feel about your child's emotional or behavioural problem (Subjective Externalised Strain)' and 'How worried did you feel about your child's future (Subjective Internalised Strain)'.

Part three of the questionnaire examined perceptions of child safety from environmental hazards such as traffic, dangerous materials and outdoor spaces (α=0.928, 7 point scales: low-high safety/security). Participants were asked to rate how strongly they agreed or disagreed with respect to their child's safety and security over the past 3 months e.g., 'I am confident that my child with autism is secure from environmental hazards when we go on walks in our neighbourhood.' Part three also assessed parents/guardians ratings on the general publics' acceptance of their child (α=0.940, 7 point scales: low-high acceptance). In

this case participants were asked to rate the public's perception of their child over the past three months on items such as 'I am sure that people make allowances for my child with autism when we are in a restaurant'. Scales for part three were developed with reference to the format and structure of the Neighbourhood Environment Walkability Scale – Youth, [31] and via consultation with parents and author MC, who is a psychologist specialising in children with ASD. Part four asked participants to list their views of the main benefits/constraints of having an assistance dog via 'free text'. Those on the waiting list were asked to give the benefits/constraints that they feel a dog will bring.

Pilot

We piloted the questionnaire with eight parents/guardians, four of which have an assistance dog and four who are on the waiting list. Minor modifications were made to the final questionnaire on the basis of their responses.

Procedures

The primary caregiver from each family with an assistance dog, and each family on the waiting list received a postal questionnaire from the contact person at the assistance dog centre. In the interests of confidentiality, the researchers at University College Cork did not have access to names and addresses of participants. The assistance dog's centre did not have access to the completed questionnaires. Each questionnaire pack contained a consent form with study details, a questionnaire, a stamped addressed envelope, and an envelope marked 'Research'. Participants were requested to place completed questionnaires in the envelope marked 'Research' and to seal it. They were asked to place the sealed envelope together with the signed consent form in the stamped addressed envelope, and to post

back to the assistance dog centre. Participants were assured that participation in the study would have no impact on their status with the centre, and that staff at the centre would have no access to the survey data.

Data Analysis

Descriptive statistics are reported using frequencies tables. Chi Square tests were used to test for differences between the categorical demographic variables. T-tests were used to examine differences between parents of children with an assistance dog and those waiting to receive one, within the data on competence, caregiver strain (CGSQ), environmental hazards and public awareness. We then fitted a linear regression that included having a dog or being on the wait list as a dichotomous variable and each of gender, age, home location and education as factors.

Qualitative data were analysed via open coding, followed by a process of categorisation which facilitated the emergence of themes. Author LB analysed the qualitative data initially and author LD completed a second analysis and cross check.

Results

Demographics

A total of 134 parents/guardians with an assistance dog (65% response), and 87 parents/guardians from the wait list (81% response) completed the questionnaire. A large proportion of participants with a dog have children over the age of ten (40%) compared to

just three participants from the wait list. For this reason we eliminated the 'over tens' from further analysis in this paper.

A breakdown of the demographic characteristics of participants' children is in Table 2. A majority are male (87.5% with dog; 91.7% waiting list) and similar percentages have other medical conditions in addition to ASD (35% with dog; 32.1% wait list). Other conditions include mild to moderate learning difficulties, ADHD, asthma and epilepsy. The largest group live in suburban areas (41.3% with dog; 57% wait list) followed by the countryside (45% with dog; 34% wait list). Over half of the children with a dog are verbal (52.5%) and under half of those waiting for a dog are verbal (42%). There are differences in types of school attended between participants whose children have an assistance dog and those who do not yet have a dog. These are reflective of the remaining age differences between the two groups post removal of the over tens from the total sample. The main difference is that 61.3% of children with a dog attend a special school for ASD compared to 35.7% of the wait list. Conversely 34.5% of children on the wait list are in a special class in primary school compared to 21.3% who have a dog.

With regard to conventional interventions received there are some descriptive differences between participants whose children have an assistance dog and those on the wait list for a dog (Table 2). There is a less than 10% difference between the groups for regular speech and language therapy (47.5% with dog; 38.1% wait list) and regular occupational therapy (46.3% with dog; 38.1% wait list). Similar percentages from both groups have a resource teacher (25% with dog; 26.2% wait list), and there is a 12% difference with regard to special needs assistants (80% with dog; 67.9% wait list)

There are significant differences between profiles of children who have a dog and children waiting for a dog with respect to age and schooling. There are no significant differences between the groups for other conditions in addition to ASD, whether a child is verbal or nonverbal, conventional interventions and home location.

Environmental Hazards & Public Awareness

The environmental hazards scales are summarized in Table 3. Ratings are from low perceived safety to high safety. T-test results showed that mean ratings are significantly higher ($p<0.001$) for parents/guardians whose children have a dog (32.43) than for those on the waiting list (22.97). These differences remain significant after adjusting for gender, age, home location and school type ($p<0.001$). We did however find a significant interaction between school types and whether children have a dog. Although there are significant differences between the rating of parents/guardians with a dog and those on the waiting list for children attending a special school for autism (mean difference=6.62: 95%CI 0.639, 12.61), the effect is not as large as it is for children attending a primary school (mean difference=12.53: 95%CI 4.16, 20.90) or a special class in a primary school (mean difference=19.49: 5%CI 13.171, 25.821).

The range of scores from the public perception scales (Table 3) are from low to high, with higher scores indicating a perception from parents/guardians that people act more respectfully and responsibly towards children with ASD when in public settings. T test results showed that parents/guardians mean ratings are significantly higher ($p<0.001$) for those whose children have an assistance dog (15.87) than for the wait list (10.67). For the

most part these differences remain significant after adjusting for gender, age, home location and education level ($p<0.001$). However, there was a significant interaction between type of school attended and whether children have an assistance dog. Although there are significant differences between the ratings of parents/guardians with a dog and those on the waiting list where their children attend a special school for autism (mean difference=6.65: 95%CI 3.79, 9.51), and a special class in primary school (mean difference=7.01: 95%CI 2.88, 11.13), there is no significant difference in the ratings of parents/guardians who have a child in a main stream primary school ($p=0.09$).

Perceived Competence and Caregiver Strain

A summary of results from parents/guardians perceived competencies with regard to caring for and managing their child with ASD are in Table 3. T-test results show that mean scores for parents/guardians whose children have an assistance dog (19.75), are significantly higher ($p=0.02$) in terms of perceived competencies than those on the waiting list (17.91). This difference remained significant after adjusting for gender, age, home location and education level ($p=0.02$). Results from the Caregiver Strain Questionnaire (CGSQ) (Table 3) show that parents/guardians who have a dog rated slightly lower levels of strain than those on the wait list. However we found no significant differences between the groups with regard to any of the individual items on the scales, or the summarized scores for 'objective strain', 'subjective internalized strain', and 'subjective externalized strain'.

Benefits and Constraints

Qualitative data were analysed using a thematic approach and constant comparison techniques by authors LB and LD. Each participant response was reviewed and codes were assigned to each 'segment of meaning'. Open codes were assigned to representative categories. The process of coding and categorisation facilitated the emergence of themes from within the data. Initial qualitative analysis was performed by LB, and these results were cross-checked and refined by LD. We analysed the first and second listed benefits and constraints of having an assistance dog. Data beyond the first two benefits and constraints are sparse and not reported.

Three themes were identified under 'benefits'. These were; physical factors, relationship factors and family factors (Figure 1). 'Physical factors' is divided into four categories and focuses on how assistance dogs can keep a child safe whilst facilitating parents' ability to manage: *"A sense of security & protection for our daughter especially walking in local environments" (parent of girl 7-9yo with a dog), "(Dog) will stop child from bolting from home" (parent of boy 4-6yo on waiting list)*. For 3 out of 4 categories, this theme is evenly dispersed between parents who have a dog and waiting list controls. For the fourth category 'no bolt', more parents/guardians from the waiting list state the benefit of the dog being able to stop the child from eloping. 'Relationship factors' is grouped into two categories and centres on the direct positive relationship between the child with ASD and his/her assistance dog: *"She is his very best friend" (parent of boy 4-6yo with a dog), "It might calm him down instead of him head banging the windows" (parent of boy 4-6yo on waiting list).* The categories making up this theme are almost evenly dispersed between parents/guardians who have a dog and waiting list controls. 'Family factors' is split into five categories and is about how day to day family and social life is affected by the introduction

of an assistance dog: *"Ability to do maybe ordinary things and go to ordinary places" (parent of boy 7-9yo on waiting list)*, *"a sense of responsibility, for example he can feed the dog" (parent of boy 4-6yo with a dog).* There were differences in the dispersal of this theme among parents/guardians with a dog and those on the waiting list. For example benefits listed by those with a dog formed more of the category 'visibility', which is about public reception and awareness of ASD. Benefits listed by parents/guardians on the waiting list formed more of the categories 'social' and 'emotion and stress'. 'Social' is about a child with ASD's sociability with family and outside the home. 'Emotion and stress' is about levels of emotion/stress in the family, and to a lesser extent the ability of the child to express emotion.

Four themes emerged from the data on constraints. These were; 'change factors', 'relationship factors', 'limiting factors' and 'no constraints' (Figure 2). Change factors has three categories and focuses on life style challenges that parents/guardians experience or anticipate experiencing when they have an assistance dog: *"Its' like an additional child in the family"(parent of boy 4-6yo with a dog), "To make time to go for walks everyday" (parent of boy 7-9yo on waiting list).* The categories comprising this theme are quite evenly dispersed between parents/guardians of children with a dog and those on the waiting list. Slightly more parents/guardians waiting for a dog list 'dedication', which is the time and effort given to care for the dog as a main constraint. As with the benefits themes, 'relationship factors' is about the direct relationship between the child with ASD and the dog: *"My son may not connect with the dog" (parent of boy 4-6yo on waiting list), "my concern is when the dog has to retire, how will my child cope?" (parent of boy 7-9yo with a dog).* More parents/guardians on the waiting list make up the category 'acceptance', which is

concerned about how the dog will be accepted by the child and other family members. The third theme 'limiting factors' has four associated categories and centres on day to day constraints of having a dog on family life; *"Extra expense for food, vet bills etc" (parent of boy 7-9yo with a dog), "it will be a bit difficult to travel" (parent of boy 4-6yo on waiting list).* There are large differences in the dispersal of two of the categories within this theme. In particular, more parents/guardians whose children have a dog contributed to the category 'clean' , which is about day to day hygiene activities related to the dog e.g., dog hair in the house and dealing with dog toileting. More parents/guardians on the waiting list contributed to a category on 'holidays', which expressed concerns about going on holidays with the dog. The final theme 'no constraints' has just one category. This was a category in which parents/guardians stated no issues for concern or anticipated drawbacks; *"There are none….our dog is a valuable and much loved addition to the family" (parent of boy 7-9yo with a dog), "don't anticipate any, feeling very positive about it" (parent of boy 4-6yo on waiting list).* This category was almost evenly dispersed between parents whose children have a dog and those on the waiting list.

Discussion

Our study is the first to capture the views of a large group of parents/guardians on an assistance dog intervention. Quantitative findings indicate the value of dogs in promoting safety, security and positive public reception for children with ASD. They also suggest that the presence of an assistance dog may make parents/guardians feel more competent with managing their child. Qualitative findings indicate the role assistance dogs play in promoting child safety, calmness and provision of friendship. They also highlight the role the dog has in facilitating 'normal' family functioning, such as being able to visit a shopping

centre. Constraints associated with having a dog relate to specific lifestyle changes experienced by parents/guardians and the larger family group, such as dedicated care of the dog.

There are several study limitations. Firstly, our findings are based on self-reports and parents/guardians personal perceptions and are thus subject to participant overestimation, recall bias and possible subject expectancy effects. Also since we did not include any objective measures, we cannot know if parents perceptions reflect reality e.g., were children actually safer and did the public actually view them more positively when accompanied by an assistance dog. Secondly, there were differences in children's ages and type of schools attended between our two sample groups which resulted in removal of the over tens from our analyses and a reduction in sample size. Thirdly we did not assess the views of parents/guardians who are not registered with the assistance dog centre. Our results therefore can only be relevant to parents who are open to the possibility of having an assistance dog. A fourth limitation of the study is that we assessed the perceptions of waiting list controls as opposed to using a RCT design, where controls are randomly assigned to another intervention. Ideally we would employ a planned activity, another animal such as a cat, or a robotic dog as a control. Such a design was not feasible however and the current data do provide insights.

Recognition of the value animal interventions play in promoting human health is gaining momentum. Animal interventions have been shown to produce increases in self-efficacy and coping in psychiatric patients [32-33] promote recovery from ill health [34, 3, 35], and improve academic performance, adaptive functioning and behavioural/emotional problems with

special education adolescents. [36] Autism spectrum disorder is one of the areas within which animal interventions have had most success. [8] This is particularly the case for assistance dog interventions, since dogs not only provide a possible mechanism for promoting improvements in social and behavioural functioning, they also play a part in control of elopement and promotion of child safety. Once a child is attached to a dog via the leash and belt system they cannot 'bolt'. In this study parents/guardians with a dog rated their child as considerably more safe from environmental hazards than did waiting list controls. We did find a reportable interaction between having an assistance dog, type of school attended and parents/guardians ratings. This interaction indicated a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for ASD. The smaller effect may be due to the specific care that children and families receive from ASD schools. Currently there are no interventions that can successfully eliminate elopement among children with ASD. [20] Our quantitative findings support the role of assistance dogs in providing this service. Our qualitative findings provide additional validation with safety and security being the most frequently stated benefit of having a dog.

Behavioural, social and emotional difficulties that encompass the lives of children with ASD can impact on parents/guardians wellbeing. [21-22] Our findings suggest that assistance dogs can provide parents/guardians with a higher sense of competency with regard to managing their child than waiting list controls. This result may reflect added supports dogs provide in public settings. Indeed public tantrums and reactions from the public are regarded as one of the more difficult aspects of a child with ASD's behaviour. [25] Qualitative results from this study highlight the role that an assistance dog has in promoting public awareness and acceptance of ASD. Quantitative results suggest that parents/guardians whose children

have assistance dogs rate the public's perception of their child as more positive. Our regression analysis did show an interaction between having an assistance dog and type of school attended. On examination we found that whilst the ratings of parents/guardians remained significantly different where their children attend a special school for autism or a special class in primary school, they were not significantly so where children attend a main stream primary school. Such a result may reflect a lack of awareness/acceptance of ASD in main stream schools.

Our findings from the caregiver strain questionnaire (CSGQ) show no significant differences between parents/guardians who have a child with a dog, and those waiting to receive a dog. There are three sub scales within the CGSQ. 'Objective strain' deals with the caregiver burden on day to day tasks related to care, 'subjective internalized strain' deals with negative feelings internal to the caregiver, and 'subjective externalized strain' deals with negative feelings by the caregiver towards the child. We considered two reasons which may explain the lack of any real differences between the groups with regard to caregiver strain. Firstly, it is known that being a parent/guardian of a child with ASD can affect quality of life with respect to levels of care and support required, and the resulting impacts on family finance and family time. [37-38] In our study parents/guardians expressed that the dedication required to care for a dog is a main constraint. Assistance dogs require feeding, exercise, affection, grooming, regular company and financial expenditure. The added tasks of looking after an assistance dog may not therefore impact positively upon levels of caregiver strain. Secondly, we noticed that our sample scores on the CSGQ were generally less positive than scores from parents/guardians who took part in the most recent CSGQ validation study. [30] This may reflect a lower provision of services for families of children with autism in the

Republic of Ireland. It is interesting to note that although there were no significant differences between parents/guardians who have a dog and those on the wait list for a dog with respect to caregiver strain, there were significant differences with respect to perceived competence. Why do parents/guardians with a dog feel more competent but no less strained? A possible explanation is that the process and actual event of getting an assistance dog, and the specific procedures followed with respect to working with the dog, may make parents/guardians feel more competent. Having a dog may add more structure to parent's management technique without necessarily reducing levels of strain associated with having a child with ASD.

The ability of assistance dogs to provide a sense of calm and comfort for children with ASD is documented. [11, 13] Qualitative results from this study lend support to this view. Parents/guardians with an assistance dog frequently mentioned the dogs' ability to promote calmness in their child. Those on the waiting list anticipated ways in which the dog would aid their child in times of distress. Previous research has recognised the role that dogs have in facilitating social development in children with ASD. [12, 36 & 39] Our qualitative findings point to the idea that assistance dogs can act as a 'bridge' between children and the physical and social environment. However, more parents/guardians on the waiting list for a dog wrote about the anticipated ability of a dog to promote social development in their children than those with a dog. Those with a dog wrote more about the increased public awareness and acceptance of their child as a main benefit. It may be that although parents waiting for a dog anticipate changes in social interaction, this does not emerge as the most important benefit once they actually get a dog. That assistance dogs may facilitate social interaction in children with ASD is not in dispute. However, this role may be more suited to animal

assisted therapy (AAT), where a trained therapist may work with a dog to reach specific cognitive or behavioural goals for a child. Parents/guardians listed constraints of having an assistance dog were centred on the lifestyle changes. Such changes include the care and costs required to ensure a dogs' health and wellbeing in addition to the restrictions associated with the dogs' requirements for exercise and companionship. It is important to recognise that each parent/guardian has a different level of tolerance for specific canine behaviours. [40] Whilst many of the parents/guardians in our study discounted the constraints of having a dog, some were explicit about their concerns. More of those with an assistance dog expressed concern about the increase in housekeeping tasks, and specific hygiene activities associated with having a dog in the family home. Parents/guardians with children on the wait list were more concerned about whether the dog will be accepted by the child and family, and logistics during family holiday time. Our results suggest that some of the anticipated constraints do not necessarily emerge as the most important constraints once a dog is placed in the home.

Conclusions

Our findings indicate that parents/guardians perceive assistance dog interventions are valuable in the treatment of ASD, particularly in relation to the control of elopement. They also perceive that assistance dogs help to promote calmness and provide a source of comfort for children.

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Table 1 Questionnaire subsections, details and measures.

Section	Details	Measure
Part 1. Demographics	1. Gender, age, other medical conditions, age of diagnosis, home location. 2. Education, learning level, verbal/non verbal Interventions and therapies received	Tick boxes, yes/no options, free text.
Part 2. Parenting & Autism	1. Perceived competence From: Self Determination Theory *Deci & Ryan (1985 & 2000)* 2. Caregiver strain questionnaire *From: Brannan et al (1997) & Khanna et al., (2011)* *Objective strain* *Subjective internalised strain* *Subjective externalised strain*	Four items on a 7-point scale 21 items on a 5 point scale. *11 items* *6 items* *4 items*
Part 3. Environment & Public	1. Environment safety and security Adapted from scale structures: *Rosenberg et al., (2009)* 2. Public Perception	Eight items on a 7-point scale. Four items on a 7-point scale.
Part 4. Benefits & constraints	1. Benefits of having an assistance dog 2. Constraints of having an assistance dog	Free text.

Table 2 Participant Characteristics (With Dog n=80, Waiting list for Dog n=84)

Characteristics		*With Dog N (%)*	*Waiting for Dog N (%)*	*P-value*
Gender	Male	70 (87.5)	77 (91.7)	*
Age	0-6 years	30 (37.5)	60 (71.4)	<0.001
	7-9 years	50 (62.5)	24 (28.6)	
Location	Town/city centre	11 (13.8)	8 (9.0)	0.217
	Suburb	33 (41.3)	47 (57.0)	
	Countryside	36 (45.0)	28 (34.0)	
Other conditions	Yes	24 (30.0)	27 (32.1)	0.767
Verbal	Yes	42 (52.5)	35 (42.0)	0.165
Education	Preschool	0	10 (11.9)	*
	Home tuition	1 (1.0)	4 (5.0)	*
	Primary	13 (16.3)	11 (31.1)	0.025
	Special class (Primary)	17 (21.3)	29 (34.5)	
	Special school (ASD)	49 (61.3)	30 (35.7)	
Interventions	Speech and Language	38 (47.5)	32 (38.1)	0.224
	Occupational Therapy	37 (46.3)	32 (38.1)	0.290
	Resource Teacher	20 (25.0)	22 (26.2)	0.861
	Special Needs Assistant	64 (80.0)	57 (67.9)	0.077

P-values are from valid chi-square tests. *not included in chi-square analysis – numbers do not meet minimum expected count.

Table 3. Summary of results from Environmental Hazards, Public Awareness, Competence and Caregiver Strain scales.

Item	Description	Mean (95%CI)			P-value
		With Dog (n=80)	Waiting Dog (n=84)	Diff* (95% CI)	
HAZ	Environmental Hazards (range 8 -56)	32.43 (29.47: 35.39)	22.97 (20.83: 25.11)	10.9 (6.97, 14.89)	<0.001[1]
PUBLIC	Public Acceptance(range 4 –28)	15.87 (14.23: 17.50)	10.67 (9.56:11.77)	5.80 (3.69, 7.90)	<0.001[2]
SD	Competence (range 4 – 28)	19.75 (18.74:20.77)	17.91 (16.52: 18.92)	1.97 (0.273, 3.68)	0.023
OS	Objective strain (range 11-55)	35.03 (32.81: 37.20)	35.91 (34.08:38.01)	-0.54 (-3.78, 2.70)	0.744
SIS	Subjective Internalised strain (range 6-35)	22.47 (21.21:23.60)	23.63 (22.89:25.03)	-0.81 (-2.63, 1.00)	0.380
SES	Subjective Externalised strain (range 4-20)	7.74 (7.01: 8.46)	7.88 (7.28:8.49)	-0.34 (-1.37, .69)	0.522

*Adjusted for gender, age, location, education

1. There was a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for children with ASD
2. There is no significant difference in ratings of parents/guardians who have a child in a main stream primary school (p=0.09)

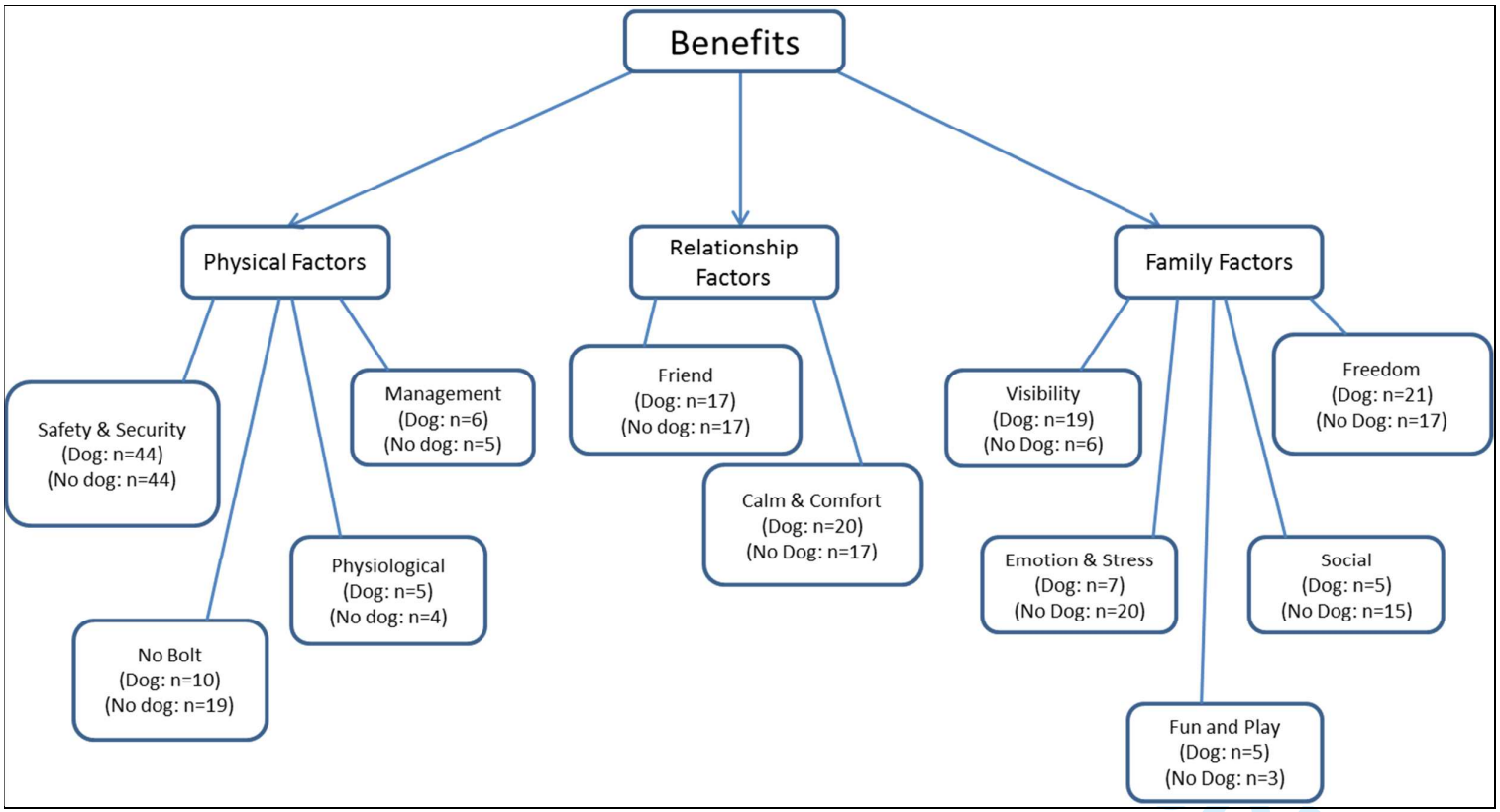


Figure 1 – Parents/Guardians perceived benefits of having an assistance dog (themes and categories)

99% of parents/guardians with a dog listed at least two benefits.
99% of parents/guardians on the wait list for a dog listed at least two benefits.
Category 'Physiological' refers to how assistance dogs can facilitate a child with respect to mobility and ambulation.
Category 'Management' refers to how assistance dogs can facilitate day to day management of their child.

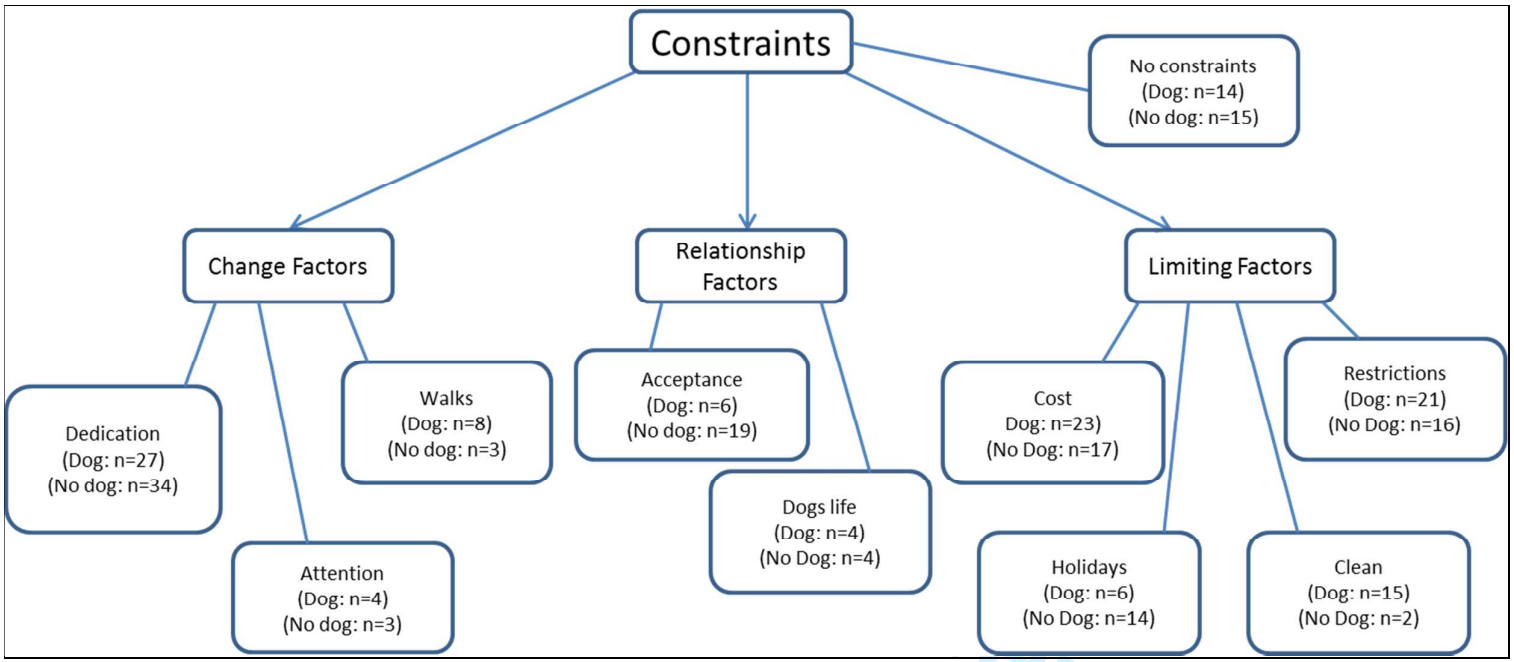


Figure 2 – Parents/Guardians perceived constraints of having assistance dog (themes and categories)

66% of parents/guardians with a dog listed at least two constraints.
64% of parents/guardians on the wait list for a dog listed at least two constraints.
*Please note that one category 'other' from the waiting list group second constraint is not included in the figure.
Category 'Dogs life' refers to concerns about what happens when an assistance dog retires/dies.
Category 'Acceptance' refers to challenges around family and children's acceptance of an assistance dog.

STROBE Statement—parents perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study.

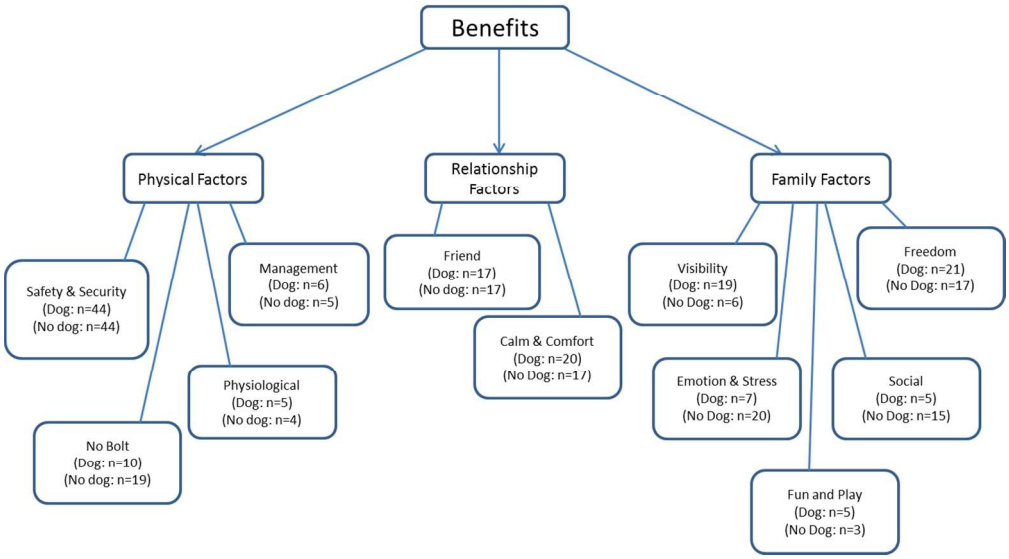
	Item No	Recommendation
Title and abstract	1	(*a*) We have indicated the study's design with a commonly used term in the title
		(*b*) We have provided in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	We have explained the scientific background and rationale for the investigation being reported
Objectives	3	Specific objectives, including any prespecified hypotheses are stated at end of the introduction
Methods		
Study design	4	We have presented key elements of study design early in the paper – details given in Methods section and at end of Introduction.
Setting	5	We have described the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	*Cross-sectional study*—We have given the eligibility criteria, and the sources and methods of selection of participants
Variables	7	We have clearly defined all outcomes, exposures, predictors, potential confounders, and effect modifiers.
Data sources/ measurement	8*	We have provided full descriptions of our measures and assessments in the methods section
Bias	9	We have addressed biases in our procedures section and in our regression analysis - adjusting for key demographic variables.
Study size	10	We sampled the total population of users of a national assistance dog's organisation. Explained in Methods section.
Quantitative variables	11	Data management techniques are described in the data analysis section at end of the Methods.
Statistical methods	12	(*a*) We have described all statistical methods, including those used to control for confounding – in the Methods section.
		(*b*) We have described methods used to examine subgroups and interactions in the Results section.
		(*c*) We had minimal missing data.
		Cross-sectional study—we used data analysis techniques appropriate for comparing two independent groups.
		(*e*) Describe any sensitivity analyses – we did not do a sensitivity analysis.

Continued on next page

Results		
Participants	13*	(a) We have reported numbers of individuals in our cross sectional study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, and analysed
		(b) We omitted the over tens from our analysis for this study – described in Results section.
		(c) We have the maximum of 5 tables and figures included – these were considered essential and so we do not have space for a flow diagram. We are happy to provide one if requested.
Descriptive data	14*	(a) We have given characteristics of the study participants (eg demographic, clinical, social) and information on exposures and potential confounders (start of Results section)
		(b) We had minimal missing data.
Outcome data	15*	
		Cross-sectional study—We have reported the numbers of outcome events or summary measures in the Results section.
Main results	16	(*a*) We have given unadjusted and adjusted means and 95% confidence intervals. We have explained the reasons for adjustment in the results section.
		(*b*) We did not categorise continuous variables.
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period – this was not relevant.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions – main interactions are reported in the Results section and in the Discussion.
Discussion		
Key results	18	We have summarised key results with reference to study objectives
Limitations	19	We have discussed limitations of the study, taking into account sources of potential bias or imprecision.
Interpretation	20	We have given a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	We have discussed the generalisability (external validity) of the study results at the end of the Discussion.
Other information		
Funding	22	This study was not funded from any particular source. It was done at University College Cork and by kind permission of the Irish Guide Dogs for the Blind. They assisted us in contacting their service users. We did not have access to their service users lists. They did not have access to the study data.

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.



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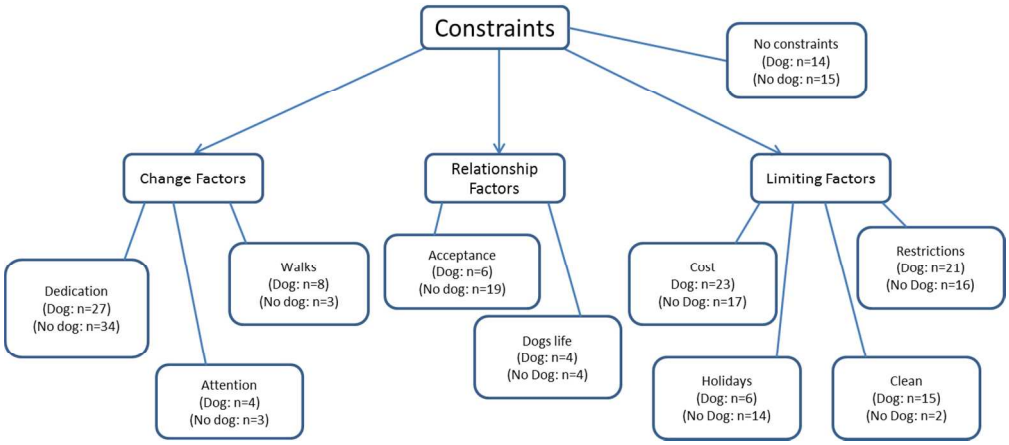

Figure 2 – Parents/Guardians perceived constraints of having assistance dog (themes and categories)

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64% of parents/guardians on the wait list for a dog listed at least two constraints.
*Please note that one category 'other' from the waiting list group second constraint is not included in the figure.
Category 'Dogs life' refers to concerns about what happens when an assistance dog retires/dies.
Category 'Acceptance' refers to challenges around family and children's acceptance of an assistance dog.

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BMJ Open

Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study

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Keywords:	EPIDEMIOLOGY, PUBLIC HEALTH, PRIMARY CARE

Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study

Corresponding Author: Louise Burgoyne,

Institution: Department of Epidemiology & Public Health, University College Cork (UCC).

Contact: l.burgoyne@ucc.ie, ph.: 00-353-4205517, fax: 00-353-214205469.

Co-authors

Lisa Dowling, Final Year Medical Student, School of Medicine, UCC

Anthony Fitzgerald, Biostatistician, Department of Epidemiology & Public Health, UCC

Micaela Connolly, Psychologist, Brothers of Charity, Cork.

John Browne, Professor, Department of Epidemiology & Public Health, UCC

Ivan J Perry, Professor & Head of Department of Epidemiology & Public Health, UCC.

Key Words

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ABSTRACT

Objectives: Whilst there is an emerging literature on the usefulness of assistance dogs for children with Autism Spectrum Disorder (ASD), there is a dearth of quantitative data on the value of assistance dog interventions for the family unit and family functioning. Using previously validated scales and scales developed specifically for this study, we measured parents/guardians perceptions of having an assistance dog on (a) child safety from environmental dangers, (b) public reception of ASD, (c) levels of caregiver strain and sense of competence. We also obtained open ended response data from parents/guardians on benefits and constraints of having an assistance dog.

Setting: This study was based in the primary care setting, within the context of a specific accredited assistance dog centre in Ireland. Participants: A total of 134 parents/guardians with an assistance dog, and 87 parents of children on the wait list were surveyed.

Primary and Secondary Outcome Measures: The primary outcome measures were scores on environmental hazards and public reception scales. Secondary outcome measures were scores on caregiver strain and competence scales.

Results: Parents/guardians of children who have ASD and an assistance dog rate their child as significantly safer from environmental dangers ($p<0.001$), perceive that the public act more respectfully and responsibly towards their child ($p<0.001$), and feel more competent about managing their child ($p=0.023$) compared to parents on the wait list. There was a concentration of positive feeling towards assistance dog interventions with particular focus on safety and comfort for children, and a sense of freedom from family restrictions associated with ASD. The amount of dedication and commitment required to care for a dog were viewed as the primary constraints.

Conclusions: Our findings indicate that parents perceive that assistance dog interventions can be a valuable intervention for families with children who have ASD.

Main Strengths and Limitations of this study

- This study is the first to capture the views of a large group of parents/guardians on an assistance dog intervention.
- Findings suggest that parents perceive a high value in dogs for promoting safety, security and positive public reception for children with ASD.
- This study assessed the perceptions of parents/guardians on the wait list for a dog as opposed to using a stronger randomised control trial (RCT) design, where controls are randomly assigned to another intervention.

Introduction

There is an expanding literature indicating the human mental and physical health benefits derived from interaction with companion animals. [1] The presence of animals as an intervention tool was first studied by psychotherapist Boris Levinson via a series of case studies. [2] At the time animals were seen as inferior replacements for human social interactions. [3] Since the 1970's animals have been used as a means of improving human physical, emotional, cognitive and social functioning. Animal assisted interventions (AAI) are classified into three groupings; animal assisted activities (AAA), animal assisted therapies (AAT) and service animal programmes (SAP). [4]

Animal assisted activities are delivered by trained personnel in environments such as hospitals and educational settings with an emphasis on quality of life enhancement via recreation and education e.g., therapeutic horse riding to treat populations with physical and mental disabilities. [5-6] Animal assisted therapies are practiced by professionals with individualised therapy goals. [7] The emphasis is on improvements in physical, social and cognitive functioning e.g., an occupational therapist working to facilitate fine motor skills development in a child via a series of structured tasks such as grooming and feeding a cat. A meta-analysis of the literature on AAT has shown that they are associated with moderate effect sizes in improving outcomes in four areas: autism spectrum symptoms, medical difficulties, behavioural problems, and emotional well-being. [8] A recent systematic review of the literature on AAI for ASD has indicated preliminary 'proof of concept', but highlights the needs for more rigorous research to establish a convincing evidence base. [9] This view is

upheld by another recent review pointing to the need for better research designs and larger sample sizes. [10]

Service animal interventions (SAP) use dogs to assist people with a disability in performing daily activities. Service dogs live in-house with the people they work with. Of late assistance dogs have received growing attention as a means of aiding children with Autism Spectrum Disorder (ASD) . Qualitative inquiry on the integration of assistance dogs into ten families with a child who has ASD, showed that the presence of a dog can improve quality of life for children and parents. [11] A study examining risks and benefits of assistance dogs using a series of structured interviews with 17 families, reported social and cognitive benefits in addition to physical and medical benefits. [12] An experimental study which assessed the effects of assistance dogs on basal salivary cortisol secretion of 42 children with ASD, demonstrated a reduction in the cortisol awakening response and the number of disruptive behavioural incidents post introduction of the dog. [13] Assistance dogs complete a unique triad between parent/guardian and child. Typically the child is attached to the dog via a lead (leash) and belt. The dog walks with the child but takes commands from the parent (handler). [14] If the child tries to step off a footpath or attempts to bolt, the dog will use all his/her power to slow the child down. Assistance dogs prohibit dangerous behaviour such as elopement (bolting) and provide a calming presence.

Elopement or the tendency to 'bolt' is characteristic of ASD. Such behaviour can result in a child's exposure to dangerous traffic situations or encounters with strangers. [15] Despite reports of higher mortality rates in ASD populations owing to accidents such as suffocation, drowning and injuries, research on elopement behaviour is sparse. [16-18] If left untreated

elopement may result in the need for a child to be moved to a restrictive setting. [19] In a systematic review of the literature on current elopement treatments such as function based interventions, Lang and colleagues conveyed that just two of ten studies examined reported complete elimination of elopement. [20] Treatments that effectively eliminate elopement behaviours are warranted.

Social, emotional and behavioural challenges at home and in public mean that parents/guardians of children with ASD experience stress in most areas of their lives. [21-24] In addition to behaviours such as elopement, public tantrums and the reaction from others are regarded as being some of the more difficult aspects of a child with ASD's behaviour. Situations can leave parents/guardians feeling judged as 'bad' parents, or feeling like a failure. [25] In this context assistance dogs can provide a unique support by facilitating child safety and promoting positive public reception. Outings to public places can become less stressful and families can enjoy greater freedom and mobility. Given the resource implications of assistance dog interventions for ASD, there is a need to assess the value of acceptability and likely uptake of services.

Currently there are 188 service animal interventions registered with the standards body Assistance Dogs International (ADI). These interventions include guide dogs for the blind, hearing dogs for the hard of hearing, and service dogs for people with other disabilities including ASD. In this study we measured parents/guardians ratings on: (a) the impact of having an assistance dog on child safety from environmental hazards, (b) public acceptance and awareness of ASD, (c) sense of competence with managing a child with ASD and (d)

levels of caregiver strain. We also obtained parents/guardians views on the primary benefits and constraints of having an assistance dog.

Methods

Study Design and Participants

Our study was based in the primary care setting, within the context of a specific national assistance dog intervention in the Republic of Ireland. All children who receive an assistance dog from this centre have been formally diagnosed with ASD via the Irish Health Services Executive (HSE) using standard tools such as the ADOS (Autism Diagnostic Observation Schedule), the ADI-R (Autism Diagnostic Interview) and the DISCO (Diagnostic Interview for Social Communication). Outside formal diagnosis, certain conditions such having a child with particularly strong aggression issues may preclude participation on the assistance dog programme.

Parents/guardians with an assistance dog (N=205) and parents/guardians on the waiting list for an assistance dog (N=107) were eligible to take part in the study. Expedited ethical approval was granted from the Clinical Research Ethics Committee of the Cork Teaching Hospitals. Data were gathered between October 2012 and March 2013.

Measures

Parents/guardians were asked to complete a four part questionnaire (Table 1). Part one examined child demographics. Part two measured parents/guardians sense of competence for managing a child with ASD using Perceived Competence Scales (PCS) [26] ($\alpha = 0.876$, 7 point scales: low-high competence). The PCS is a measure of one of three fundamental

psychological needs within Self Determination Theory. [27-28] Like other measures within behavioural change theory, items on the PCS are typically written to be specific to the relevant behaviour or domain being examined. A sample item from the PCS we used for this study is 'I am able to do my own routine caring for my child with autism'. Part two also assessed levels of strain using the Caregiver Strain Questionnaire CGSQ [29] (α = 0.940, 5 point scales: low-high strain), which has been validated to assess burden among caregivers of children with autism. [30] The CGSQ asked participants to consider the past 6 months in terms of the problems presented by items such as: 'interruption of personal time resulting from your child's emotional or behavioural problem (Objective Strain)', 'how embarrassed did you feel about your child's emotional or behavioural problem (Subjective Externalised Strain)' and 'How worried did you feel about your child's future (Subjective Internalised Strain)'.

Part three of the questionnaire examined perceptions of child safety from environmental hazards such as traffic, dangerous materials and outdoor spaces (α=0.928, 7 point scales: low-high safety/security). Participants were asked to rate how strongly they agreed or disagreed with respect to their child's safety and security over the past 3 months e.g., 'I am confident that my child with autism is secure from environmental hazards when we go on walks in our neighbourhood.' Part three also assessed parents/guardians ratings on the general publics' acceptance of their child (α=0.940, 7 point scales: low-high acceptance). In this case participants were asked to rate the public's perception of their child over the past three months on items such as 'I am sure that people make allowances for my child with autism when we are in a restaurant'. Scales for part three were developed with reference to the format and structure of the Neighbourhood Environment Walkability Scale – Youth, [31]

and via consultation with parents and author MC, who is a psychologist specialising in children with ASD. Part four asked participants to list their views of the main benefits/constraints of having an assistance dog via 'free text'. Those on the waiting list were asked to give the benefits/constraints that they feel a dog will bring.

Pilot

We piloted the questionnaire with eight parents/guardians, four of which have an assistance dog and four who are on the waiting list. Minor modifications were made to the final questionnaire on the basis of their responses.

Procedures

The primary caregiver from each family with an assistance dog, and each family on the waiting list received a postal questionnaire from the contact person at the assistance dog centre. In the interests of confidentiality, the researchers at University College Cork did not have access to names and addresses of participants. The assistance dog's centre did not have access to the completed questionnaires. Each questionnaire pack contained a consent form with study details, a questionnaire, a stamped addressed envelope, and an envelope marked 'Research'. Participants were requested to place completed questionnaires in the envelope marked 'Research' and to seal it. They were asked to place the sealed envelope together with the signed consent form in the stamped addressed envelope, and to post back to the assistance dog centre. Participants were assured that participation in the study would have no impact on their status with the centre, and that staff at the centre would have no access to the survey data.

Data Analysis

Descriptive statistics are reported using frequencies tables. Chi Square tests were used to test for differences between the categorical demographic variables. T-tests were used to examine differences between parents of children with an assistance dog and those waiting to receive one, within the data on competence, caregiver strain (CGSQ), environmental hazards and public awareness. We then fitted a linear regression that included having a dog or being on the wait list as a dichotomous variable and each of gender, age, home location and education as factors.

Qualitative data were analysed via open coding, followed by a process of categorisation which facilitated the emergence of themes. Author LB analysed the qualitative data initially and author LD completed a second analysis and cross check.

Results

Demographics

A total of 134 parents/guardians with an assistance dog (65% response), and 87 parents/guardians from the wait list (81% response) completed the questionnaire. A large proportion of participants with a dog have children over the age of ten (40%) compared to just three participants from the wait list. For this reason we eliminated the 'over tens' from further analysis in this paper.

A breakdown of the demographic characteristics of participants' children is in Table 2. A majority are male (87.5% with dog; 91.7% wait list) and similar percentages have other medical conditions in addition to ASD (35% with dog; 32.1% wait list). Other conditions include mild to moderate learning difficulties, ADHD, asthma and epilepsy. The largest group live in suburban areas (41.3% with dog; 57% wait list) followed by the countryside (45% with dog; 34% wait list). Over half of the children with a dog are verbal (52.5%) and under half of those waiting for a dog are verbal (42%). There are differences in types of school attended between participants whose children have an assistance dog and those who do not yet have a dog. These are reflective of the remaining age differences between the two groups post removal of the over tens from the total sample. The main difference is that 61.3% of children with a dog attend a special school for ASD compared to 35.7% of the wait list. Conversely 34.5% of children on the wait list are in a special class in a main stream primary school compared to 21.3% who have a dog.

With regard to conventional interventions received there are some descriptive differences between participants whose children have an assistance dog and those on the wait list for a dog (Table 2). There is a less than 10% difference between the groups for regular speech and language therapy (47.5% with dog; 38.1% wait list) and regular occupational therapy (46.3% with dog; 38.1% wait list). Similar percentages from both groups have a resource teacher (25% with dog; 26.2% wait list), and there is a 12% difference with regard to special needs assistants (80% with dog; 67.9% wait list)

There are significant differences between profiles of children who have a dog and children waiting for a dog with respect to age and schooling. There are no significant differences

between the groups for other conditions in addition to ASD, whether a child is verbal or nonverbal, conventional interventions and home location.

Environmental Hazards & Public Awareness

The environmental hazards scales are summarized in Table 3 and details of individual items are in Supplementary Table 1. Ratings are from low perceived safety to high safety. T-test results showed that mean ratings are significantly higher ($p<0.001$) for parents/guardians whose children have a dog (32.43) than for those on the waiting list (22.97). These differences remain significant after adjusting for gender, age, home location and school type ($p<0.001$). We did however find a significant interaction between school types and whether children have a dog. Although there are significant differences between the rating of parents/guardians with a dog and those on the waiting list for children attending a special school for autism (mean difference=6.62: 95%CI 0.639, 12.61), the effect is not as large as it is for children attending a primary school (mean difference=12.53: 95%CI 4.16, 20.90) or a special class in a primary school (mean difference=19.49: 5%CI 13.171, 25.821).

The range of scores from the public perception scales (Table 3 and Supplementary Table 2) are from low to high, with higher scores indicating a perception from parents/guardians that people act more respectfully and responsibly towards children with ASD when in public settings. T test results showed that parents/guardians mean ratings are significantly higher ($p<0.001$) for those whose children have an assistance dog (15.87) than for the wait list (10.67). For the most part these differences remain significant after adjusting for gender, age, home location and education level ($p<0.001$). However, there was a significant interaction between type of school attended and whether children have an assistance dog.

Although there are significant differences between the ratings of parents/guardians with a dog and those on the waiting list where their children attend a special school for autism (mean difference=6.65: 95%CI 3.79, 9.51), and a special class in primary school (mean difference=7.01: 95%CI 2.88, 11.13), there is no significant difference in the ratings of parents/guardians who have a child in a main stream primary school (p=0.09).

Perceived Competence and Caregiver Strain

A summary of results from parents/guardians perceived competencies with regard to caring for and managing their child with ASD are in Table 3. Details of individual items are in Supplementary Table 2. T-test results show that mean scores for parents/guardians whose children have an assistance dog (19.75), are significantly higher (p=0.
02) in terms of perceived competencies than those on the waiting list (17.91). This difference remained significant after adjusting for gender, age, home location and education level (p=0.02). Results from the Caregiver Strain Questionnaire (CGSQ) (Table 3) show that parents/guardians who have a dog rated slightly lower levels of strain than those on the wait list. However we found no significant differences between the groups with regard to any of the individual items on the scales, or the summarized scores for 'objective strain', 'subjective internalized strain', and 'subjective externalized strain'.

Benefits and Constraints

Qualitative data were analysed using a thematic approach and constant comparison techniques by authors LB and LD. Each participant response was reviewed and codes were assigned to each 'segment of meaning'. Open codes were assigned to representative categories. The process of coding and categorisation facilitated the emergence of themes

from within the data. Initial qualitative analysis was performed by LB, and these results were cross-checked and refined by LD. We analysed the first and second listed benefits and constraints of having an assistance dog. Data beyond the first two benefits and constraints are sparse and not reported.

Three themes were identified under 'benefits'. These were; physical factors, relationship factors and family factors (Figure 1). 'Physical factors' is divided into four categories and focuses on how assistance dogs can keep a child safe whilst facilitating parents' ability to manage: *"A sense of security & protection for our daughter especially walking in local environments" (parent of girl 7-9yo with a dog)*, *"(Dog) will stop child from bolting from home" (parent of boy 4-6yo on waiting list)*. For 3 out of 4 categories, this theme is evenly dispersed between parents who have a dog and waiting list controls. For the fourth category 'no bolt', more parents/guardians from the waiting list state the benefit of the dog being able to stop the child from eloping. 'Relationship factors' is grouped into two categories and centres on the direct positive relationship between the child with ASD and his/her assistance dog: *"She is his very best friend" (parent of boy 4-6yo with a dog), "It might calm him down instead of him head banging the windows" (parent of boy 4-6yo on waiting list).* The categories making up this theme are almost evenly dispersed between parents/guardians who have a dog and waiting list controls. 'Family factors' is split into five categories and is about how day to day family and social life is affected by the introduction of an assistance dog: *"Ability to do maybe ordinary things and go to ordinary places" (parent of boy 7-9yo on waiting list)*, *"a sense of responsibility, for example he can feed the dog" (parent of boy 4-6yo with a dog).* There were differences in the dispersal of this theme among parents/guardians with a dog and those on the waiting list. For example benefits

listed by those with a dog formed more of the category 'visibility', which is about public reception and awareness of ASD. Benefits listed by parents/guardians on the waiting list formed more of the categories 'social' and 'emotion and stress'. 'Social' is about a child with ASD's sociability with family and outside the home. 'Emotion and stress' is about levels of emotion/stress in the family, and to a lesser extent the ability of the child to express emotion.

Four themes emerged from the data on constraints. These were; 'change factors', 'relationship factors', 'limiting factors' and 'no constraints' (Figure 2). Change factors has three categories and focuses on life style challenges that parents/guardians experience or anticipate experiencing when they have an assistance dog: *"Its' like an additional child in the family"(parent of boy 4-6yo with a dog), "To make time to go for walks everyday" (parent of boy 7-9yo on waiting list).* The categories comprising this theme are quite evenly dispersed between parents/guardians of children with a dog and those on the waiting list. Slightly more parents/guardians waiting for a dog list 'dedication', which is the time and effort given to care for the dog as a main constraint. As with the benefits themes, 'relationship factors' is about the direct relationship between the child with ASD and the dog: *"My son may not connect with the dog" (parent of boy 4-6yo on waiting list), "my concern is when the dog has to retire, how will my child cope?" (parent of boy 7-9yo with a dog).* More parents/guardians on the waiting list make up the category 'acceptance', which is concerned about how the dog will be accepted by the child and other family members. The third theme 'limiting factors' has four associated categories and centres on day to day constraints of having a dog on family life; *"Extra expense for food, vet bills etc" (parent of boy 7-9yo with a dog), "it will be a bit difficult to travel" (parent of boy 4-6yo on waiting list).*

There are large differences in the dispersal of two of the categories within this theme. In particular, more parents/guardians whose children have a dog contributed to the category 'clean' , which is about day to day hygiene activities related to the dog e.g., dog hair in the house and dealing with dog toileting. More parents/guardians on the waiting list contributed to a category on 'holidays', which expressed concerns about going on holidays with the dog. The final theme 'no constraints' has just one category. This was a category in which parents/guardians stated no issues for concern or anticipated drawbacks; *"There are none….our dog is a valuable and much loved addition to the family" (parent of boy 7-9yo with a dog), "don't anticipate any, feeling very positive about it" (parent of boy 4-6yo on waiting list).* This category was almost evenly dispersed between parents whose children have a dog and those on the waiting list.

Discussion

Our study is the first to capture the views of a large group of parents/guardians on an assistance dog intervention. Quantitative findings indicate the value of dogs in promoting safety, security and positive public reception for children with ASD. They also suggest that the presence of an assistance dog may make parents/guardians feel more competent with managing their child. Qualitative findings indicate the role assistance dogs play in promoting child safety, calmness and provision of friendship. They also highlight the role the dog has in facilitating 'normal' family functioning, such as being able to visit a shopping centre. Constraints associated with having a dog relate to specific lifestyle changes experienced by parents/guardians and the larger family group, such as dedicated care of the dog.

There are several study limitations. Firstly, our findings are based on self-reports and parents/guardians personal perceptions and are thus subject to participant overestimation, recall bias and possible subject expectancy effects. Also since we did not include any objective measures, we cannot know if parents perceptions reflect reality e.g., were children actually safer and did the public actually view them more positively when accompanied by an assistance dog. Secondly, there were differences in children's ages and type of schools attended between our two sample groups which resulted in removal of the over tens from our analyses and a reduction in sample size. Thirdly we did not assess the views of parents/guardians who are not registered with the assistance dog centre. Our results therefore can only be relevant to parents who are open to the possibility of having an assistance dog. A fourth limitation of the study is that we assessed the perceptions of waiting list controls as opposed to using a RCT design, where controls are randomly assigned to another intervention. Ideally we would employ a planned activity, another animal such as a cat, or a robotic dog as a control. Such a design was not feasible however and the current data do provide insights.

Recognition of the value animal interventions play in promoting human health is gaining momentum. Animal interventions have been shown to produce increases in self-efficacy and coping in psychiatric patients [32-33] promote recovery from ill health [34, 3, 35], and improve academic performance, adaptive functioning and behavioural/emotional problems with special education adolescents. [36] Autism spectrum disorder is one of the areas within which animal interventions have had most success. [8] This is particularly the case for assistance dog interventions, since dogs not only provide a possible mechanism for promoting improvements in social and behavioural functioning, they also play a part in control of

elopement and promotion of child safety. Once a child is attached to a dog via the leash and belt system they cannot 'bolt'. In this study parents/guardians with a dog rated their child as considerably more safe from environmental hazards than did waiting list controls. We did find a reportable interaction between having an assistance dog, type of school attended and parents/guardians ratings. This interaction indicated a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for ASD. The smaller effect may be due to the specific care that children and families receive from ASD schools. Currently there are no interventions that can successfully eliminate elopement among children with ASD. [20] Our quantitative findings support the role of assistance dogs in providing this service. Our qualitative findings provide additional validation with safety and security being the most frequently stated benefit of having a dog.

Behavioural, social and emotional difficulties that encompass the lives of children with ASD can impact on parents/guardians wellbeing. [21-22] Our findings suggest that assistance dogs can provide parents/guardians with a higher sense of competency with regard to managing their child than waiting list controls. This result may reflect added supports dogs provide in public settings. Indeed public tantrums and reactions from the public are regarded as one of the more difficult aspects of a child with ASD's behaviour. [25] Qualitative results from this study highlight the role that an assistance dog has in promoting public awareness and acceptance of ASD. Quantitative results suggest that parents/guardians whose children have assistance dogs rate the public's perception of their child as more positive. Our regression analysis did show an interaction between having an assistance dog and type of school attended. On examination we found that whilst the ratings of parents/guardians remained significantly different where their children attend a special school for autism or a

special class in primary school, they were not significantly so where children attend a main stream primary school. Such a result may reflect a lack of awareness/acceptance of ASD in main stream schools.

Our findings from the caregiver strain questionnaire (CSGQ) show no significant differences between parents/guardians who have a child with a dog, and those waiting to receive a dog. There are three sub scales within the CGSQ. 'Objective strain' deals with the caregiver burden on day to day tasks related to care, 'subjective internalized strain' deals with negative feelings internal to the caregiver, and 'subjective externalized strain' deals with negative feelings by the caregiver towards the child. We considered two reasons which may explain the lack of any real differences between the groups with regard to caregiver strain. Firstly, it is known that being a parent/guardian of a child with ASD can affect quality of life with respect to levels of care and support required, and the resulting impacts on family finance and family time. [37-38] In our study parents/guardians expressed that the dedication required to care for a dog is a main constraint. Assistance dogs require feeding, exercise, affection, grooming, regular company and financial expenditure. The added tasks of looking after an assistance dog may not therefore impact positively upon levels of caregiver strain. Secondly, we noticed that our sample scores on the CSGQ were generally less positive than scores from parents/guardians who took part in the most recent CSGQ validation study. [30] This may reflect a lower provision of services for families of children with autism in the Republic of Ireland. It is interesting to note that although there were no significant differences between parents/guardians who have a dog and those on the wait list for a dog with respect to caregiver strain, there were significant differences with respect to perceived competence. Why do parents/guardians with a dog feel more competent but no less

strained? A possible explanation is that the process and actual event of getting an assistance dog, and the specific procedures followed with respect to working with the dog, may make parents/guardians feel more competent. Having a dog may add more structure to parent's management technique without necessarily reducing levels of strain associated with having a child with ASD.

The ability of assistance dogs to provide a sense of calm and comfort for children with ASD is documented. [11, 13] Qualitative results from this study lend support to this view. Parents/guardians with an assistance dog frequently mentioned the dogs' ability to promote calmness in their child. Those on the waiting list anticipated ways in which the dog would aid their child in times of distress. Previous research has recognised the role that dogs have in facilitating social development in children with ASD. [12, 36 & 39] Our qualitative findings point to the idea that assistance dogs can act as a 'bridge' between children and the physical and social environment. However, more parents/guardians on the waiting list for a dog wrote about the anticipated ability of a dog to promote social development in their children than those with a dog. Those with a dog wrote more about the increased public awareness and acceptance of their child as a main benefit. It may be that although parents waiting for a dog anticipate changes in social interaction, this does not emerge as the most important benefit once they actually get a dog. That assistance dogs may facilitate social interaction in children with ASD is not in dispute. However, this role may be more salient in animal assisted therapy (AAT), where a trained therapist may work with a dog to reach specific cognitive or behavioural goals for a child. Parents/guardians listed constraints of having an assistance dog were centred on the lifestyle changes. Such changes include the care and costs required to ensure a dogs' health and wellbeing in addition to the restrictions

associated with the dogs' requirements for exercise and companionship. It is important to recognise that each parent/guardian has a different level of tolerance for specific canine behaviours. [40] Whilst many of the parents/guardians in our study discounted the constraints of having a dog, some were explicit about their concerns. More of those with an assistance dog expressed concern about the increase in housekeeping tasks, and specific hygiene activities associated with having a dog in the family home. Parents/guardians with children on the wait list were more concerned about whether the dog will be accepted by the child and family, and logistics during family holiday time. Our results suggest that some of the anticipated constraints do not necessarily emerge as the most important constraints once a dog is placed in the home. Differences in expectations highlight the importance of working with families to best understand their needs and concerns both before and after obtaining an assistance dog.

Conclusions

Our findings indicate that parents/guardians perceive assistance dog interventions are valuable in the treatment of ASD, particularly in relation to the control of elopement. They also perceive that assistance dogs help to promote calmness and provide a source of comfort for children.

Funding Statement

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Competing Interests

There are no competing interests. This study was an independent University led project. Families with an assistance dog from the Irish Guide Dogs for the Blind, and families on the waiting list for a dog took part in the study.

Contributorship Statement

-Louise Burgoyne was the lead researcher and was involved in the design, implementation, analysis and reporting of the study.

-Lisa Dowling took part of the project as her final year medical project. She was involved in the qualitative analysis and interpretation together with the overall reporting of the study and approval of the manuscript.

-Anthony (Tony) Fitzgerald is the study statistician responsible for interpretation of the quantitative data and final approval of the manuscript.

-Micaela Connolly is a psychologist specializing in children with autism. She was involved in the study design and was clinical adviser to the group throughout the course of research. She was also involved in the study reporting and approval of the manuscript.

-John Browne is a psychologist and health services researcher. He was involved in the study analysis critical review and approval of the manuscript.

-Ivan J Perry was the main project supervisor. He was responsible for overseeing the project from start to finish and approved the final manuscript.

Data Sharing Statement

Technical appendix, statistical code, and dataset available from the corresponding author at University College Cork, who will provide a permanent home for the dataset.

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Table 1 Questionnaire subsections, details and measures.

Section	Details	Measure
Part 1. Demographics	1. Gender, age, other medical conditions, age of diagnosis, home location. 2. Education, learning level, verbal/non verbal Interventions and therapies received	Tick boxes, yes/no options, free text.
Part 2. Parenting & Autism	1. Perceived competence From: Self Determination Theory *Deci & Ryan (1985 & 2000)* 2. Caregiver strain questionnaire *From: Brannan et al (1997) & Khanna et al., (2011)* *Objective strain* *Subjective internalised strain* *Subjective externalised strain*	Four items on a 7-point scale 21 items on a 5 point scale. *11 items* *6 items* *4 items*
Part 3. Environment & Public	1. Environment safety and security Adapted from scale structures: *Rosenberg et al., (2009)* 2. Public Perception	Eight items on a 7-point scale. Four items on a 7-point scale.
Part 4. Benefits & constraints	1. Benefits of having an assistance dog 2. Constraints of having an assistance dog	Free text.

Table 2 Participant Characteristics (With Dog n=80, Waiting list for Dog n=84)

Characteristics		*With Dog N (%)*	*Waiting for Dog N (%)*	*P-value*
Gender	Male	70 (87.5)	77 (91.7)	_
Age	0-6 years	30 (37.5)	60 (71.4)	<0.001
	7-9 years	50 (62.5)	24 (28.6)	
Location	Town/city centre	11 (13.8)	8 (9.0)	0.217
	Suburb	33 (41.3)	47 (57.0)	
	Countryside	36 (45.0)	28 (34.0)	
Other conditions	Yes	24 (30.0)	27 (32.1)	0.767
Verbal	Yes	42 (52.5)	35 (42.0)	0.165
Education	Preschool	0	10 (11.9)	_
	Home tuition	1 (1.0)	4 (5.0)	_
	Primary	13 (16.3)	11 (31.1)	0.025
	Special class (Primary)	17 (21.3)	29 (34.5)	
	Special school (ASD)	49 (61.3)	30 (35.7)	
Interventions	Speech and Language	38 (47.5)	32 (38.1)	0.224
	Occupational Therapy	37 (46.3)	32 (38.1)	0.290
	Resource Teacher	20 (25.0)	22 (26.2)	0.861
	Special Needs Assistant	64 (80.0)	57 (67.9)	0.077

P-values are from valid chi-square tests.

'-' Not included in chi-square analysis as numbers do not meet minimum expected count.

Table 3. Summary of results from Environmental Hazards, Public Awareness, Competence and Caregiver Strain scales.

Item	Description	Mean (95%CI)			P-value
		With Dog (n=80)	Waiting Dog (n=84)	Diff* (95% CI)	
HAZ	Environmental Hazards (range 8 -56)	32.43 (29.47: 35.39)	22.97 (20.83: 25.11)	10.9 (6.97, 14.89)	<0.001[1]
PUBLIC	Public Acceptance(range 4 –28)	15.87 (14.23: 17.50)	10.67 (9.56:11.77)	5.80 (3.69, 7.90)	<0.001[2]
SD	Competence (range 4 – 28)	19.75 (18.74:20.77)	17.91 (16.52: 18.92)	1.97 (0.273, 3.68)	0.023
OS	Objective strain (range 11-55)	35.03 (32.81: 37.20)	35.91 (34.08:38.01)	-0.54 (-3.78, 2.70)	0.744
SIS	Subjective Internalised strain (range 6-35)	22.47 (21.21:23.60)	23.63 (22.89:25.03)	-0.81 (-2.63, 1.00)	0.380
SES	Subjective Externalised strain (range 4-20)	7.74 (7.01: 8.46)	7.88 (7.28:8.49)	-0.34 (-1.37, .69)	0.522

*Adjusted for gender, age, location, education

1. There was a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for children with ASD
2. There is no significant difference in ratings of parents/guardians who have a child in a main stream primary school (p=0.09)

Figure 1 – Parents/Guardians perceived benefits of having an assistance dog (themes and categories)

99% of parents/guardians with a dog listed at least two benefits.
99% of parents/guardians on the wait list for a dog listed at least two benefits.
Category 'Physiological' refers to how assistance dogs can facilitate a child with respect to mobility and ambulation.
Category 'Management' refers to how assistance dogs can facilitate day to day management of their child.

Figure 2 – Parents/Guardians perceived constraints of having assistance dog (themes and categories)
66% of parents/guardians with a dog listed at least two constraints.
64% of parents/guardians on the wait list for a dog listed at least two constraints.
*Please note that one category 'other' from the waiting list group second constraint is not included in the figure.
Category 'Dogs life' refers to concerns about what happens when an assistance dog retires/dies.
Category 'Acceptance' refers to challenges around family and children's acceptance of an assistance dog.

Parents' perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study

Corresponding Author: Louise Burgoyne,

Institution: Department of Epidemiology & Public Health, University College Cork (UCC).

Contact: l.burgoyne@ucc.ie, ph.: 00-353-4205517, fax: 00-353-214205469.

Co-authors

Lisa Dowling, Final Year Medical Student, School of Medicine, UCC

Anthony Fitzgerald, Biostatistician, Department of Epidemiology & Public Health, UCC

Micaela Connolly, Psychologist, Brothers of Charity, Cork.

John Browne, Professor, Department of Epidemiology & Public Health, UCC

Ivan J Perry, Professor & Head of Department of Epidemiology & Public Health, UCC.

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Main Strengths and Limitations of this study

- This study is the first to capture the views of a large group of parents/guardians on an assistance dog intervention.
- Findings suggest that parents perceive a high value in dogs for promoting safety, security and positive public reception for children with ASD.
- This study assessed the perceptions of parents/guardians on the wait list for a dog as opposed to using a stronger randomised control trial (RCT) design, where controls are randomly assigned to another intervention.

Introduction

There is an expanding literature indicating the human mental and physical health benefits derived from interaction with companion animals. [1] The presence of animals as an intervention tool was first studied by psychotherapist Boris Levinson via a series of case studies. [2] At the time animals were seen as inferior replacements for human social interactions. [3] Since the 1970's animals have been used as a means of improving human physical, emotional, cognitive and social functioning. Animal assisted interventions (AAI) are classified into three groupings; animal assisted activities (AAA), animal assisted therapies (AAT) and service animal programmes (SAP). [4]

Animal assisted activities are delivered by trained personnel in environments such as hospitals and educational settings with an emphasis on quality of life enhancement via recreation and education e.g., therapeutic horse riding to treat populations with physical and mental disabilities. [5-6] Animal assisted therapies are practiced by professionals with

individualised therapy goals. [7] The emphasis is on improvements in physical, social and cognitive functioning e.g., an occupational therapist working to facilitate fine motor skills development in a child via a series of structured tasks such as grooming and feeding a cat. A meta-analysis of the literature on AAT has shown that they are associated with moderate effect sizes in improving outcomes in four areas: autism spectrum symptoms, medical difficulties, behavioural problems, and emotional well-being. [8] A recent systematic review of the literature on AAI for ASD has indicated preliminary 'proof of concept', but highlights the needs for more rigorous research to establish a convincing evidence base.[9] This view is upheld by another recent review pointing to the need for better research designs and larger sample sizes. [10]

Service animal interventions (SAP) use dogs to assist people with a disability in performing daily activities. Service dogs live in-house with the people they work with. Of late assistance dogs have received growing attention as a means of aiding children with Autism Spectrum Disorder (ASD) . Qualitative inquiry on the integration of assistance dogs into ten families with a child who has ASD, showed that the presence of a dog can improve quality of life for children and parents. [11] A study examining risks and benefits of assistance dogs using a series of structured interviews with 17 families, reported social and cognitive benefits in addition to physical and medical benefits. [12] An experimental study which assessed the effects of assistance dogs on basal salivary cortisol secretion of 42 children with ASD, demonstrated a reduction in the cortisol awakening response and the number of disruptive behavioural incidents post introduction of the dog. [13] Assistance dogs complete a unique triad between parent/guardian and child. Typically the child is attached to the dog via a lead (leash) and belt. The dog walks with the child but takes commands from the parent

(handler). [14] If the child tries to step off a footpath or attempts to bolt, the dog will use all his/her power to slow the child down. Assistance dogs prohibit dangerous behaviour such as elopement (bolting) and provide a calming presence.

Elopement or the tendency to 'bolt' is characteristic of ASD. Such behaviour can result in a child's exposure to dangerous traffic situations or encounters with strangers. [15] Despite reports of higher mortality rates in ASD populations owing to accidents such as suffocation, drowning and injuries, research on elopement behaviour is sparse. [16-18] If left untreated elopement may result in the need for a child to be moved to a restrictive setting. [19] In a systematic review of the literature on current elopement treatments such as function based interventions, Lang and colleagues conveyed that just two of ten studies examined reported complete elimination of elopement. [20] Treatments that effectively eliminate elopement behaviours are warranted.

Social, emotional and behavioural challenges at home and in public mean that parents/guardians of children with ASD experience stress in most areas of their lives. [21-24] In addition to behaviours such as elopement, public tantrums and the reaction from others are regarded as being some of the more difficult aspects of a child with ASD's behaviour. Situations can leave parents/guardians feeling judged as 'bad' parents, or feeling like a failure. [25] In this context assistance dogs can provide a unique support by facilitating child safety and promoting positive public reception. Outings to public places can become less stressful and families can enjoy greater freedom and mobility. Given the resource implications of assistance dog interventions for ASD, there is a need to assess the value of acceptability and likely uptake of services.

Currently there are 188 service animal interventions registered with the standards body Assistance Dogs International (ADI). These interventions include guide dogs for the blind, hearing dogs for the hard of hearing, and service dogs for people with other disabilities including ASD. In this study we measured parents/guardians ratings on: (a) the impact of having an assistance dog on child safety from environmental hazards, (b) public acceptance and awareness of ASD, (c) sense of competence with managing a child with ASD and (d) levels of caregiver strain. We also obtained parents/guardians views on the primary benefits and constraints of having an assistance dog.

Methods

Study Design and Participants

Our study was based in the primary care setting, within the context of a specific national assistance dog intervention in the Republic of Ireland. All children who receive an assistance dog from this centre have been formally diagnosed with ASD via the Irish Health Services Executive (HSE) using standard tools such as the ADOS (Autism Diagnostic Observation Schedule), the ADI-R (Autism Diagnostic Interview) and the DISCO (Diagnostic Interview for Social Communication). Outside formal diagnosis, certain conditions such having a child with particularly strong aggression issues may preclude participation on the assistance dog programme.

Parents/guardians with an assistance dog (N=205) and parents/guardians on the waiting list for an assistance dog (N=107) were eligible to take part in the study. Expedited ethical

approval was granted from the Clinical Research Ethics Committee of the Cork Teaching Hospitals. Data were gathered between October 2012 and March 2013.

Measures

Parents/guardians were asked to complete a four part questionnaire (Table 1). Part one examined child demographics. Part two measured parents/guardians sense of competence for managing a child with ASD using Perceived Competence Scales (PCS) [26] (α = 0.876, 7 point scales: low-high competence). The PCS is a measure of one of three fundamental psychological needs within Self Determination Theory. [27-28] Like other measures within behavioural change theory, items on the PCS are typically written to be specific to the relevant behaviour or domain being examined. A sample item from the PCS we used for this study is 'I am able to do my own routine caring for my child with autism'. Part two also assessed levels of strain using the Caregiver Strain Questionnaire CGSQ [29] (α = 0.940, 5 point scales: low-high strain), which has been validated to assess burden among caregivers of children with autism. [30] The CGSQ asked participants to consider the past 6 months in terms of the problems presented by items such as: 'interruption of personal time resulting from your child's emotional or behavioural problem (Objective Strain)', 'how embarrassed did you feel about your child's emotional or behavioural problem (Subjective Externalised Strain)' and 'How worried did you feel about your child's future (Subjective Internalised Strain)'.

Part three of the questionnaire examined perceptions of child safety from environmental hazards such as traffic, dangerous materials and outdoor spaces (α=0.928, 7 point scales: low-high safety/security). Participants were asked to rate how strongly they agreed or

disagreed with respect to their child's safety and security over the past 3 months e.g., 'I am confident that my child with autism is secure from environmental hazards when we go on walks in our neighbourhood.' Part three also assessed parents/guardians ratings on the general publics' acceptance of their child (α=0.940, 7 point scales: low-high acceptance). In this case participants were asked to rate the public's perception of their child over the past three months on items such as 'I am sure that people make allowances for my child with autism when we are in a restaurant'. Scales for part three were developed with reference to the format and structure of the Neighbourhood Environment Walkability Scale – Youth, [31] and via consultation with parents and author MC, who is a psychologist specialising in children with ASD. Part four asked participants to list their views of the main benefits/constraints of having an assistance dog via 'free text'. Those on the waiting list were asked to give the benefits/constraints that they feel a dog will bring.

Pilot

We piloted the questionnaire with eight parents/guardians, four of which have an assistance dog and four who are on the waiting list. Minor modifications were made to the final questionnaire on the basis of their responses.

Procedures

The primary caregiver from each family with an assistance dog, and each family on the waiting list received a postal questionnaire from the contact person at the assistance dog centre. In the interests of confidentiality, the researchers at University College Cork did not have access to names and addresses of participants. The assistance dog's centre did not have access to the completed questionnaires. Each questionnaire pack contained a consent

form with study details, a questionnaire, a stamped addressed envelope, and an envelope marked 'Research'. Participants were requested to place completed questionnaires in the envelope marked 'Research' and to seal it. They were asked to place the sealed envelope together with the signed consent form in the stamped addressed envelope, and to post back to the assistance dog centre. Participants were assured that participation in the study would have no impact on their status with the centre, and that staff at the centre would have no access to the survey data.

Data Analysis

Descriptive statistics are reported using frequencies tables. Chi Square tests were used to test for differences between the categorical demographic variables. T-tests were used to examine differences between parents of children with an assistance dog and those waiting to receive one, within the data on competence, caregiver strain (CGSQ), environmental hazards and public awareness. We then fitted a linear regression that included having a dog or being on the wait list as a dichotomous variable and each of gender, age, home location and education as factors.

Qualitative data were analysed via open coding, followed by a process of categorisation which facilitated the emergence of themes. Author LB analysed the qualitative data initially and author LD completed a second analysis and cross check.

Results

Demographics

A total of 134 parents/guardians with an assistance dog (65% response), and 87 parents/guardians from the wait list (81% response) completed the questionnaire. A large proportion of participants with a dog have children over the age of ten (40%) compared to just three participants from the wait list. For this reason we eliminated the 'over tens' from further analysis in this paper.

A breakdown of the demographic characteristics of participants' children is in Table 2. A majority are male (87.5% with dog; 91.7% wait list) and similar percentages have other medical conditions in addition to ASD (35% with dog; 32.1% wait list). Other conditions include mild to moderate learning difficulties, ADHD, asthma and epilepsy. The largest group live in suburban areas (41.3% with dog; 57% wait list) followed by the countryside (45% with dog; 34% wait list). Over half of the children with a dog are verbal (52.5%) and under half of those waiting for a dog are verbal (42%). There are differences in types of school attended between participants whose children have an assistance dog and those who do not yet have a dog. These are reflective of the remaining age differences between the two groups post removal of the over tens from the total sample. The main difference is that 61.3% of children with a dog attend a special school for ASD compared to 35.7% of the wait list. Conversely 34.5% of children on the wait list are in a special class in a main stream primary school compared to 21.3% who have a dog.

With regard to conventional interventions received there are some descriptive differences between participants whose children have an assistance dog and those on the wait list for a

dog (Table 2). There is a less than 10% difference between the groups for regular speech and language therapy (47.5% with dog; 38.1% wait list) and regular occupational therapy (46.3% with dog; 38.1% wait list). Similar percentages from both groups have a resource teacher (25% with dog; 26.2% wait list), and there is a 12% difference with regard to special needs assistants (80% with dog; 67.9% wait list)

There are significant differences between profiles of children who have a dog and children waiting for a dog with respect to age and schooling. There are no significant differences between the groups for other conditions in addition to ASD, whether a child is verbal or nonverbal, conventional interventions and home location.

Environmental Hazards & Public Awareness

The environmental hazards scales are summarized in Table 3 and details of individual items are in Supplementary Table 1. Ratings are from low perceived safety to high safety. T-test results showed that mean ratings are significantly higher ($p<0.001$) for parents/guardians whose children have a dog (32.43) than for those on the waiting list (22.97). These differences remain significant after adjusting for gender, age, home location and school type ($p<0.001$). We did however find a significant interaction between school types and whether children have a dog. Although there are significant differences between the rating of parents/guardians with a dog and those on the waiting list for children attending a special school for autism (mean difference=6.62: 95%CI 0.639, 12.61), the effect is not as large as it is for children attending a primary school (mean difference=12.53: 95%CI 4.16, 20.90) or a special class in a primary school (mean difference=19.49: 5%CI 13.171, 25.821).

The range of scores from the public perception scales (Table 3 and Supplementary Table 2) are from low to high, with higher scores indicating a perception from parents/guardians that people act more respectfully and responsibly towards children with ASD when in public settings. T test results showed that parents/guardians mean ratings are significantly higher ($p<0.001$) for those whose children have an assistance dog (15.87) than for the wait list (10.67). For the most part these differences remain significant after adjusting for gender, age, home location and education level ($p<0.001$). However, there was a significant interaction between type of school attended and whether children have an assistance dog. Although there are significant differences between the ratings of parents/guardians with a dog and those on the waiting list where their children attend a special school for autism (mean difference=6.65: 95%CI 3.79, 9.51), and a special class in primary school (mean difference=7.01: 95%CI 2.88, 11.13), there is no significant difference in the ratings of parents/guardians who have a child in a main stream primary school ($p=0.09$).

Perceived Competence and Caregiver Strain

A summary of results from parents/guardians perceived competencies with regard to caring for and managing their child with ASD are in Table 3. Details of individual items are in Supplementary Table 2. T-test results show that mean scores for parents/guardians whose children have an assistance dog (19.75), are significantly higher ($p=0.02$) in terms of perceived competencies than those on the waiting list (17.91). This difference remained significant after adjusting for gender, age, home location and education level ($p=0.02$). Results from the Caregiver Strain Questionnaire (CGSQ) (Table 3) show that parents/guardians who have a dog rated slightly lower levels of strain than those on the wait list. However we found no significant differences between the groups with regard to

any of the individual items on the scales, or the summarized scores for 'objective strain', 'subjective internalized strain', and 'subjective externalized strain'.

Benefits and Constraints

Qualitative data were analysed using a thematic approach and constant comparison techniques by authors LB and LD. Each participant response was reviewed and codes were assigned to each 'segment of meaning'. Open codes were assigned to representative categories. The process of coding and categorisation facilitated the emergence of themes from within the data. Initial qualitative analysis was performed by LB, and these results were cross-checked and refined by LD. We analysed the first and second listed benefits and constraints of having an assistance dog. Data beyond the first two benefits and constraints are sparse and not reported.

Three themes were identified under 'benefits'. These were; physical factors, relationship factors and family factors (Figure 1). 'Physical factors' is divided into four categories and focuses on how assistance dogs can keep a child safe whilst facilitating parents' ability to manage: *"A sense of security & protection for our daughter especially walking in local environments" (parent of girl 7-9yo with a dog)*, *"(Dog) will stop child from bolting from home" (parent of boy 4-6yo on waiting list)*. For 3 out of 4 categories, this theme is evenly dispersed between parents who have a dog and waiting list controls. For the fourth category 'no bolt', more parents/guardians from the waiting list state the benefit of the dog being able to stop the child from eloping. 'Relationship factors' is grouped into two categories and centres on the direct positive relationship between the child with ASD and his/her assistance dog: *"She is his very best friend" (parent of boy 4-6yo with a dog), "It*

might calm him down instead of him head banging the windows" (parent of boy 4-6yo on waiting list). The categories making up this theme are almost evenly dispersed between parents/guardians who have a dog and waiting list controls. 'Family factors' is split into five categories and is about how day to day family and social life is affected by the introduction of an assistance dog: *"Ability to do maybe ordinary things and go to ordinary places" (parent of boy 7-9yo on waiting list)*, *"a sense of responsibility, for example he can feed the dog" (parent of boy 4-6yo with a dog).* There were differences in the dispersal of this theme among parents/guardians with a dog and those on the waiting list. For example benefits listed by those with a dog formed more of the category 'visibility', which is about public reception and awareness of ASD. Benefits listed by parents/guardians on the waiting list formed more of the categories 'social' and 'emotion and stress'. 'Social' is about a child with ASD's sociability with family and outside the home. 'Emotion and stress' is about levels of emotion/stress in the family, and to a lesser extent the ability of the child to express emotion.

Four themes emerged from the data on constraints. These were; 'change factors', 'relationship factors', 'limiting factors' and 'no constraints' (Figure 2). Change factors has three categories and focuses on life style challenges that parents/guardians experience or anticipate experiencing when they have an assistance dog: *"Its' like an additional child in the family"(parent of boy 4-6yo with a dog), "To make time to go for walks everyday" (parent of boy 7-9yo on waiting list).* The categories comprising this theme are quite evenly dispersed between parents/guardians of children with a dog and those on the waiting list. Slightly more parents/guardians waiting for a dog list 'dedication', which is the time and effort given to care for the dog as a main constraint. As with the benefits themes, 'relationship factors'

is about the direct relationship between the child with ASD and the dog: *"My son may not connect with the dog" (parent of boy 4-6yo on waiting list), "my concern is when the dog has to retire, how will my child cope?" (parent of boy 7-9yo with a dog).* More parents/guardians on the waiting list make up the category 'acceptance', which is concerned about how the dog will be accepted by the child and other family members. The third theme 'limiting factors' has four associated categories and centres on day to day constraints of having a dog on family life; *"Extra expense for food, vet bills etc" (parent of boy 7-9yo with a dog), "it will be a bit difficult to travel" (parent of boy 4-6yo on waiting list).* There are large differences in the dispersal of two of the categories within this theme. In particular, more parents/guardians whose children have a dog contributed to the category 'clean' , which is about day to day hygiene activities related to the dog e.g., dog hair in the house and dealing with dog toileting. More parents/guardians on the waiting list contributed to a category on 'holidays', which expressed concerns about going on holidays with the dog. The final theme 'no constraints' has just one category. This was a category in which parents/guardians stated no issues for concern or anticipated drawbacks; *"There are none….our dog is a valuable and much loved addition to the family" (parent of boy 7-9yo with a dog), "don't anticipate any, feeling very positive about it" (parent of boy 4-6yo on waiting list).* This category was almost evenly dispersed between parents whose children have a dog and those on the waiting list.

Discussion

Our study is the first to capture the views of a large group of parents/guardians on an assistance dog intervention. Quantitative findings indicate the value of dogs in promoting safety, security and positive public reception for children with ASD. They also suggest that

the presence of an assistance dog may make parents/guardians feel more competent with managing their child. Qualitative findings indicate the role assistance dogs play in promoting child safety, calmness and provision of friendship. They also highlight the role the dog has in facilitating 'normal' family functioning, such as being able to visit a shopping centre. Constraints associated with having a dog relate to specific lifestyle changes experienced by parents/guardians and the larger family group, such as dedicated care of the dog.

There are several study limitations. Firstly, our findings are based on self-reports and parents/guardians personal perceptions and are thus subject to participant overestimation, recall bias and possible subject expectancy effects. Also since we did not include any objective measures, we cannot know if parents perceptions reflect reality e.g., were children actually safer and did the public actually view them more positively when accompanied by an assistance dog. Secondly, there were differences in children's ages and type of schools attended between our two sample groups which resulted in removal of the over tens from our analyses and a reduction in sample size. Thirdly we did not assess the views of parents/guardians who are not registered with the assistance dog centre. Our results therefore can only be relevant to parents who are open to the possibility of having an assistance dog. A fourth limitation of the study is that we assessed the perceptions of waiting list controls as opposed to using a RCT design, where controls are randomly assigned to another intervention. Ideally we would employ a planned activity, another animal such as a cat, or a robotic dog as a control. Such a design was not feasible however and the current data do provide insights.

Recognition of the value animal interventions play in promoting human health is gaining momentum. Animal interventions have been shown to produce increases in self-efficacy and coping in psychiatric patients [32-33] promote recovery from ill health [34, 3, 35], and improve academic performance, adaptive functioning and behavioural/emotional problems with special education adolescents. [36] Autism spectrum disorder is one of the areas within which animal interventions have had most success. [8] This is particularly the case for assistance dog interventions, since dogs not only provide a possible mechanism for promoting improvements in social and behavioural functioning, they also play a part in control of elopement and promotion of child safety. Once a child is attached to a dog via the leash and belt system they cannot 'bolt'. In this study parents/guardians with a dog rated their child as considerably more safe from environmental hazards than did waiting list controls. We did find a reportable interaction between having an assistance dog, type of school attended and parents/guardians ratings. This interaction indicated a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for ASD. The smaller effect may be due to the specific care that children and families receive from ASD schools. Currently there are no interventions that can successfully eliminate elopement among children with ASD. [20] Our quantitative findings support the role of assistance dogs in providing this service. Our qualitative findings provide additional validation with safety and security being the most frequently stated benefit of having a dog.

Behavioural, social and emotional difficulties that encompass the lives of children with ASD can impact on parents/guardians wellbeing. [21-22] Our findings suggest that assistance dogs can provide parents/guardians with a higher sense of competency with regard to managing their child than waiting list controls. This result may reflect added supports dogs provide in

public settings. Indeed public tantrums and reactions from the public are regarded as one of the more difficult aspects of a child with ASD's behaviour. [25] Qualitative results from this study highlight the role that an assistance dog has in promoting public awareness and acceptance of ASD. Quantitative results suggest that parents/guardians whose children have assistance dogs rate the public's perception of their child as more positive. Our regression analysis did show an interaction between having an assistance dog and type of school attended. On examination we found that whilst the ratings of parents/guardians remained significantly different where their children attend a special school for autism or a special class in primary school, they were not significantly so where children attend a main stream primary school. Such a result may reflect a lack of awareness/acceptance of ASD in main stream schools.

Our findings from the caregiver strain questionnaire (CSGQ) show no significant differences between parents/guardians who have a child with a dog, and those waiting to receive a dog. There are three sub scales within the CGSQ. 'Objective strain' deals with the caregiver burden on day to day tasks related to care, 'subjective internalized strain' deals with negative feelings internal to the caregiver, and 'subjective externalized strain' deals with negative feelings by the caregiver towards the child. We considered two reasons which may explain the lack of any real differences between the groups with regard to caregiver strain. Firstly, it is known that being a parent/guardian of a child with ASD can affect quality of life with respect to levels of care and support required, and the resulting impacts on family finance and family time. [37-38] In our study parents/guardians expressed that the dedication required to care for a dog is a main constraint. Assistance dogs require feeding, exercise, affection, grooming, regular company and financial expenditure. The added tasks of looking

after an assistance dog may not therefore impact positively upon levels of caregiver strain. Secondly, we noticed that our sample scores on the CSGQ were generally less positive than scores from parents/guardians who took part in the most recent CSGQ validation study. [30] This may reflect a lower provision of services for families of children with autism in the Republic of Ireland. It is interesting to note that although there were no significant differences between parents/guardians who have a dog and those on the wait list for a dog with respect to caregiver strain, there were significant differences with respect to perceived competence. Why do parents/guardians with a dog feel more competent but no less strained? A possible explanation is that the process and actual event of getting an assistance dog, and the specific procedures followed with respect to working with the dog, may make parents/guardians feel more competent. Having a dog may add more structure to parent's management technique without necessarily reducing levels of strain associated with having a child with ASD.

The ability of assistance dogs to provide a sense of calm and comfort for children with ASD is documented. [11, 13] Qualitative results from this study lend support to this view. Parents/guardians with an assistance dog frequently mentioned the dogs' ability to promote calmness in their child. Those on the waiting list anticipated ways in which the dog would aid their child in times of distress. Previous research has recognised the role that dogs have in facilitating social development in children with ASD. [12, 36 & 39] Our qualitative findings point to the idea that assistance dogs can act as a 'bridge' between children and the physical and social environment. However, more parents/guardians on the waiting list for a dog wrote about the anticipated ability of a dog to promote social development in their children than those with a dog. Those with a dog wrote more about the increased public awareness

and acceptance of their child as a main benefit. It may be that although parents waiting for a dog anticipate changes in social interaction, this does not emerge as the most important benefit once they actually get a dog. That assistance dogs may facilitate social interaction in children with ASD is not in dispute. However, this role may be more salient in animal assisted therapy (AAT), where a trained therapist may work with a dog to reach specific cognitive or behavioural goals for a child. Parents/guardians listed constraints of having an assistance dog were centred on the lifestyle changes. Such changes include the care and costs required to ensure a dogs' health and wellbeing in addition to the restrictions associated with the dogs' requirements for exercise and companionship. It is important to recognise that each parent/guardian has a different level of tolerance for specific canine behaviours. [40] Whilst many of the parents/guardians in our study discounted the constraints of having a dog, some were explicit about their concerns. More of those with an assistance dog expressed concern about the increase in housekeeping tasks, and specific hygiene activities associated with having a dog in the family home. Parents/guardians with children on the wait list were more concerned about whether the dog will be accepted by the child and family, and logistics during family holiday time. Our results suggest that some of the anticipated constraints do not necessarily emerge as the most important constraints once a dog is placed in the home. Differences in expectations highlight the importance of working with families to best understand their needs and concerns both before and after obtaining an assistance dog.

Conclusions

Our findings indicate that parents/guardians perceive assistance dog interventions are valuable in the treatment of ASD, particularly in relation to the control of elopement. They also perceive that assistance dogs help to promote calmness and provide a source of comfort for children.

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Table 1 Questionnaire subsections, details and measures.

Section	Details	Measure
Part 1. Demographics	1. Gender, age, other medical conditions, age of diagnosis, home location. 2. Education, learning level, verbal/non verbal Interventions and therapies received	Tick boxes, yes/no options, free text.
Part 2. Parenting & Autism	1. Perceived competence From: Self Determination Theory *Deci & Ryan (1985 & 2000)* 2. Caregiver strain questionnaire *From: Brannan et al (1997) & Khanna et al., (2011)* *Objective strain* *Subjective internalised strain* *Subjective externalised strain*	Four items on a 7-point scale 21 items on a 5 point scale. *11 items* *6 items* *4 items*
Part 3. Environment & Public	1. Environment safety and security Adapted from scale structures: *Rosenberg et al., (2009)* 2. Public Perception	Eight items on a 7-point scale. Four items on a 7-point scale.
Part 4. Benefits & constraints	1. Benefits of having an assistance dog 2. Constraints of having an assistance dog	Free text.

Table 2 Participant Characteristics (With Dog n=80, Waiting list for Dog n=84)

Characteristics		*With Dog N (%)*	*Waiting for Dog N (%)*	*P-value*
Gender	Male	70 (87.5)	77 (91.7)	_
Age	0-6 years	30 (37.5)	60 (71.4)	<0.001
	7-9 years	50 (62.5)	24 (28.6)	
Location	Town/city centre	11 (13.8)	8 (9.0)	0.217
	Suburb	33 (41.3)	47 (57.0)	
	Countryside	36 (45.0)	28 (34.0)	
Other conditions	Yes	24 (30.0)	27 (32.1)	0.767
Verbal	Yes	42 (52.5)	35 (42.0)	0.165
Education	Preschool	0	10 (11.9)	_
	Home tuition	1 (1.0)	4 (5.0)	_
	Primary	13 (16.3)	11 (31.1)	0.025
	Special class (Primary)	17 (21.3)	29 (34.5)	
	Special school (ASD)	49 (61.3)	30 (35.7)	
Interventions	Speech and Language	38 (47.5)	32 (38.1)	0.224
	Occupational Therapy	37 (46.3)	32 (38.1)	0.290
	Resource Teacher	20 (25.0)	22 (26.2)	0.861
	Special Needs Assistant	64 (80.0)	57 (67.9)	0.077

P-values are from valid chi-square tests.

'-' Not included in chi-square analysis as numbers do not meet minimum expected count.

Table 3. Summary of results from Environmental Hazards, Public Awareness, Competence and Caregiver Strain scales.

Item	Description	Mean (95%CI)			P-value
		With Dog (n=80)	Waiting Dog (n=84)	Diff* (95% CI)	
HAZ	Environmental Hazards (range 8 -56)	32.43 (29.47: 35.39)	22.97 (20.83: 25.11)	10.9 (6.97, 14.89)	<0.001[1]
PUBLIC	Public Acceptance(range 4 –28)	15.87 (14.23: 17.50)	10.67 (9.56:11.77)	5.80 (3.69, 7.90)	<0.001[2]
SD	Competence (range 4 – 28)	19.75 (18.74:20.77)	17.91 (16.52: 18.92)	1.97 (0.273, 3.68)	0.023
OS	Objective strain (range 11-55)	35.03 (32.81: 37.20)	35.91 (34.08:38.01)	-0.54 (-3.78, 2.70)	0.744
SIS	Subjective Internalised strain (range 6-35)	22.47 (21.21:23.60)	23.63 (22.89:25.03)	-0.81 (-2.63, 1.00)	0.380
SES	Subjective Externalised strain (range 4-20)	7.74 (7.01: 8.46)	7.88 (7.28:8.49)	-0.34 (-1.37, .69)	0.522

*Adjusted for gender, age, location, education

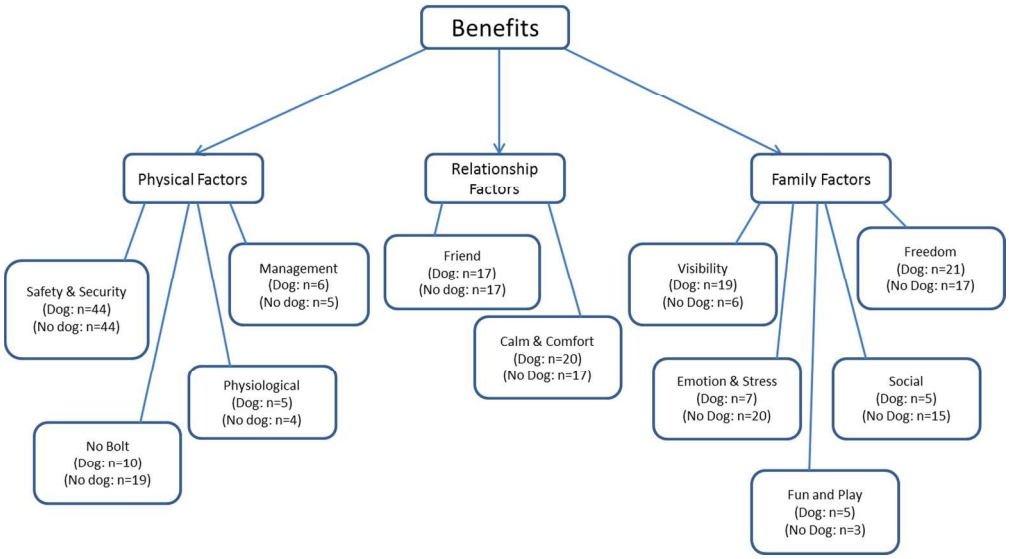
1. There was a lesser albeit significant effect of having a dog for parents/guardians whose children attend a special school for children with ASD
2. There is no significant difference in ratings of parents/guardians who have a child in a main stream primary school (p=0.09)

Figure 1 – Parents/Guardians perceived benefits of having an assistance dog (themes and categories)

99% of parents/guardians with a dog listed at least two benefits.
99% of parents/guardians on the wait list for a dog listed at least two benefits.
Category 'Physiological' refers to how assistance dogs can facilitate a child with respect to mobility and ambulation.
Category 'Management' refers to how assistance dogs can facilitate day to day management of their child.

Figure 2 – Parents/Guardians perceived constraints of having assistance dog (themes and categories)

66% of parents/guardians with a dog listed at least two constraints.
64% of parents/guardians on the wait list for a dog listed at least two constraints.
*Please note that one category 'other' from the waiting list group second constraint is not included in the figure.
Category 'Dogs life' refers to concerns about what happens when an assistance dog retires/dies.
Category 'Acceptance' refers to challenges around family and children's acceptance of an assistance dog.



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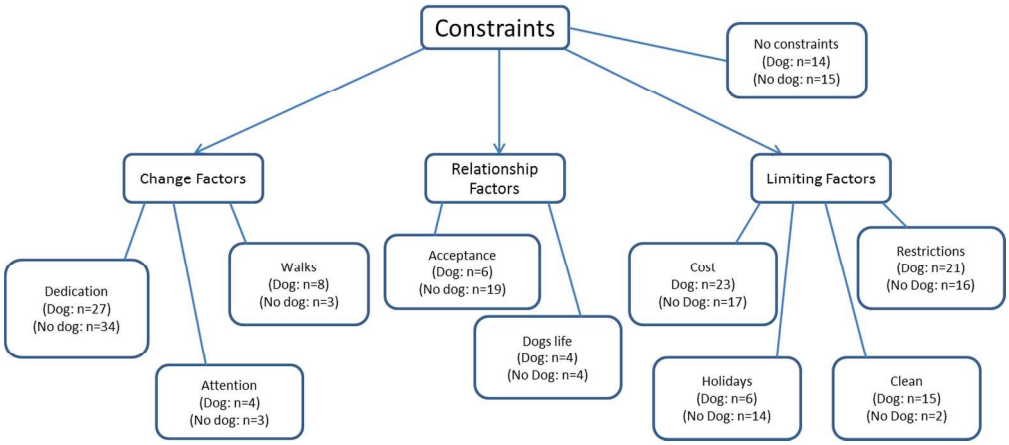
163x90mm (300 x 300 DPI)



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205x90mm (300 x 300 DPI)

Supplementary Tables

Table 1. Environment Safety and Security. Instructions given to Participants. Please rate how strongly you agree or disagree with the statements below. These statements are focused on how you feel about your child's safety and security in particular public areas over the past 3 months. You can place an 'V' in the appropriate box to indicate your choice. *Environmental hazards include, traffic, dangerous materials, outdoor areas where a child could easily run away/get lost, inappropriate contact with others.*

Percentage Scores on Individual Items for Environmental Hazards Scales (7-point scale from strongly disagree to strongly agree)

	Item	%	1	2	3	4	5	6	7
1	I am confident that my child with autism is secure from environmental hazards when we go on walks	With Dog Wait List	22.5 48.8	12.5 23.8	6.3 8.3	5.0 9.5	16.3 3.6	20.0 4.8	17.5 1.2
2	I am sure that my child with autism is secure from environmental hazards when we visit a park	With Dog Wait List	18.8 29.8	15.0 31.0	10.0 15.5	12.5 10.7	15.0 4.8	18.8 6.0	10.0 2.4
3	I am certain that my child with autism is secure from environmental hazards when we visit friends	With Dog Wait List	22.5 19.0	12.5 23.8	20.0 27.4	13.8 6.0	8.8 10.7	10.0 9.5	12.5 3.6
4	I am confident that my child with autism is secure from environmental hazards when we travel in a car	With Dog Wait List	6.3 11.9	7.5 13.1	16.3 19.0	7.5 10.7	20.0 11.9	22.5 17.9	20.0 15.5
5	I am convinced that my child with autism is safe from environmental hazards in our home	With Dog Wait List	2.5 4.8	6.3 9.5	7.5 16.7	6.3 13.1	11.3 25.9	40 15.5	26.3 15.5
6	I am sure that my child with autism is safe from environmental hazards in a shopping centre	With Dog Wait List	25.6 46.4	11.5 25.0	12.8 10.7	12.8 6.0	17.9 8.3	9.0 2.4	10.3 1.2
7	I am confident that my child with autism is safe from environmental hazards in a restaurant	With Dog Wait List	21.8 38.1	17.9 22.6	11.5 17.9	9.0 10.7	16.7 8.3	14.1 2.4	9.0 0
8	In general I feel calm that my child with autism is safe from environmental hazards	With Dog Wait List	19.2 46.4	16.7 21.4	12.8 15.5	12.8 3.6	10.3 2.4	15.4 8.3	12.8 2.4

Table 2. Public Perception. Instructions given to Participants. These statements are focused on how you rate the public's perception of your child over the past 3 months. Please note: To 'make allowances' means that people react responsibly and respectfully towards you and your child when you are out in public.

Percentage Scores on Individual Items for Public Perception Scales (7-point scale from strongly disagree to strongly agree)

	Item	%	1	2	3	4	5	6	7
1	I feel confident that people make allowances for my child with autism when we are in a shopping area	With Dog Wait List	10.3 26.5	14.1 28.9	16.7 18.1	17.9 15.7	10.3 8.4	15.4 2.4	15.4 0
2	I am sure that people make allowances for my child with autism when we are in a restaurant	With Dog Wait List	12.8 38.1	19.2 29.8	17.9 10.7	17.9 11.9	5.1 6.0	14.1 3.6	12.8 0
3	I am certain that people make allowances for my child with autism when we are in a park	With Dog Wait List	17.9 20.2	9.0 21.4	20.5 26.2	17.9 10.7	12.8 11.9	11.5 6.0	10.3 3.6
4	I am sure that people make allowances for my child with autism when we are out walking	With Dog Wait List	10.0 19.3	11.3 28.9	13.8 14.5	17.5 19.3	15.0 8.4	17.5 8.4	15.0 1.2

Table 3. Perceived Competence. Instructions given to participants. Please respond to each of the following items in terms of how true they are for you with respect to being a parent of a child with autism. You can circle the number which represents how true you feel each statement is.

Percentage Scores on Individual Items for Perceived Competence Scales (7-point scale from 'not at all true' to 'very true')

	Item		1	2	3	4	5	6	7
1	I feel confident in my abilities to manage my child with autism	With Dog Wait List	1.3 1.2	2.5 7.1	6.3 16.7	18.8 26.2	35.0 26.2	27.5 14.3	8.8 8.3
2	I am capable of dealing with my child with autism	With Dog Wait List	1.3 1.2	2.5 4.8	5.0 14.3	15.0 22.6	25.0 28.6	38.8 17.9	12.5 10.7
3	I am able to do my own routine caring for my child with autism	With Dog Wait List	2.5 8.3	7.5 10.7	10.0 13.1	23.8 21.4	18.8 20.2	27.5 11.9	10.0 14.3
4	I am able to meet the challenges of being a parent of a child with autism	With Dog Wait List	2.5 6.0	3.8 4.8	11.3 21.4	17.5 10.7	31.3 26.2	30.0 20.2	3.8 10.7

STROBE Statement—parents perspectives on the value of assistance dogs for children with autism spectrum disorder: a cross sectional study.

	Item No	Recommendation
Title and abstract	1	(*a*) We have indicated the study's design with a commonly used term in the title
		(*b*) We have provided in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	We have explained the scientific background and rationale for the investigation being reported
Objectives	3	Specific objectives, including any prespecified hypotheses are stated at end of the introduction
Methods		
Study design	4	We have presented key elements of study design early in the paper – details given in Methods section and at end of Introduction.
Setting	5	We have described the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	*Cross-sectional study*—We have given the eligibility criteria, and the sources and methods of selection of participants
Variables	7	We have clearly defined all outcomes, exposures, predictors, potential confounders, and effect modifiers.
Data sources/ measurement	8*	We have provided full descriptions of our measures and assessments in the methods section
Bias	9	We have addressed biases in our procedures section and in our regression analysis - adjusting for key demographic variables.
Study size	10	We sampled the total population of users of a national assistance dog's organisation. Explained in Methods section.
Quantitative variables	11	Data management techniques are described in the data analysis section at end of the Methods.
Statistical methods	12	(*a*) We have described all statistical methods, including those used to control for confounding – in the Methods section.
		(*b*) We have described methods used to examine subgroups and interactions in the Results section.
		(*c*) We had minimal missing data.
		Cross-sectional study—we used data analysis techniques appropriate for comparing two independent groups.
		(*e*) Describe any sensitivity analyses – we did not do a sensitivity analysis.

Continued on next page

Results		
Participants	13*	(a) We have reported numbers of individuals in our cross sectional study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, and analysed
		(b) We omitted the over tens from our analysis for this study – described in Results section.
		(c) We have the maximum of 5 tables and figures included – these were considered essential and so we do not have space for a flow diagram. We are happy to provide one if requested.
Descriptive data	14*	(a) We have given characteristics of the study participants (eg demographic, clinical, social) and information on exposures and potential confounders (start of Results section)
		(b) We had minimal missing data.
Outcome data	15*	
		Cross-sectional study—We have reported the numbers of outcome events or summary measures in the Results section.
Main results	16	(*a*) We have given unadjusted and adjusted means and 95% confidence intervals. We have explained the reasons for adjustment in the results section.
		(*b*) We did not categorise continuous variables.
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period – this was not relevant.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions – main interactions are reported in the Results section and in the Discussion.
Discussion		
Key results	18	We have summarised key results with reference to study objectives
Limitations	19	We have discussed limitations of the study, taking into account sources of potential bias or imprecision.
Interpretation	20	We have given a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	We have discussed the generalisability (external validity) of the study results at the end of the Discussion.
Other information		
Funding	22	This study was not funded from any particular source. It was done at University College Cork and by kind permission of the Irish Guide Dogs for the Blind. They assisted us in contacting their service users. We did not have access to their service users lists. They did not have access to the study data.

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.