

THE CANINE CARE PROJECT

A REPORT INTO DISABLED YOUNG PEOPLE'S EXPERIENCES OF THEIR ASSISTANCE DOGS



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CONTENTS

<u>Acknowledgments</u>	<u>2</u>
<u>Contents</u>	<u>3</u>
<u>Executive Summary</u>	<u>5</u>
Summary of key findings	6
<u>Accessible Summary</u>	<u>9</u>
<u>Introduction</u>	<u>13</u>
What is the Canine Care Project?	15
The Canine Care Project Research Team - Who are we?	16
What is an assistance dog?	16
What did we do?	17
How is this report written?	18
Ethics	18
<u>Who responded to our online questionnaire?</u>	<u>19</u>
Respondents' experiences in different areas	21
Physical well-being and safety	22
Emotional wellbeing	24
Motivation, confidence and embracing new challenge	27
Social Inclusion	30
Relationships and emotional support	38
Meeting expectations	40
What next?	42
<u>Appendix 1:</u>	<u>43</u>



EXECUTIVE SUMMARY

The Canine Care Project is a research project that explored the experiences of disabled young people who have assistance dogs.

The Canine Care Project is a project by the University of Sheffield in collaboration with Canine Partners, a registered charity that transforms the lives of disabled people by partnering them with assistance dogs. This project is closely connected to Living Life to the Fullest: life, death, disability and the human [ES/P001041/1] in which young people told us about the importance of assistance dogs in their lives.

An assistance dog is the internationally established term for a dog that provides assistance to a disabled person, and is task trained to help support them in their lives. Our research has also shown that assistance dogs provide many psychological and social benefits such as increased independence, confidence, motivation and self-esteem.

In partnership with Canine Partners, The Canine Care Project administered an online questionnaire to young people (aged 18-35) who are partnered with an assistance dog. The report is supplemented by data from The Living Life to the Fullest Project and by eight case study examples provided by Canine Partners. In this Executive Summary we offer an overview of our key findings. On the following pages of this report, we detail these findings in more detail through focusing on specific areas of people's experiences. These include:

- Physical wellbeing and safety
- Emotional wellbeing
- Motivation, confidence and embracing new challenges
- Social inclusion
- Independence
- Care
- Relationships and emotional support
- Meeting expectations

Summary of key findings

Physical well-being and safety

Nearly all of the disabled young people who participated in our research said that they felt less vulnerable both inside (93.1%) and outside (96.6%) of the home in the company of their assistance dog. Many also felt that their assistance dog has helped them take better care of their physical health (60.3%).

Emotional wellbeing

Disabled young people readily reported to us that their assistance dog has made them feel more optimistic (86.2%) and that they have taken greater joy in everyday activities (91.4%). Moreover, many said that their assistance dog has, at the same time, helped to reduce a range of negative feelings. Notably, most respondents reported an improvement in feelings of loneliness (91.4%), followed by anxiety (87.9%), isolation (86.2%) and fear (77.6%).

Motivation, confidence and embracing new challenges

Disabled young people were clear that their assistance dog helped them cope with difficult things in life. Assistance dogs were also said to boost confidence (89.7%) and help them in various areas of motivation such as setting new goals (87.9%), giving a sense of purpose (86.2%) and trying new things (84.5%). Some of these goals attained with an assistance dog were major life events such as getting a degree or moving to live independently. Interestingly, during their interviews, many disabled young people explained how their assistance dogs had helped them embrace their disability (67.2%).

Social inclusion

Disabled young people reported profound impacts as to how their assistance dog has helped with feeling less “invisible” (87.9%) in social situations. Many said their assistance dogs make them more confident to engage in conversations (86.2%) with others in public, as well as more confident to express themselves (70.7%) to others. Many stated they now had a more active social life (81%) and that they were able to take part in social opportunities (81%).

It is worth noting that assistance dogs may also have a positive impact on other people. Many disabled young people asserted that their assistance dog puts other (non-disabled) people at ease in social situations (84.5%).

Independence

Most disabled young people stressed that their assistance dog has generally made them more independent (87.9%). They felt they could achieve more on their own and that they felt more independent, particularly when at home. Some others said that, with their assistance dog, they were more able to go out and about on their own (75.9%).

Care

Over two thirds of disabled young people said that, since getting their assistance dog, they now relied less on support from human carers (67.2%). Others said that their assistance dog reduced the discomfort they often feel when relying on human carers, such as discomfort due to dependence on another person, guilt that a caregiver may feel obligated to care and a consequent lowering of self-worth due to the need to be cared for or feeling pitied (81%). Others said their assistance dog helps them achieve tasks more quickly (72.4%), and that assistance dogs could be better at certain tasks than human carers.

Relationships and emotional support

Every single disabled young person in our research said that they were very affectionate (100%) with their assistance dog and that they feel that their dog loves them unconditionally (100%). Many considered their assistance dog a friend and/or significant other (87.9%) and that their dog was sensitive to their mood and health (86.2%), and would always be there for them (93.1%).

The bond between an assistance dog and young person can be so strong that the assistance dog is seen as an extension of the young person. The importance of this bond and the emotional support it yields can be seen to help mitigate emotional struggles many disabled young people experience.

Meeting expectations

The majority of disabled young people said that their expectations were exceeded (84.2%) by their assistance dog, with some reporting surprising benefits; for example, their stamina or physical symptoms improving, as well as positive changes going far beyond physical tasks.

Key Recommendations

1. Enable every disabled young person with physical impairments to be aware of the possibilities and benefits of canine care.
2. This small-scale project has opened up more questions about the impact of canine care that need to be explored more fully. So, we recommend:
 - a. *Developing research that engages with the views of all people who are supported by Canine Partners across the life course, paying attention to the intersections of disability, class, race, ethnicity, gender, age, poverty and sexuality.*
 - b. *There should be more research about, and awareness of, the ways in which inter-species relationships are a fundamental element of rethinking future human relationships - especially for those who are marginalised and displaced. For future discussions see <http://ihuman.group.shef.ac.uk/humanity-under-duress/>*



ACCESSIBLE SUMMARY



The Canine Care Project

The Canine Care Project is a partnership project between the charity Canine Partners and the University of Sheffield.



What did we want to find out?

We wanted to find out what disabled young people who have an assistance dog think about having a dog who helps them.



What did we do?

We asked young people to fill in an online questionnaire to tell us what they think. We also asked young people questions and collected information they had already shared with Canine Partners.

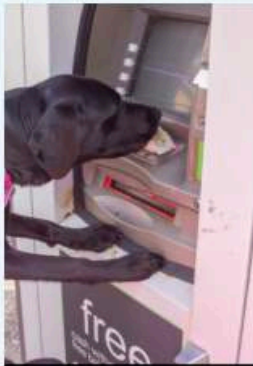


What did we find out?

We found out that assistance dogs that help are really important to disabled young people for lots of different reasons.



Assistance dogs make disabled young people feel more independent.



Assistance dogs make disabled young people feel like they don't have to ask other human beings for as much help.



Disabled young people say they love their dog and their dog loves them...



Disabled young people say that having an assistance dog is better than they thought it would be.



Assistance dogs make disabled young people feel safe and well.



Assistance dogs make disabled young people feel happy and less lonely.



Assistance dogs make disabled young people feel more confident to try new things.




Assistance dogs help disabled young people to have the social lives they want to have.





INTRODUCTION

THE CANINE CARE PROJECT



“Around the university campus I had gone from being the girl in the wheelchair to being the girl with the amazing dog and that was a very liberating feeling.”

Living Life to the Fullest Participant

What is the Canine Care Project?

The Canine Care Project is a research project that explored the experiences of young disabled people aged 18-35 years who have assistance dogs.

The Canine Care Project is a project by the University of Sheffield in collaboration with Canine Partners, a registered charity that transforms the lives of adults with physical disabilities by partnering them with assistance dogs, and the Economic and Social Research Council (ESRC).

Through a small collective Research Team of academic researchers, Canine Partners collaborators, and a disabled young co-researcher who has a Canine Partner, we wanted to further explore related early findings emerging from a larger umbrella project called the Living Life to the Fullest Project.

Living Life to the Fullest (livinglifetothefullest.org) is a research project based at the University of Sheffield and funded by the Economic and Social Research Council (ESRC) which seeks to forge new understandings of the lives, hopes, desires and contributions of children and young people with 'life-limiting' or 'life-threatening' impairments.

Early findings from the Living Life to the Fullest Project showed that assistance dogs can play a significant part in the lives of disabled young people and can transform their experiences of living with disability. For example, young people told us that an assistance dog did far more for them than practical tasks (although these are very important), but actually made them feel happier, safer and more at ease in social situations. The Canine Care Project began with a desire to explore these findings further, using a wider online questionnaire to explore disabled young people's experiences.



Photo of Black Assistance dog retrieving cash from an ATM

"Making sure she's ok [assistance dog] is a reason for me to make sure I am ok – I look after myself better so that I can look after her as she deserves. People treat me differently too, they ask about the dog rather than asking why I'm in a wheelchair."

Living Life to the Fullest Participant

The Canine Care Project Research Team - Who are we?

The Canine Care Project has been carried out by a small but varied team of people.

Sally Whitney is an academic researcher working as part of a collective of disabled young women as part of the Living Life to the Fullest Project. She is also a speaker for Canine Partners, giving talks to the general public. In addition, Sally appears in the media discussing the impact her assistance dog Ethan has had. She also works passionately towards supporting the Church, to make it more inclusive to all. She is a research associate in collaboration with the University of Sheffield in other projects.

Dr Kirsty Liddiard is a sociologist and Research Fellow at the University of Sheffield. Her research explores the lives of disabled people. Currently, she is co-leading Living Life to the Fullest, an ESRC-funded project centred on the lives of disabled children and young people living with life-limiting and life-threatening impairments (LL/LTIs) [ES/P001041/1].

Nikola Bakalov is an interdisciplinary mixed-methods researcher in disability and employment at the University of Sheffield.

Canine Partners Advisory team: Anita Frediani (Applications and Assessment manager), Nicky Springthorpe (Communications manager) and Nicola Martin (CEO).

Professor Dan Goodley is the Principal Investigator for the Living Life to the Fullest: life, death, disability and the human project [ES/P001041/1] at the University of Sheffield.

Professor Katherine Runswick-Cole is a Co-Investigator for the Living Life to the Fullest: life, death, disability and the human project [ES/P001041/1] at the University of Sheffield.

What is an assistance dog?

An assistance dog is a dog that supports a disabled person with tasks in everyday living. Canine Partners' assistance dogs are trained to help with everyday tasks such as opening and closing doors, unloading the washing machine, picking up dropped items, pressing buttons and switches and fetching help in an emergency. They can even help people to get undressed and remove a card from an ATM.

Canine Partners' assistance dogs also provide many psychological and social benefits such as increased independence, confidence, motivation and self-esteem; companionship, sense of security and unconditional love; a talking point, increasing social interaction; helping to return to work, voluntary positions or further education and reducing reliance on human carers and, in some cases, medication. Canine Partners is a registered charity that assists people with physical disabilities to enjoy a greater independence and quality of life through the provision of specially trained dogs. Over the past 29 years the charity has provided and trained more than 800 dogs that help disabled people, including 440 that are in action today. It takes approximately 18 months to train a canine partner from selection at eight weeks old through puppy training and advanced training until they are partnered with a disabled person with physical impairments (See appendix 1 for more details about Canine Partners).



Black assistance dog with its paws on the lap of a disabled young woman in a wheelchair being affectionate with one another at an outside event

What did we do?

Supported by Canine Partners, The Canine Care Project administered an online questionnaire to young people (aged 18-35) who are partnered with a canine partner. Participants were identified through Canine Partners, the community research partner. In the information about participation we stressed that any care or services the young people receive from Canine Partners would not be affected by their choice (or not) to participate.

We chose an online questionnaire as this is an accessible method that can be completed quickly and easily by participants. However, we recognise that many disabled people are digitally excluded and that the questionnaire relies heavily on text. We see this as a limitation of the current study.

We devised all questions as a Research Team. Particular care and attention was paid to the questionnaire design in order to ensure that the answers would be as unbiased and informative as possible and to gain the depth of understanding we required. As someone with lived experience of having an assistance dog, Sally Whitney was key to this process as her experiences informed many of the questions we later asked in the questionnaire. We also based questions on early findings from young people's stories collected from our sister project, the Living Life to the Fullest Project. The questionnaire included closed questions and one open question where participants were asked to give one word to describe their assistance dog. Analysis was carried out using descriptive statistics. The questionnaire was supplemented by narrative data from the Living Life to the Fullest Project and from case studies from Canine Partners.

Our early drafts of the online questionnaire were sent to different 'content experts' – six

people from different backgrounds that could advise us as to the wording and content of questions. Content experts included people with lived experience of disability who had assistance dogs and academic researchers with experience in disability research and/or quantitative methods (e.g. survey/questionnaire design). These content experts made useful suggestions towards improving the questions and helped us think through how we might analyse the resulting data.

How is this report written?

The findings we discuss in this report are taken from our online questionnaire, the stories collected from disabled young people within the Living Life to the Fullest Project, and Canine Partners case studies - short stories from Canine Partners clients that detail their experiences of having an assistance dog. For clarity, in this report we include two young people's stories from the Living Life to the Fullest Project; eight Canine Partner case studies and the experiences of 58 disabled young people who responded to our online questionnaire.

In each section of the report we have purposefully divided online questionnaire findings (percentages in tables and our interpretations of them) from the stories of people collected by the Living Life to the Fullest Project and Canine Partners. This is to show how people's voicing of their individual stories supported the much broader findings of our online questionnaire.

Ethics

The project was informed by the principles of informed consent, anonymity and confidentiality and carried out in-line with the British Educational Research Association (BERA) Code of Ethics.

The 58 participants in the online survey were not required to give their names. We obtained informed consent through an online 'consent form' which featured as a front page at the very beginning of the web-based questionnaire. This information reiterated the importance of consent to ensure the participant understood and fully consented to their participation in the project. Participants were required to read a number of statements pertaining to consent, and were asked to click in agreement. If consent was not given, the participation ended prior to answering any questions on the questionnaire. We included a debrief page at the end of the questionnaire, detailing how to get in touch with the Research Team (if needed) and a list of sources of support. The project was reviewed and approved by The Ethics Committee for The School of Education at the University of Sheffield.

Participants whose short stories are included from the Living Life to the Fullest Project have received information about the project and given consent for their anonymised data to be shared. The Living Life to the Fullest Project was also reviewed and approved by The Ethics Committee for The School of Education, at the University of Sheffield.

Participants whose case studies were collected by Canine Partners have given their permission for their anonymised stories and photos to be shared in the public domain.

All the photos used in the report are from the Canine Partner library and do not depict participants in the study.

Who responded to our online questionnaire?

In total, 102 disabled young people were invited to participate, and a total of 58 (57%) completed the online questionnaire. Given the tendency for typically low response rates for online research surveys this represents a very good response rate.

Respondents were aged between 21-35 years, with an average age of 28.65 years. In terms of gender, 10 (17.2%) were male and 45 (77.6%) were female. One person (1.7%) reported their gender as "Other" and two people (3.4%) chose not to disclose their gender.

Thirty respondents (51.7%) said their disability was progressive, which was defined as a disability or health condition that gradually develops over time, and 22 (37.9%) said that their disability or health condition was not progressive.

Respondents were also asked about the level of care they require from a human carer in addition to the support they received from their assistance dog. Respondents were provided with a rating scale from 0 (No care) to 10 (a lot of care). The average level of care that respondents reported was 5.88.

Respondents had been with their dogs for periods ranging from 10 weeks to 8 years 7 months. The average length of service was approximately 3 years and 3 months. Overall, 39 respondents (67.2%) lived with someone other than their assistance dog.

Initially, we asked young people about the kind of tasks that their assistance dog helped them with. They were given pre-set categories of typical tasks (see Figure 1). These pre-set categories were decided within the Research Team.

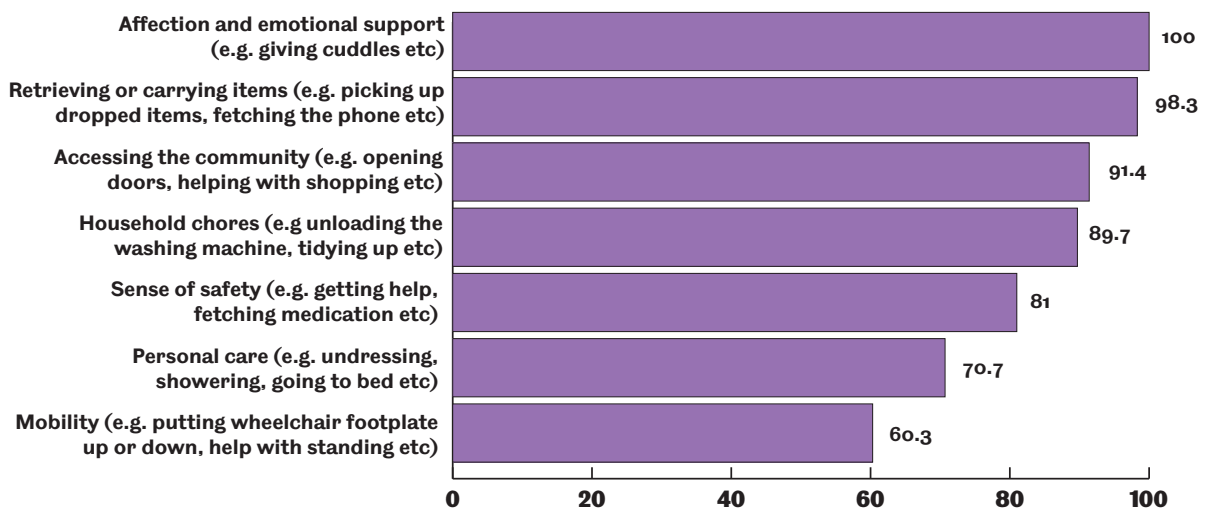


Figure 1: Tasks where assistance dogs helped (%)

As Figure 1 shows, all respondents said that their assistance dog supports them by giving affection and emotional support. This was immediately followed by retrieving and carrying items, and the ways in which assistance dogs helped people access their local communities. Further down the list were tasks such as personal care and mobility.

Over the next few pages, we detail these findings further. We also move beyond these preliminary findings to speak about the ways in which disabled young people in our research feel that having an assistance dog affects their physical wellbeing and safety; emotional wellbeing; motivation, confidence and their embracing of new challenges; their sense of social inclusion; their independence and thoughts about their care; and their relationships with assistance dogs as a key form of emotional support.



Two smiling young women in wheelchairs with a white curly haired assistance dog next to one and a ginger labrador assistance dog next to the other

CHAPTER REFERENCES

1. *Four respondents did not disclose their age.*
2. *Six respondents (10.3%) preferred not to disclose this information.*
3. *One person did not disclose how long they had been with their assistance dog.*

A black dog is sitting on a light-colored wooden floor, looking towards the right. It is wearing a purple long-sleeved shirt with the words 'Canine Partners' and a logo printed on it. To the left of the dog, a person is sitting in a wheelchair, wearing a purple long-sleeved shirt with the word 'Canine' printed on the sleeve. The person's hand is resting on the dog's back. In the background, there is a grey washing machine and dark grey cabinets. A blue plastic crate is visible in the bottom right corner.

RESPONDENTS' EXPERIENCES IN DIFFERENT AREAS

THE CANINE CARE PROJECT

Physical well-being and safety

This domain incorporates items on a young person's perceptions of physical health and symptoms, as well as their feelings of safety when with their assistance dog.

In our initial interviews with disabled young people, they told us that they felt their physical symptoms of illness and/or disability had improved since getting their assistance dog. Imogen, who has a canine partner called Olive, states, *"The change in my health in the time I have had her is outstanding. My stamina has consistently improved far beyond what I had ever dared hope I would ever achieve again."*

Some of the young people interviewed put this down to the assistance dog doing tasks for them: *"Life after Sylvester is much less painful as I don't have to do everything, because he can do things for me,"* says Jay.

Rachel emphasised the perception of lowered physical symptoms due to her assistance dog doing tasks for her as she says, *"The physical tasks she does like helping me dress, picking up dropped items, lifting my wheelchair footplates, opening/closing doors, along with many more meant I had less pain and fatigue."*

From our research, it was apparent that disabled young people often have a very acute sense of their vulnerability when they are alone, both at home and when out in the community. Imogen describes this sense of vulnerability when she says; *"Like a lot of disabled people I've also experienced discrimination and ignorance which is incredibly frightening when you are so vulnerable."*

However, this feeling of vulnerability seems to be mitigated by the presence of an assistance dog, which provides a sense of both physical and psychological security.

Stuart highlighted the power of his canine partner, Rupert, in his life in overcoming this vulnerability as he reports, *"I can be at home on my own AND I take Rupert out for a long walk on my own every day. I enjoy every second of it. Being able to be on my own is quite a big thing for me. For the last 4 ½ years I haven't been able to be on my own, even for a ten minute wander round the block, due to ill health or the fact that if I drop something I can't pick it up."*

The significance of this change in feelings of vulnerability in disabled young people should not be underestimated. For example, Rachel says, *"I had previously done whatever I could to avoid going out on my own as I was acutely aware of my vulnerabilities but now I don't think twice before taking a spontaneous walk with Eve."* Importantly, our online questionnaire findings (below) reflect this change.

Our interview data also suggests that young people may take better care of their health when they have an assistance dog. This raises an important question of why disabled young people might not be taking the best care of their health before they are partnered with an assistance dog.

Sam, who is partnered with canine partner dog Blue, suggests one reason why this might be the case, *"...making sure she's ok is a reason for me to make sure I am ok – I look after myself better so that I can look after her as she deserves."*

As Sam shows above, becoming responsible for an assistance dog may be the first time disabled young people have a dependent – someone or something to care for – and thus the impetus to take care of themselves is to ensure they are well enough to look after their assistance dog.

This sense of responsibility that is often required when looking after an assistance dog can bring about both a greater sense of purpose and meaning for some young people, but importantly it can also involve work for the young person. For example, the types of work young people mentioned included feeding, training, and walking, but also included the responsibility of caring for another living being. Imogen states, *"Suddenly she was entirely my responsibility and I just wanted to do everything correctly. In the beginning both Olive and I were learning about each other and adapting to our new routine."*

However, this perception may change as the relationship progresses; Imogen added that she and Olive are, *"now ... in sync."* Similarly, Tash comments, *"...it was a daunting task knowing I would be responsible for looking after Cuthbert, [but] it really helped me to rediscover my independence."*

Online questionnaire responses are shown in Table 1, below.

	Strongly disagree or disagree	Neither agree nor disagree	Agree or strongly agree
Since I got my assistance dog, my physical symptoms seem to have improved.	32.8	36.2	31
I feel less vulnerable at home now that I have my assistance dog.	0	6.9	93.1
I feel less vulnerable when I'm out and about with my assistance dog.	1.7	1.7	96.6
My assistance dog has helped me take better care of my physical health.	12.1	27.6	60.3
Taking care of my assistance dog makes me feel fatigued at times.	36.2	25.9	37.9

Table 1: Respondents' responses within the domain of physical well-being and health (%)

As shown in Table 1, nearly all respondents reported that they felt less vulnerable both at home and outside the home in the company of their assistance dog. In addition, around three-fifths of respondents felt that their assistance dog has helped them take better care of their physical health.

However, nearly two-fifths of respondents felt that taking care of their assistance dog can make them feel fatigued at times and around a quarter were unsure. This finding suggests that having an assistance dog can involve considerable labour on the part of the disabled young person. Nevertheless, surprisingly, about a third of respondents felt that their assistance dog improved their physical symptoms.

Emotional wellbeing

This domain incorporates items about a young person's emotional well-being.



Black assistance dog and young woman in a wheelchair gaze at each other smiling while outside some buildings

In our previous interviews with disabled young people in the Living Life to the Fullest Project we found that the emotional effects of living with a disability as a young person can be momentous. One young woman we interviewed, Tash, reports, *"I have had to remain very strong to cope with the emotional impact that my disabilities have had on me. Multiple people have said things that remind me of my limitations, such as 'you're too ill to come to rehab', 'come back to the hospital when you're better', and 'you're unemployable because of how your disability restricts you'. The things that are said to me really do have a way of bringing me down and makes me feel like I'm fighting the impossible."*

However, in our interviews respondents discussed a change in their emotional well-being upon receiving their assistance dogs. They report a decrease in negative feelings and an increase in positive ones. For example, Stuart states, *"Since having Rupert I am no longer anxious."*

It is interesting to note that this positive impact on emotional well-being is something that our young respondents did not anticipate. We asked interviewees whether there are any benefits to having an assistance dog that they didn't expect. Sam responded without hesitation, saying *"Definitely emotional. She's made me far happier."* Rachel adds, *"When I applied [for her assistance dog] I was largely focused on the physical tasks but Eve gives me sooooo much more than that – and I now live with a 24/7 comedian so it's pretty hard to be down for too long!"*

This extra benefit that Rachel mentions is the significant emotional support Eve provides, *"During my training course with Eve I laughed more than I had ever laughed before and the heavy weight I had been carrying lifted. I started my final year at university feeling much more optimistic with Eve by my side. I often felt lonely and homesick at university and it was very reassuring to wake up every morning to Eve's chocolate nose and waggy tail."*

In the above quote, Rachel clearly describes the impact of her assistance dog on her mood and her feelings of loneliness. Shelly gave an example of how the practical help of Paddington (her canine partner) has directly affected her mood and emotional well-being and decreases her fear and worry: *"I used to get so nervous and worry about making a fool of myself [when] passing my purse to the cashier [but now] I don't need to worry about dropping the money."*

Rachel also goes on to describe her emotional state before and after getting her canine partner, Eve. She says, *"I was losing interest in everything I had previously loved. This all changed when I went down to Canine Partners [Headquarters] to meet a dog they had in mind for me. I gazed into her incredible amber eyes and saw so much joy, enthusiasm and possibilities. In that instant she stole my heart and something came alive inside me again."*

We should note that the responsibility and work involved in having an assistance dog can be a cause of anxiety to some young people. Discussing her domiciliary training with her assistance dog, Tash admits that the course led to some difficult emotions, *"It was very overwhelming and frustrating. I wanted everything to be perfect so when it wasn't I got upset and felt like a failure."*

	Strongly disagree or disagree	Neither agree nor disagree	Agree or strongly agree
Since I got my assistance dog I have been feeling more optimistic.	5.2	8.6	86.2
Since I got my assistance dog I have taken greater joy in everyday activities.	1.7	6.9	91.4
My assistance dog has helped me with feelings of anxiety.	1.7	10.3	87.9
My assistance dog has helped me with feelings of loneliness.	3.4	5.2	91.4
My assistance dog has helped me with feelings of fear.	6.9	15.5	77.6
My assistance dog has helped me with feelings of isolation.	3.4	10.3	86.2
The responsibilities of having an assistance dog have made me feel burdened at times.	60.3	24.1	15.5
The responsibilities of having an assistance dog have made me feel anxious at times.	53.4	19.0	27.6

Table 2: Respondents' responses in the domain of emotional well-being (%)

Our online questionnaire findings show that more than four-fifths of respondents felt that their assistance dog has made them feel more optimistic and that they have taken greater joy in everyday activities. Moreover, respondents agreed that their assistance dog has helped with a range of negative feelings. Most respondents reported an improvement in feelings of loneliness, followed by anxiety, isolation and fear.

Although an assistance dog itself can, for some, be a source of negative feelings in terms of the work they can require, our online questionnaire findings show that this was not an issue for the majority of respondents. In fact, only around a quarter of respondents agreed that the responsibility of having an assistance dog has made them feel anxious at times. Even fewer (less than a fifth), agreed that it has made them feel burdened at times, but it is worth noting that about a quarter of respondents were unsure about their answer.



Young man in wheelchair outside stroking his Golden retriever assistance dog that has his eyes closed

Motivation, confidence and embracing new challenge

Items in this domain focus on a young person's sense of self-confidence, purpose and identity, as well as their attitude towards new challenges.



Black assistance dog accompanies young woman in a wheelchair to a sporting event

In our interviews, disabled young people overwhelmingly reported that having an assistance dog is an effective tool for coping with the difficulties that can come with disability by changing their outlook and motivation. We suggest that this comes about by the increased sense of self-confidence that having an assistance dog can bring. Our online questionnaire results affirm this finding (see Table 3).

The interplay of increased self-confidence, a desire to set new goals, try new things and find purpose shapes a disabled young person's understanding of themselves and their identity. For example, Rachel said, *"Eve's unquestioning acceptance has allowed me to accept myself and given me so much confidence. I recently landed my dream job of being an advocate for young disabled people."*

The effect on confidence and a desire to try new things achieved by the partnership of a disabled young person and an assistance dog is further evidenced by Imogen when she says *"I feel safe and brave [with Olive], and we are starting to explore new opportunities."*

Rachel discusses her sense of self-confidence and identity before gaining a canine partner saying, *"...before [Eve] I would have turned down opportunities due to lack of self-esteem."*

Similarly Imogen says, *"I was afraid of my own body, the outside world and what my future would be."* She then describes the profound impact having an assistance dog can have and explains the change in her outlook after being placed with Olive: *"Olive was the light at the end of my tunnel and my motivation throughout."*

This is a significant finding as it resonates with our Living Life to the Fullest Project findings where young people have described the fear and worry associated with having a life-limiting

or life threatening condition; as well as the impact this has on confidence and self-esteem, and the difficulties incurred when looking to the future.

However, Rachel also reinforces another finding from the Living Life to the Fullest Project – that many disabled young people are actively striving to live full lives – when she says, *“As a young woman, I now feel like I have everything to live for and want to get out there and seize every adventure that comes my way but this wasn’t always the case [before Eve].”*

The desire to set goals (and have faith they might be fulfilled) that has arisen for many as a result of having an assistance dog was further evident in our interviews. For example, Imogen said, *“While I am completing my degree I am focused on building my health and stamina up to a point where I would be capable of working and/or entering postgraduate education. Before it was a dream, but now with Olive it is an achievable reality.”*

Rachel describes her pride at being able to accomplish her goals, *“It was a very proud moment when I graduated from university with Eve by my side. I had accomplished my dreams and had achieved the First Class degree I was striving for.”*

This profound change in belief about what is possible in the lives of the disabled young people we interviewed is remarkable and should not be underestimated. Neither can the positive effect of having an assistance dog on the outlook and sense of purpose of disabled young people.

Stuart highlights this when he says *“I’m no longer in and out of hospital constantly. I don’t know if it’s the fresh air I’m getting or the fact I now have a purpose in life.”*

One of the findings from our interviews with disabled young people that has been most thought-provoking for us is how having an assistance dog helps a young person shape their identity and can contribute to the embracing of a disabled identity. Faith discusses her sense of identity and how other people perceive her before and after getting her canine partner, *“I have always wanted to have the confidence to know that I can influence my own world and allow people to see me rather than just my condition. [Now] when out and about with Ted, I feel that people are talking to me as my own person and seeing me rather than treating me just as someone who has cerebral palsy and is in a wheelchair. My confidence has grown so much...Ted has helped me to show everyone the real me!”*

It can be said that many of the disabled young people interviewed welcomed the refreshing change of being seen solely for who they are both by their assistance dog and consequently others around them. They express the pleasure of not being defined by their disability or their dependence on a human carer. Rachel says, *“It has also been a great confidence boost to feel so accepted by her - she doesn’t see my disability, I’m just Rachel.”*

We suggest that this shedding of labels seems to afford a space and freedom for young people to consider their identity and relationship to their disability. For some, we then see an emergence of a prouder disabled identity.

	Strongly disagree or disagree	Neither agree nor disagree	Agree or strongly agree
The responsibility of caring for my assistance dog has given me a sense of purpose.	6.9	6.9	86.2
Having an assistance dog has encouraged me to set new goals.	0	12.1	87.9
Having an assistance dog has boosted my confidence.	0	10.3	89.7
The support I get from my assistance dog has encouraged me to try new things.	5.2	10.3	84.5
My assistance dog helps me cope with difficult things in life.	1.7	6.9	91.4
Having an assistance dog has helped me embrace my disability.	10.3	22.4	67.2

Table 3: Respondents' responses in the domain of motivation, confidence and embracing new challenges (%)

Our online questionnaire findings show that more than four-fifths of disabled young people agreed that their assistance dog helped them cope with difficult things in life. This was closely followed by agreement that their assistance dog has boosted their confidence.

A similar number of respondents expressed agreement that their assistance dog has helped them in various areas of motivation such as (in descending order of agreement) encouraging them to set new goals, giving them a sense of purpose and encouraging them to try new things. Above three-fifths of respondents agreed with the statement that their assistance dog has helped them embrace their disability.

Social Inclusion

This domain includes items about both a young person's sense of social inclusion as well as their feelings and confidence in being in social situations.



Young woman in a wheelchair outdoors surrounded by friends and family with her black assistance dog

In our previous interviews with disabled young people they told us that the presence of an assistance dog in their lives affected their sense of social inclusion in a whole variety of ways. Tash reports, *"When you gain a canine partner into your life, you also gain a whole new community of people who love and support you and your dog, just like your family would. I now have so many more friends and a much more active social life than I did before."*

This illustrates that an assistance dog can profoundly change a young person's sense of their social life and environment and can lead to a new network of friends and associates, as well as providing more access to social opportunities. As Faith poignantly says, *"...he [canine partner Ted] helps me to find true friends."*

We know from our previous explorations in the Living Life to the Fullest Project that disabled young people often feel that there is a social barrier between themselves and non-disabled people, and that this can lead to feelings of exclusion. Describing her feelings before getting canine partner Eve, Rachel says, *"I was desperate to be socially included but the large majority of [university] students saw me as totally different to them as they could not see past my wheelchair and would choose not to interact with me."*

However, we want to stress here the positive difference an assistance dog relationship can have on other people in society, and not just disabled young people themselves. We suggest that an assistance dog partnership goes some way to breaking down the barriers between disabled and non-disabled people. Our research shows that the presence of an assistance dog can positively change the response of the public, where previously they may have been *"scared to interact"* as Rachel says. She notes, *"I think a dog provides that common ground*

for people to talk about something they know about and it [having canine partner Eve] was a gateway for them getting to know me better” and “provided the bridge for them to come and talk to me.”

Faith describes how her own ability to interact with the public (both in her confidence to have conversations with others and as well as how she feels about expressing herself) has changed since having her canine partner Ted when she says, *“My confidence has grown so much that I can now talk to strangers at bus stops, shops, and on buses without turning to whoever is accompanying me for help.”*

Moreover, the feelings of invisibility that disabled young people told us about in the Living Life to the Fullest Project are somewhat overcome by having an assistance dog. Faith says, *“I feel that I am seen and noticed more when I am out and about with Ted and people genuinely want to stop and talk to us.”* This sense of being seen and included by others is echoed by Shelly when she says that having her canine partner Paddington *“...makes me feel stronger and more part of society.”*

	Strongly disagree or disagree	Neither agree nor disagree	Agree or strongly agree
My assistance dog seems to put people at ease in social situations.	1.7	13.8	84.5
Ever since I got my assistance dog, I've had a more active social life.	5.2	13.8	81.0
Since I got my assistance dog, I feel more included in things by others.	3.4	27.6	69.0
Since I got my assistance dog, I am able to join/take part in social opportunities more than before.	3.4	15.5	81.0
My assistance dog makes me more confident to express myself to people.	12.1	17.2	70.7
When I am with my assistance dog, I no longer feel invisible in social situations.	8.6	3.4	87.9
My assistance dog makes me more confident to engage in conversations with others in public.	6.9	6.9	86.2

Table 4: Respondents' responses in the domain of social inclusion (%)

Over four-fifths of respondents reported that their assistance dog makes them more confident to engage in conversations with others in public. A similar proportion agreed that their assistance dog has helped with feeling less “invisible” in social situations. While two-thirds agreed that their assistance dog makes them more confident to express themselves to people. Moreover, around four-fifths of respondents also agreed that they had a more active social life and that they were able to take part in social opportunities.

It is worth noting that assistance dogs may also have a positive impact on other people. Over four-fifths of respondents agreed that their assistance dog puts other people at ease in social situations. In addition, slightly over two-thirds felt more included in things by others.



Black assistance dog and young woman paying at shop counter

Independence

This domain incorporates items about both a young person's sense of independence in terms of their ability to accomplish things and their own perception of their independence (see Table 4).



Black assistance dog pressing a door entry button with his nose outside a public building next to a young woman in a wheelchair

In the Living Life to the Fullest Project, the desire for independence brought about by having an assistance dog was one of the most discussed themes. A lack of independence at home, in public and in general was one of the most problematic issues for the disabled young people interviewed. Tash describes her sense of independence before and after her canine partner Cuthbert came into her life. She says, “...before *Cuthbert*, I couldn't do much at all and I was in bed most of the day. I had no independence and I was relying on my husband or my mum to do most things for me... Since having *Cuthbert* in my life I feel more confident [and] independent.”

Our interviews with disabled young people revealed that they were able to do more on their own since being partnered with an assistance dog. Jay says, “[*Sylvester*] has definitely made me more independent and I can now do those things on my own that I couldn't do before.”

The importance of this can be seen by the fact that with increased feelings of independence comes an increased sense of confidence (and vice versa), whereas the feeling of dependence can be seen to negatively impact feelings around self-esteem.

Imogen says of her time before canine partner Olive, “I was dependent on other people for basic tasks and had no sense of independence or value.” Jay discusses the fact that he now feels confident enough to live alone. He describes the reason for moving “...is to give me more independence and start a new chapter in my life as I'm now 25 years old. If I didn't have *Rupert* (his canine partner) I think I would be very nervous and not looking forward to it but he gives me the confidence I need to know that I'll be fine on my own.”

The importance of the relationship between independence and confidence that having an assistance dog elicits is further highlighted by the fact that it seems it allows disabled young people to reach major life goals.

Our interviews also revealed that having an assistance dog affected disabled young people's sense of independence both in the home and in the outside world. Stuart states, *"I can be at home on my own and I take Rupert out for a long walk on my own every day – I enjoy every second of it."*

Clearly, this independence means a lot to Stuart. Shelly also describes the impact of new found independence in her life now she has canine partner Paddington, she says, *"Even just being able to go to the corner shop on my own is amazing."*

	Strongly disagree or disagree	Neither agree nor disagree	Agree or strongly agree
Because of my assistance dog I am more able to go out on my own.	8.6	15.5	75.9
Since I got my assistance dog, I feel more independent.	0	12.1	87.9
Since I got my assistance dog, I can achieve more on my own*.	3.5	7.0	89.5
Because of my assistance dog, I can be more independent at home*.	1.8	5.3	93.0

* One person did not provide a response to this item

Table 5: Respondents' responses in the domain of independence (%)

Table 5 shows that over four-fifths of respondents agreed that their assistance dog has generally made them more independent. An even greater proportion said they could achieve more on their own and that they felt more independent, particularly at home. At the same time, a lower proportion of respondents (just above three-quarters) agreed that they were more able to go out and about on their own.

Care

This domain explores a young person's feelings surrounding the care carried out by their assistance dogs in comparison to human care, and how their assistance dog can impact upon the care they need.



Black assistance dog removes boot from young woman sat on a sofa by tugging it with his mouth

In our previous interviews with disabled young people in the Living Life to the Fullest Project, we found that the emotional labour involved in receiving and relying on care from human carers can be heavy – because of its emotional consequences as well as practical implications. Emotional labour can be described as the performances of emotion we are expected to give in certain situations. For example, our disabled young interviewees in the Living Life to the Fullest Project often talked about having to show gratitude upon receiving care and support from others, even if they did not feel it.

Shelly described to us the complexity of needing care and support, but not wanting another person around. She says, *“I felt really frustrated with myself and wanting to be able to do more but not necessarily wanting support all the time.”*

Shelly went on to describe the difficulties with human-to-human models of care. Some of those difficulties may include a discomfort with feeling dependent and claustrophobic, as she explains: *“I didn’t want to have another adult, carer or PA with me all the time, not that there’s anything wrong with that, but I’m very independent and always try to be as independent as possible.”* Similarly, Rachels admits to the same difficulty, stating, *“I’ve always been very independent and have struggled to ask for help.”*

The discomfort of dependence or reliance on another human being is echoed by Faith, *“Due to my condition I am always relying on others for my needs.”* But Faith goes on to describe how having her canine partner helps her cope with this feeling as the situation is reversed: *“... now I have Ted I am responsible for someone else.”* Rachel agrees as she says, *“[the difficulty in asking for help] isn’t an issue with Eve because everything is a game and feels much more equal.”*

In fact, it seems that the emotional labour associated with being dependent on other humans for care can, for some disabled young people, really affect self-esteem. As Imogen says, *"I was dependent on other people for basic tasks and had no sense of independence or value."*

Many of our respondents describe their assistance dogs doing tasks that previously only other human beings were able to do. Shelly recounts *"...being able to get things off the shelf without having to ask another human being [is amazing]."*

Disabled young people, like Shelly, also described how tasks are achieved more effectively and quickly, *"All of the little things that would take ages, like opening my back door to go outside, it was such a mission, by the time you had done it you wanted to just go back to bed [but now] I can do so much more because I can conserve my energy."*

Rachel further emphasises this when she says, *"...through Eve I saw how such everyday things like taking off my jacket could be fun whereas before they had been laborious tasks."* This highlights how tasks can be achieved more effectively with help from an assistance dog.

Shelly very articulately explains the multiple benefits of receiving care from her canine partner and the liberation this can bring. She explains, *"...not relying on other people anymore is really freeing and [it is] like I'm my own person. I can stand on my own two feet (excuse the pun!) or my own four wheels, whichever way you want to look at it!"*

The fact that this change in care provision from human to dog can bring about a positive change in Shelly's sense of identity and feeling of independence is important. Shelly also describes how relying on her canine partner lessens her emotional labour of guilt surrounding whether the care-giver wants to be providing her care and the perceived obligation to do so. She enthuses, *"What I love about our partnership more than anything is that I know he wants to do what he does for me. He's not being forced and he does it because he genuinely cares. I don't think I've ever felt that before from anybody, that unconditional love."*

Faith describes the practical difficulties of having care from humans, *"I choose to have people from my own age group helping me. However, this means that carers and assistants often move on [leave]."* But, she goes on to describe how her canine partner Ted mitigates some of this emotional work, *"...now I have Ted I know my best friend ever will always be with me and will not leave."*

Sam admits, *"...there are many things I need doing [for me] that are beyond a dog's capabilities."* However, Sam says because canine partner Blue has *"reduced the amount of dislocations and POTS symptoms [physical symptoms] I have by helping me with day to day tasks, that in itself has made me able to do more things."* It is clear that Sam believes Blue helps achieve more tasks.

Rachel goes so far as to say that her canine partner is actually able to carry out some care that her human carers can't do, and that sometimes her canine partner can do it more effectively. Rachel states, *"...in some ways she surpasses humans with how she can support me both mentally and physically, for example the angle she takes my coat off is much better for my arms."*

Sam said, “*Seeing Blue [canine partner] pick up something I’ve dropped or tug off my jacket is funny and cute and adorable, people love watching it; having another human do the same thing makes people feel sorry for me or feel sorry for the person helping me. People love watching an assistance dog work but can be uncomfortable watching another person provide care and assistance, in my experience. Again I think agency plays a part.*”

	Strongly disagree or disagree	Neither agree nor disagree	Agree or strongly agree
After getting my assistance dog, I now rely less on support from human carers.	10.3	22.4	67.2
My assistance dog helps me achieve tasks more quickly.	8.6	19.0	72.4
Having an assistance dog seems to have reduced the discomfort of relying on human carers.	8.6	10.3	81.0
Taking care of my assistance dog (e.g. Grooming, feeding, toileting, exercising) is manageable.	5.2	19.0	75.9

Table 6: Respondents’ responses in the domain of care (%)

As Table 6 shows, around two-thirds of disabled young people said they now relied less on support from human carers and four-fifths of respondents agreed that their assistance dog has reduced the discomfort of relying on human carers. Around three-quarters said their assistance dog helps them achieve tasks more quickly. A similar proportion of respondents agreed that the care they had to provide for their dog is manageable.

Relationships and emotional support

This domain explores the bonds between a young person and their assistance dog and how this shapes perceptions of their emotional well-being and perception of the partnership (between the assistance dog and the young person).



Young woman holding head of her black labrador assistance dog while looking at each other lovingly

From our interviews with disabled young people in the Living Life to the Fullest Project, we found that the level of connection between a human and an assistance dog can be profound. As Jay explains, *“the bond between us is strong, it’s almost like he’s an extension of me.”* For many young people the bond seems to yield effects far beyond the carrying out of physical tasks.

For example, Faith reports the importance of these effects: *“The biggest thing he has brought into my life is companionship and love.”* Tash reported feelings of *“...sheer devotion, fulfilment and unconditional love.”* In her interview, Faith went on to describe the importance of having such a central figure in her life who is unchanging, *“I know my best friend ever will always be with me and will not leave.”* When we consider the emotional struggles many disabled young people experience, it is not surprising that those we interviewed see this unconditional presence and source of love as one of the most important positive impacts of having an assistance dog.

Moreover, we suggest that this strong bond can lead to further impacts. Tash explains that the bond that has developed with her canine partner Cuthbert has led to him being aware of her physical symptoms, and even more, that he tries to help with those symptoms, *“He cuddles the areas where I am in pain and makes them warm... Cuthbert has taught himself how to help me push [my dislocated joints] back into place, this isn’t something he was taught at Canine Partners.”* This can also be seen with emotional symptoms too, for example, Tash says, *“He knows exactly what to do when I’m at my worst. If I am having a rough day Cuthbert will*

bring me his favourite teddy bear.”

Other disabled young people said similar things about emotional support and affection.

Imogen said, *“Olive is very sensitive to my mood and health. When I wake up in the morning*

she already knows if I am going to have a bad day.” Faith said, *“Ted is my best friend... he*

gives me cuddles when I ask him.” Tash said, *“...through both the good and bad days, [canine partner Cuthbert is] my rock and my support through life. I would be so lost without [him].”*

The importance disabled young people put upon affection (cuddles and physical closeness) from their dogs is also seen in the online questionnaire responses below, with all respondents describing themselves as being very affectionate with their assistance dogs (see Table 7).

	Strongly disagree or disagree	Neither agree nor disagree	Agree or strongly agree
My assistance dog is like a friend to me.	0	1.7	98.3
My assistance dog is sensitive to my physical health*.	1.8	14.0	84.2
I feel my assistance dog will always be there for me.	1.7	5.2	93.1
My assistance dog and I are very affectionate with each other.	0	0	100
I feel that my assistance dog loves me unconditionally.	0	0	100
My assistance dog is like a significant other to me.	1.7	10.3	87.9
My assistance dog is sensitive to my mood.	5.2	8.6	86.2
It has been hard for me and my assistance dog to get used to each other.	91.4	1.7	6.9

* One person did not respond to this item

Table 7: Respondents' responses in the domain of Relationships and emotional support (%)

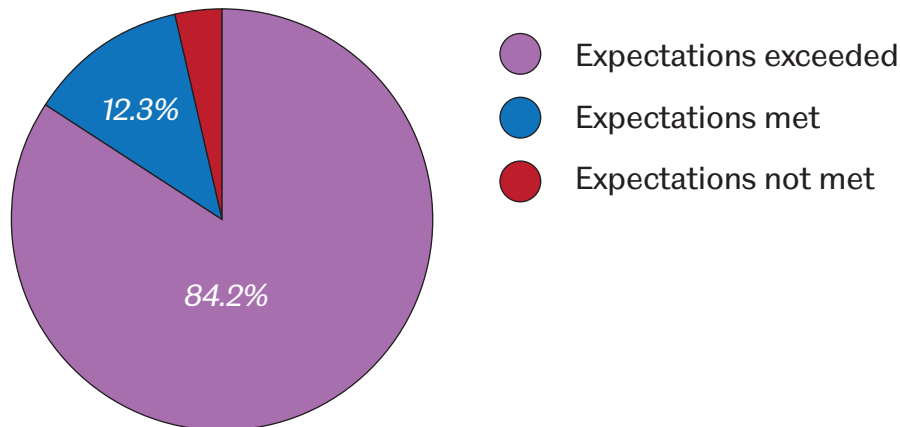
A finding worth noting from Table 7 is that all respondents said that they were very affectionate with their dog and that they feel that their dog loves them unconditionally. Moreover, nearly all respondents said that their assistance dog is like a friend to them. A slightly lower proportion of respondents felt that their dog would always be there for them and that their dog is like a significant other. Slightly fewer respondents felt that their dog was sensitive to their mood and their health. Only a small number of respondents (less than 10%) said that the process of adjustment between themselves and their dog was challenging.

Meeting expectations

Respondents were asked about the overall extent to which their assistance dog had met their expectations (see Figure 2). Over four-fifths of respondents (84.2%) said that their assistance dog had exceeded their expectations. Only 2 respondents (3.5%) said that their assistance dog had not met their expectations.

Overall, to what extent has your assistance dog met your expectations?

57 responses

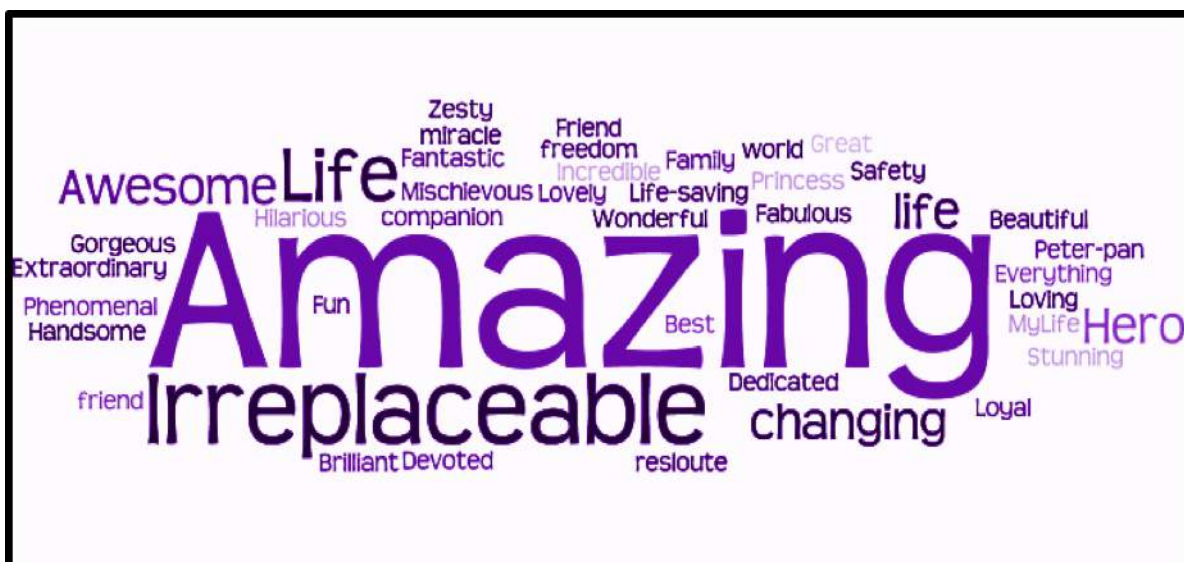


“My stamina has consistently improved far beyond what I had ever dared hope I would ever achieve again”

Imogen and her canine partner, Olive.

Which one word describes your assistance dog?

At the end of the online questionnaire, respondents were asked to give one word that they feel describes their dog. A word map of the responses is given below. In this word map, the size of the word corresponds to its popularity. So, as the word map below shows, the words “amazing” and “irreplaceable” were most commonly used by disabled young people.





What next?

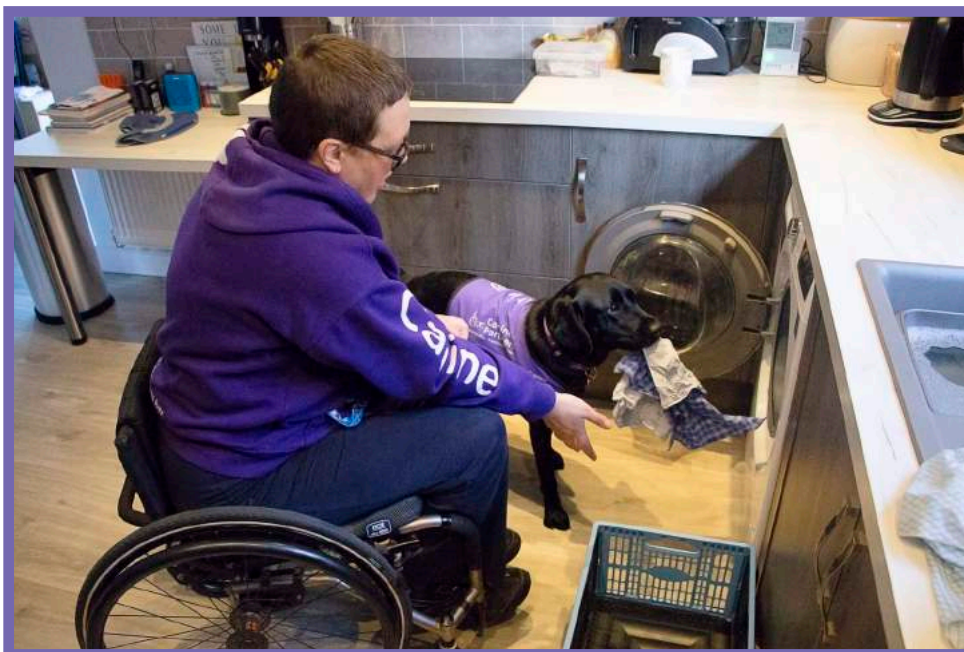
A key aim of the Canine Care Project has been to produce a quantitative analysis of the impacts of an assistance dog on disabled young people and relate this to our qualitative research of young people's stories and existing findings from the Living Life to Fullest Project.

This report has shown our initial findings. In the future, we would like to delve further into exploring the impact of assistance dogs within disabled young people's lives and futures. We are interested in how impact may differ in the different domains and according to different characteristics, such as gender, age and disability. To do this we would need to check if the questions we co-produced are a valid and reliable measure of the domains. However this was not achievable in this small project, due to limited time and the small number of people who responded to the online questionnaire. Therefore, in the future we would need to collect more data to further explore these initial findings.

As well as being able to demonstrate the impact that an assistance dog brings to the lives of young people, Canine Partners will be utilising the findings to further develop and promote their impact work, services and support for all their partnerships.

Our aim now, as a Research Team, is to share these important findings with multiple audiences: disabled young people and their parents, carers, families and allies; policy makers; commissioners; local authorities; and health, education and social care professionals.

We are also co-producing a short animated film to narrate and animate these findings, and to again emphasise how transformative this unique form of care and support is for disabled young people, and its impact in their lives in the present and the future.



Black assistance dog removing laundry from the washing machine with her mouth while young woman in a wheelchair directs

For more information about anything you've read in this report, please email k.liddiard@sheffield.ac.uk

APPENDIX 1:

Information about Canine Partners

- Canine Partners is a registered charity that assists people with physical disabilities to enjoy a greater independence and quality of life through the provision of specially trained dogs.
- Over the past 29 years the charity has provided and trained more than 800 dogs that help disabled people including 440 that are in action today.
- The dogs are carefully matched to the applicant's needs and lifestyle, no matter how challenging. They are trained to help with everyday tasks such as opening and shutting doors, unloading the washing machine, picking up dropped items, pressing buttons and switches and getting help in an emergency.
- It takes approximately 18 months to train a canine partner from selection at eight weeks old through puppy training and advanced training until they are partnered with a person with physical disabilities.
- Each partnership has regular visits from the charity's aftercare assistants and support and advice is available 24 hours a day.
- There are 13 puppy training satellites across

the UK where the pups are looked after by volunteers under the guidance of a Canine Partners' trainer, during which time they learn obedience and some basic core tasks. When the pups are around 14-16 months old they come into one of the charity's training centres in West Sussex or Leicestershire for five months to learn the advanced task work and to be matched with their future partner.

- These life transforming dogs also provide practical, physiological, psychological and social benefits including increased independence and confidence as well as increased motivation and self-esteem. A canine partner also brings companionship, a sense of security and increases social interaction.
- Canine Partners receives no government funding and relies solely on public donations.

For further information visit caninepartners.org.uk or phone 08456 580 480.



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