

Inclusive tourism and children with a diagnosis of autism spectrum disorders: Systematic review of the literature

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Abstract

The present work undertakes a systematic review of the literature and research on the subject, using the PRISMA-P guidelines. The research was carried out in five electronic databases. It was found that there are few publications on inclusive tourism aimed at families with children with diagnosis of autism spectrum disorders (n=11). Most of them are qualitative studies. They focus on the needs of families, from which they draw implications in terms of necessary practical responses. Except for a study on the airport context, there are no studies that seek to empirically validate responses or tourist products. The need for empirical validation of tourist offers that are truly inclusive and beneficial to the psychological well-being of families and children is discussed. Some important guidelines/evidence that must be met in inclusive tourism aimed at this population are highlighted.

Keywords: inclusive tourism, families, children, diagnosis of autistic spectrum disorder, systematic review, tourist needs

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1. Introduction

The concern with inclusion has been increasingly the focus of attention by researchers in the field of tourism, looking for ways to reduce or eradicate the exclusion and/or marginalization of minority and more vulnerable groups (Gillovic & McIntosh, 2020). This is the case of individuals with disabilities, in the sense of creating tourism opportunities that benefit them or over which they may have some sense of control (Darcy *et al.*, 2020; Gillovic & McIntosh, 2020). Among individuals with disabilities, children with the Diagnosis of Autism Spectrum Disorders (CwDASD) constitute a very specific group to be considered by tourism companies, either because of their prevalence - worldwide one in 160 children have a diagnosis of ASD (WHO, 2021) - or because, necessarily, they must travel with their caregivers, expanding the number of tourism consumers when considering this target group.

In addition, the changes in the conceptualization of disability and the Diagnosis of Autism Spectrum Disorders (DASD) have contributed to the growing interest of tourism by this target group, as well as contributing to people with DASD and their family's seeing tourism as an important activity in their lives. Contrary to the medical model, which emphasized deficits and pathology, current models (psychosocial and neurodiversity models) emphasize that DASD should not be considered a disturbance but assumed as a form of diversity in terms of brain functioning and development (Hamed, 2013; Robertson, 2010). These perspectives implied changes at the intervention level, suggesting the need for social responses that consider the diversity of CwDASD and promote/stimulate their capacities, resources, and competences (Saldana *et al.*, 2009).

In addition, currently increasing the quality of life of CwDASD is seen as a priority objective, namely their emotional well-being, interpersonal relationships, physical well-being and social inclusion (Saldana *et al.*, 2009), as dimensions that imply tourism (e.g., recreation and leisure activities, involvement in activities and social interactions). Thus, tourism is progressively seen to promote and improve the quality of life of CwDASD (Blichfeldt & Nicolaisen, 2011; Hamed, 2013). However, it should be noted that CwDASD can be a challenge, namely due to the great variability of their characteristics and degree of impairment (Hamed, 2013).

Given the specificities of CwDASD and the growing interest in tourism in this group, it is important to understand the degree of knowledge and current research on inclusive tourism (IT) and the needs of CwDASD, in order to establish/define appropriate practices and guidelines within the scope of IT, as well as identify guidelines for future research.

2. Literature Review

2.1. *Inclusive tourism - from an economic to a social perspective*

In recent years, the term of inclusive tourism (IT) has greater visibility in the literature. However, the concern of tourism with inclusion has been present for some time under other nomenclatures, such as accessible tourism (Darcy & Dickson, 2009), tourism for all (Bélanger & Jolin, 2011) or universal tourism (Prescott, 2012). Indeed, researchers have long focused on the social benefits of tourism and sought strategies to maximize them (Biddulph & Scheyvens, 2018).

Traditionally, tourism has long been understood and even marketed as an exclusive activity (Biddulph & Scheyvens, 2018). The greater the uniqueness and eccentricity of destinations and tourism experiences, the higher the costs, being something within reach of some privileged and more favoured groups. With the evolution of technologies, globalization, and the reduction in the cost of travel, tourism has grown exponentially and has become massive. Paradoxically, despite bringing economic growth, its massification may have negative consequences (Biddulph & Scheyvens, 2018) - both for

residents of tourism destinations (e.g., rising prices, worsening environmental conditions) and for consumers themselves (overcrowding, standardization of services and activities). In this context, IT emerged as an attempt to respond to the problems of social exclusion and inequality, seeking to integrate and benefit those who are typically marginalized or excluded (Gillovic & McIntosh, 2020; Scheyvens & Biddulph, 2018).

However, in this attempt, it appears that IT was initially approached from an economic point of view, seeking to respond to the problems of exclusion of local populations, involving them in the provision of activities/tourism products (e.g., Saarinen, 2017). Thus, within the scope of the social responsibility of large tourism companies, the notion of inclusive business emerged, which aims to contribute to the reduction of poverty and inequality, integrating the poorest and disadvantaged local communities into the tourism market. Subsequently, the notion of inclusive development emerged, based on the definition of the United Nation Development Program (UNDP, 2009). UNDP postulates that development is inclusive and reduces poverty when all groups contribute to creating opportunities, share the benefits of development and participate in decision-making. However, this definition continues to focus essentially on economic growth, obscuring social development and ethical concern for people (Lawson, 2010).

In this context, it has been indicated that inclusive development should be a broader concept and not be limited to economic growth but include the notion of well-being of marginalized groups (Lawson, 2010; Scheyvens & Biddulph, 2018). Gradually, it is suggested that the notion of IT should follow this reconceptualization of inclusive development, not being reduced to the economic criteria (e.g., Scheyvens & Biddulph, 2018).

Thus, IT must be understood as “Transformative tourism in which marginalized groups are engaged in ethical production or consumption of tourism and the sharing of its benefits” (Scheyvens & Biddulph, 2018, p. 4). This proposal conveys a holistic and comprehensive conception: on the one hand, the term “transformer” implies that it must respond to inequality, challenge stereotypes and contribute to the understanding of marginalized groups; on the other hand, it conveys that the involvement of marginalized groups is not limited to the production of ethical tourism (e.g. how to integrate the most vulnerable local groups) but also encompasses tourism consumers - that is, minority groups that are not usually considered as a target population for tourism and who are subject to stigmatization/social exclusion (e.g., people with disabilities or special needs).

Therefore, not only the production component of tourism, but also the consumption component must be inclusive, implying that tourism has conditions and overcomes barriers so that marginalized groups can have access to tourism as consumers (Scheyvens & Biddulph, 2018). In this context, the UNDP (2018) has explicitly emphasized that inclusive development must consider marginalized and/or excluded groups. A clear example is the guidelines for the inclusive development of people with disabilities (UNDP, 2018), stating that inclusive development must necessarily cover them. Thus, tourism has also sought to respond to this imperative, increasingly attending people with disabilities.

2.2. *Disability and Inclusive Tourism (vs. Accessibility)*

Following the UNDP (2018) to address the inclusive development of people with disabilities, researchers and academics have increasingly referred to the importance of IT emphasizing individuals with disabilities. It is also mentioning that several social movements claimed the rights of people with disabilities in various areas of citizenship, including tourism and travel (Darcy *et al.*, 2020).

First, it should be noticed that disability is a phenomenon with a significant worldwide prevalence (Gillovic & McIntosh 2020; WHO, 2011), directly affecting about 15% of the population and, if one considers families and/or caregivers indirectly, affects 30% of the population (WHO, 2011). Thus, there is a significant percentage of the population that, until then, has not been covered by the tourism industry. Research in the field of tourism indicates that not including people with disabilities implies excluding about 10–20% of the population (Darcy *et al.*, 2020; Gillovic & McIntosh, 2020).

Furthermore, despite the small number of studies, there is empirical evidence that IT aimed at people with disabilities brings economic gains for tourism activity and occupation (Gillovic & McIntosh, 2020), increasing the customer base, reducing the effects of seasonality, and increasing competitive advantages (Dwyer & Darcy, 2011; Gillovic & McIntosh, 2020).

From the literature review, it appears that when addressing tourism and the inclusion of people with disabilities, the most recurrent term is accessibility or accessible tourism (e.g., Darcy *et al.*, 2020; Gillovic & McIntosh, 2020) used frequently as synonymous (Biddulph & Scheyvens, 2018). However, Biddulph and Scheyvens (2018) indicate that these are different concepts: while accessible tourism focuses on access for people with disabilities to tourism, IT focuses on access to tourism for all types of marginalized people. From this perspective, it can be said that IT is more comprehensive, and that accessible tourism is integrated into IT, given that people with disabilities are, due to their specificities and differences, the target of stigmatization and social exclusion (McIntosh, 2020; Sedgley *et al.*, 2017).

In turn, regarding the inclusion of people with disabilities in tourism, there are authors who advocate the use of the terminology accessibility or access tourism, arguing the need for tourism to focus on becoming accessible for people with access needs (Darcy *et al.*, 2020). Although accessible tourism is not restricted to mobility and includes sensory and cognitive aspects (Buhalis & Darcy, 2011), we consider that the term accessibility can be understood in a restricted way and can be confused with simply reducing barriers and/or facilitating access. According to the Sustainable Development Goals (UNDP, 2018), the principle of inclusion is only fully fulfilled when the empowerment and active participation of people and marginalized groups (including people with disabilities) are promoted, which goes far beyond facilitating access or reducing barriers.

So, we consider that the terminology “inclusive tourism” does not only reflect the added value of integrating all forms of marginality and intersectionality, but it also incorporates the transformative component and, therefore, the empowerment. Focusing on the inclusion of people with disabilities, IT should provide products and experiences that promote people's development, namely psychological well-being, self-esteem, and self-confidence. Tourism can create unique opportunities for people, through leisure and fun, to experience some sense of mastery and autonomy and can be a catalyst for transformation (Blichfeldt & Nicolaisen, 2011; Gillovic & McIntosh, 2020).

2.3. *Diagnostic of Autism Spectrum Disorder and inclusive tourism*

A review of recent literature on the prevalence of DASD (Chiarotti & Venerosi, 2020), indicates the difficulty in estimating more accurately the prevalence worldwide, with a large variability of rates. However, it is estimated that around 10% of the population under 18 years of age has some type of disability and that around 2% suffers from ASD (WHO, 2021). WHO's estimation (2021) suggests that 1 in every 160 children has a DASD, resulting from the average value of the studies, but, in fact, more detailed studies indicate much higher values (WHO, 2021). Also in recent decades, research has reported an increase in its prevalence (Chiarotti & Venerosi, 2020; Fombonne, 2020), due to advances in diagnostic methodologies, as well as a greater awareness of the phenomenon (Fombonne, 2020).

ASD includes a variety of symptoms characterized by repetitive behaviours, sensory problems and difficulties in speech, non-verbal communication, and socialization. The word "spectrum" indicates a wide range of symptoms and characteristics (American Psychiatric Association, 2013; Hamed, 2013), whose combination varies from individual to individual and can involve mild impairment to more severe problems (APA, 2013).

Similarly, to what happened in the conceptualization of disability, there has also been a rejection of the medical model and the adoption of the perspective of neurodiversity in ASDs. Contrary to the medical model, which conceptualizes ASD as a neurodevelopmental disorder, the neurodiversity approach describes autism as a form of diversity of brain functioning and of the typical developmental pattern (Robertson, 2010).

Regardless of the perspective adopted (deficit or neurodiversity), the concept of quality of life is consensual. In this context, the literature indicates eight essential dimensions for the quality of life of people with DAsD, among which emotional well-being (feelings of pleasure, happiness, reduced levels of stress), interpersonal relationships (interaction with others, friendship relationships and social support), physical well-being (which implies recreation and leisure) and social inclusion (involvement in community activities) (Saldana *et al.*, 2009).

Tourism, considered an activity that provides human and social experiences that integrates recreation, leisure, and social and environmental interaction activities, can constitute a key feature/resource to attain those dimensions, contributing to the increase of feelings of well-being and reduced levels of stress (Hamed, 2013; Saldana *et al.*, 2009). Tourism can be, also in the case of CwDAsD and their families, a way to promote and improve their quality of life, providing experiences that meet the needs of this population and, thus, configuring an empowerment tool (Blichfeldt & Nicolaisen, 2011; Hamed, 2013).

It should also be mentioned that people with disabilities generally travel with caregivers, which is obvious in the case of CwDAsD due to lack of autonomy or capacity for decision-making. The choice or decision about the destination where the family can travel will be the one where this population can go, due to the personal conditions or limitations of the child and, mainly, due to the conditions (often scarce or lacking) of the tourist destination. In this context, the investigation indicates that informal caregivers are subject to high levels of demand and burden, also needing leisure and recreation experiences (Kim & Letho, 2013). So, family members or caregivers of CwDAsD should also be target of attention, requiring specific responses from tourism, which may include joint activities with the children.

Despite the growing interest of researchers in individuals with disabilities, studies have mostly focused on people with physical or mobility (Card *et al.*, 2006) and sensory impairments, especially visual ones (Deville & Kstenholtz, 2018). Research focused on other kind of mental problems - as intellectual disability (Gillovic, 2019) and dementia (Innes *et al.*, 2016) - is beginning to emerge, but it is fewer. Research on ASD is scarce (e.g., Hamed, 2013) and, even more, that includes CwDAsD and/or their caregivers (e.g., Sedgley *et al.*, 2017).

Given the evidence of economic profitability and greater competitiveness of tourism directed at people with disabilities or special needs (Dwyer & Darcy, 2011; Gillovic & McIntosh, 2020) - which includes CwDAsD and its caregivers - associated with the imperative of inclusion and the goals of sustainable development (UNDP, 2018) in tourism, there is an increasingly growing interest of tourism in offering

products to this population. However, the enormous variability of the CwDASD, in association with the specificities arising from the different developmental stages, can be a great challenge.

Thus, considering the specificities of CwDASD and their caregivers and the growing interest in tourism in this population, it is extremely important to understand the current knowledge and research on the tourism needs of families with children with a DASD and on targeted IT to these children.

3. Objective

It to obtain a detailed description of the literature and research on the tourism needs of families with CwDASD and on IT aimed at these children and their caregivers. Research question: What does the literature and the research inform about IT aimed at CwDASD and the specifics/needs of these children and their caregivers?

4. Method

The protocol adopted followed the guidelines of PRISMA-P (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols) (Shamseer *et al*, 2015).

4.1. Eligibility criteria (Participants-Interventions-Comparison-Outcomes-Studies - PICOS)

P - Type of Participants: CwDASD between 3 and 17 years old and/or tourism companies/services aimed at CwDASD between 3 and 17 years old.

I - Type of Interventions: not applicable

C - Comparison - not applicable

O - Outcomes - Characterization or discussion of the needs of CwDASD and/or their caregivers in terms of tourism, leisure activities, recreation, and travel; and/or identification/description of services, activities, procedures, guidelines, or recommendations in those areas for CwDASD and/or their caregivers.

S - Studies - Quantitative studies, qualitative studies, and other publications of a scientific nature (systematic reviews, meta-analyses, theoretical reviews).

The eligibility criteria translate into the following inclusion and exclusion criteria.

Inclusion criteria:

- a) Studies with children and/or caregivers of CwDASD that focus on the needs of children and/or their caregivers in terms of tourism.
- b) Studies or publications on tourism companies or services directed at or considering CwDASD and/or their caregivers.
- c) Empirical studies (quantitative and/or qualitative), theoretical reviews, systematic reviews and/or meta-analyses.
- d) Publications between 1990-2021, given that it was in the 1990s that the autistic rights movement emerged, boosting research
- e) Publications available on the web, given that all publications currently have digital record.
- f) Publications in English, Portuguese, and Spanish, to reduce the research bias.

Exclusion criteria:

- a) Studies that focus on tourism needs or tourism responses/proposals for caregivers of CwDASD, without considering children or their needs.
- b) Works that focus on needs and/or tourism services/activities/proposals aimed at people diagnosed with some type of disability, but do not specify CwDASD.
- c) Studies that consider young people, adults and CwDASD but do not carry out a specific analysis of children.

- d) Studies or publications on services or activities aimed at or considering CwDASD and their caregivers, but which are not of a touristic or leisure/recreation nature (e.g., sport, community services).
- e) Non-scientific publications (e.g., website information)

4.2. Information sources

The research was carried out in electronic databases that most index research in the area of tourism, health and psychology: b-On, EBSCO, Pub-Med, Web of science and Scielo. Google scholar was also used to identify any publication that was not included in the databases. The survey was conducted between June 1st and August 30th, 2021.

4.3. Research

The same search terms were used in all databases, taking the search option in the "abstract" or "search terms" to limit the focus, as well as the "peer-reviewed" limiter to obtain publications with greater scientific rigor.

Search Terms:

1. *autism OR asd OR autism spectrum disorder OR autistic disorder OR asperger*
2. *AND (tourism OR travel OR leisure OR recreation OR vacation OR holiday)*

To validate the systematic review process, the same research strategy was replicated by a pair, obtaining the same results. At the end of the review, the survey was updated, and no changes were identified.

4.4. Selection of publications

The selection was carried out independently and "blindly" by two researchers. Specifically, the entire process was carried out in a first phase by the responsible investigator. Following, the search criteria and eligibility criteria were indicated to a second investigator, in order to carry out the selection process applying the same criteria.

4.5. Data collection procedure

Considering the inclusion and exclusion criteria, the data collection process took place in five stages (cf. Figure 1 - Flowchart).

- Stage 1 - 1135 publications were identified. 206 were duplicates, therefore eliminated, leaving 919 publications.
- Step 2 - The screening of the 919 publications was carried out by reading the title and led to the exclusion of 701 publications. Remained 218 publications.
- Step 3 - The 218 publications were screened by reading the abstract and 156 publications were excluded as they did not meet the eligibility criteria. Specifically:
 - 55 do not focus on leisure, tourism services or activities
 - 55 do not focus on tourism or leisure needs
 - 15 included young or adult population
 - 7 on the cognitive functioning of CwDASD
 - 9 on the use of technologies and Virtual Reality
 - 4 focused on children diagnosed with disability but do not include ASD
 - 3 non-scientific publications (e.g., news)

- 3 on validation/adaptation of instruments
 - 3 on coping/resilience strategies
 - 2 in other languages
- Step 4 – Full reading of the 62 publications, proceeding to a careful analysis of the eligibility criteria. 52 publications were excluded, because:
- 19 on intervention without considering the touristic/leisure dimension
 - 11 do not focus on tourism/leisure needs
 - 11 on activities/services aimed at CwDASD or their caregivers but are not of a tourist or leisure nature
 - 4 included young and/or adult population
 - 5 non-scientific publications
 - 2 on adapting museums from an educational perspective

In the end, a Google scholar search was carried out, which did not result in any publication that met the inclusion criteria.

- Step 5 - After reading all the articles, 10 articles were included.

Before the final resubmission of this work, in February 2023, the search was replicated both in electronic databases and on Google, in order to assess the publication of new works. From this final research, one more article was identified that met the inclusion criteria, so it was added to the articles that are part of the systematic review (see figure 1).

5. Results

Eleven publications integrate this systematic review - described individually and in accordance with PICOS (see Table 1). Thus, an integrative description of the publications is carried out.

5.1. Type of publication, year, and country

Regarding the type of publication, seven empirical articles were identified, two theoretical publications (Neo & Flaherty, 2019; Petroman & Vaduva, 2012) and two literature reviews (non-systematic reviews): one about on travel with children in need of special health services, including CwDASD (Kohl & Barnett, 2020) and another about the vacation experience of families with CwDASD (Fazil *et al.*, 2022).

Empirical studies are mostly qualitative (n=5) (Andersson & Tuuri, 2020; Chiscano, 2021; Kim *et al.*, 2018; Schaaf *et al.*, 2011; Sedgley *et al.*, 2017), being fewer of a quantitative nature (Freund *et al.*, 2019; Sak *et al.*, 2020).

As for the years of publication, the oldest are from 2011 and 2012 but they do not have an exclusive focus on the tourism experiences of families and/or CwDASD. The first is a qualitative study (Schaaf *et al.*, 2011), where the authors explore a wide range of daily experiences of parents with CwDASD, including the experience in the context of vacations and leisure/ recreation activities outside the family context. The second is a theoretical article on forms of active tourism, which refer to equestrian tourism and the use of hypnotherapy with CwDASD (Petroman & Vaduva, 2012). The growing focus and the greater number of publications centred on the tourism aimed at CwDASD and/or their families has occurred in the last 6 years, indicating a greater awareness and interest in the subject in recent years.

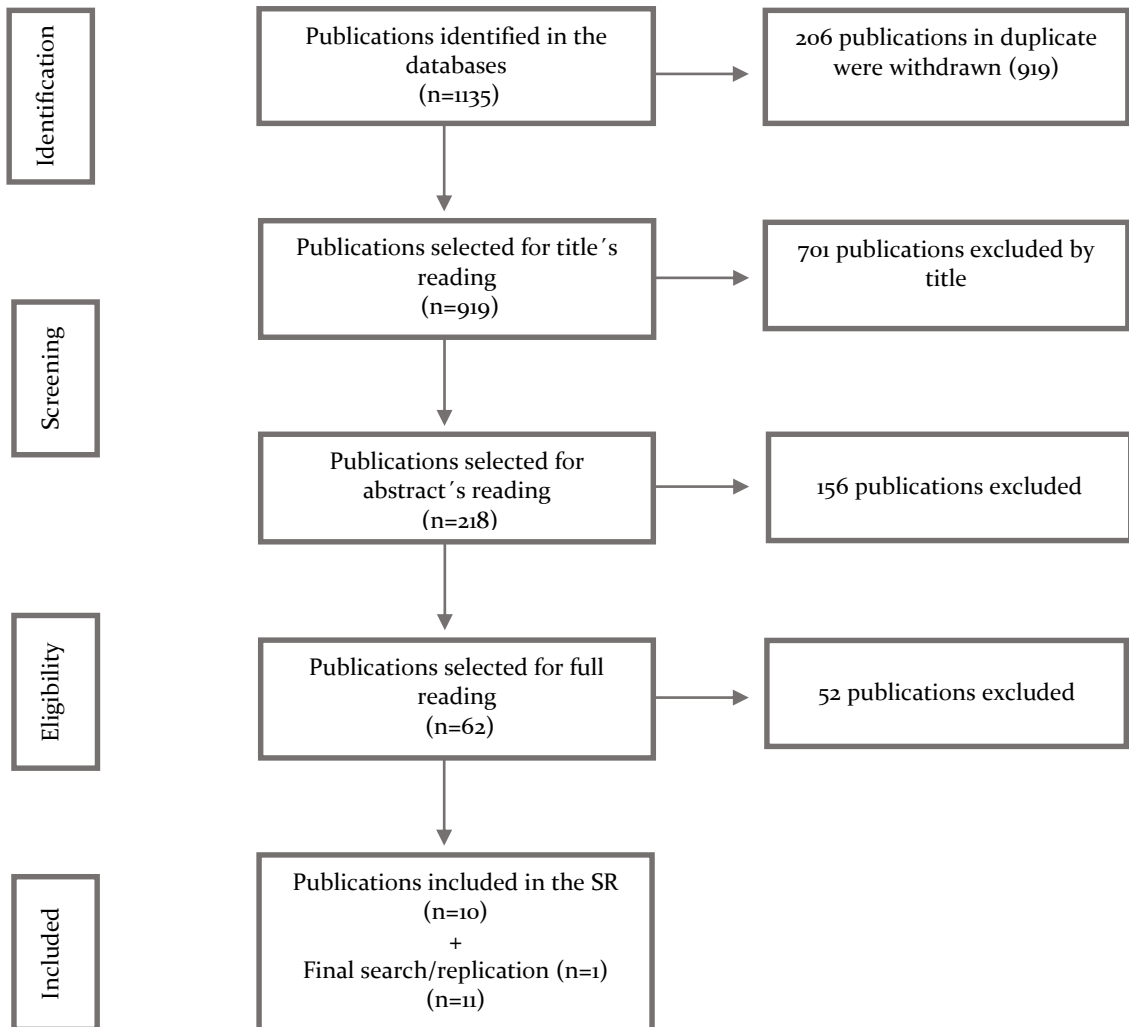


Figure 1. Flowchart of the systematic review process

Considering all types of publications, most appear on the Europe (n=7) three in United States of America (USA) and one in Malaysia. The same trend is seen in empirical studies, with five studies carried out in European countries (Andersson & Turi, 2020; Chiscano, 2021; Freund *et al.*, 2019; Sak *et al.*, 2020; Sedgley *et al.*, 2017) and two studies developed in the USA (Kim *et al.*, 2018; Schaaf *et al.*, 2011). At the European level, Spain stands out globally, with a quantitative (Freund *et al.*, 2019) and a qualitative study (Chiscano, 2021). The article from Malaysia is a theoretical analysis of some studies on holidays and recreational activities of families with children with ASD (Fazil *et al.*, 2022).

Table 1. Individual description of the publications

		P – Participants	I – Intervention (Not applicable)	C – Comparison (Not applicable)	O – Outcomes	S – Studies	Conclusions
1	Schaaf <i>et al.</i> , 2011	Five parents of children between 7 and 12 years old with DASD	Seeks to explore the daily experiences of parents, including in the contexts of leisure/recreation outside the house.	_____	Describes difficulties in having family vacations and going to events, namely related to: - Children manifest difficulties in managing the stimuli associated with air travel, sightseeing, long car rides and crowds - The sensory impact of the environment on children (multiple stimuli, small spaces with many objects, waiting lines, fluorescent lamps)	Qualitative	Families have more difficulty with family activities outside their house as they are they are unable to control environmental variables. Need to develop structuring activities that meet the child's sensory processing needs (introducing relaxation sensory activities into a highly stimulating activity).
2	Sedgley <i>et al.</i> , 2017	5 mothers of CwDASD	Seeks to understand the tourism experiences of mothers of CwDASD.	_____	Mothers spend weeks planning all aspects of the holidays and familiarizing the child with the holiday's space. Due to the sensory sensitivity of children, airport security procedures are described as stressful. Holidays generate stress for mothers due to their difficulty in finding tourism contexts that meet the needs of CwDASD.	Qualitative	Mothers choose vacation and accommodation destinations that have more specific and detailed information, so they can prepare the child. They select quieter, more reserved vacation destinations and accommodations. They always carry the objects/toys that the child prefers and make sure that the place where they will stay has what the child needs (e.g., Wi-Fi, television).
3	Kim <i>et al.</i> , 2018	12 mothers of CwDASD	Seeks to understand the leisure behaviours of caregivers' mothers and the restrictions they experience	_____	Mothers choose leisure activities based on their responsibility to take care of children. They experience various difficulties in leisure and recreation activities: lack of time for themselves, constant attention to children, and difficulty in finding a suitable professional caregiver.	Qualitative	Need for services and leisure activities, and occupational/recreational therapists, to provide more effective support to parents - through the development of recreational opportunities for children and help parents in the act of caring.
4	Chiscano, 2021	<i>Focus group</i> with 7 stakeholders: 2 directors of two airlines, 2 representatives of an association for people with ASD 3 families with relatives with DASD. Ethnographic study and survey of 25 families with CwDASD regarding their	Seeks to identify critical situations at the airport and create inclusive solutions for families with CwDASD and assess the experience of families at the airport.	_____	The <i>focus group</i> identified 3 critical situations and possible solutions: (i) communication (e.g., information in adapted format about the characteristics of the airport, visual format of the distinct phases of the airport experience); (ii) airport access (e.g., adequate allocation, sensory rooms and priority check-in and boarding) (iii) Services and related procedures (e.g., training on accessibility and dealing with passengers with special needs to airport	Qualitative	- The results indicate important procedures to be taken at airports, allowing an adequate context to the needs of families with CwDASD. - Importance of considering the contribution of both airport professionals and families, involving all stakeholders in the process of co-creation of inclusive resources.

	P – Participants	I – Intervention (Not applicable)	C – Comparison (Not applicable)	O – Outcomes	S – Studies	Conclusions	
	experience at the airport.			operators and airline personnel) They positively evaluated the implemented actions.			
5	Andersson & Tuuri, 2020	8 mothers of children diagnosed with Asperger's syndrome.	Understand the experience of families traveling with children with Asperger's syndrome (international air travel)	_____	Trip planning – buy the trip online, look for inclusive hotels that are close to leisure and recreation activities. The trip includes priority boarding. The journey itself – the most challenging stage, including the trip through the airport. Waiting lines and security procedures have a negative impact on the child. In the holiday destination - the child needs to have many activities and be able to practice the ones they like the most. Homecoming - differs from child to child; some readjust to previous routines; others need clear instructions to go back to them.	Qualitative	A set of recommendations to parents is suggested for each step: 1. Plan the trip carefully, get priority boarding, include the child in the planning and show pictures or videos of the holiday destination, take some child's favorite items. 2. During the trip, provide activities that redirect the child's attention (telling stories, watching videos, headphones) 3. At the holiday destination, provide entertainment activities for the child that can be reached on foot, in order to avoid public transport. 4. When returning home, must remember their routines before the holidays.
6	Freund <i>et al.</i> , 2019	117 Spanish families with CwDASD	Seeks to analyse the intention of families with CwDASD to travel to affordable accommodation, considering the travel restrictions, the severity of the diagnosis and the families' strategies to deal with such restrictions.	_____	Restrictions and the greater severity of the diagnosis lead families to seek affordable and inclusive accommodation. Families mentioned the need to include professionals dedicated to children's leisure with specific training.	Quantitative	Guidelines are drawn for hotel services to provide improvements in terms of access to services, safety, and satisfaction of families with CwDASD. They emphasise the need for staff to be trained on ASD and its unique needs, as well as create partnerships between health professionals, associations, and companies to expand leisure opportunities for families with CwDASD.
7	Sak <i>et al.</i> , 2020	392 family members with CwDASD.	Analyse the problems that families face in tourism experiences, the criteria they consider when choosing a tourism destination and their intention to do tourism	_____		Quantitative	Families do not find tourism activities that meet the children's needs and feel an interruption in their development process, so they have difficulties in choosing touristic products. Promoting the development of CwDASD should continue during the vacation period. They suggest that games, group activities and training should be provided to CwDASD by a specialized child development team working in the hotel.

	P – Participants	I – Intervention (Not applicable)	C – Comparison (Not applicable)	O – Outcomes	S – Studies	Conclusions
8	Petroman & Loredana, 2012				Theoretical article on forms of active tourism.	One of the forms of active tourism indicated is equestrian tourism - tourist services in specialized farms use hippotherapy in the treatment and rehabilitation of CwDASD).
9	Neo & Flaherty, 2019	Discusses the difficulties that CwDASD experience in international travel and describes some measures that can make travelling easier.			Theoretical article	Lack of familiarity with the space, queues and security procedures at the airport are the main constraints. The role of health professionals who can advise touristic companies is highlighted, to make them aware of the specific needs of this population.
10	Kohl & Barnett, 2019	Article on travel for children with special health needs.			Literature review	With CwDASD is important to carefully plan the trip and warn of travel situations (avoid high noise, waiting lines, unfamiliar foods, altered sleep habits). There is a lack of official guidelines.
11	Fazil <i>et al.</i> , 2022	Theoretical analysis of some studies that focus on the vacation experience of families with children with ASD.			Research review	Holidays are experienced in an ambiguous way by families and may be an opportunity to promote the development and well-being of the child, but at the same time be a source of tension and complications. Given the different characteristics and special needs of children, they emphasize the importance of articulation between tour operators and therapists in the area of autism.

5.2. Design of empirical studies and sample characteristics

Regarding the design, all adopt a transversal and retrospective design in collecting information on the needs of CwDASD and/or their families or on their perception of tourism contexts. Qualitative studies, by their nature, integrate a small number of participants, between five (Schaaf *et al.*, 2011; Sedgley *et al.*, 2017) to 25 participants (Chiscano, 2021), performing in-depth data analysis.

About the quantitative studies, one of the studies, developed with Spanish families, includes 117 participants (Freud *et al.*, 2018) and another, developed in Turkey, includes 392 participants (Sak *et al.*, 2020). Either in the qualitative studies or in the quantitative one's, the participants are mainly the children's mothers.

5.3. Recruitment context and sampling process

The majority (n=5) collected the samples using dissemination among autism associations, groups of parents of CwDASD or support services (n=5) (Chiscano, 2021; Freund *et al.*, 2019; Sak *et al.*, 2020; Schaaf

et al., 2011; Sedgley *et al.*, 2017). There is one study that recruited participants through an advertisement aimed at mothers of CwDASD (Kim *et al.*, 2018) and another that used groups of parents on Facebook (Andersson & Tuuri, 2020).

Qualitative studies used snowball sampling, except the study by Kim *et al.* (2018) that used the judicious intentional sampling technique to identify and select study participants. As for the quantitative studies, one collected data exclusively online, being a self-selection sampling, in which the participants autonomously participate in the study (Freund *et al.*, 2019). The other study used both online and face-to-face collection, resorting to both the self-selection sampling and the snowball sampling strategies (Sak *et al.*, 2020).

5.4. Instruments

Qualitative studies used semi-structured interviews for data collection, developed specifically according to the objectives of each study. Most interviews, in addition to the sociodemographic data of the participant and the child, seek to explore the travels and tourism experiences of the children's parents and the restrictions/difficulties they face (Andersson & Tuuri, 2020; Kim *et al.*, 2018; Sedgley *et al.*, 2017). There is a qualitative study on the airport experience of families with CwDASD that articulated the focus group, the ethnographic method, and a qualitative questionnaire (Chiscano, 2021). Quantitative studies used self-report instruments - questionnaires purposely developed/adapted for the study.

5.5. Theoretical publications and reviews

One of the theoretical articles does not specifically focus on tourism dedicated to CwDASD but seeks to describe various forms of active tourism (Petroman & Vaduva, 2012). Among these, equestrian tourism is mentioned, indicating the existence of tourism services provided in specialized farms that use hippotherapy. In this context, CwDASD are mentioned, indicating that horses have been increasingly used in their treatment and rehabilitation.

The second theoretical article specifically describes the difficulties that CwDASD experience in international travel, proposing measures that can facilitate travelling (Neo & Flaherty, 2019). In terms of the difficulties, they state that, depending on the degree of their condition, there are specific aspects in the travelling that can be sources of high stress: the unpredictability, the difficulty in maintaining fixed routines, the uncertainty of the routes, the auditory over-stimulation (airports, places with high population density or traffic volume), the waiting lines, manual searches at security posts, lack of familiarity with the contexts, unplanned and overly stimulating activities for the child and difficulties with safety rules when transporting CwDASD.

Faced with these difficulties, the authors emphasize the importance that health professionals can assume in advising touristic companies, to make them aware of the specific needs of this population. As an example, they refer to the video modelling technique to prepare CwDASD for air travel used in Ireland and indicate Shannon Airport as being the first airport in Europe to create a sensory room for people with DASD. They also report that touristic sites have tried to become more understandable and accessible (greater use of images, symbols and simple text, less structural variation between web pages).

Finally, there is a literature review on travelling with children with special health needs (Kohl & Barnett, 2019). This article covers various types of special health needs, including CwDASD. It suggested the importance of carefully preparing the trip to minimize travel situations (high noise, waiting lines, unfamiliar foods, altered sleep habits) that can have an impact negative in the child. It refers the lack

of specific official guidelines and describes some strategies that parents use to minimize the effects of travelling - earphones to prevent noise, adoption of behavioural strategies for better tolerance of waiting time and including priority check-in for avoid waiting lines.

5.6. Difficulties/tourism needs of children with diagnostic of autism spectrum disorder and their families and tourism responses

Regarding the difficulties/tourism needs of CwDASD and their families, both the theoretical articles and the results of the studies tend to be consensual.

Firstly, most articles (n=6) indicate the multisensory nature of contexts as the main obstacle, making it difficult to properly manage the stimuli associated with travelling and tourism destinations (Andersson & Tuuri, 2020; Chiscano, 2021; Kohl & Barnett, 2019; Neo & Flaherty, 2019; Schaaf *et al.*, 2011; Sedgley *et al.*, 2017). They state that air travel, long touristic trips, contexts involving crowds and excessive noise, security procedures (e.g., at airports) and waiting lines are major challenges for CwDASD (Andersson & Tuuri, 2020; Chiscano, 2021; Kohl & Barnett, 2019; Neo & Flaherty, 2019; Schaaf *et al.*, 2011; Sedgley *et al.*, 2017). For these children, characterized by their hypersensitivity or hyposensitivity, contexts involving new foods, smells, sights, touches or tastes can be extremely stressful (Schaaf *et al.*, 2011; Kohl & Barnett, 2019; Neo & Flaherty, 2019; Sedgley *et al.*, 2017). It should be noted that studies (Andersson & Tuuri, 2020; Chiscano, 2021) and theoretical articles (Kohl & Barnett, 2019; Neo & Flaherty, 2019) that specifically focus on airport travel by families with CwDASD highlight sensory overstimulation from the airport as a factor of stress for families and children – crowds, noise, queues, security procedures.

Secondly, the majority of empirical (n=4) and theoretical (n=2) publications also indicate the lack of familiarity and the unpredictability of contexts, travel, and tourism activities as an obstacle (Andersson & Tuuri, 2020; Chiscano, 2021; Kohl & Barnett, 2019; Neo & Flaherty, 2019; Schaff *et al.*, 2011; Sedgley *et al.*, 2017). Given the need for routinization of CwDASD, vacations require prior planning, familiarization and anticipation of spaces and routines. One of the studies indicates that families report that this task becomes difficult due to the lack of specific/ adequate information about the travel itineraries, the context and spaces of accommodation and about spaces, services and activities for leisure/recreation (Sedgley *et al.*, 2017). According to Sedgley *et al.* (2017) mothers of CwDASD spend several hours doing research to provide clear information to the child. However, tourism companies lack the information provided, making it difficult for families to make informed decisions according to the child's needs, skills, and preferences. Empirical (Chiscano, 2021) and theoretical (Kohl & Barnett, 2019; Neo & Flaherty, 2019) articles on international travel and airport experiences also refer to the need for tourism/airport websites to have information adapted to people and CwDASD (use of images, video, technological resources).

Thirdly, another difficulty identified in the studies (n=3) and in the literature review is the absence of services or professional qualified to take care of children in tourism contexts or during leisure activities, causing parents to be always hyper-vigilant and constantly monitoring them (Andersson & Tuuri, 2020; Fazil *et al.*, 2022; Kim *et al.*, 2018; Schaff *et al.*, 2011). This handicap prevents caregivers from enjoying time and leisure activities for themselves or as a couple (Schaff *et al.*, 2011; Kim *et al.*, 2018; Sak *et al.*, 2020). Two of the studies clearly highlight the need for professionals specialized in the field of child development and ASD (Freund *et al.*, 2019; Sak *et al.*, 2020). According to Sak *et al.* (2020), the promotion of the development of CwDASD should continue during the holiday period, so it is essential that tourism companies, such as hotels or resorts, integrate a team specialized in child development that can develop and implement activities, games, or therapeutic training with children (Sak *et al.*,

2020). The article by Petroman and Loredana (2012) on active forms of tourism also refers to the therapeutic dimension of equestrian tourism, which uses hypnotherapy with CwDASD.

Fourthly, studies (n=3), theoretical articles (n=1) and literature review (n=1) also indicate the scarcity of diversified activities that meet the child's preferences (Andersson & Tuuri, 2020; Sak *et al.*, 2020; Schaff *et al.*, 2011; Fazil *et al.*, 2022). One of the studies indicates that families consider that the activities are insufficient (Sak *et al.*, 2020). Other studies (Andersson & Tuuri, 2020; Schaff *et al.*, 2011) indicate the need for leisure/recreation activities to be close to the place where they are staying or that it is easily accessible, to avoid public transport. Public transport is indicated as a very destabilizing factor for CwDASD (Andersson & Tuuri, 2020; Schaff *et al.*, 2011), hence the preference for activities that are close or easily accessible.

Fifthly, another difficulty identified in empirical studies (n=3) is the lack of professionals in tourism companies and services with knowledge about the specificities of CwDASD and their families (Chiscano, 2021; Freund *et al.*, 2019; Sak *et al.*, 2020). Thus, in tourism, leisure/recreation contexts and activities, parents perceive the lack of understanding, empathy, and sensitivity and, therefore, the lack of resources and support to deal with the child's behaviour (Freund *et al.*, 2019). The study by Chiscano (2021) also indicates the importance of airport operators and airline personnel having specific training on the specifics and how to attend/deal with CwDASD and their families. Additionally, a theoretical article (Neo & Flaherty, 2019) and a literature review (Fazil *et al.*, 2022) highlights the need for tourism companies to have consultancy (and/or work together) from health professionals/therapists, to sensitize them to the specific needs of this population and implement inclusion measures.

Regarding tourism responses, there are few studies that attempt to empirically validate actions for improvement and inclusion in tourism contexts aimed at CwDASD. The exception is the study by Chiscano (2021) that sought to identify critical moments of families at the airport, generate responses and implement changes, evaluating the perception of families with CwDASD about these changes. Despite not being an experimental study, with no pre-test and post-test, it allows evaluating the implementation of improvement actions through the experience and perception of the families. In addition, it also considers the appreciation of the airport operators and airline personnel on the training action they received in the context of the needs of CwDASD and ways of performing.

The results indicate that all changes and all-inclusive resources were evaluated positively: in communication, namely the creation of a storybook that allowed the child to familiarize himself in advance with passing through the airport, visual aids, simple language, and the use of pictograms; in airport use, specifically signalling and adapted location systems, sensory room, silent spaces, and priority access; and in assistance and services, namely the training of professionals that allowed them to understand and respond better to the needs of this population.

As already mentioned, the remaining empirical studies and theoretical articles focus mostly on the constraints felt by families in travel/tourism experiences or leisure/recreation but indicate some important guidelines to be considered by tourism companies. Specifically, and according to the identified needs and constraints, they highlight:

- ✓ Adapting contexts to the sensory needs of children, controlling environmental stimuli, such as avoiding exposure to crowds, noise, bright lights, and fluorescent lamps (Freund *et al.*, 2019; Kohl & Barnett, 2019; Schaff *et al.*, 2011) or even creating sensory or silent rooms (e.g., airports) (Neo & Flaherty, 2019).

- ✓ The development of diversified and structured activities that meet the child's preferences (Andersson & Tuuri, 2020; Freund *et al.*, 2019; Sak *et al.*, 2020) and their sensory processing needs (e.g., introduce sensory relaxation activities into a highly stimulating activity) (Fazil *et al.*, 2022; Schaff *et al.*, 2011; Sedgley *et al.*, 2017)
- ✓ The activities should take place at or near the accommodation, or that they can be accessed without using public transport (Andersson & Tuuri, 2020; Freund *et al.*, 2019; Sedgley *et al.*, 2017)
- ✓ The offer of more reserved and calm vacation destinations and accommodation services (Schaff *et al.*, 2011; Sedgley *et al.*, 2017)
- ✓ The dissemination of tourism products that use more detailed/specific information, more visual or in a story format, so that they can familiarize the child with the contexts, including airports (Andersson & Tuuri, 2020; Freund *et al.*, 2019; Neo & Flaherty, 2019; Schaff *et al.*, 2011; Sedgley *et al.*, 2017)
- ✓ Allow the entry of objects and toys that the child prefers (including when traveling by plane) or offer resources that some children may need (e.g., Wi-Fi, television, etc.) (Andersson & Tuuri, 2020; Freund *et al.*, 2019; Neo & Flaherty, 2019; Schaff *et al.*, 2011; Sedgley *et al.*, 2017)
- ✓ The existence of a team of occupational therapists and/or other health professionals specialized in child development and ASD that develop and implement recreational activities that promote the development and well-being of children (Andersson & Tuuri, 2020; Fazil *et al.*, 2022; Freund *et al.*, 2019; Kim *et al.*, 2018; Neo & Flaherty, 2019; Sak *et al.*, 2020; Sedgley *et al.*, 2017), such as pool and nature activities, indoor and outdoor games (Sak *et al.*, 2020). This allows caregivers to have leisure time for themselves or better enjoy joint leisure time with the child (Fazil *et al.*, 2022; Freund *et al.*, 2019; Sedgley *et al.*, 2017)
- ✓ Priority access – check-in, security checkpoints, airport boarding, accommodation check-in and check-out, access to dining areas, etc. (Andersson & Tuuri, 2020; Chiscano, 2021; Freund *et al.*, 2019; Kohl & Barnett, 2019)
- ✓ That tourism professionals have training on ASD, the needs of CwDASD and adequate forms of communication and care (Andersson & Tuuri, 2020; Freund *et al.*, 2019; Kohl & Barnett, 2019).

6. Discussion

There is a scarce number of publications (n=11), including empirical studies (n=7), that specifically focus on tourism aimed at CwDASD and their families (n=11). However, despite some incursions in the beginning of the second decade of the present century, there has been a greater interest in the subject, especially in the last 6 years. This data seems to reveal the growing awareness of IT for the needs of families with CwDASD, which may be due to the guidelines of The United Nations Convention on the Rights of Persons with Disabilities (CRPD) – associated with the movement for the rights of autistic people, as well as the reconceptualization of IT which, according to Scheyvens and Biddulph (2018), must involve responding to all types of marginalized groups, including people with DASD. This recent interest also expresses the recognition that the diagnosis of “disability” or special needs is not limited to physical, mobility or sensory problems, it also integrates intellectual and behavioural problems, such as the ASD (Hamed, 2013).

The fact that most publications and recent empirical studies have been developed on Europe may be associated with the recent recommendations of the Council of Europe Strategy on Disability (2017-2023) (Council of Europe, 2017). The Parliamentary Assembly of Europe recommends that its member states adopt specific legislation on autism and develop national strategies that meet the CRPD guidelines, as

well as eradicate any type of discrimination. In fact, the countries where the studies were carried out (Spain, England, Turkey) are part of the group of European countries that have implemented specific action plans to respond to the needs of people with DASD (see Council of Europe, 2017).

Regarding the empirical articles, these mostly adopt qualitative methodologies, seeking to understand the needs and experiences of families. Compared to quantitative studies, these allow for more detailed and in-depth data on the needs and experiences, but it does not allow generalizing the results. In turn, quantitative studies are small ($n=2$) but end up corroborating the results and conclusions of qualitative studies - e.g., barriers related to sensory overstimulation, waiting lines, scarcity of diversified and adapted activities, need for tourism services having professionals specialized in child development and ASD (Freund *et al.*, 2019; Sak *et al.*, 2020). The scarcity of quantitative studies may be because this is a very specific population, which does not allow the collection of large samples. Thus, most use qualitative methodologies, seeking the representation of the phenomenon (needs and experiences of families with CwDASD) and not the population or its numerical expression (Englander, 2019). However, considering that triangulation is indicated as a strategy that allows for greater validity of results through the convergence of information from different sources or the use of different data collection methods (Leung, 2015), mixed methodologies may be suitable for analysing the tourism needs of these families - combining quantitative and qualitative methodologies.

Furthermore, there is a scarcity of studies on the adequacy or effectiveness of measures or concrete actions for inclusion in tourism contexts aimed at families with CwDASD. Although almost all publications indicate action guidelines or measures to be implemented, only one study assesses their implementation in the airport context (Chiscano, 2021). Thus, on the one hand, it is important to develop mixed studies that seek to assess the tourism needs of families with CwDASD, as well as obtain information on suggestions for improvement or concrete actions that facilitate their participation in tourism trips/activities. On the other hand, sequentially, it is essential to carry out the empirical validation of the implementation of measures that result from (i) the needs identified in families and children, (ii) from the guidelines suggested in the literature and (iii) from the proposals suggested by the families themselves.

Another aspect is the need to develop studies with international samples, as more and more tourism consumers are from different countries and with different cultural backgrounds (Hamed, 2013). As can be seen from the analysis of the empirical articles, they all include national and/or resident samples, not considering families with CwDASD from other countries. Given the globalization/internationalization of tourism and considering the concept of IT, it is relevant that research includes participants from different geographic and cultural contexts. It is noteworthy that from 2017 to 2021, an international standard of accessible tourism has been developed because of the lack of common criteria of accessibility among destinations (ISO, 2021). So, considering the progress that this field of research and practice has gained in the last years, it is essential that research on tourism for families with CwDASD must consider this international component.

It is also pertinent to emphasize that tourism companies should delineate tourism products and activities that consider the family, simultaneously including parents and children - planning joint activities, but also activities that allow their own leisure time for parents (Freund *et al.*, 2019; Sedgley *et al.*, 2017). In terms of the needs of families, most studies (and the parents' report) focus on the tourism needs of CwDASD, but caregivers/parents also need leisure and recreation experiences (e.g., Freund *et al.*, 2019; Sedgley *et al.*, 2017). The difficulties and barriers that parents report, particularly when they report that they have to be in constant hypervigilance and monitoring of children due to the absence of

qualified technicians to take care of the children in tourism contexts (Andersson & Tuuri, 2020; Schaff *et al.*, 2011; Kim *et al.*, 2018), indicates the need to also enjoy leisure activities and time for themselves in the context of vacation/leisure, but also to provide activities together with the child that can be beneficial to both.

As stated by Cloquet *et al.* (2018), tourism should offer family leisure activities, which favours interaction and communication between family members. Literature and research indicate that family leisure activities contribute to better family functioning, namely greater communication, cohesion, well-being and family and marital satisfaction (Cloquet *et al.*, 2018). Whereas parents and caregivers of CwDASD are subject to a huge burden (Kim & Letho, 2013; Townsend & Van Puymbroeck, 2017), with tensions and demanding daily stress (Fazil *et al.*, 2022; Cloquet *et al.*, 2018), family leisure activities take on even greater importance.

However, activities aimed exclusively at parents should not be neglected, as research and literature also indicate that parents of CwDASD end up excluding or denying themselves from leisure and recreational activities (Kim *et al.*, 2018), reporting higher levels of stress and psychological problems (Kim *et al.*, 2018). Thus, tourism companies should seek to reconcile the different leisure needs of families with CwDASD, offering family activities, activities for parents and activities for children.

It should also be noted that, for this convergence to be possible, other needs must be safeguarded, namely, the provision of services and qualified technicians to take care of children in tourism contexts or during leisure activities (Andersson & Tuuri, 2020; Kim *et al.*, 2018; Schaff *et al.*, 2011), preferably there are professionals specialized in child development and ASD (Fazil *et al.*, 2022; Freund *et al.*, 2019; Sak *et al.*, 2020). Only in this way, parents can enjoy leisure time with peace of mind for themselves or as a couple. On the other hand, the existence of a team of specialized professionals who can develop and implement activities, games, or therapeutic training appropriate to the needs of children (Freund *et al.*, 2019; Sak *et al.*, 2020), promotes the continuation of the process of development and learning of children, being another aspect that reassures parents and reinforces their investment in tourism products of this nature.

In addition, the awareness and training of all professionals involved in tourism products aimed at families with CwDASD should also be considered (Chiscano, 2021; Freund *et al.*, 2019; Sak *et al.*, 2020), for these families to obtain services adequate to the needs of children, both in terms of care and environmental conditions (Freund *et al.*, 2019). The component of training tourism professionals on the needs of CwDASD is highlighted in several publications (Andersson & Tuuri, 2020; Freund *et al.*, 2019; Kohl & Barnett, 2019), and should therefore be considered by tourism companies.

7. Conclusion

In response to the research question of the present work, what the investigation and the literature indicate on inclusive tourism aimed at families with CwDASD, the research found that there is more empirical information about the tourism needs of these families than about adequate tourism responses and services. In fact, empirically validated guidelines for action are not identified, and some indications resulting from studies on the constraints and needs of families (mostly of a qualitative nature) are extracted.

Thus, this study concluded that it is crucial to develop more research on the needs of families and, mainly, on the necessary tourist responses adapted to these needs. The investigation must contemplate three central components in an articulated way: (i) the assessment of the families' needs, (ii) the

development of concrete measures and responses to the identified needs, and (iii) the evaluation of the effectiveness of the implementation of these measures and responses. This will allow establishing objective guidelines on changes or improvements to be implemented by companies that have or seek to reach this target audience, which constituted an important market niche for tourism (Hamed, 2013). As already mentioned, the mixed methodology is indicated for this type of investigation, and priority should be given to the systematic integration of quantitative and qualitative data during its collection, analysis, and discussion. This is particularly indicated when trying to assess the implementation of new practices (Wisdom & Creswell, 2013), being one of the needs identified by this systematic review. To respond to this need, a multiphase design based on a community-based participatory approach may be more advantageous (Wisdom & Creswell, 2013). A study of this nature would involve the participation of various stakeholders (families with CwDASD, suppliers of tourism products, specialized health professionals and/or therapists) in the diverse stages of the investigation to bring and implement changes (Mertens, 2009; Wisdom & Creswell, 2013). In this way, it would be possible, at all stages, to evaluate and refine measures and tourism practices suitable for the inclusion of families with CwDASD. As noted by Wisdom and Creswell (2013), key stakeholders must participate in the research as co-investigators, providing information about their needs and how to implement changes. It would be a "double inclusive" research project, considering not only its objective but also the research methodology used: the voice and experience of families are included and considered in the process of deciding and evaluating the inclusion measures addressed to them.

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