ESPERGESIA
REVISTA LITERARIA Y DE INVESTIGACIÓN
https://doi.org/10.18050/esp.2014

Universidad César Vallejo

Artículo Original

Cooperation and its influence on solidarity with mothers of children with autism

La cooperación y su incidencia en la solidaridad hacia madres de niños con autismo

Eliana Aracely García Mejía[1]

[1] Maestría en Trabajo Social, mención Desarrollo Local y Cooperación, Facultad de Posgrado, Universidad Laica Eloy Alfaro de Manabí, Manta, Ecuador.

Fecha de recepción: 14.02.2025
Fecha de revisión: 02.04.2025
Fecha de aprobación: 08.04.2025

Cómo citar: García Mejía, E. A. (2025). Cooperation and its influence on solidarity with mothers of children with autism. *Espergesia, 12*(1), e120104. https://doi.org/10.18050/rev.espergesia.v12i1.3436

Abstract

This study analyzed the influence of cooperation in the solidarity towards mothers of chil-dren with autism spectrum disorder (ASD), specifically in the multisensory room of the Manta canton during the period 2023-2024. The main objective was to understand how inter-institutional coordination, support networks and reciprocity among mothers influence their well-being. A qualitative approach with a hermeneutic phenomenological design was used to capture the subjective experiences of the participants. Data collection was carried out through in-depth interviews validated by experts and structured in 21 key dimensions. The results showed that, although there were institutional efforts to support mothers, im-portant limitations persisted: lack of curricular adaptation, poor communication between families and schools, and little community empathy. The most effective support networks came from the family nucleus and mother-to-mother support. Inter-institutional coopera-tion was valued when there was articulation, but was fragmented in many cases. Likewise, reciprocity among peers helped to mitigate the emotional burden, especially in the ab-sence of family support. It was concluded that effective cooperation and solidarity strengthen the resilience of mothers, although there is still a need to consolidate inclusive public policies and autism-sensitive community structures. The study provides contextual evidence on the importance of weaving collaborative networks to improve the quality of life of these women and their children.

Key words: cooperation, solidarity, mothers, autism, support networks, inclusion.

Resumen

Este estudio analizó la influencia de la cooperación en la solidaridad hacia las madres de niños con Trastorno del Espectro Autista (TEA), específicamente en la sala multisensorial del cantón Manta durante el periodo 2023-2024. El objetivo principal fue comprender cómo la coordinación interinstitucional, las redes de apoyo y la reciprocidad entre madres afectan el bienestar de estas cuidadoras. Se utilizó un enfoque cualitativo con diseño fenomenológico hermenéutico, que permitió captar las vivencias subjetivas de las participantes. La re colección de datos se realizó mediante entrevistas en profundidad validadas por expertos y estructuradas en 21 dimensiones clave. Los resultados evidenciaron que, aunque existían esfuerzos institucionales por apoyar a las madres, persistieron importantes limitaciones: falta de adaptación curricular, comunicación deficiente entre familias y escuelas, y escasa empatía comunitaria. Las redes de apoyo más efectivas provenían del núcleo familiar y del acompañamiento entre madres. La cooperación interinstitucional fue valorada cuando existió articulación, pero resultó fragmentada en muchos casos. Asimismo, la reciprocidad entre pares ayudó a mitigar la carga emocional, especialmente en contextos de ausencia de apoyo familiar. Se concluyó que la cooperación efectiva y la solidaridad fortalecen la resiliencia de las madres, aunque aún se requiere consolidar políticas públicas inclusivas y estructuras comunitarias sensibles al autismo. El estudio aporta evidencia contextual sobre la impor-tancia de tejer redes colaborativas para mejorar la calidad de vida de estas mujeres y sus hijos.

Palabras clave: cooperación, solidaridad, madres, autismo, redes de apoyo, inclusión.

INTRODUCCIÓN

The United Nations, in Sustainable Development Goal 10, seeks to reduce inequalities and ensure equal opportunities, especially for people with disabilities, by improving access to basic resources and services (UN, 2025). In this context, social and governmental cooperation is essential to create conditions that promote the social inclusion of mothers of children with autism, who often face a disproportionate burden of responsibilities without adequate support. However, their effectiveness will depend on the implementation of policies that promote their participation and access to opportunities.

Article 47 of the Constitution of the Republic of Ecuador (2008) establishes that "The State must guarantee equal opportunities for persons with disabilities, including their relatives". Likewise, guarantee that educational establishments are accessible and free of architectural barriers; therefore, the effective implementation of these policies may face challenges such as the availability of resources and adequate training of educational personnel to meet the needs of students with disabilities. In this sense, there are still significant gaps in the implementation of public policies that favor this type of inclusion.

In Ecuador, the Organic Law on Disabilities (2016) establishes a legal framework for the protection of the rights of persons with disabilities and their social integration. This legislation seeks to promote social integration and ensure that persons with disabilities, such as children with autism, can access rights and services. In this sense, inequality represents a barrier to economic and social progress, which limits the development opportunities of individuals, affects their self-esteem, as well as the perception of their ability to achieve their goals. It has also been identified as a threat to economic and social development.

In the Mexican context, Hernández Martínez (2023) found that 62.80% and 41.20% of the participants presented significant symptoms of anxiety and depression, which are related to the lack of perceived social support; highlighting that social support is a relevant factor that alone, however, is insufficient to prevent anxiety and depression. Therefore, it is necessary to adopt a comprehensive approach that also takes into account mental health interventions.

A study in Ecuador revealed that 56.5% of children with autism did not have a comprehensive care system, which exacerbates maternal overload (López Chávez *et al*., 2020). In addition, problems of physical exhaustion, financial worries and, in many cases, the absence of family support networks were found; factors which, taken together, increase the sense of isolation and make it difficult to provide adequate care for the children.

Research on care and support for children with autism spectrum disorder (ASD) shows the importance of coordination and collaboration across sectors to ensure comprehensive care. For Escobar-Villacrés *et al*. (2024) the support of the community, family, educational and social context is fundamental to achieve school inclusion for children with ASD. These ele-ments must be provided for in school curricula in order to support the inclusion needs of these students (Sulaiman *et al*., 2019). A combination of expertise and specific resources from collaboration is necessary. For example, partnerships among educators, parents, and health professionals. Effective collaboration among these sectors strengthens the entire social structure. On the other hand, cooperative strategies among mothers are a valuable aspect in reducing the overload associated with caring for children with ASD.

For Zapata Rogel (2021) there are factors that influence the overload given to parents of autistic children, among them are coping strategies. Coping allows mothers to address chal-lenges through emotional regulation and problem solving, to extract resources, that is, to draw strength from weaknesses, as expressed by (Torres-Lista, 2019). Consequently, cooperation among all mothers, who face challenges, strengthens the social network and the search with other actors. To this end, the institutional framework plays a decisive role in the articulation of inclusive strategies. For Vítores Barranco (2024) it is important to have trained specialists in the institutions to provide psychological support to the family to over-come the grief of the diagnosis. To provide counseling and follow-up on how to help the person with autism get ahead. Based on this, the promotion of cooperation and solidarity alternatives in the field of autism requires the articulation between different institutions and actors, both vertically and horizontally. In other words, coordination across sectors, between mothers and the family make up an interconnected system of comprehensive care.

According to Herrera-Kit *et al*. (2021), collaborative mechanisms serve to link entities lo-cated in different parts of the state organization chart and can connect actors vertically or horizontally. Likewise, interinstitutional coordination mechanisms prevent fragmentation, through shared communication platforms, and unified agreements, fundamental to identify challenges and design early corrective alternatives that positively impact student motiva-tion and wellbeing (Correia *et al*., 2024).

This ensures that educational institutions, health and community entities work in a cohesive manner, guaranteeing continuous care with access to resources for families of children with autism. Thus, inter-institutional coordination and constant supervision improve the quality and efficiency of services. According to Salazar Echavarría and Posada Silva (2022), the existence of an empathetic environment in understanding the management of emotions and facing the barriers that may arise allows providing the necessary support in the environment of children with ASD. The support networks formed by family, friends and communities constitute the emotional and practical support for mothers. However, since there is no support programs in the community designed for children in this situation, social inclusion is limited and the feeling of isolation grows.

On the other hand, close family support constitutes the fundamental pillar, although the need to expand these networks to the social and professional spheres is evident. Collaboration between parents and educators facilitates the integration of children with autism in the classroom. Thus, support networks through educational strategies and intersectoral collaborations allow the creation of safe and supportive spaces. In view of this, Gonzalez (2020) expressed that the support of the family in these cases is primordial, as it is the close environment that provides the most help to parents. These family support networks constitute cooperation, and make possible the resilience and emotional well-being of mothers of children with autism.

In the same way, the collaborative support of these networks provides emotional relief and reduces the burden faced by families. It also enables them to attend intervention programs tailored to individual needs. Therefore, support networks should be built from the individual and social perspective. At the same time, Rivera Domínguez *et al*. (2024) highlight that there is a poor cultural capital incorporated in the agents of socialization, about the particularities of autism and the representational elements that make up the ideal in the joy of having a child and raising him/her. In this sense, in the context of cultures that value cooperation, families of children with autism tend to receive greater social support. In contrast, in contexts where stigmas about autism predominate, these families face barriers and social isolation. In other words, cultural differences influence the type and extent of support received by families of children with autism. As indicated by Rodas-Jara *et al*. (2023) the meanings that parents assign to their experiences could be used to inform future policies and the development of programs that begin to address the person with autism from the macrosystem. However, the lack of information and stigmas about autism hinder the inclusion of the community in these processes.

It is also essential to have specialized centers, trained personnel, and inclusive education that encourages participation in the integration of policies and programs for a comprehensive approach. Furthermore, to the extent that support is available, it could be assumed that more of these mothers' needs are met, and their levels of stress and distress decrease (Bagnato, 2019). Consequently, support networks are of great importance in promoting the well-being of mothers of children with autism (Escobar-Villacrés *et al*., 2024).

According to Leyva-Arévalo *et al*. (2019), an appropriate educational strategy allows families to be guided to enhance the development of children with autism in a novel, enjoyable, and creative way, which enables better preparation for families. Educational workshops and family counseling are effective strategies for inclusive education. These initiatives reinforce communication and teamwork among family members, fostering overall cohesion and local development. Similarly, the impact of cooperation on maternal well-being reduces the emotional and physical burden faced by mothers, as support networks provide tangible resources and a safe environment. In this sense, effective cooperation within support networks contributes to strengthening mothers' resilience and social well-being.

However, the absence of family support significantly increases the stress of mothers of children with autism, affecting both their emotional and physical well-being. Monje Santana (2021) points out that when parents lack emotional support, they present stressful out-comes in the upbringing of children. Therefore, the lack of support networks among fami-lies aggravates the feeling of loneliness and stress, triggering emotional crises, while sharing experiences in therapeutic spaces relieves part of the emotional burden. This means that the lack of empathy and support from family members has a negative impact on the well-being of mothers, leading to socioemotional difficulties of all kinds (Escobar-Villacrés *et al*., 2024).

Several authors report that emotional and social support are fundamental for the emotional growth of children with ASD, and that the lack of community support can lead to difficulties in their emotional skills, and affect their self-esteem, resilience and confidence. Major factors contributing to the social isolation of mothers of children with autism include lack of knowledge about autism and emotional stress. According to Bonfim et al. (2023) the challenges faced, the time dedicated to the child, changes in family dynamics and social isola-tion are configured in a challenging context experienced by families. Additionally, social prejudices based on misconceptions about autism generate a significant emotional burden, as mothers perceive themselves alone in their role as caregivers.

The justification for this study lies in the need to address a high impact social problem: the lack of support for mothers of children with autism attending the multisensory room, who face great challenges associated with autism. From a social point of view, the research is relevant because it seeks to promote solidarity and cooperation as key mechanisms to improve the quality of life of these mothers.

The fundamental purpose of this research was to understand how cooperation impacts solidarity toward mothers of children with autism in the Manta Canton multisensory room 2023-2024. It begins by analyzing cooperation through coordination and collaboration among involved actors, evaluating its impact on the institutional functioning of the multi-sensory room, as well as establishing the role of support networks in the partner communities and determining how reciprocity and mutual support can mitigate the lack of family support for mothers of children with autism.

METHODOLOGY

Following the methodological guidelines proposed by Hernández-Sampieri and Mendoza Torres (2018), a qualitative research approach was applied, which helped to understand the experiences and perceptions of mothers of children with autism in relation to cooperation and solidarity received. Likewise, it responds to a hermeneutic phenomenological design, useful to facilitate a deep understanding of the experiences and perceptions (Fuster, 2019). In this case, related to the subjective experiences of the mothers of children with autism included in the present research.

In this research, the hermeneutic phenomenological approach was applied according to the guidelines of Fuster (2019), who takes up the contributions of Husserl and Heidegger to understand the lived experience from the perspective of the subject, recognizing the me-diation of language, context and interpretation. In this sense, the analysis was organized in three progressive phases, in coherence with this theoretical framework.

Table 1.
Phases of qualitative analysis applied from the hermeneutic phenomenological method

Phases	Theoretical description (Fuster, 2019)	Application in research
Open Reading	Initial phenomenological opening that seeks to capture the phenomenon as it manifests itself in the consciousness of the individual	An open reading of the interviews was developed. The purpose was to approach the discourses of the participating mothers in a comprehensive manner and without preconceptions. This reading made it possible to capture the general sense of their experiences, in tune with what Fuster (2019) called the initial phenomenological opening, which seeks to capture the phenomenon as it manifests itself in the consciousness of the individuals.
Structural Analysis	Identification and structuring of units of meaning, without forcing the expression of the phenomenon.	A structural analysis was carried out in which the units of meaning present in the testimonies were identified, decomposed and grouped. These units were organized around three major thematic axes: interinstitutional cooperation, support networks and reciprocity among mothers.
Critical Understanding	Fusion of horizons between the participant's account and the researcher's understanding; situated, contextual and ethical interpretation.	A critical understanding or indepth interpretation was carried out, contrasting the findings with the theoretical framework and the scientific literature reviewed. This interpretative phase sought not only to describe, but also to understand in depth the phenomenon of solidarity and cooperation experienced by the mothers, taking into account the social and affective context in which they are inscribed.

An in-depth survey (validated by five experts on the subject) was applied as a data collection instrument, composed of 21 dimensions, fundamental to understand the incidence of cooperation in solidarity with mothers of children with autism in the multisensory room of the Manta canton, Ecuador, 2023-24.

This study complied with the ethical principles framed in the Declaration of Helsinki (World Medical Association, 2013), the same that protect the national regulations for research on human beings. In this case, the mothers participated voluntarily and expressed this by signing the informed consent form prior to the application of the instruments. The confidentiality of the information was guaranteed throughout the process, which was anonymous and collected in an environment of respect and privacy. The instruments were reviewed by experts to ensure their relevance. In addition, the research was developed under the endorsement of the Universidad Laica Eloy Alfaro de Manabí, respecting the corresponding institutional ethical protocols.

RESULTS

In this presentation of results, the responses of the interviews were analyzed based on three ideas of analysis, starting from the research objectives.

Table 2.
Cooperation through coordination and collaboration among actors and its impact on the operation of the multisensory room.

Dimension analyzed	Evidence of the testimony	Analytical interpretation
Institutional educational support	"The school allowed me to take her shadow teacher, but there was no curricular adaptation..."	Some institutions provided partial support, but without ensuring appropriate pedagogical adaptations.
Access to the health system	"In Jaramijó they gave me a hand, but in Manta it was terrible."	Inequities in the quality of the service according to the locality were evidenced.
Communication with the families	"I felt like we needed to talk more with parents and provide guidelines on what we were working on with our children."	Mothers identified deficits in school-family communication for joint follow-up.
Multi-sensory room attendance	"I went twice a week to the multisensory room and they had a psychologist there who helped quite a bit..."	The assistance was positively valued, especially the psychological and therapeutic component.
Interinstitutional coordination	"There was a lack of coordination to give clear guidance to the teachers..."	The absence of shared guidelines made it difficult to work with children with ASD in school settings.
Assessment of services received	"The goal was for the children to progress... which helped them sleep better."	The multisensory room was perceived as a space for progress and inclusion.
Operational limitations	"There was not enough communication" and "It would be good if there were more schedules and more professionals..."	Structural limitations persist in the supply of services, which affects comprehensive coverage.

According to Table 2, the mothers expressed that, in the school setting, some institutions allowed the children to have the support of a shadow teacher, but the necessary curricular adaptations were not implemented. In the health area, reception varied according to the institution and location. However, despite progress, they identified the need for more communication with families. Likewise, attendance at institutions also showed variability among mothers. Also, inter-institutional cooperation was crucial to improve children's well-being. Mothers valued the positive influence of the multisensory room, especially in social and inclusive aspects. However, some mentioned communication problems and the need for more schedules and professionals.

Table 3.
Support networks and their influence on associated communities

Dimension analyzed	Evidence of the testimony	Analytical interpretation
Primary sources of support	"My networks were the school, my family, my husband, my children and the people doing the therapy."	The strongest support network came from the nuclear family and specialized professionals.
Limited support networks	"In my case, it was me, the shadow teacher and the psychologist who gave me guides."	Some mothers faced greater emotional burden as they had a limited circle of support.
Role of family cooperation	"At home, my husband and children helped me take care of him. They were trying to get along better with him...".	The active participation of immediate family members partially alleviated maternal overburden.
Limitations of community support	"At home, my husband and children helped me take care of him. They were trying to get along better with him...".	The local social infrastructure is not adapted to the needs of inclusion.
Lack of information about resources	"We found out about the support because outsiders informed us."	There is an information gap that limits access to essential resources.
Perception about institutional support	"There should be some neighborhood committee directly involved with autism cases."	Institutional support is valued, but there is a perceived lack of community initiatives.
Community empathy	"The neighbors didn't understand autism, I explained to them, but they kept playing the speakers at full volume."	Lack of community awareness generates conflict and reinforces social isolation.

Table 3 indicates that support networks were essential for mothers of children with autism, varying among the interviewees. Family and some professionals were identified as the fun-damental pillars of support. However, some mothers faced a greater burden because they did not have a large network. Family cooperation also played a key role in the management of care. However, community support was limited. One mother mentioned that "you could not value community support, because everything was made for typical children, there was no support for children with autism." Lack of information about available resources was another challenge. Despite these challenges, they valued institutional support, but stressed the need for greater community engagement. There were also issues of empathy in the community.

Table 4.
Cooperation based on reciprocity and mutual support as a mechanism to mitigate the lack of family support to mothers

Dimension analyzed	Evidence of the testimony	Analytical interpretation
Support among mothers	"Of the two moms I knew, we were always trying to be supportive."	Reciprocity among mothers generated a spontaneous and significant support network.
Shared management of care	"We would give each other advice to help each other, for example, with eating or taking medicine."	The exchange of everyday experiences strengthened the capacity to respond to the challenges of caregiving.
Limitations of family support	"My mom didn't live with me, so I felt more alone at certain times."	Physical distances limited the effectiveness of extended family support.
Maternal burden regarding care	"Before, we were frustrated; now, we had to organize ourselves and look for solutions."	The burden of caregiving fell mainly on the mothers, increasing the overload.
Emotional support and shared experiences	"In my case, I also received support from another mom who lived this situation on a daily basis."	Emotional support among peers alleviated isolation and strengthened resilience.
Need for parental training	"We dads were also supposed to receive trainings and share experiences."	Mothers identified the need to involve fathers through structured training.

Lack of community spaces	"It would be nice to have a community, but I didn't have that experience yet."	The lack of community spaces prevented the consolidation of broader support networks.

According to Table 4, mutual support among the mothers attending the multisensory room was key for many of them. This type of cooperation facilitated daily care management. Although many mothers had constant family support, some experienced limitations due to distance. In general, family support was strong, but caregiving fell mainly on the mothers. In addition, mother-to-mother support became an important compensatory mechanism to ease the emotional burden. They agreed on the need for more training for fathers. On the other hand, the lack of inter-active formative spaces limited the scope of support. However, sharing experiences among them promoted an inclusive environment.

DISCUSSION

The results of this research were key to understanding how cooperation affects solidarity with the mothers of children with autism in the multisensory room of the Manta Canton, finding as essential factors cooperation through coordination and collaboration among the participants, as well as the impact on the institutional functioning of the multisensory room. In addition, establishing the role of support networks in the associated communities and determining how reciprocity and mutual support can mitigate the lack of family support for mothers of children with autism. At the same time, it became evident that educational institutions have implemented some strategies, but there are still disparities in educational quality, such as, for example, access to curricular adaptations and specialized ther-apies.

Although some educational institutions offered the possibility of incorporating shadow teachers (alternative teachers) as support for children with autism, the absence of adequate curricular adaptations limited the children's effective learning. In this regard, Sulaiman *et al*. (2019) propose that the mere presence of an alternative teacher does not guarantee inclusion, if it is not accompanied by a curriculum adapted to the student's needs. Nevertheless, the role of the alternative teacher was valued by families as a useful, albeit insufficient, resource. According to Yung et al. (2023), education complemented with alternative teachers generates spaces as a complementary strategy, but its effectiveness depends on continuous teacher training and fluid communication with families.

In relation to health services, while some mothers found committed and helpful professionals in certain areas such as Jaramijó, Ecuador, others described very negative experi-ences in institutions of the same system, such as in Manta-Ecuador. This variability in service quality was noted by Pinto et al. (2017), who pointed to the lack of standardization in the provision of health services for children with special needs. In addition, although the mothers valued the support of institutions such as the multisensory room and health centers, they clearly expressed their longing for greater community engagement. Studies indi-cate that while school and clinical interventions are important, their impact is limited when accompanied by inclusive public policies and contextualized awareness programs (Ghasemianrad et al., 2024; Brisini & Solomon, 2020).

Communication problems were identified between educational institutions and families, a gap that limits the construction of collaborative solutions and the full right to inclusion. In this sense, effective communication is essential to identify challenges and design contextualized responses, an aspect that directly affects the motivation and well-being of students (Correia *et al*., 2024). In spite of this, the participants expressed that they usually felt ex-cluded from the pedagogical and therapeutic processes, a situation that generated frustra-tion and uncertainty about their children's progress.

On the other hand, the participants highlighted the importance of the multisensory room, valuing it not only for its therapeutic function, but also

for its social, educational and inclu-sive impact. According to Vítores Barranco (2024) inclusive education, which values and respects individual differences, is essential to ensure that all children have the opportunity to reach their full academic and social potential. Furthermore, inclusive education not only improves children's academic performance, but also contributes to their emotional and social well-being. This perception is shared and coincides with John-Akinola & Nic-Gabhainn (2014), who demonstrated that multisensory, educational and inclusive spaces foster social skills and strengthen participation.

Also, support networks family, institutional and peer support are essential for mothers of children with ASD, especially when they face emotional and physical overload scenarios (Klinger *et al*., 2020; Pereira Máximo, *et al*., 2023). Thus, the participants' testimonies revealed that the support of the family and some professionals allowed them to reorganize their care routines and receive emotional support. In this same line, Bonfim *et al*. (2023) emphasized that the family of a child with ASD has needs related both to the demands of care and to changes in the family dynamics and the routine of its members. This fact reinforces the need of mothers for comprehensive interventions that address the therapeutic needs of children with autism.

On the other hand, the school, the psychologist in the multisensory room and the bonds among mothers were identified as pillars that alleviated the experience of daily care. According to Escobar-Villacrés *et al*. (2024), emotional and social support is essential in the development of children with ASD, and the lack of community support can lead to difficulties in their emotional skills and affect their self-esteem, resilience and confidence. We also found profound inequalities in the availability and quality of these networks. Some mothers had only a shadow teacher or a psychologist who offered occasional guidance, reflecting a limited and fragile network. In this regard, the observations of Machalicek et al. (2014) indicate that unequal access to specialized services can affect the emotional and functional stability of mothers.

One of the most critical points found was the weakness of community support, which coin-cides with the research consulted which emphasizes the need for public policies and com-munity programs which address the specific needs of children with autism and their families, as an alternative to significantly improve the quality of life of all (Prychodco & de Camargo Bittencourt, 2022; Pereira Máximo *et al*., 2023). However, the mothers pointed out that in their neighborhoods there were not many programs designed for children with ASD and that public spaces were designed only for typical children, a situation that limits social inclusion and deepens the feeling of isolation.

Another specific finding was the lack of information about available resources, a situation that limits timely access to essential services. This lack, which can delay interventions and increase the burden of care (Perlman & Howe, 2022), was mentioned by mothers who dis-covered the existence of certain support resources, thanks to third parties. In this sense, the scarce dissemination of existing programs and resources, together with long waiting lists and insufficient trained professionals, reinforce Ferreira da Silva *at al*. (2024), who con-sider that, without an effective communication and orientation policy, even the available resources may be ineffective.

They also highlighted that sharing experiences, offering practical advice and accompanying each other emotionally constituted an important relief from the stress and burden that this task entails. This dynamic of accompaniment is in line with Gill *et al*. (2023), who explained that communication networks among mothers, especially in contexts of vulnerability, make it possible to build authentic and empowering social bonds, especially when there is little or no family support. Furthermore, they felt that peer reciprocity not only strengthened their resilience, but also contributed to their ability to adapt routines, make informed decisions, and feel emotionally understood. This finding is consistent with Allen *et al*. (2024), who identified that mothers of children with sensory challenges benefited significantly from the companionship of other women going through similar experiences, through active listening, sharing of strategies, affection and emotional validation.

The testimony of mothers who felt lonely or without direct family support - for example, because of physical distance from their extended networks - is reinforced by the contributions of Sundary (2024), who explained that affective isolation weakens traditional support and makes it even more urgent to develop new forms of support organized by the community or the affected fami-

lies themselves. Likewise, the participants stated that they did not have formally constituted communities where they could share experiences or receive guidance. This deficiency confirms that the absence of cooperative and interactive spaces for training and accompaniment prevents many mothers from accessing emotional and practical tools that are fundamental to sustain their role (Gill *et al*., 2023). In this regard, Zapata Rogel (2021) pointed out that, if the resources derived from cooperation are not sufficient, the overload of mothers of children with ASD leads to problems at the physical, social, economic and quality of life levels.

CONCLUSIONS

The study showed how inter-institutional cooperation, support networks and reciprocity among mothers significantly influence the quality of life of those who care for children with ASD in the multisensory room of the Manta canton, during the period 2023-2024. Although efforts by some educational and health institutions were identified, deficiencies persisted in the articulation among actors, the lack of curricular adaptations and the limited availability of specialized human resources. Likewise, the support networks that emerged among the mothers themselves stood out as a key component in the emotional management and practice of caregiving. Peer-to-peer cooperation offered emotional relief, promoted resili-ence and facilitated the exchange of daily strategies to face the challenges associated with autism. This type of bonding, built on shared experience, proved more effective than institutional support in contexts where fragmentation of services predominated.

It was also noted that the community environment presents weaknesses in terms of empa-thy, understanding and accessibility. The scarcity of information and the absence of educa-tional spaces contribute to reinforcing the social isolation of these mothers. Against this background, the consolidation of inclusive policies, awareness-raising programs and intersectoral networks is of strategic importance. Finally, the findings reinforce the need to fos-ter a culture of active and sustained cooperation among families, institutions and the com-munity to ensure the well-being of caregiving mothers and the full inclusion of children with ASD.

Contribution to knowledge

This work contributes to the field of social work and inclusive education by highlighting the urgency of public policies that promote cooperative, sustainable and autism-sensitive envi-ronments. Promoting training spaces, strengthening intersectoral networks and guarantee-ing support to families are essential actions to advance towards a fairer, more inclusive and supportive society for caregiving mothers.

Limitations and recommendations

One limitation of the study was the lack of uniformity in the educational and health services received by the mothers, which made it difficult to compare institutions. In addition, since there was no direct space for communication with the mothers, the interview had to be adapted to the time available to them and in a space that was not fully adapted for a more open dialogue.

It is recommended to broaden the sample of participants and ensure that all have access to the same institutions to obtain more representative results. In addition, it is important to investigate successful models of inter-institutional cooperation in different contexts. At the practical level, it is suggested that training and awareness-raising opportunities for families, teachers, health professionals and communities be strengthened, promoting a comprehen-sive support environment. It is also necessary to reinforce community policies and strate-gies to improve the inclusion and participation of families through structured support net-works.

Conflicts of interest
The authors declare that there are no conflicts of interest

REFERENCES

Allen, S., Branson, A., Lane, S. J., & Knott, F. J. (2025). Mothers' perspectives: daily life when your child has sensory differences. OTJR: *Occupational Therapy Journal of Re-search, 45*(1), 29-37. https://doi.org/10.1177/15394492241238357

Asociación Médica Mundial. (2013). *Declaración de Helsinki de la AMM – Principios éticos para las investigaciones médicas en seres humanos*. 64.ª Asamblea General. https://www.wma.net/es/policies-post/declaracion-de-helsinki-de-la-amm-principios-eticos-para-las-investigaciones-medicas-en-seres-humanos/

Bagnato, M. J. (2019). El bienestar emocional en madres de hijos con diagnóstico de TEA. *Revista de Psicología - Tercera época, 18*(1), 46–60. https://sedici.unlp.edu.ar/handle/10915/76363

Bonfim, A., Giacon-Arruda, B.., Galera, S., Teston, E., Do Nascimento, F., & Marcheti, M. (2023). Asistencia a familias de niños con Trastornos del Espectro Autista: percepciones del equipo multidisciplinario. Revista Latino-Americana de Enfermagem, 31, e3779. https://doi.org/10.1590/1518-8345.5694.3780

Brisini, K. S. C., & Solomon, D. H. (2020). Relational turbulence and perceptions of social network support for parents of children with autism spectrum disorder. Southern Communication Journal, 85(5), 279-289. https://doi.org/10.1080/1041794X.2020.1816608

Constitución de la República del Ecuador. (2008). Art. 47: Inclusión y acceso a la educación para personas con discapacidad. https://educacion.gob.ec/wp-content/uploads/downloads/2022/03/OEI-PND-dic-2021-VF.pdf

Correia, S. G., Leite, L. M. P., Dias, A. A. S., Pires, C. de A., Araújo, B. S., dos Santos, D. J., dos Anjos, E. F., Sinimbu, T. C. M. de O., Moreira, J. H. F., Marques, D. F., da Silva, L. M. S., Caldas, R. D., & Diniz, L. C. de S. (2024). School inclusion and autism: The importance of family collaboration to support autistic students. *LUMEN ET VIRTUS, 15*(39), 3305-3314. https://doi.org/10.56238/levv15n39-133

Escobar-Villacrés, L., Sánchez-López, C., Andrade-Albán, J., & Saltos-Salazar, L. (2024). El tras-torno del espectro autista (tea) y los métodos de enseñanza para niños en el aula de clases. *593 Digital Publisher CEIT, 9*(1-1), 82-98. https://doi.org/10.33386/593dp.2024.1-1.2263

Ferreira da Silva, S., Fernandes Ramos, M., & Resgala Jr, R. C. (2024). Desafios e resiliência: uma análise das dificuldades enfrentadas por mães de filhos no espectro autista. Revista ft, 28(139). https://revistaft.com.br/desafios-e-resiliencia-uma-analise-das-dificuldades-enfrentadas-por-maes-de-filhos-no-espectro-autista/

Fuster, D. E. (2019). Investigación cualitativa: Método fenomenológico hermenéutico. *Propósitos y Representaciones, 7*(1), 201-229. https://doi.org/10.20511/pyr2019.v7n1.267

Ghasemianrad, M., Nematollahi Maleki, R. and Rasoulpoor, S. (2024). Mothers' experiences: A missing puzzle piece in caring for children with autism spectrum disorder. *Journal of Nursing Reports in Clinical Practice, 2*(Issue 2), 121-122. https://doi.org/10.32598/JNRCP.2312.1003

Gill, A., Page, S. M., & Hairston, M. (2023). Communities of Support for Care-Experienced Mothers. *The British Journal of Social Work, 53*(3), 1775-1783. https://doi.org/10.1093/bjsw/bcad032

Hernández Martínez, V. A. (2023). *La depresión y la ansiedad en padres mexicanos de niños con Trastornos del Espectro Autista* [Tesis Doctoral, Departamento de Psicología Evolutiva y de la Educación, Universidad Autónoma de Madrid]. Repositorio institucional. http://hdl.handle.net/10486/708141

Hernández-Sampieri, R., & Mendoza Torres, C. P. (2018). *Metodología de la investigación: Las rutas cuantitativa, cualitativa y mixta* (1.ª ed.). McGraw-Hill.

Herrera-Kit, P., Balanzó Guzmán, A., Parra Moreno, J., & Rivera Chávez, M. (2021). Mecanismos de colaboración interinstitucional: prácticas típicas. *Innovar, 31*(79), 145-159. https://doi.org/10.15446/innovar.v31n79.91888

John-Akinola, Y. O., & Nic-Gabhainn, S. (2014). Children's participation in school: a cross-sectional study of the relationship between school environments, participation and health and well-being outcomes. *BMC public health, 14*, 1-10. https://doi.org/10.1186/1471-2458-14-964

Klinger, E. F., de Bodas Lopes, H., Oliveira, D. P., de Meneses, I. C., & Suzuki, J. S. (2020). Dinâmica familiar e redes de apoio no Transtorno do Espectro Autista. *Amazônia: Science & Health, 8*(1), 123-137. https://ojs.unirg.edu.br/index.php/2/article/view/3112

Ley Orgánica de Discapacidades. (2016). Art. 5: *Protección y reconocimiento de los cuidadores de personas con discapacidad*. https://www.consejodiscapacidades.gob.ec/wp-content/uploads/downloads/2016/06/Ley-Organica-de-Discapacidades.pdf

Leyva-Arévalo, D., Olbine-Yais, S., & Peña-Hernández, N. (2019). Estrategia de orientación a familias de niños con Trastorno del Espectro Autista. *Luz*, 18(3), 70-79. https://luz.uho.edu.cu/index.php/luz/article/view/982

López Chávez, C., Larrea Castelo, M. de L., Breilh, J., & Tillería, Y. (2020). La determinación social del autismo en población infantil ecuatoriana. *Revista Ciencias de la Salud, 18*, 1–27. https://doi.org/10.12804/revistas.urosario.edu.co/revsalud/a.8993

Machalicek, W., Didden, R., Lang, R., Green, V., Lequia, J., Sigafoos, J., ... & O'Reilly, M. F. (2014). Families of Children with Autism Spectrum Disorders: Intervention and Family Supports. In: Tarbox, J., Dixon, D., Sturmey, P., Matson, J. (eds) *Handbook of Early Intervention for Autism Spectrum Disorders. Autism and Child Psychopathology Series* (pp. 511–532). Springer. https://doi.org/10.1007/978-1-4939-0401-3_24

Monje Santana, J. A. (2021). Rol de la familia en la atención de niños con Trastorno Espectro Autista: Un nexo indisoluble. *Explorador Digital, 5*(3), 6-16. https://doi.org/10.33262/exploradordigital.v5i3.1749

ONU. (2025). Objetivo 10: *Reducir la desigualdad en y entre los países*. https://www.un.org/sustainabledevelopment/es/inequality/

Pereira Máximo, T. K., Rosas, M. A., da Silva, M. M., Jucá, A. L., Dutra Facundes, V. L., Gomes da Nóbrega, K. B., & Ferreira, M. B. (2023). Perspectivas das mães de crianças e adolescentes com Transtorno do Espectro do Autismo sobre a rede de cuidados/Perspective of mothers of children and adolescents with autism spectrum disorder on the care network. *Revista Interinstitucional Brasileira De Terapia Ocupacional - REVISBRATO, 7*(1), 1527–1542. https://doi.org/10.47222/2526-3544.rbto53231

Perlman, J., & Howe, N. (2022). Mothers' Experiences of Obtaining a Diagnosis and Support for their Child with Autism Spectrum Disorder. *Canadian Journal of Family and Youth/ Le Journal Canadien de Famille et de la Jeunesse, 14*(3), 1-19. https://doi.org/10.29173/cjfy29789

Pinto, M. B., Dantas Soares, C. C., Santos, N. C. C. de B., Pimenta, E. A. G., Reichert, A. P. da S., & Collet, N. (2017). Percepção de mães acerca da inclusão escolar de crianças com doença crônica. *Revista De Enfermagem UFPE on Line, 11*(3), 1200–1206. https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/13495

Prychodco, R. C., & de Camargo Bittencourt, Z. Z. L. (2022). Desafios no Cotidiano de Famílias com Crianças e Adolescentes com Transtorno do Espectro do Autismo/Challenges in the Daily Life of Families with Children and Adolescents with Autism Spectrum Di-sorder. *ID on line. Revista de psicologia, 16*(63), 204-221. https://doi.org/10.14295/idonline.v16i63.3542

Rivera Domínguez, O., Guzmán Miranda, O., & Caballero Rodríguez, T. (2024). El capital cultural de la familia en el desarrollo social del niño. *EduSol, 24*(87), 111-126. http://scielo.sld.cu/scielo.php?script=sci_arttext&pid=S1729-80912024000200111&lng=es&tlng=es.

Rodas-Jara, R., Franco, N. M., Rodas Jara, L. R., Franco, F., Gómez Leiva, E., Villalba Salinas, D., Chromey, N., Torales, J. C., & Báez, D. (2023). Apoyo, Desafíos y Oportunidades de una Persona con el Trastorno del Espectro Autista en Paraguay: Análisis desde la Perspectiva de los Padres. *Revista científica Ciencias De La Salud, 5*, 01–07. https://revistascientificas.upacifico.edu.py/index.php/PublicacionesUP_Salud/article/view/343

Salazar Echavarría, C., & Posada Silva, W. Y. (2022). Evaluación y trastorno del espectro autis-ta: significados de los actores sociales. *Latinoamericana de Estudios Educativos, 18*(2), 147–173. https://revistasojs.ucaldas.edu.co/index.php/latinoamericana/article/view/8369

Sulaiman, N. F., Rasit, H. H., Toran, H., & Abdullah, N. (2019). Parents Satisfaction with Services Provided by Shadow Aides in an Inclusive Classroom. In *3rd International Conference on Special Education (ICSE 2019)* (pp. 181-184). Atlantis Press. https://www.atlantis-press.com/proceedings/icse-19/126007875

Sundary, S. (2024). The Role Of Family Support In Childbirth: Implications For Maternal And Infant Well-Being. (2024). *Oshada, 1*(4), 61-72. https://doi.org/10.62872/9ep2er27

Torres-Lista, V. (2019). Impacto psicosocial del diagnóstico del Trastorno del Espectro Autista (TEA) en los principales cuidadores. *Investigación y Pensamiento Crítico, 7*(1), 27–39. https://doi.org/10.37387/ipc.v7i1.13

Vítores Barranco, M. (2024, febrero 20). Autismo en el aula: Desafíos y estrategias para una educación inclusiva. *Ventana Abierta*. https://revistaventanaabierta.es/autismo-en-el-aula-desafios-y-estrategias-para-una-educacion-inclusiva/

Yung, K. W. H., Entrich, S. R., & Bautista, A. (2023). Shadow education: new areas of inquiry in teaching, learning and development. *Journal for the Study of Education and De-velopment, 46*(4), 707-727. https://doi.org/10.1080/02103702.2023.2245227

Zapata Rogel, F. A. (2021). *Sobrecarga del cuidador y estrategias de afrontamiento al estrés en padres y madres de niños, niñas y adolescentes con Trastorno del Espectro Autista [Trabajo Final de Licenciatura, Pontificia Universidad Católica Argentina "Santa María de los Buenos Aires"]*. Repositorio Institucional UCA. https://repositorio.uca.edu.ar/handle/123456789/13183