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Communication*

More than Hero Stories: Experiences of Families with Autism Assistance Dogs in Germany

A Qualitative Interview Study

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ABSTRACT

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Children with autism spectrum disorder (ASD) experience several biological, psychological, emotional, and social limitations, including restricted participation. Various interventions are available to support children with ASD, with autism assistance dogs (AADs) as a recently emerging option. This study aimed to investigate the experiences of families living with an AAD in Germany. Benefits and challenges for families and children with ASD, as well as a potential impact on the children's participation, were investigated. The study followed a qualitative abductive approach, using semi-structured interviews and thematic analysis with inspiration from phenomenography. Data was collected in interviews with two parents of children with an AAD and one AAD user from Germany. The direct impact of the AAD on children with ASD was primarily positive, and a positive influence on their participation was described. However, they also encountered some challenges, mainly related to societal limitations. Within the family, the AAD was perceived as calming and facilitating structure and routine. Various obstacles for families could be identified, including the need for all family members to adjust, an additional burden of care for the dog, and several barriers within the society such as misrepresentations in the media, ignorance of strangers, and organizational limitations. Nevertheless, the positive and sustainable impact of AADs was emphasized, while highlighting the need for better public education and more resources and research directed at AADs as a helpful intervention for children with ASD.

Kinder mit einer Autismus-Spektrum-Störung erleben verschiedene biologische, psychologische, emotionale und soziale Einschränkungen sowie eingeschränkte Teilhabe. Es gibt unterschiedliche Interventionen, die zur Unterstützung von Kindern mit Autismus zur Verfügung stehen, wobei Autismus-Assistenzhunde eine neu entstehende Intervention darstellen. Ziel dieser Studie war es, die Erfahrungen von Familien zu untersuchen, die mit einem Autismus-Assistenzhund in Deutschland leben. Dafür wurden die Vorteile und Herausforderungen für Familien und Kinder mit Autismus sowie die möglichen Auswirkungen des Assistenzhundes auf die Teilhabe der Kinder untersucht. Die Studie folgte einem qualitativen Ansatz mit semi-strukturierten Interviews und einer thematischen Analyse mit Inspiration aus der Phänomenographie wurde durchgeführt. Die Daten wurden in Interviews mit zwei Eltern von Kindern mit einem Autismus-Assistenzhund und einer assistenznehmenden Person aus Deutschland gesammelt. Die direkten Auswirkungen der Assistenzhunde auf Kinder mit Autismus waren in erster Linie positiv, und ein positiver Einfluss auf ihre Teilhabe wurde beschrieben. Es wurde jedoch auch von Herausforderungen berichtet, hauptsächlich im Zusammenhang mit gesellschaftlichen Einschränkungen. Innerhalb der Familie wurde der Autismus-Assistenzhund als beruhigend wahrgenommen und erleichterte Struktur und Routinen. Verschiedene Hindernisse für Familien konnten identifiziert werden, einschließlich der Notwendigkeit für alle Familienmitglieder, sich anzupassen, eine zusätzliche Last

durch die Pflege des Hundes und mehrere Hindernisse innerhalb der Gesellschaft wie z.B. falsche Darstellungen in den Medien, Unwissenheit von Fremden und institutionelle Einschränkungen. Dennoch wurde der positive und nachhaltige Einfluss von Autismus-Assistenzhunden hervorgehoben, wobei gleichzeitig die Notwendigkeit einer besseren öffentlichen Bildung sowie der Bedarf für weitere Ressourcen und Forschungen für Autismus-Assistenzhunde als hilfreiche Intervention für Kinder mit Autismus betont wurde.

Keywords: Autism Spectrum Disorder, Participation, Animal-Assisted Intervention, Assistance Dogs, Families

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Introduction

Children with autism spectrum disorder (ASD) experience different limitations and difficulties related to their social, emotional, and physical functioning, as well as participation restrictions. Various interventions can be implemented to support children with ASD in their development and well-being. A newly emerging intervention are autism assistance dogs (AADs), which should compensate for some of the limitations that children experience due to their disability and are believed to have beneficial effects in multiple areas of children's lives. The evidence behind this intervention stems mainly from Australia and Canada, with limited studies from the Western European context, and no identified research from Germany. Insight into the experienced effects and difficulties of AAD users in Germany is crucial to understand whether this intervention has a similar outcome as it does in other cultural and legislative contexts, and if it should be promoted for families with a child with ASD. The present paper will investigate the perspectives of family members of families with an AAD, as a first step towards knowledge about AADs in the German context.

Theoretical Framework

Two conceptual frameworks are used in this study, complementing each other to explain the findings: the International Classification of Functioning, Disability, and Health (ICF; World Health Organization [WHO], 2001) and the family of participation-related constructs (fPRC; Imms et al., 2016). While the ICF provides a biopsychosocial perspective on the health and development of children with a detailed view of body functions and environment, the fPRC is applied to provide a deeper and more detailed insight into their participation.

The ICF as a Biopsychosocial Model

All children have the right to be supported in order to protect their health and well-being, enhance development, and ensure participation, regardless of their current life situation or background, according to the United Nations Convention on the Rights of the Child (UNCRC; 1989). Depending on each individual child, more or less support may be needed to enable them to live up to those rights. Early models of disability explained disability in terms of medical and biological deficits and accordingly designed interventions for the individual to better fit into their context (Engel, 1992). Contrasting this perspective, social models of disability emphasize the impact of the immediate and broader social environment and factors such as attitudes, legislation, and culture as defining disability, and advocate for the context to be adjusted (Bickenbach et al., 1999). Building on these models, a biopsychosocial perspective developed, which highlights the interdependence of biological, psychological, and social

aspects, and illustrates the influence of individuals and context on each other (Engel, 1992).

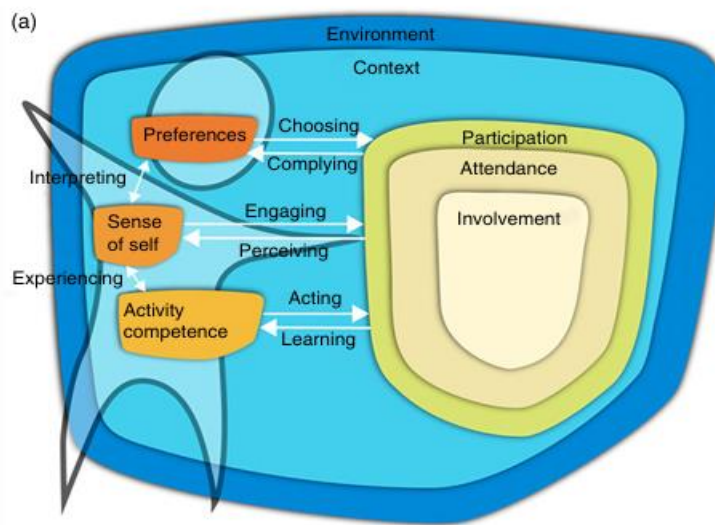
The ICF (WHO, 2001) is a biopsychosocial model, taking into account interactions of body functions and structures, activity, participation, and contextual factors. Firstly, the body functions and structures relate to a child's individual physical and psychological functioning and impairments. Secondly, activity describes the ability or capacity of the child for certain tasks or activities, whereas participation is seen as involvement in those tasks or situations. Finally, the contextual factors are divided into environmental and personal aspects. The environment comprises a child's physical and social context, including people, objects, culture, legislation, attitudes, and more. Personal factors relate to the innate characteristics of the child but are not further specified in the ICF (WHO, 2001). Combined, the ICF factors impact each other, and children's health, functioning, and development. The ICF helps to provide a holistic picture of the different factors influencing a child and can be used as an international and universal tool of communication and documentation across professional fields, as well as a suitable research framework (Simeonsson & Lee, 2018).

Family of Participation-Related Constructs (fPRC)

Participation is one of the ICF factors and can be influenced by a child's individual and contextual aspects, but it also impacts them in return. The ICF defines participation as "involvement in a life situation" (WHO, 2001, p. 10). From this definition, the family of participation-related constructs (fPRC; Figure 1) evolved, providing a more detailed and specific framework for participation (Imms et al., 2016). In the fPRC definition of participation, the two components of attendance and involvement are highlighted, where *attendance* describes the possibility of physically being present in a situation, whereas *involvement* is a subjective factor of perceiving oneself as being engaged in a situation (Imms et al., 2016). In research and intervention, participation can be considered a desired outcome (e.g., interventions aimed at increasing participation), or as an influencing factor leading to other desired outcomes (e.g., enhanced well-being due to high levels of participation; Imms et al., 2016). The framework further specifies *preferences*, a *sense of self*, and *activity competencies* as individual intrinsic factors related to a child's participation through various processes (see Figure 1). In line with the ICF- Children and Youth Version, stating that "The role of the family environment and others in the immediate environment is integral to understanding participation, especially in early childhood" (WHO, 2007, p. xvi), participation is also embedded in contextual factors in the fPRC.

Figure 1

Family of Participation-Related Constructs



Note. From „Participation, both a means and an end: A conceptual analysis of processes and outcomes in childhood disability” by Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., and Gordon, A. M., *Developmental Medicine & Child Neurology*, 59(1), p. 19. <https://doi.org/10.1111/dmcn.13237> Copyright 2016 Mac Keith Press. Reproduced with permission.

Background

Autism Spectrum Disorder (ASD)

Autism spectrum disorder (ASD) is a neurodevelopmental disability, characterized by a variety of symptoms. Neurodevelopmental disorders have their onset in childhood, often early childhood, and interfere with an individual’s everyday functioning in different ways (American Psychiatric Association, 2016). ASD is classified as a neurodevelopmental disorder in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2022), as well as in the International Classification of Diseases (WHO, 2024), which are used globally for health and mental health diagnostics. It is one of the more common neurodevelopmental disorders, with a worldwide recorded prevalence of around 1% (WHO, 2023). The core symptoms of ASD are social-emotional deficits, deficits in verbal and non-verbal social interaction and communication, and restricted and repetitive behaviors, activities, and interests, causing clinically significant impairment. An ASD diagnosis is specified with a severity level ranging from one to three (mild to severe), depending on the severity of symptoms and the amount of support individuals need. Although not required for the diagnosis, impaired or atypical sensory and motor functioning are common among children with ASD (American Psychiatric Association, 2016; Neely et al., 2019), and they often show lower levels of engagement in physical activity than their typically developing

peers (Sung et al., 2021). For children with ASD, these symptoms can lead to difficulties in dealing with social situations, participation limitations, and exclusion (Hodges et al., 2020).

It is important to note that next to the individual with ASD, the disorder can also impact the lives of their surrounding family members. Families with a child with ASD tend to experience social isolation (Rao & Beidel, 2009), and parents, especially mothers, in those families have shown increased stress levels (Di Renzo et al., 2022). Siblings of children with ASD were also found to be affected, although this impact could have both, positive and negative aspects (Ferraioli & Harris, 2009; Lovell & Wetherell, 2016).

In line with the various ways in which ASD can present in an individual, possible interventions are diverse, including but not limited to social skills training (Tripathi et al., 2022), psychotherapy (Wood et al., 2021), and occupational therapy (Reche-Olmedo et al., 2021), and there is not one best intervention for all children with ASD (Trembath et al., 2023). Instead, they need to be selected according to the individual child and family's needs and preferences (Roberts & Simpson, 2019; Trembath et al., 2023). Nevertheless, some aspects have been identified which can influence the success of such interventions. They can take place in specialized contexts, in the school context, or at home (Volkmar et al., 2017) and should be context-specific (King et al., 2022). Furthermore, interventions should be evidence-based (Roberts & Simpson, 2019; Volkmar et al., 2017), although the definition of evidence-based is unclear and partly depends on the assessor (Trembath et al., 2023; Vivanti, 2022). Finally, a family-centered approach has been recommended for interventions with children with ASD (Roberts & Simpson, 2019). If caregivers learn to implement interventions in their everyday lives, children can receive consistent, high-quality support at a higher frequency compared to intervention from professionals, leading to positive outcomes across ASD symptoms (DuBay et al., 2019).

Participation of Children with ASD

Children with developmental disorders commonly experience participation restrictions (King et al., 2010), which have been found to be related to their mental health and well-being as well as school achievement and other important life areas (Carlberg & Granlund, 2019). For children with ASD, the above-described symptoms in relation to social interactions and communication can limit their levels of participation (Hodges et al., 2020). In the social context, children with ASD show participation restrictions in after-school activities, have fewer friends and rely more on their parents than on peers (Kaljača et al., 2019). Possible explanations for the restricted social participation of children with ASD may be based on their lack of understanding of others' perspectives and their special interests and behaviors (Ghanoumi et al., 2019).

Moreover, their participation in the family is often restricted in everyday family life and routines such as mealtime, as well as at special events and occasions (Khalifa et al., 2020; Ledford & Gast, 2006; Rodger & Umaibalan, 2011). Similarly, participation in community activities is restricted for both the child with ASD and the family, possibly due to the unpredictability of the environment and parents' concerns (Khalifa et al., 2020). Furthermore, low participation in physical activity has been identified among children with ASD. Arnell et al. (2018) suggest that participation in physical activities may depend on various factors, including predictability of the activity, confidence rather than anxiety concerning the activity, and enjoyment of an activity. Considering these restrictions and the above-described importance of participation for children's health and development, it is essential to foster participation through interventions for children with ASD. One type of such intervention can be animal-assisted interventions, including autism assistance dogs.

Animal-Assisted Interventions

Animal Assisted Interventions (AAIs) have been defined by the International Association of Human-Animal Interaction Organizations (IAHAIO) as a “goal-oriented and structured intervention that intentionally includes or incorporates animals in health, education, and human services (e.g., social work) for the purpose of therapeutic gains in humans” (2018, p. 5). They can be divided into three broad areas: therapeutic interventions, educational interventions, and activities, where the level of structure, professional requirements, and contexts and settings differ (Fine et al., 2015; IAHAIO, 2018). AAIs are highly variable, and a wide range of animals are used, ranging from wild animals like dolphins (Griffioen et al., 2019) to domesticated farm animals such as chickens, sheep, and cows (e.g., Barnhart et al., 2023; Kapustka et al., 2020), to pets like guinea pigs and bunnies (e.g., Molnár et al., 2020; O’Haire et al., 2013). However, the most commonly used animals are horses and dogs (Sissons et al., 2022). It has been suggested that dogs may be the most fitting species for intervention with humans, due to their generally open and social nature and because they are highly domesticated and adapted to humans (Chan et al., 2022).

Research reports generally positive outcomes of AAIs for people with ASD, where effects on socialization (Barnhart et al., 2013), social interaction, communication, decreased stress, and general improvement in ASD symptoms and more have been noticed (O’Haire et al., 2013). Specifically, AAIs involving dogs have shown a positive impact on people with ASD (e.g., Cammarano et al., 2024; Martens, 2023). For example, the inclusion of a dog in therapy for children with ASD could facilitate the relationship with the therapist (Hill et al., 2020) and

increase social behavior and speech production (Fung & Leung, 2014; Grigore & Rusu, 2014; Hardy & Weston, 2020; Hill et al., 2019). Moreover, the presence of a dog in an educational setting was found to positively impact the social interactions of children with ASD with their teacher (Stevenson et al., 2015). Besides these professional settings, assistance dogs are increasingly implemented in families of children with ASD (e.g., Guay et al., 2023; Morgan & O’Byrne, 2023; Pavlides, 2008).

Assistance Dogs

Service- and assistance dogs are an AAI, where the dog is implemented to support people with different disabilities, in the form of guidance, medical alerts, and various other forms of assistance (Howell et al., 2022). The definition and differentiation between the terms service dogs and assistance dogs is unclear, varies between countries and regions (Tedeschi et al., 2015), and is used inconsistently, especially in relation to people with mental health disorders (Foltin & Glenk, 2023). In relation to ASD, the most common terminology is autism assistance dog (Pavlides, 2008), and it has been proposed that in the future, the term service dog may be entirely replaced by assistance dog (Howell et al., 2022). Therefore, the term autism assistance dog (AAD) will be used in this thesis, referring to a dog that is specifically trained to support a specific individual with autism. In the German law of equality for people with disabilities (Behindertengleichstellungsgesetz [BGG], 2002), assistance dogs are defined as dogs specially trained to support an individual in their needs, enhance and facilitate their participation in society, and compensate for disadvantages experienced due to disability (§12e Abs. 2b; Bundesgesetzblatt [BGBI], 2022, Absch. 6, §25). Generally, a positive influence of assistance dogs on participation and psychosocial factors has been found, although the implementation and success of assistance dog placements are also strongly affected by environmental factors (Futran et al., 2022).

Assistance Dogs for Children

Assistance dogs for children can play a slightly different role in comparison to assistance dogs for adults. While assistance dogs for adults usually work in a human-dog dyad, young children often have an adult facilitator such as a parent or teacher to support them in handling the dog (Davis et al., 2004), thereby creating a child-dog-facilitator triad relationship. In those cases, the dog can only assist children in contexts where the adult dog handler is also present. Nevertheless, children with assistance dogs have shown improvements in physical and mental well-being and decreased stress (Lindsay & Thiyagarajah, 2021), as well as benefits in social inclusion and interaction and positive effects on their participation in community and

family life (Davis et al., 2004; Lindsay & Thiyagarajah, 2021). Overall, the social benefits of an assistance dog seem more prevalent for children than physical or medical benefits, which is different from the adult population (Davis et al., 2004).

Autism Assistance Dogs for Children and Adolescents

Children and adolescents with ASD can receive the support of an assistance dog in their everyday lives. As was described earlier, research has found a high affinity of people with ASD to dogs (Cammarano et al., 2024), making them suitable partners. Autism assistance dogs (AADs) for children are often handled with the help of a parent or caretaker, creating the above-described triangle relationship, where in some cases the child is connected to the dog via a harness. The Specific role of an AAD varies greatly, depending on the needs of the family and the child they are supporting. Common tasks of an AAD are to keep the child from running away through the attached harness, alerting adults if the child attempts to run away, search for the child, provide deep pressure and a sensory stimulus, and facilitate communication and social interaction (Pavlidis, 2008). Guay et al. (2023) found that parents are more satisfied with the support they perceive from an AAD compared to “just” a companion dog. However, smooth collaborations between adults in a child’s environment need to be emphasized for the implementation of an AAD to be successful (Morgan & O’Byrne, 2023).

Various positive effects of assistance dogs have been found for children with ASD on a medical, physical, social and participatory, and emotional level. From the medical and physical perspective, the implementation of an AAD was found to lead to reduced morning cortisol levels in children with ASD, which is potentially related to reduced stress levels (Viau et al., 2010) and decreased self-harming behavior (Guay et al., 2022). Furthermore, increased physical activity (Hellings et al., 2022), enhanced motor control and functioning (Burrows et al., 2008), and improved sleep (Guay et al., 2022) have been found in relation to AADs. Additionally, the sensory stimulation provided by the AAD, and the associated development of improved sensory tolerance have been highlighted repeatedly (Appleby et al., 2022; Hellings et al., 2022; Leighton et al., 2023; Leung et al., 2022; Morgan & O’Byrne, 2023). On the social level, having an AAD can positively impact social interaction and communication (Guay et al., 2022; Hellings et al., 2022; Morgan & O’Byrne, 2023) as well as social behaviors (Guay et al., 2023; Leung et al., 2022; Morgan & O’Byrne, 2023), where the dog is often described as an easy conversation starter and social facilitator (e.g., Berry et al., 2013; Dollion et al., 2022). Furthermore, the AAD is viewed as providing companionship for the child (Burgoyne et al., 2014; Hellings et al., 2022; Morgan & O’Byrne, 2023) and as a positive influence on social skills (Morgan & O’Byrne, 2023) and social participation (Leung

et al., 2022), as well as general participation and skill attainment (Agnew et al., 2023). On the emotional level, positive outcomes related to emotion regulation (Guay et al., 2022) and learning about one's own emotions and those of others are reported (Davis et al., 2004), where the AAD is described as an “emotional bridge” (Berry et al., 2013). Most highlighted is the stress-reducing and calming effect the AAD has on children (Appleby et al., 2022; Berry et al., 2013; Burgoyne et al., 2014; Hellings et al., 2022; Tseng, 2023). Lastly, many caretakers state that the AAD significantly enhances their children’s physical safety and security in their everyday lives (Burgoyne et al., 2014; Burrows et al., 2008; Morgan & O’Byrne, 2023).

Besides the impact of the AAD on the child, effects on the whole family have been found. Some of the most reported factors are less worry for their child (Burgoyne et al., 2014; Burrows et al., 2008) and a decrease in stress levels of parents (Hellings et al., 2022; Morgan & O’Byrne, 2023), which may be associated with lower morning cortisol levels (Fecteau et al., 2016). Similarly, overall increased family well-being (Leighton et al., 2023; Leung et al., 2022) and an increase in quality of life within the family (Appleby et al., 2022) were found. Moreover, the implementation of an AAD in the family was perceived to lead to siblings spending more time together, more time spent in family activities (Guay et al., 2022), and increased bonding within the family (Leighton et al., 2023; Morgan & O’Byrne, 2023). Additionally, families with an AAD experience more freedom to move around (Appleby et al., 2022; Morgan & O’Byrne, 2023) and increased participation in everyday life and the community (Agnew et al., 2023; Leighton et al., 2023). In some cases, the dog can facilitate public awareness of the child’s disability and encourage conversation (Burrows et al., 2008).

Despite the large number of beneficial outcomes, it is important to highlight that many families who decide to have an AAD for their child, can also be met with numerous challenges in their daily life. Within the family, the most commonly named difficulties are the additional burden of having to care for the dog as an additional family member, especially in the beginning when everything is still new (Appleby et al., 2022; Hellings et al., 2022; Leighton et al., 2023), and potential problems to adjust to the new situation, especially for parents who have high expectations of the dog beforehand (Burrows et al., 2008). Outside of the home, most parents described issues within the community, where they were denied access to public spaces with the dog and experienced confrontational encounters with people not accepting the dog as an assistance dog (Hellings et al., 2022). Some caretakers emphasize a need for better community education in relation to assistance dogs (Appleby et al., 2022; Hellings et al., 2022). Lastly, some people are afraid that children with ASD might react hostile towards the dogs and potentially harm them. However, a study observing initial

meetings between children with ASD and assistance dogs found no indication of such behavior (Dollion et al., 2022). Overall, scientific research on the topic of AADs is still emerging, and for the most part, conducted in Australia and Canada. Research from the European context is very limited, and no evidence could be identified from Germany. To gain knowledge about the topic of AADs in Germany, the experiences of families with an AAD can provide valuable first insights and serve as a starting point for further research.

Aim and Research Questions

This study aims to explore the experiences of AAD owners in Germany, to identify perceived barriers and facilitators for children with an AAD as well as their families, and to investigate the potential impact of AADs on children's participation. Accordingly, the study aims to answer the following three research questions:

1. What are perceived supporting factors and challenges for their *child* in relation to the AAD?
2. What are perceived supporting factors and challenges for their *family* in relation to the AAD?
3. What is the impact of having an AAD in the family on the participation of the child with ASD?

Method

Design

The present research was conducted as a qualitative interview study where semi-structured interviews were used to investigate the abovementioned research questions. This design allows a deeper insight into participant's perspectives while requiring only a small number of participants (Creswell et al., 2018). Within this design, a thematic analysis following the guidelines of Braun and Clarke (2006) was applied. These guidelines are appropriate to use for less experienced researchers and help to identify patterns across the semantic and latent content of qualitative data (Braun & Clarke, 2006). Within this analysis, a phenomenographic perspective allowed for an emphasis on the variability of experiences between participants and has been suggested as a useful approach for various fields, including psychology (Zygmunt & Naidoo, 2022).

Participants

Three participants took part in this study, of which one was an adult AAD owner, and two were parents to children with ASD who had an AAD. In all three cases, children were under

the age of 15 when the first AAD was introduced into the family, and currently had an AAD at the time of the study. Initially, parents were recruited as participants in this research, however, one adult participant speaking about their own experiences as a child was included in the study at a later point (see ethical considerations). The study aimed at participants from Germany who have a child with an ASD diagnosis and have an assistance dog for this child. They could have had the dog for any amount of time. Parents of all children with all levels of severity of ASD and until the age of 25 were eligible to participate. Although the age of 18 marks the beginning of adulthood in many Western countries, research has suggested that developmental patterns of adolescence reach into the mid-twenties (Sawyer et al., 2018), which is why this age range was chosen for the present study. Moreover, even if the participants' first experiences with AADs lay in the past, they still exist as valid experiences, and parental retrospective reports can be valid and useful in many fields (Bornstein et al., 2020). Participants had to speak the researcher's first language, German, fluently to avoid the influence of a language barrier on the data. Voluntary response sampling was used, aiming to recruit around 20 participants and to secure at least five to 10 useable interviews, which is a usual number for this kind of research and can be expected to lead to an appropriate amount of data (e.g., Creswell et al., 2018).

To protect parents and avoid a persuading influence of the researcher on their participation, contact persons from organizations were contacted (Appendix A), who forwarded information about the research to members of their association who may be potential participants (i.e., those who have collaborated with them in matters regarding their AAD). Parents could read the information (Appendix B) and were asked to contact the researcher via email if they wished to participate. Two organizations agreed to act as the gatekeepers in this study. The German Assistance Dog Center (<http://www.assistenzhunde-zentrum.de/>) distributed information about the study to their trainers who work with assistance dog owners and posted a call for participation in their newsletter and on their blog. A call for participation was also posted on the website of the German Federation for the Promotion of People with Autism Spectrum Disorder (<https://www.autismus.de/>). Additionally, emails were sent out directly to 13 assistance dog trainers who offered the training of AADs on their website. Lastly, three Facebook groups of people with assistance dogs in Germany were identified, and their administrators were contacted to find more participants, and a post was made on the researcher's personal Instagram account, but no reactions resulted from this. Through this recruitment process, six people were interested in the research, three of whom participated in the study.

Instruments

Semi-structured interviews were used to collect the data in this study. An interview guide was developed beforehand based on the research questions. Based on the idea of a problem-centered interview (Witzel & Reiter, 2012), three main areas for the interview were identified: the family, the child, and the child's participation. Within each area, two main questions (e.g., "What does a typical day in the everyday life of your family with the dog look like?") and several possible follow-up questions (e.g., "What kind of positive experiences have you had with the dog? What kind of difficulties do you see for your family in relation to the assistance dog?") and clarifications were developed (Appendix C). This also falls within the recommendations of Creswell et al. (2018) of using five to seven questions for this type of interview. The interviews lasted between 45 and 90 minutes. Due to the nature and limitations of time and the number of participants in the project, piloting the interviews with potential participants was not possible. However, to practice the interview flow and have the opportunity to adjust questions, if necessary (Creswell et al., 2018), small-scale testing of the interview guide took place with two German-speaking people from the researcher's private environment. No changes were made to the interview guide after this. In addition to the interviews, some demographic information was collected from participants about the age of the child, how long the family had had the AAD, and the age, breed, and training specifications of the dog.

Procedure

After the project was confirmed by the thesis supervisor, an information letter (Appendix B) was distributed to the abovementioned contact persons, who forwarded it to potential participants. Participants were asked to contact the researcher via email to take part in the study. They received an informed consent form and needed to confirm their voluntary and informed participation in written form. Parallel to this process, the interview guide was designed and tested as described above before data collection could begin.

Interviews with participants took place via video call on the platform Zoom (Version 5.17.11[34827]), at a time that fitted best for the participants. After the researcher introduced herself, the study was explained again, and the demographic information was collected. Subsequently, the semi-structured interviews took place. The interviews were audio-recorded using the Zoom software and subsequently transcribed verbatim by the researcher. To prepare the data for the analysis, information that would make participants identifiable, such as names, gender, and places, was anonymized. Participants were given the opportunity to review their interview transcripts, however none of them wished to do this. Only parts of the

interview that were cited in the study report were translated from German to English.

Data Analysis

An abductive approach was taken in this study, where inferences are made based on the interaction of preexisting theoretical ideas of the researcher, and theoretical interpretations emerging from the collected data (Timmermans & Tavory, 2022). Thematic analysis (Braun & Clarke, 2006) was used, where the interview transcripts served as the data for this research. Concurrently, a phenomenography-inspired perspective was taken. Phenomenography highlights how the same phenomenon can be experienced differently by different people (Zygmunt & Naidoo, 2022; Åkerlind, 2012) and could be applied to emphasize the value of each of the three participant’s descriptions and insights within the thematic analysis. In the first step, the researcher read each transcript repeatedly and highlighted all aspects that appeared to be relevant and important. The highlighted units were labeled with codes, which were then examined critically for common patterns which were subsequently grouped into sub-themes and themes accordingly (Table 1). Influenced by phenomenography (Zygmunt & Naidoo, 2022; Åkerlind, 2012), participants’ differently lived experiences relating to the same topic, were highlighted within these themes. While the focus was more on the semantic level of analysis, some latent content was included as well, and the final themes are intended to represent the core aspects of the data (Braun & Clarke, 2006). Generally, it is recommended to complete this data analysis process and discuss the findings with a team of researchers (Elo et al., 2014). In this thesis, only one researcher carried out the study; however, discussion and exchange with the supervisor and fellow students took place throughout the whole process.

For the report of the results, adjustments were made to protect the identity and privacy of the participants and their families. Firstly, they are referred to in a gender-neutral way, using the pronouns they/them. Secondly, they were each given a fictional name unrelated to their real name or gender: Alex, Leslie, and Noah. Thirdly, all children who received assistance from the AAD are called “children”, regardless of whether they were children or adolescents at the time, and the term “AAD owners” is used as an umbrella term for children, parents, and adult AAD users. Lastly, although there were only three participants, they are

Table 1

Example of the Development of Codes, Sub-Themes, and Themes

Highlighted Interview Extract	Code	Sub-Theme	Theme
“I mean, there was more freedom because of the dog, also for the siblings, they could also sometimes do something.”	Sibling independence	Assistance dogs affecting family patterns	The assistance dog as a “regulator” of immediate social contexts

often referred to as a group (e.g., “all of them” or “they all”) to minimize the risk of readers being able to identify any of them individually.

Ethical Considerations

Ethical considerations need to be made in all research. Firstly, the ethical principles of justice and beneficence state that research shall not cause harm to participants, they must be treated fairly and benefit in some way from their participation (American Psychological Association, 2017). The present research was not expected to have any harmful consequences for participants. In cases where sensitive information was shared, the researcher ensured the participant’s well-being via a follow-up email. By taking part in the study, participants contributed to increasing scientific knowledge on AADs, which concerns them directly and is a topic that is lacking research. No additional compensation was given to participants; however, participants’ time and effort were valued by adjusting the time of the interview to their schedule, and by providing access to the findings of the study once the project was completed. Additionally, they were encouraged to reach out to the researcher and the thesis supervisor if they should experience any discomfort or concerns in relation to the research. Ideally, the children themselves should also be interviewed about their own experiences, valuing their views that may differ from their caregivers’ (Huus et al., 2015; Nilsson et al., 2015) and respecting their right to be heard (United Nations, 1989). Due to ethical constraints, this was not possible within the scope of the master thesis (e.g., Powell et al., 2012), but should be the subject of future research. Nevertheless, one adult participant was interviewed about their own experiences because their parents were not available for the study. In close communication with several experienced researchers, it was decided to include this participant after they volunteered to participate since their experience could significantly add to the reports of the other participants. Special attention was given to ensuring this participant’s well-being by informing them about the topics of the interview beforehand and reminding them of the possibility of skipping questions or stopping the interview on several occasions, including at the beginning of the interview.

Secondly, participants need to be thoroughly informed about the research and sign a written informed consent form, confirming their voluntary participation in the research (American Psychological Association, 2017; World Medical Association, 2000). They must be aware that they can end their participation at any point without negative consequences. Furthermore, participants' information must be treated with confidentiality (American

Psychological Association, 2017), which includes the removal of identifiable information like names and places from the data. Moreover, each participant was assigned an identification number, and following that, all personal data was stored separately from the data used in the research to enhance the protection of participants' privacy. Specifically, interview data was stored online on a safe server handled by the university, whereas the information connecting participants to the data was manually written on paper and locked away separately.

Finally, validity, quality, and trustworthiness are crucial in determining the usability and impact of research, thereby confirming the justification for conducting it (Olanipekun et al., 2022). For qualitative studies, Lincoln and Guba (1985) highlighted credibility, dependability, confirmability, transferability, and authenticity as important factors that affect trustworthiness. These aspects were addressed in the current research, for example, by giving participants the chance to read their transcribed interviews (member checking), careful work in the data analysis and interpretation (Graneheim & Lundman, 2004), structuring of the data collection through the interview guide, audio recordings of the interviews, and relation of the findings to existing research and theory. Truthfulness, accuracy, and transparency of the researcher contribute to research integrity (American Psychological Association, 2017). This was done through detailed documentation of the research, which also enables other researchers to follow each step of the study and facilitate replication. Lastly, researcher neutrality contributes to trustworthiness (Elo et al., 2014).

Researcher Characteristics

In the present research project, a single researcher with limited prior research experience conducted the study. Researcher characteristics need to be considered in qualitative studies because the researcher is involved in the data, and there may be interactions between researcher characteristics, participants, and the data (Creswell et al., 2018). In this study, the researcher had personal interest and previous experience in the field of animal-assisted interventions in the form of voluntary work. Furthermore, the researcher has completed a bachelor's in psychology and has conducted a scientific literature review about AAs for children with neurodevelopmental disorders. However, no experience or personal connection to the studied field of assistance dogs existed. Measures were taken to minimize the influence of the researcher's personal interest on the study outcomes, for example, by consulting with the supervisor and fellow students.

Animal Ethics

In research and work that includes animals, animal ethics must be considered as well.

Although the specific requirements can vary between regions, general ethical considerations always apply (Tedeschi et al., 2015). Animals that take part in AAIs need to undergo regular veterinarian care; they need to be carefully selected to fit the task and be well trained. In the field of AAIs, assistance dogs take on a unique role. Because they live in the family and are 24/7 “at work”, special attention needs to be paid to enough breaks and off-duty time, as well as the dog’s retirement, to protect their health and well-being (Fine & Andersen, 2021; Tedeschi et al., 2015). In the present research, participants were asked about their dog’s age, training background, and certification to give the researcher some insight into the above-mentioned aspects. All participants gave additional information regarding the maintenance of their AAD's well-being at different points during the interviews. Moreover, laws such as the German Federal Law Gazette (BGBl, 2022, Absch.6, §25) regulate the health and well-being of assistance dogs, for example, by requiring each assistance dog to be thoroughly examined by a veterinarian every year, confirming their well-being and continuing suitability for the tasks of an assistance dog.

Results

This study aimed to identify perceived barriers and facilitators for children and families with an AAD and investigate the potential impact of AADs on children’s participation. Through thematic analysis (Braun & Clarke, 2006), 21 subthemes were developed from the rich data, and defined into six overarching themes, to represent recurring and emphasized patterns (see Table 2). Within each of the described themes, aspects related to several of the research questions could be found.

Contradicting Emotions

Different emotions in relation to experiences with the AAD were prominent in the reports of all participants. While they mostly talked about positive feelings created by the dog's presence, worries and sadness emerged, especially when discussing sickness and loss of assistance dogs. This was summarized in the first theme, *The Assistance Dog Evokes Contradicting Emotions Within the Family*.

The Dog Creates Feelings of Happiness and Gratefulness

Happiness about and gratefulness towards the AAD were named repeatedly throughout the interviews. Participants felt that their AAD was spreading happiness, and especially parents were glad to see their child appearing happy and enjoying life with the dog. This was highlighted specifically by those who had struggled severely before the AAD came to the family and who saw the dog as a last hope. They felt that the presence of the AAD improved the mood

Table 2*Themes and Sub-Themes*

Themes	Sub-Themes
The assistance dog evokes contradicting emotions within the family	<p>The dog creates feelings of happiness and gratefulness</p> <p>Feeling safe and secure with the dog</p> <p>Children fear to lose their dog one day</p>
Children’s individual development is fostered by the AAD	<p>Children learning important life skills</p> <p>Improved physical activity</p> <p>Changes in psychological aspects</p> <p>Sensory adaption and support through interaction with the AAD</p>
Life is centered around the assistance dog	<p>Routine and structure are built around the assistance dog</p> <p>The assistance dog has a balancing effect</p> <p>Creating deeper interest and developing passion for the field of assistance dogs</p>
Families need to adjust and fully engage with the implementation of the AAD	<p>Unpredictability and dependence of having an assistance dog</p> <p>Additional responsibility for the dog handler</p> <p>Various resources need to be invested in the dog</p> <p>Families need time to adjust to the new situation</p>
The assistance dog as a “regulator” of immediate social contexts	<p>Assistance dogs affecting family patterns</p> <p>Social contacts and communication of children and adolescents</p> <p>The assistance dog as a bridge or shield in different social situations</p> <p>Participation in learning and education</p>
AAD owners are met with difficulties in the broader societal context	<p>Critical and reflected media consumption is necessary</p> <p>Obstacles to accessibility in society</p> <p>Having to deal with inconsiderate strangers in public</p>

of their children as well as other family members and noted that life felt lighter and more manageable with the dog. Leslie described: “It is so... everything is so much easier since we got the dog”. Receiving unconditional approval and liking from the dog was experienced as reassuring and uplifting for both parents and children. Alex described the power and energy their child received from the dog: “Because... so [my child] always says ‘the dog is like an additional battery. Where I can charge if I have her with, then I always have some extra power’”.

Furthermore, all participants described their dog’s specific characteristics as especially fitting for them and their needs, and they expressed feeling lucky for having found their perfect dog. Alex described: “I mean, we just had some insane luck with this dog”. Additionally, it was emphasized that although their dog was trained with a certain skill set initially, they continuously adjusted their tasks over time. This way, the AADs were perceived as growing and developing alongside the children and families, and their needs. Participants felt that this could not be taken for granted, and that they were lucky that such variability was possible with their AAD. One participant stated explicitly that this aspect contributed to the fact that they thought the effect of the AAD for children could be seen as sustainable in the long term. Moreover, following these positive emotions about their dogs, a growth mindset was observed in all participants, where they could grow from challenges together with the AAD, were motivated to make the best of difficult situations, and kept a sense of optimism, thanks to the dog. “It’s the...the relaxation through the dog, when I don’t know what to do anymore, when you’re desperate, . . . I see the dog . . . and I know what I do it for, and I keep on” (Alex)

Feeling Safe and Secure with the Dog

A feeling of safety and security because of the presence of the AAD was highlighted for children and parents. Parents felt more secure in leaving their child unsupervised for some time, while children gained a friend, family member, and companion with the AAD. Even if they physically did not spend every hour of every day together, this led to a feeling of never having to be alone and always having support, thereby decreasing feelings of loneliness. “Like, I don’t have to do any situation by myself, the dog is always there, and even if it just that we sit together on a bench somewhere.” (Noah).

Moreover, the AAD provided an increased level of safety outside of the house. Only in one case attachment to the dog with a harness was used, however, after a short time the child did not feel comfortable with this visible connection anymore. They developed alternatives such as holding a handle attached to the dog’s harness to ensure that the child would not get into danger, for example by running into traffic. The dog could also be sent after the child and block their way until the parent could reach them and find the child if it would disappear by following

their scent. For some children, the dog increased their feelings of safety when passing strangers on the road or in crowded places. In these cases, the dog was also trained for small guiding tasks, such as finding the way out of an overcrowded space or finding their way home if the child would feel overwhelmed and disoriented when out in public.

Children Fear to Lose Their Dog One Day

In contrast to the positive emotions, some participants also talked about sadness, worry, and fear. These feelings were primarily related to the dog's well-being and the realization that the dog may become sick, retire, or die one day. In a few situations, this could go so far that children experienced a happy moment with their AAD and were suddenly overwhelmed by sadness because one day their dog would not be with them for these experiences anymore, which hindered the enjoyment of the moment. However, although participants described these feelings, they strongly emphasized the positive emotions towards the dog over the occasional worry and fear.

“But my [child] often gets quite emotional and panics, when [they have] extremely good days with the dog... and then [they] says ‘Will [the dog] . . . will he die?’ . . . And then I say ‘yeeees, but until then he is going to have a really nice life with us!’”

(Leslie)

Enhanced Development of Children

The second theme was *Children's Individual Development is Fostered by the AAD*. When looking at the effect of the AAD on the individual child, an impact could be seen on the levels of skill attainment, physical activity, psychological factors, and sensory stimulation. Importantly, on this individual level, participants only named positive and supporting factors for children.

Children Learning Important Life Skills

With the help of the AAD, attainment of important life skills was facilitated for children, and parents felt that the AAD contributed to their children's development. This included continuous developmental aspects such as improved communication, and the development of specific skills and behaviors such as being able to spend time without the supervision of an adult and being alone in the home for certain times, with the company of the dog. Alex described: “That [my child] could also stay alone again, that was also something essential”. Parents also used the close relationship of their children to the dog to teach specific behaviors, which the children could observe in the dog, imitate those behaviors, and thereby understand how they should act themselves.

Participants especially highlighted how children learned to be considerate of the needs and perspectives of others through their dogs and observed an overall increase in empathy. One parent described how their child used to frequently hurt them but quit this behavior after getting the AAD. Even children of a young age understood their dog's vulnerability and dependence on humans and gained an age-appropriate sense of responsibility, as described by Leslie:

“I am already so happy that [my child] pays attention that the dog doesn't eat anything bad. Or [they] look out that the tail doesn't get stuck in the elevator. Not even I always pay attention to that, I just take the dog in with me into the elevator and [my child] is always there at once, goes to the back and takes the tail with in. And I just think 'cool!'”

Older children were assigned tasks, such as walking the dog every day or being responsible for the dog's food and water. Involvement in the care of the dog helped children understand signs and expressions of needs as well as awareness of their surroundings and potential obstacles for their dog. Moreover, things that were difficult to explain to the child before sometimes even developed naturally in the dog's presence. A child who was never able to share with anyone else was happy to share with the AAD. Participants experienced that these skills that children learned through the dog, were also applied in other contexts around humans, and improved their child's ability to navigate everyday life.

“[my child] doesn't like to share, but since we have the dog [my child] has learned to share. It doesn't always work, it depends on the thing, you know, but sharing food for example, [my child] never did that before” (Leslie)

Improved Physical Activity

The integration of the AAD improved the level of physical activity and fitness of the children. Some of the children barely left the house before the AAD moved in with them: “[my child] did not leave the house. Yeah, and the first contacts to the outside, that was together with the dog” (Alex). Having the dog motivated and enabled them to go outdoors to walk or play with their dog, which positively impacted their physical health. Children's overall fitness and stamina improved, enabling them to take part in activities they could not do before or to keep on with tasks for longer than before. One participant also reported improvements in their child's posture and muscle tone because they regularly carried the dog in their arms, forcing them to take on a more upright, open, and confident position. Furthermore, having an assistance dog encouraged them to take regular active breaks and to physically leave a situation before it became too much (for example at school). Participants acknowledged that it could be hard at times to be active, but that it was overall viewed as something positive by both the parents and the children themselves. “Like, I mean I could train my endurance a bit like this, or rather, I had

to also, and it was actually quite good I would say.” (Noah)

Improvement of Psychological Aspects

Next to the physical improvements, participants mentioned positive psychological changes, a general improvement in children’s mental health, and an overall calming effect of AADs. All AADs were trained to detect signs of stress at an early stage, usually before any human knew that something was going on, and to alert the children if they sensed increasing distress. This made it possible for the children and surrounding adults to take immediate action to counteract such stress and prevent negative consequences such as large meltdowns or running away. The AADs were also trained to intervene, to break an upcoming stress or panic in the children. This could be in the form of distracting and doing things like pulling on clothes or barking until the child gave them a reaction like petting them, picking them up, or interacting with them in some other way. For others, the AAD would give them strong nudges with the nose until they calmed down.

“The dog realizes immediately, he is now conditioned by the noises, but also by the stress hormones, maybe he smells it, so he gives [my child] a push. A really strong one. And he basically gets [my child] out of this loop.” (Leslie)

Apart from reducing distress, AADs also promoted positive psychological factors. Interactions with the dogs provided opportunities for experiencing success and gaining a sense of achievement when doing tricks with the dog, being involved in important caregiving tasks, or mastering certain situations together. Alex explained: “Self-affirmation, that as well... yeah, we also say self-efficacy, so the... if the dog, I trained something with the dog . . . then [my child] did it [the command] with the dog and then that is an experience of success.” Participants reported that children were better able to concentrate with the AAD, which facilitated successful outcomes even for small everyday tasks and boosted their self-confidence and self-efficacy in various areas of life. Often, the AAD was described as providing hope and increasing resilience because children saw it as a reason to keep on when they otherwise felt distraught or hopeless.

Sensory Adaptation and Support Through Interaction with the AAD

Participants discussed sensory stimulations for children by the AAD, which were mainly different forms of physical contact between the AAD and children. This could be stroking and cuddling or laying their face in the dog’s fur, which was perceived as calming. Additionally, different forms of pressure could be provided. As mentioned above, dogs were trained to touch, push, and nudge the children, which gives a specific type of deep but punctual pressure that cannot be provided with other common pressure tools such as a weighted blanket. Leslie described: “So everything centrifugal... what has to do with inner pressure...that... then

my child feels [themselves] and therefore the dog is super important because the dog just pushes [them]... pressures [them]. And my child loves that.” Some of the AADs had also learned to lay on the children’s feet in restaurants or waiting rooms, and some had learned to fully lay on the children, which was described as improving the effect of resting and providing a form of recharge for the children. Several children initially struggled with the sensory experience of the dog’s hair, its smell, and the smell of dog food, but through their own motivation and constant exposure, they quickly learned to appreciate physical contact. In the same way as the life skills, the effects of exposure to these sensory stimulations by the dogs were seen to transfer to other contexts. Children learned to tolerate and enjoy different structures (e.g., being able to play with sand) and to adjust more easily to new sensory experiences.

Life is Centered Around the Assistance Dog

The third theme highlighted how the families’ *Life is Centered Around the Assistance Dog*. Once families had integrated an AAD into their lives, it seemed that quickly, many aspects of their lives were changed to adapt to the new family member. The AAD affected the patterns of families’ everyday lives and influenced personal interests and priorities of family members.

Routine and Structure are Built around the Assistance Dog

Consistent structure and daily routines were strongly supported by the AADs. Depending on the specific family, their living situation, and the child's age, children were involved in daily tasks around the dog to different extents. Due to the needs of the dog to be fed and walked regularly, a certain regularity in their everyday life was created for all families. Children joined at least one walk with the dog every day, usually during the afternoons. AADs could also provide structure during parts of the day that were especially difficult for the children. Using the dogs to create and enforce such routines around their needs was perceived as helpful by the parents and made children more willing to participate in them. Alex talked about their child's difficulties with starting the day, and how with the dog's help, they could give their mornings a clear structure and create a routine that helped the child to wake up in a positive mood:

“Supporting the morning routine, that my child gets into the day, that is important . . . And, what the dog is taking over at the moment again is that in the mornings [my child] . . . comes with [on the morning walk]. . . . But at the moment it is more ‘I follow my obligations, I have the possibility to structure and start my day’, yeah, to move...”

The Assistance Dog Has a Balancing Effect

Participants perceived the presence of the AAD as centering, grounding, and calming. In

overwhelming situations, in public, at school, or at home, children could use their dog to have something to focus on and relax. The AAD was described as a reliable “safe base”, that is always there and where children could always turn to and find support. Participants felt that the dog created an atmosphere where they were present in the moment, alert to both the dog and their child, and less affected by anything else happening around them. Leslie described:

“It gives me security... what gives me extreme security is to be out with them both [child and dog]. Because it’s like a center. It's like a bubble, a cosmos, it’s like we are the three of us, we are out together.”

Creating Deeper Interest and Developing Passion for the Field of Assistance Dogs

The efforts and consequences of acquiring an assistance dog increased personal interest and self-education in participants. They expressed great passion for the work with assistance dogs and AADs specifically and were highly motivated to learn as much as they could. Some were so invested in the topic due to their own experiences, that they engaged in professional education to become assistance dog trainers. They talked enthusiastically about AADs and expressed that they experienced exchange and discussion about the topic as fulfilling and fun.

“I have to say, the thing is, this is one of my main interests! I mean, it wasn’t work at all for me to do this [the interview], I gladly do these kinds of things. Therefore, it was nice for me too!” (Leslie)

With increasing knowledge about AADs, the wish and need to pass it on to others increased. Some participants initially needed to explain the idea of an AAD to other members of their family, before integrating the first assistance dog into the home. Additionally, they often needed to educate people in their environment on a daily basis, explaining the tasks of their dogs and the rights they had with them. By learning to become trainers, they gained official qualifications to support and advise others in the future. Encountering a generally uneducated public with regard to assistance dogs evoked a wish to raise awareness and led to some participants also representing the (autism) assistance dog community in media and social media. For example, Noah explained, “Like, I have a [social media] account where I educate”.

Family Adjustment and Engagement

The fourth theme describes how *Families need to adjust and fully engage with the implementation of the AAD*. Having an AAD in their family required high levels of adjustability, flexibility, and engagement from the participants. They often needed to adapt their lives to the dog, deal with unpredictable situations, and invest many resources.

Unpredictability and Dependence of Having an Assistance Dog

Having an assistance dog was perceived as being unpredictable at times and made it necessary for families to be well-prepared for possible future scenarios. Especially sudden sickness, unexpected or early retirement, and the eventual death of the AAD were named as potential destabilizing factors. Such events could be challenging and disturbing for the children, but also for the rest of the family. Some families, therefore, began to prepare early, by reading books with their children about losing an animal, and by talking about the topic in a natural way. They furthermore highlighted the importance of having a backup plan in case the dog should suddenly be unable to work in the short or long term so that a complete breakdown of the family could be prevented. In such a scenario, children could lose a close friend and an assistance “tool” significant for their everyday functioning at the same time, and a good network is needed to work against the negative consequences of that. “So, there always has to be a plan B, the dog cannot be the only plan, there always, always when you work therapeutically with animals, I always need a plan B, and that is additional work you have.” (Alex)

Having an AAD was experienced as requiring a high level of organization while remaining flexible and open to changes. Parents noted that they themselves, as well as others in their closer environment, became more adaptable to changes to previously made plans. At the same time, such flexibility is often difficult for children with ASD, but over time, the children learned to better adjust to changed circumstances with the dog's help. Leslie observed that their child was able to change their afternoon routine if it was for the dog's well-being, which they could not imagine possible without the AAD:

“For example, if my child comes home and just wants to rest . . . and we need to go to the vet . . . then [the child] says ‘OK’ and then [the child] comes with. But that wouldn't have been the case before, [they] wouldn't have cared.”

The successful integration of the AAD into the families was closely interrelated with the parents' workplace. The process of getting the AAD could, in some cases, only be initiated after the parents' work life had been changed to more flexible hours, allowing them to be at home with the dog. In other cases, parents negotiated solutions where the dog could join them at work. Leslie explained: “It works with some jobs, with others it doesn't.” Some were forced to discontinue their job or decline new opportunities, to take care of the AAD. This link between the AAD and the parents' work and income added to the insecurities experienced by families. Participants emphasized that families who are thinking about getting an assistance dog should be very well informed about this aspect and made aware of the difficulties it could entail.

Additional Responsibility for the Dog Handler

Getting an AAD generally gave the dog handler a lot of responsibility. Participants

highlighted the need to protect the AAD and to be aware that they are not an independent human, but an animal that needs constant and thorough care. The AAD's health and well-being needed special attention, focusing on any stress signs or changes in the dog's behavior. To ensure their AADs' well-being, giving the dogs enough rest and regular breaks and protecting them from “overachieving” and eventually becoming overwhelmed, were highlighted. This was done with specific cues, by separating the AAD from the child, and by assuring that the dog was only “on duty” during the day or the night. Moreover, participants mentioned the responsibility to carefully consider their dog’s specific tasks and to uphold their training so that the assistance of and collaboration with the AAD can work in the best way possible. It was especially difficult for parents when they had to balance and prioritize the child’s and the dog’s needs and well-being. The participants required a lot of self-reflection to fulfill these demands. “But in the end, you are the one who is carrying even more responsibility, and that is a high price, and that you have to think about very well, if you’re prepared to pay that” (Alex)

Various Resources Need to be Invested in the Dog

Besides taking on responsibility, getting an AAD was related to high financial, time, and energy investments. Families faced high initial costs to purchase the dog and for its training. Regular costs for feed, the veterinarian and medications, and re-certifications added up to high ongoing costs. Additionally, the everyday care of the dog, continuous training, and re-certifications required a large amount of time. Leslie explained: “And I trained for hours, every day. I... and it worked! Then we had... we needed to do three more examinations during the first year.” Participants further pointed out the effort involved in caring for another individual and the mental and physical energy they spent on their AADs. Parents and siblings of children with ASD often needed to make sacrifices in order to provide for the AAD's needs. Participants found it important to be aware that an AAD is a high investment for a limited period of assistance. However, they also clarified that they thought it was worth it.

Families Need Time to Adjust to the New Situation

An adjustment period was needed for all family members until the AAD was fully integrated into the family’s everyday life. Even though children wanted to have the AAD, they expressed initial rejection of the dog because they found it difficult to experience such a change within their home and to adjust to the new situation. Leslie remembered: “When we first got the dog, and we thought ‘nice, [our child] loves dogs, this will be great!’ [they] needed... it took half a year to get used to the dog.” Similarly, Noah explained: “Yeah, that was difficult for me in the first weeks. Like, when the dog was there, because the dog sometimes wanted to get in contact of course, and I just couldn’t. So that was really hard for me.” Consequently,

parents described some doubts and regrets they had when they saw how much their children were struggling. This adjustment period could take between a few weeks and one year. Despite these difficulties, everyone experienced a slowly growing bond between the dog and all family members, and participants were glad that they went through with it and still had their dog today.

AADs as “Regulators” of Social Contexts

In the fifth theme, the role of *The Assistance Dog as a “Regulator” of Immediate Social Contexts* was developed. The AAD played an important role in social interactions within the families, with other known people and strangers, and in the context of children’s education.

Assistance Dogs Affecting Family Patterns

Once the AAD was fully integrated into the family, parents and siblings experienced great relief. Freedom and independence increased especially for siblings, who could engage in more own activities and social life. Participants reported that the social participation of every single family member, but also of the family as a whole, improved significantly with the AAD. Shared activities such as going to the store or spending time in the park became possible again. “I mean, we always take the dog, no matter where we go, museums, restaurants, ... the life, like to take part in social life... that has gotten significantly better.” (Leslie)

In the beginning, the AAD could lead to some conflicts within the families. Existing patterns and structures needed to be reorganized, and new roles were developed. There could be disagreements about the dog’s behaviors and tasks, and about what should be allowed and what not. It was important that generally, the whole family stood behind the idea of the AAD. “You need to consider really well as a family, what does the whole family think, are they standing behind it, do they support this, the dog needs to be cared for.” (Alex). Eventually, the AAD was perceived as having a more connecting effect within the family, as being able to loosen some tensions between family members and strengthen family bonds.

Social Contacts and Communication of Children and Adolescents

Children’s contact and communication with people outside of the family improved with the AAD's help. Some children had no social contacts and only slowly began to interact when supported by the AAD. The AAD also enabled contact with therapists and for them to work with the child. The overall social participation of the children was perceived to improve, and the dog was described as a facilitator of social engagement, especially in connection to younger children. Some children found new social contacts within the assistance dog community, where they experienced support and exchange about their experiences and possibilities to train and spend time with the assistance dogs together. “Through the dog and the community, I also got

to know other people with assistance dogs, where also a lot of friendships developed.” (Noah)

The Assistance Dog as a Bridge or Shield in Different Social Situations

Two main perspectives on how the AAD could be a support in social situations were named. On one side, the dog could be perceived as a “bridge” between family members, with peers, or with strangers. Dogs could make eye contact with people to facilitate the initiation of interaction for children, new conversations could be created about the dog, and their friendly and open nature was inviting for others to interact with the children. “But it... yes, everything was always just possible via this bridge with the dog, yeah... I mean always.” (Alex)

In contrast, the AAD could also act as a shield around the child, making them feel more comfortable and secure in social situations. This could be by standing at some distance from the child to create a physical space from other people, or by barking on command to prevent strangers from coming close to them on the streets. The AAD could also be an “exit strategy” for children, for example, to cross the street when people were approaching, or to leave a social situation without feeling awkward, with the excuse that the dog needs to go out.

“Yeah, but for my [child] this is great, [they] pick up [the dog] and then [they] can think, ‘do I stay sitting here, do I calm down by petting [the dog], or do I say the dog needs to go out and leave?’” (Alex)

Participation in Learning and Education

Next to social interactions in general, the AADs impacted children’s participation in the context of preschool/school. The dog could be involved in social situations such as drop-off in the morning or special “meet and greets” with the dog, where peers could ask questions and create new contacts. Leslei described: “We always brought [my child] to the door of the classroom. Then [they] could say goodbye to the dog and other children also came, approached the dog and my child was super proud.” When the AAD joined children in school, it supported their education, and increased children’s concentration, and their ability to learn, mostly through presence and calmness. Several participants insisted that certain milestones (e.g., high school graduation) would have never been possible without the AAD. Noah highlighted that “Like that I had the possibility pretty much to go to school at all.” Although participants described various benefits of the AAD in the educational context, it was also described that the level to which the AAD could be involved depended heavily on the specific institution and their openness and willingness to collaborate. While in some cases preschools/schools were open, supportive, and inspired by the AAD in their class, it was more difficult for others. This could go as far as the dog not being welcome on the entire property at all. Parents speculated that this could be due to other parents’ complaints, concerns about hygiene, or insurance-related issues.

Societal Difficulties

The sixth and last theme explained how *AAD owners are met with difficulties in the broader societal context*. This included media representation, accessibility issues, and public encounters with strangers.

Critical and Reflected Media Consumption is Necessary

Different forms of media and social media played an important role for the participants. Some criticized that traditional media in Germany tended to misrepresent the topic of assistance dogs. They felt that the media was unwilling to report difficulties related to assistance dogs in general, and they were only interested in “hero stories” rather than realistic representations. “I mean, these are really conditions... but I also think through the media, the media is destroying a lot here. ... Yeah, they want hero stories, I also had to learn that the hard way, yeah.” (Alex). Social media had supportive and destructive consequences for children. While they could share their experience, raise awareness of AADs, find support, and connect with like-minded people whom they would not have met otherwise, they also needed a high level of resilience to handle people questioning their experiences or the training of their dog.

Obstacles to Accessibility in Society

Accessibility issues created one of the largest restrictions for children’s participation in society. They often struggled with access to public buildings like restaurants or shops and were used to having to discuss and educate people about assistance dog rights before being granted access. This led to the feeling that they constantly had to fight for their rights if they wanted to do these kinds of activities, making it more challenging than fun. Noah described how the goal of an assistance dog, to facilitate participation, is missed this way: “So, the system, where the dog should be a factor of participation in society... and then society comes, and you basically get kicked out again.” Still, some participants could observe small changes in their environment over time, indicating a growing understanding for assistance dog owners, such as a growing number of signs stating “assistance dogs welcome” in their neighborhoods.

Having to Deal with Inconsiderate Strangers in Public

A major difficulty named by all participants were other people without assistance dogs. Participants talked about never getting any peace when leaving the house with the AAD. Noah said: “Ehm... I think [to be approached] often is an understatement . . . yeah actually always, I feel like.” They experienced a great lack of knowledge and understanding from others and often needed to deal with ignorant and rude strangers. Besides a general lack of knowledge, participants described how they were constantly approached by strangers who asked them very personal questions. They had people touch their AAD despite them wearing a vest stating that

they should not be distracted, and even people calling for the dog from afar. Leslie explained:

“Many think, if they have good intentions, then you’re obligated to take the offer [to talk to them]. But I also just want to shop in peace! You just want to shop. I don’t want to be approached all the time.”

While younger children could be curious and open-minded, it was especially adults who were perceived as disrespectful and intrusive. These experiences forced parents and children to learn to recognize their own boundaries and develop strategies that could help them set those boundaries. This could be deciding to ignore people talking to them, using the dogs’ skills (e.g., barking) to keep people away, or confronting people about their inappropriate behavior.

“So now I always say, since a few years, ‘my child does not want it’ [tell strangers about their disability]. And actually, in 90% of the cases, people accept that, but there are always some who say ‘but why? Now I’m curious!’” (Leslie)

Summary

Altogether, the findings highlight complex, and partially paradoxical experiences of AAD owners in Germany, implying variability in the responses to the three research questions of this study. The first research question was, “What are perceived supporting factors and challenges for their *child* in relation to the AAD?”. The direct impact of the AAD on children with ASD was mostly positive on the physical, psychological, emotional, social, and sensory level, on learning and education, and skill acquisition. Some difficulties could be found, such as long periods of adjustment or fear of losing the dog. Obstacles within the broader societal context included media representation, accessibility issues, organizational aspects, and meeting people in public. The second research question concerned the perceived supporting factors and challenges for their *family* regarding the AAD. The effect of the AAD on the family was mixed. The challenges found for children within the society were often perceived as barriers for the whole family, and having the AAD added responsibilities, especially for parents, and sacrifices had to be made to provide for the AAD. Despite these challenges, families reported a variety of benefits such as feeling relieved, increased freedom, and overall enhanced participation of the family in society. Moreover, the AAD was a reason for everyday structure and routine and could be seen as a balancing center of their lives. The third research question investigated the impact of having an AAD on the participation of the child with ASD. Apart from the overall increase of participation of the family, the participation of the children with ASD in school, family, and society outside of the family, improved significantly through the AAD. However, the issue of restricted participation due to societal barriers was raised by participants as well.

Discussion

This study aimed to investigate the impact of AADs on children and their families in Germany, as well as the influence on children's participation. A majority of the findings aligned with previous research from other countries, where AAD owners perceive various benefits from the dog, but also highlight certain difficulties and obstacles (e.g., Appleby et al., 2022; Burrows et al., 2008; Hellings et al., 2022). Effects for the children with ASD were more directly received from the AAD, whereas family members reported more benefits that were consequences of the effects of the dog on the child (e.g., freedom, relief, social participation). All participants described how getting the AAD into their family influenced the development of a strong personal interest and passion for the topic of assistance dogs for various family members.

The stories told by participants of the present study were complex and characterized by dilemmas. These included contradicting emotions such as happiness and fear and feeling relieved and simultaneously carrying the additional burden of care for the dog, which has been mentioned in previous studies (Appleby et al., 2022; Hellings et al., 2022; Leighton et al., 2023). Appleby et al. (2022) described how, paradoxically, the AAD could increase families' freedom through the limitation of the child being attached to the dog. Corresponding to those findings but in a broader sense, participants of the present study reported increased independence, while being restricted in some areas due to the AAD. Similarly, the AAD helped to build routine and structure highlighted by earlier research (e.g., Berry et al., 2013; Leighton et al., 2023; Leung et al., 2022) while requiring families to remain flexible and adaptable to unforeseen situations.

The AAD Within the ICF and the fPRC

A biopsychosocial approach has been established as useful in explaining the impact of dogs on humans (Gee et al., 2021), and a dynamic view on the interaction of the different influences is recommended (Lehman et al., 2017; Tseng, 2023). This dynamic aspect could be seen in the changes in the AAD's impact and role over time, and the required flexibility to continuous adjustment and adaptations for AAD owners. The fPRC (Imms et al., 2016) and the ICF (WHO, 2001) help to understand the effects of an AAD on the individual child, as well as their family members. Because the effects of the AAD on the child with ASD and the other family members are so closely connected and interrelated, it is suitable to discuss them together.

On the level of *body functions*, the physical and mental functions of both children and parents were affected by the AAD. While research in the past was more focused on general emotion perception and regulation (Berry et al., 2013; Davis et al., 2004; Guay et al., 2022),

participants in this study described emotional aspects more concretely. A variety of emotions was highlighted, ranging from happiness, feeling lucky, and feeling safe, to fear and worry. Negative emotions were mostly related to sickness and death of the AAD, topics that have been identified as challenging before but still require further investigation (Appleby et al., 2022). The sense of enhanced safety and security and, therefore, more calmness and less stress and concern has been highlighted previously (Burgoyne et al., 2014; Burrows et al., 2008; Hellings et al., 2022; Morgan & O’Byrne, 2023), and seemed to be a central factor in the support of AADs for families in the present study. Furthermore, participants confirmed earlier findings of children’s improved physical activity and motor functioning (Burrows et al., 2008; Hellings et al., 2022). While Guay et al. (2022) found that the introduction of an AAD led to decreased self-harm, participants in this study described how their child stopped hurting the parents after getting the dog and instead used more healthy coping and self-regulation strategies. In line with previous findings (Appleby et al., 2022; Hellings et al., 2022; Leighton et al., 2023; Leung et al., 2022; Morgan & O’Byrne, 2023), different sensory stimuli and the development of a higher sensory tolerance were perceived to contribute to this, including active input from the dog like pushing, and passive influences such as the sensation of the dog’s hair. Overall, AADs appear to have a balancing effect on children’s physical and mental health, and consequently, on the health of their parents, leading to a better physical and psychological functioning of the whole family. This may be related to different physiological factors, including reduced cortisol levels (Fecteau et al., 2016; Viau et al., 2010) and sleeping patterns (Guay et al., 2022).

Factors from the *environment* were perhaps the most discussed by participants and the most contradicting in this study. From an ICF perspective, an assistance dog can be seen as an environmental factor that is introduced into the child’s life (WHO, 2001), which is part of a shared proportion of the child’s environment and the environment of family members. Consequently, at this level, the most direct impact on the whole family could be seen. Within the family, the influence of the AAD was bidirectional: the dog could loosen tensions within the family and had a binding and connecting effect, while at the same time, participants emphasized a large increase in freedom for family members to engage in independent activities. This adds to previously mixed findings of the effects of AADs on family bonding (Guay et al., 2022, Leighton et al., 2023; Morgan & O’Byrne, 2023) and gained freedom for the family (Appleby et al., 2022; Morgan & O’Byrne, 2023) at the same time. Additionally, participants mentioned small conflicts in the family evolving around the dog and initial disruptions of existing routines but felt they eventually strengthened family cohesion. Interestingly, these effects within the family were described differently by the participants who were parents to

children with ASD, compared to the adult AAD user, where parents described more improvements in family connections and change within the family. Because of the small number of participants, it remains unclear whether this was simply due to differences between families, or if parents and children may perceive such patterns differently. It has been found in other contexts however, that parents' and children's views can diverge, and both are important to consider for a more complete picture (Huus et al., 2015; Nilsson et al., 2015).

Observed challenges mostly had to do with people outside of the family. Previous research identified difficulties with being denied access (Hellings et al., 2022) and a need for more public knowledge (Burrows et al., 2008; Hellings et al., 2022), which were emphasized by the participants of this study as well. Interestingly, disrespect of strangers and their attitudes and lack of knowledge posed one of the largest obstacles to AAD owners and was named as the most difficult part of owning an AAD. They encountered similar problems in the context of preschools/schools, where they reported that it was dependent on the specific institution and the people working there whether the AAD could accompany the child there. This was not highlighted to the same extent in other studies and could be a coincidental finding among the few participants of the current study, or it may be particular to the German context. There, assistance dogs are mostly known for people with visual impairments, and the legislation for accessibility concerning assistance dogs was only recently adapted in 2021 (BGBI, 2022, Absch. 6, §25; BGG, 2002, §12e Abs. 2b), and people may still need time to adjust to this. Additionally, the under- and misrepresentation in the media reported by the participants may be contributing to this lack of public awareness, understanding, and knowledge. Participants expressed concern for the future of AADs if public education does not improve significantly.

Activity and participation are part of the ICF (WHO, 2001) but can be described in more detail within the fPRC (Imms et al., 2016). As discussed above, *attendance* in different situations and contexts is a prerequisite to being engaged and is closely related to and dependent on environmental factors (Imms et al., 2016). AADs are often described as facilitators or bridges (e.g., Berry et al., 2013; Dollion et al., 2022), but participants of the current study highlighted the dilemma between the AAD enabling them to go out more and participate in social activities, and thereby attracting a lot of attention. While social interaction is usually portrayed as a benefit of the AAD, it was perceived as both beneficial and hindering in the present study, where participants could no longer choose or control when and with whom they wanted to engage. As a consequence, AAD owners acquired different coping strategies and ways to set boundaries, requiring thorough preparation, a high level of mental effort, and a willingness to discuss and fight for their rights from AAD owners. Once the possibility to be

physically present was given to the child together with the AAD, the AAD facilitated *involvement* in the situation. Participants experienced peer interest, communication about and with the dog, and support of interactions with therapists. *Activity competence*, *sense of self*, and *preferences* are the factors presumed to be related to children's participation (Imms et al., 2016).

In the present study, AADs improved children's *activity competence* in several ways. In line with previous research, they facilitated learning and executing life skills and activities, and improvements in social interaction, behaviors, and skills (Agnew et al., 2023; Guay et al., 2022; Hellings et al., 2022; Leung et al., 2022; Morgan & O'Byrne, 2023), with the addition of the possibility of creating new contacts, or any contacts at all, because of the AAD. Additionally, AADs promoted empathy and understanding of others' needs and emotions, an effect that has been identified for children with various kinds of assistance dogs (Davis et al., 2004). The second suggested influencing factor is children's *sense of self*. It is well documented in the literature, that children with ASD are often exposed to stigma and negative perceptions, which can result in an internalized view of themselves as "different" or "strange" (Botha et al., 2022; Hodge et al., 2019). Participants described how the AAD could help to overcome this negative self-image through unconditional acceptance and stability. AADs were reported to positively affect their self-confidence and self-efficacy and provide opportunities for children to gain a sense of success and achievement, all contributing to a subsequently more positive *sense of self*. Moreover, autonomy was supported through responsibilities taken for the dog, and by being able to spend time unsupervised and engaging in public activities like going to the store. The AAD also helped children to detect and communicate their own needs and could be used as a reason to withdraw from a situation and as support in self-regulation. This also related to *preferences*, where children could make choices about when and where to engage, although this aspect could be restricted by people in the environment. In addition, children were encouraged to participate in various phases of the implementation of the AAD as an intervention, starting from choosing which dog was most suitable for them, to the involvement in the dog's training, decisions about which tasks the AAD should have, and later taking responsibilities in the care of the dog or deciding how much information to disclose to strangers. For example, the connection between the child and the dog with a belt, which was previously described as a common task of AADs (e.g., Appleby et al., 2022; Burgoyne et al., 2014; Morgan & O'Byrne, 2023; Pavlides, 2008), was only used in one family, and only for a limited time before the child no longer felt comfortable with it. Here, the child had the right to communicate their needs and feelings of shame and participate in finding a different, more suitable arrangement. This shows how participation is not only an outcome of AADs but may also be used as a means in

interventions, promoting desirable outcomes (Carlberg & Granlund, 2019; Imms et al., 2016). Imms et al. (2016) further indicate self-regulation as a process that connects *activity competence, sense of self, and preferences*. AADs seem to have this regulating and balancing effect both at the individual (e.g., sensory), and the social level, contributing to children's ability to be engaged and participate.

All in all, participation can be named as an outcome of implementing an AAD into a family, although some restrictions to this effect could be identified. One official purpose of an assistance dog, to compensate for participatory disadvantages for people with disabilities (BGBI, 2022, Absch. 6, §25; BGG, 2002, §12e Abs. 2b), could therefore be seen as partly fulfilled. However, if AAD owners constantly need to explain themselves, participation on equal terms to non-disabled people is not possible. Participants explicitly stated that there is a paradox where the goal of an AAD increasing participation is failed if AAD owners are not allowed access to locations in which they would like to participate in society. Again, this highlights a pressing need for better education of the public and more visibility for the rights of assistance dogs and their owners. In line with previous research (Agnew et al., 2023; Leighton et al., 2023), parents even described increased social participation for the family as a whole, and an improved social life for each family member individually. Overall, it seems that AADs provide good potential to support participation, but the right conditions must be created for this potential to be applicable.

Altogether, the health and development of children with ASD is facilitated by an AAD in the different areas of the ICF, and the impact on their participation can be understood in more detail with the help of the fPRC framework. It was highlighted in this study that AADs have the potential to target and improve the main symptomatic characteristics of ASD. Moreover, the AAD was shown to have a positive direct and indirect influence on other members of the family as well. Besides the various benefits, several challenges related to the AAD could be identified, which were largely associated with environmental aspects around the child and family. However, encountered difficulties were often described as leading to eventual growth, for example, family bonding over conflict, children developing sensory adaptability and tolerance after initial struggles, or learning about their boundaries and how to communicate them clearly. While the AAD can be seen as an environmental factor introduced to the child and family, it can also be viewed as a more holistic intervention, with the potential to simultaneously foster development in different biopsychosocial areas, which in turn influence each other. Furthermore, AADs were perceived as a sustainable intervention, with positive effects in the long term and a high changeability and adaptability over time and contexts.

Limitations

Some limitations to the present study need to be reflected on. The use of AADs is still a small and rather new field in Germany. Although a number of trainers offer training for AADs, they seem to be focusing on adults, leading to a lengthy recruitment process and a small number of participants. Several additional reasons may have contributed to this. Firstly, parents in general, and especially parents of children with disabilities, often have busy schedules, even more so with a dog, and might not have found the time to respond to the call for participation. Secondly, AAD owners have to deal with the topic a lot in their everyday lives and could be tired of discussing it. Although participants reported a high interest in sharing their experiences, there may be a response bias where those who do not enjoy the constant confrontation also did not volunteer to participate in the study. Lastly, some people might have shared their stories before without real consequences or change for them, and participating in a master's thesis research may have been perceived as not worth the effort of doing it again. In the end, two parents and one adult AAD user participated, who expressed mixed views on their experiences with AADs. This may be due to individual characteristics of the participants but could also reflect differences in experiences depending on whether parents or children are interviewed (Huus et al., 2015; Nilsson et al., 2015). While it can be seen as a weakness that the perspectives cannot be clearly distinguished, it is also a strength to include a diversity of participants. Furthermore, three participants are few, and findings based on this number of participants need to be interpreted with some caution. However, the AAD community in Germany is still extremely small, therefore it is also possible that they do provide a good representation. Additionally, following the phenomenographic approach, each of the participants' experiences provide important and valid first insights into the experiences of families with AADs in Germany, regardless of the sample size and variability (Zygmunt & Naidoo, 2022; Åkerlind, 2012). Therefore, despite the above-described limitations, rich data could be gathered, leading to important findings that can serve as a foundation for future research in the field of AADs.

The participants of this study partly recalled experiences from their past, which may result in a positive recollection bias (Bornstein et al., 2020). However, they all also currently had an AAD, minimizing the impact of such bias. Furthermore, researcher bias is a potential threat to qualitative interview studies (Creswell et al., 2018). Measures that were taken to counteract such bias were described previously under ethical considerations. Altogether, this research aimed to explore a new and understudied field, requiring the researcher to be open in the data collection and analysis, matching the applied qualitative method. Data collection was conducted via video call, which limited the researcher's impression of participants and involved

some issues with slow internet connections. No consequential impact on the participants' narrative flow was noticed.

Finally, the ICF was a suitable model to understand from a biopsychosocial perspective how the effects of AADs are experienced by families, and the fPRC served as a good extension to it for the in-depth discussion of participation. The family aspects are included in the ICF environmental factors, but although the interactions are bidirectional in the model, there is not much clarification about the actual impact of the child factors (e.g., body functions) on the family members. In addition, the aspect of variability and change over time and context is not clearly developed in the ICF. Nevertheless, it was possible to discuss and connect these aspects in addition to the existing ICF factors.

Implications and Future Directions

The findings of this study offer insights into the experiences of families in Germany with an AAD. It was established that more widespread awareness of AADs and assistance dogs in general, is needed in Germany to remove obstacles for AAD owners and create easier access and a supportive network for those potentially interested in getting one. The overall positive results can serve as a justification for more resources in the form of research, education, financial support, and more, to be directed at the topic of AADs. The findings of this study can be informative for researchers, professionals, and private persons interested in the topic of AADs, and can even be used as a basis to counteract the abovementioned barrier of limited media coverage of the topic of assistance dogs. Through transparency of both benefits and barriers, they may contribute to better public education.

Nevertheless, more research is needed to confirm the suspected effects of AADs and to clarify if their beneficial impact generally outweighs the difficulties. Growth in evidence may lead to more support (socially and financially) and thereby facilitate a clear definition and subsequent removal of the encountered challenges. Insights into children's perspectives on the topic should be a future research subject, and the views and experiences of other family members such as siblings should be considered. Furthermore, comparison studies need to determine if the effects of AADs exceed those of existing interventions for children with ASD.

Conclusion

In conclusion, the impact of AADs on families, children with ASD, and their participation is complex, shaped by dilemmas, and can be paradoxical at times. Overall, AADs were found to have a wide range of benefits for both children and their families, at the biological, psychological, emotional, and social level, which were perceived as outweighing

the associated difficulties. Moreover, AADs positively impacted the participation of children with ASD, as well as the overall social participation of the family. However, it was highlighted that this positive impact on participation was only possible if the right conditions were given and could be hindered by unknowing people and denied accessibility. Several other barriers and challenges were named, acknowledging the high investments and sacrifices families had to make, and which people should be made aware of when considering an AAD for their family. Importantly, no negative effect of the AAD on children was found and the benefits of the AAD were described as outweighing the difficulties. Altogether, this study provides a first insight into the experiences of families with an AAD in Germany. More research and resources should be directed at this field to improve conditions for AAD owners and those interested in AADs and investigate more specific effects to better establish this intervention to support children with ASD.

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Appendix A

Request for Cooperation in Master Thesis

(The German original letter that was sent to the gatekeepers and a translated version)

Sehr geehrte Damen und Herren

Mein Name ist Svenja Martens und ich mache derzeit einen Master in „Interventions in Childhood“ an der Universität in Jönköping, Schweden. Für meine Masterarbeit, die diesen Monat beginnt, interessiere ich mich für die Erfahrungen von Familien mit einem Autismus Assistenzhund in Deutschland. In meiner Studie möchte ich Eltern über ihre Erfahrungen und Ansichten zu Vorteilen sowie möglichen Schwierigkeiten befragen, die sie und ihre Kinder im Zusammenhang mit dem Assistenzhund erleben.

Da ich potentielle Teilnehmer*innen für die Studie nicht direkt kontaktieren kann/darf, möchte ich hiermit anfragen, ob es für Sie möglich ist, mich bei der Rekrutierung der Teilnehmer*innen zu unterstützen. Ich möchte Sie bitten, einen digitalen Informationsbrief, den ich Ihnen in den nächsten Wochen zukommen lasse, an Familien weiterzuleiten, die mit Ihrer Organisation zusammengearbeitet haben, um einen Autismus Assistenzhund für ihr Kind zu bekommen. Eltern die interessiert daran sind an meiner Studie teilzunehmen werden dann gebeten sich bei mir zu melden.

Der Rekrutierungszeitraum wird noch im Januar beginnen und die Interviews werden voraussichtlich zwischen Januar und März stattfinden. Diese E-Mail ist noch nicht die Information, die an die Familien weitergeleitet werden soll, hiermit möchte ich nur sicherstellen, dass Sie bereit wären mich in den nächsten Wochen zu unterstützen. Über eine Zusammenarbeit würde ich mich sehr freuen!

Bitte zögern Sie nicht mich zu kontaktieren, falls sie irgendwelche Fragen oder Bedenken haben. Ich freue mich von Ihnen zu hören!

Mit freundlichen Grüßen

Svenja Martens

Kontakt: masv22gu@student.ju.se

Betreuende Lehrkraft:

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Dear Ladies and Gentlemen,

My name is Svenja Martens, and I am currently following the master's program "Interventions in Childhood" at the university of Jönköping, Sweden. For my master's thesis, which will start this month, I am interested in the experiences of families with an autism assistance dog in Germany. In my study, I would like to interview parents about the experiences and views about benefits as well as potential difficulties, which they and their children have in relation to the assistance dog.

Because I cannot directly contact potential participants, I would like to hereby ask you if it is possible for you to support me in the recruitment of participants. I would like to ask you to forward a digital information letter, which I will send to you in the upcoming weeks, to families who have collaborated with your organization to receive an autism assistance dog for their child. Parents who are interested to participate in my study are then asked to contact me.

The time of recruitment will begin in January and interviews are planned to take place between the end of January and March. This email is not yet the information that should be forwarded to the families; with this I only want to ensure that you would be willing to support me in the coming weeks. I would greatly appreciate your collaboration!

Please do not hesitate to contact me if you have any questions or concerns. I look forward to hearing from you!

Kind regards

Svenja Martens

Contact: masv22gu@student.ju.se

Supervisor:

Helena Taubner

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Appendix B

Information Letter for participants

(Originally in German and a translated version)

Informationsbrief zur Studienteilnahme

Interviewstudie den Erfahrungen und Ansichten von Eltern zu Vorteilen und Schwierigkeiten im Einsatz von Assistenzhunden für Kinder mit Autismus.

Worum geht es in der Studie und warum werden Sie gebeten teilzunehmen?

Mein Name ist Svenja Martens und ich absolviere mein Masterstudium in „Interventions in Childhood“ an der Universität in Jönköping, Schweden. Im Rahmen der Masterarbeit möchte ich eine Studie durchführen, in der ich mich mit dem Einsatz von Assistenzhunden für Kinder mit Autismus in Deutschland auseinandersetze. In dieser Studie möchte ich Interviews mit Eltern durchführen, um Informationen zu und von deren Erfahrungen von Vorteilen und Schwierigkeiten im Zusammenhang mit Autismus Assistenzhunden zu erhalten. Außerdem möchte ich über die möglichen Auswirkungen des Assistenzhundes auf die Teilhabe der sprechen.

Das Thema Autismus Assistenzhunde ist bisher nur wenig wissenschaftlich erforscht und Autismus Assistenzhunde sind noch keine weit verbreitete Maßnahme. Deswegen können Sie mit Ihrer Teilnahme an dieser Studie und dem Teilen Ihrer Erfahrungen einen wertvollen Beitrag leisten.

Wenn Sie Interesse daran haben an der Studie teilzunehmen oder mehr Informationen möchten, kontaktieren Sie mich gerne per E-Mail: masv22gu@student.ju.se.

Was bedeutet es für Sie an dieser Studie teilzunehmen?

Die Interviews werden im Zeitraum zwischen dem 15.02.2024 und dem 01.04.2024 stattfinden. Wenn Sie sich für die Teilnahme entscheiden, werden wir ein Videotelefonat von ca. einer Stunde planen. Für das Telefonat werden wir einen für Sie passenden Zeitpunkt finden.

Während des Interviews werden wir über Ihre Erfahrungen mit dem Assistenzhund sprechen und über die Vorteile sowie die Schwierigkeiten, die Sie in ihrer Familie und vor allem Ihr Kind mit dem Hund erleben. Außerdem wird es um die Teilhabe Ihres Kindes gehen und darum, welche Rolle der Assistenzhund darin spielt.

Mögliche Nutzen und Risiken durch die Teilnahme an dieser Studie

Die Teilnahme an dieser Studie beinhaltet keine besonderen Risiken. Sollten Sie sich unwohl fühlen oder Bedenken in Bezug auf die Studie haben können Sie gerne direkt mit mir sprechen oder mich oder meine betreuende Dozentin kontaktieren. Alle Kontaktinformationen finden Sie am Ende des Informationsbriefes.

Wie werden Ihre Daten behandelt?

Alle Daten, die während der Studie erhoben werden, werden gemäß EU-Regulationen (GDPR) behandelt. Die Interviewdaten werden auf einem universitätsinternen Server gespeichert. Ihre persönlichen Daten werden separat verwahrt, sodass die Interviewdaten nicht mit Ihrer Person in Verbindung gebracht werden können. Zugang zu den Daten ist ohne Befugnis nicht möglich. Um Ihre Privatsphäre zu schützen, werden identifizierbare Informationen wie z.B. echte Namen von Menschen und Orten aus den Transkriptionen der Interviews entfernt. Anonymisierte Zitate aus den transkribierten Interviews können im Text der Masterarbeit verwendet werden. Alle Daten werden vollständig gelöscht, sobald das Projekt abgeschlossen ist.

Freiwillige Teilnahme und Abbruch der Teilnahme

Ihre Teilnahme an der Studie ist freiwillig. Sie können die Teilnahme zu jedem Zeitpunkt abbrechen, ohne dass Sie dafür einen Grund angeben müssen und ohne negative Konsequenzen. Das bedeutet zum Beispiel, dass Sie sich dazu entscheiden können bestimmte Fragen nicht zu beantworten, Sie dürfen das Interview zu jedem Zeitpunkt abbrechen und Sie können auf die Löschung von bereits erhobenen Daten bestehen. Die Entfernung der Daten aus der Studie ist nichtmehr möglich, nachdem die Masterarbeit zur Benotung eingereicht wurde.

Zugang zu den Ergebnissen der Studie

Nachdem die Masterarbeit abgeschlossen ist, haben Sie die Möglichkeit die Ergebnisse einzusehen. Wenn Sie an den Ergebnissen oder an der gesamten Arbeit interessiert sind, geben Sie mir gerne Bescheid.

Kontaktinformationen

Svenja Martens, masv22gu@student.ju.se

Betreuende Person:

Helena Taubner

Lektor i specialpedagogik / Senior Lecturer in Special Education Höskolan för lärande och kommunikation, Jönköping University

helena.taubner@ju.se

+4636-10 10 9

Einverständniserklärung

- Hiermit bestätige ich, dass ich mündliche und schriftliche Informationen zur Studie erhalten habe.
- Ich bestätige, dass ich die obenstehenden Informationen gelesen und verstanden habe und freiwillig an dieser Studie teilnehmen möchte.

Ort, Datum	Unterschrift
Vor- und Nachname	

Information Letter for Study Participation

Interview study of experiences and views of parents regarding benefits and difficulties in the implementation of assistance dogs for children with autism

What is this study about and why are you asked to participate?

My name is Svenja Martens, and I am studying in the master's program "Interventions in Childhood" at the university in Jönköping, Sweden. Within the scope of my master's thesis, I would like to conduct a study about the implementation of assistance dogs for children with autism in Germany. In this study, I want to conduct interviews with parents, to gather information about their experiences of advantages and difficulties in relation to autism assistance dogs. Additionally, I would like to speak about a possible impact of the assistance dog on the participation of the children.

The topic of autism assistance dogs is so far only scarcely scientifically studied, and autism assistance dogs are not a very widespread intervention yet. Therefore, you can make a valuable contribution by participating in this study and sharing your experiences.

If you are interested to participate in the study or would like more information, you are welcome to contact me via e-mail: masv22gu@student.ju.se.

What does it imply for you to take part in this study?

The interviews will take place between 02/15/2024 and 04/01/2024. If you decide to participate, we will plan a ca. 1-hour long video call. For the call we will find a time that fits for you.

During the interview, we will talk about your experiences with the assistance dog and about advantages as well as difficulties that your family, and especially your child experience with the dog. Additionally, we will talk about your child's participation and about the role of the assistance dog in relation to it.

Possible benefits and risks when participating in this study

The participation in this study does not contain any particular risks. If you should feel uncomfortable or have concerns in relation to the study, you are welcome to speak directly with me or to contact my supervisor. All contact information can be found at the end of this

document.

How will your data be treated?

All data that is collected during the study is treated according to EU regulations (GDPR). The interview data will be saved on an internal university server. Your personal data will be stored separately, so that the interview data cannot be connected to you. It is not possible to access any of the data without authorization. To protect your privacy, identifiable information such as real names of people and places will be removed from the transcripts of the interviews. Anonymized quotations from the interviews can be used within the text of the master's thesis. All data will be deleted completely once the project is completed.

Voluntary participation and discontinuation of participation

Your participation in the study is voluntary. You can discontinue your participation at any point without having to provide a reason and without any negative consequences. That means for example, that you can decide not to answer certain questions, you can end the interview at any point, and you can insist for the data collected from you to be deleted. Removal of the data will no longer be possible after the thesis has been submitted for grading.

Access to the results of the study

Once the thesis is completed, you will have the possibility to view the results. If you are interested in the results or the whole thesis, please let me know.

Contact information

Svenja Martens, masv22gu@student.ju.se

Supervisor:

Helena Taubner

Lektor i specialpedagogik / Senior Lecturer in Special Education Högskolan för lärande och kommunikation, Jönköping University

helena.taubner@ju.se

+4636-10 10 9

Informed consent

- I hereby confirm that I have received verbal and written information about the study.
- I confirm that I have read and understood the information above, and that I choose to participate in the study voluntarily.

Place, Date	Signature
First and last name	

Appendix C

Interview Guide

(German original and English translation)

Interview mit (Teilnehmer) am (Datum)

Einführung

Wichtige Informationen für den Anfang:

- Begrüßung
- Consent, Freiwillige Teilnahme, Abbruch oder Frage überspringen jederzeit möglich
- Fragen stellen bei Unklarheit
- Idee hinter dem Interview kurz erklären
- Ablauf Interview erklären

Demographische Informationen:

- Alter vom Kind
- Hund seit wann
- Hund Alter, Rasse, Training

Interview

- Wie kam es dazu, dass Sie/Ihr sich/euch für einen Assistenzhund für Ihr Kind entschieden haben?

Familie

- Wie sieht ein typischer Tag im Alltag Ihrer ganzen Familie mit dem Assistenzhund aus?
 - Was sind Schwierigkeiten/schwierige Erlebnisse, die Sie als Familie bisher mit dem Hund erlebt haben?
 - Was für positive Erlebnisse hat Ihre Familie mit dem Hund bisher gehabt?
- Hat sich in Ihrer Familie etwas verändert, nachdem Sie den Hund bekommen haben?
 - Erleben Sie positive Veränderung in Ihrer Familie seit Sie den Hund haben?
 - Erleben Sie negative Veränderung in Ihrer Familie seit Sie den Hund haben?

Kind

- Wie begleitet Ihr Assistenzhund Ihr Kind durch den Alltag?
- Was für eine Auswirkungen sehen Sie für Ihr Kind durch den Assistenzhund?
 - Was für positive Auswirkungen sehen sie für Ihr Kind?
 - Was für Schwierigkeiten sehen Sie für Ihr Kind in Bezug auf den Hund?

Teilhabe spezifisch

- Sehen Sie Veränderungen im sozialen Leben Ihres Kindes seit Sie den Assistenzhund haben?
 - Hat der Hund Einfluss auf Freundschaften des Kindes?
 - Einfluss auf Wahrnehmen von Freizeitangeboten → kann Kind an mehr/weniger teilnehmen, darf der Hund mit?
 - Auswirkungen in der Schule? Ist der Hund dabei?
- Denken Sie, dass Ihr Kind anders in Familienaktivitäten involviert ist durch den Hund?
 - Alltäglich, z.B. gemeinsame Mahlzeiten, Alltagsaktivitäten wie Einkäufe, Haushaltsaufgaben, gemeinsam spielen, etc.
 - Besondere Aktivitäten wie Geburtstage, Ausflüge, Familienurlaub, etc.

Abschluss

- Zum Abschluss, was würden Sie sagen ist das Schwerste und was ist das Beste daran einen Assistenzhund zu haben?
- Gibt es noch etwas, was wir nicht besprochen haben, was Sie gerne noch sagen wollen?
- Haben Sie noch Fragen?
- Möchten Sie sich das Transkript durchlesen?
- Möchten Sie am Ende die Ergebnisse/Masterarbeit per E-Mail zugeschickt bekommen?
- Bedanken!

Interview with (Participant) on (Date)

Introduction

Important information to start with:

- Welcome
- Consent, voluntary participation, discontinuation or skipping questions always possible
- Ask questions if anything is unclear
- Explain idea behind the project
- Explain structure of the interview

Demographic information:

- Age of the child
- Dog since when
- Dog age, breed, training

Interview

- How did it come that you decided to get an assistance dog for your child?

Family

- What does a typical day in the everyday life of your whole family look like with the assistance dog?
 - What are difficult experiences you have so far had with the dog as a family?
 - What are positive experiences your family has had with the dog so far?
- Has anything changed within your family after you got the dog?
 - Do you experience any positive changes in your family since you got the dog?
 - Do you experience any negative changes in your family since you got the dog?

Child

- How does the assistance dog accompany your child in everyday life?
- What kind of effects do you see for your child?
 - What positive effects do you see for your child?
 - What difficulties do you see for your child in relation to the dog?

Participation-specific

- Do you see changes in your child's social life since you have the assistance dog?
 - Does the dog influence friendships of your child?
 - Influence on attending spare time activities → can the child take part in more/less, is the dog allowed to be with?

- Effect in school? Does the dog join?
- Do you think that your child is differently involved in family activities because of the dog?
 - Everyday life, e.g., shared mealtimes, shopping, household chores, playing together, etc.
 - Special activities such as birthdays, trips, family vacation, etc.

Ending

- What would you say is the hardest and what is the best thing about having an assistance dog?
- Is there anything we have not yet talked about that you would still like to say?
- Do you have any more questions?
- Would you like to read the transcript?
- Would you like to receive the results of the thesis?
- Thank you!