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Between autonomy and uncertainty: Parental experiences of inclusion and future expectations in families of individuals with autism spectrum

Entre la autonomía y la incertidumbre: Experiencias parentales sobre inclusión y futuro en familias de personas con trastorno del espectro autista

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BETWEEN AUTONOMY AND UNCERTAINTY: PARENTAL EXPERIENCES OF INCLUSION AND FUTURE EXPECTATIONS IN FAMILIES OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER

ENTRE LA AUTONOMÍA Y LA INCERTIDUMBRE: EXPERIENCIAS PARENTALES SOBRE INCLUSIÓN Y FUTURO EN FAMILIAS DE PERSONAS CON TRASTORNO DEL ESPECTRO AUTISTA

ABSTRACT

This study aimed to understand how parents of individuals with autism spectrum disorder construct their expectations for the future regarding autonomy, social inclusion, support networks, and experiences of stigmatization. Using a qualitative interpretive approach and a systemic perspective, a narrative-phenomenological design was employed. Data were collected through in-depth, semi-structured interviews with parents and primary caregivers affiliated with a civil society organization and analyzed through reflective thematic analysis. The results showed that autonomy is conceived as a horizon of future security rather than an individual goal, while fear and uncertainty are related to the fragility of institutional support. Furthermore, inclusion is understood as a social obligation, and community networks emerge as key factors in family resilience. The study concluded that parental expectations are shaped relationally and contextually, underscoring the need for inclusive, systemic public policies and interventions.

Keywords: autism spectrum disorder, families; social inclusion, future expectations, family resilience

RESUMEN

El presente estudio tuvo como objetivo comprender cómo madres y padres de personas con trastorno del espectro autista construyen sus expectativas de futuro en relación con la autonomía, la inclusión social, las redes de apoyo y las experiencias de estigmatización. Desde un enfoque cualitativo interpretativo y una perspectiva sistémica, se empleó un diseño narrativo–fenomenológico. La información se obtuvo mediante entrevistas semiestructuradas en profundidad con madres, padres y cuidadores principales vinculados a una asociación civil, y se analizó a través de un análisis temático reflexivo. Los resultados evidenciaron que la autonomía es concebida como un horizonte de seguridad futura más que como una meta individual, mientras que el miedo y la incertidumbre se relacionan con la fragilidad de los apoyos institucionales. Asimismo, la inclusión es entendida como una deuda social y las redes comunitarias emergen como factores clave de resiliencia familiar. Se concluyó que las expectativas parentales se configuran de manera relacional y contextual, lo que subraya la necesidad de políticas públicas e intervenciones sistémicas e inclusivas.

Palabras clave: trastorno del espectro autista, familias, inclusión, expectativas de futuro, resiliencia familiar

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1. INTRODUCTION

Autism spectrum disorder (ASD) has been extensively studied from biomedical, psychological, and educational perspectives. However, there remains a significant gap in our understanding of how families, particularly mothers and fathers, construct meanings about the future of their children in contexts marked by uncertainty, structural inequality, and incomplete inclusion processes. Beyond clinical diagnosis, ASD is embedded in relational networks where caregiving practices, expectations of autonomy, anticipatory fears, and social demands for recognition converge. Therefore, it is necessary for the approach to transcend individualizing and deficit-based perspectives.

From the perspective of systemic family therapy, the experience of ASD cannot be understood as an isolated phenomenon of the individual, but rather as an event that reorganizes dynamics, roles, and meanings within the family system and its interaction with educational, community, and institutional systems. In this sense, Walsh (2020; 2021) conceptualized family resilience as a dynamic and relational process, built on bonds, shared resources, and frameworks of meaning that enable families to cope with emotionally demanding situations. In the context of ASD, this perspective is relevant for analyzing how families develop expectations for the future regarding autonomy and well-being in adulthood, even in scenarios of limited social support.

Complementarily, the narrative approach provides conceptual tools for understanding how mothers and fathers construct narratives that give meaning to their experience with the diagnosis. Parental narratives not only describe experiences, but also shape identities, positions, and horizons of possibility in the face of stigma and exclusion. White and Epston (2019) pointed out that dominant discourses, often focused on deficits, tend to restrict the perception of capabilities and alternatives, while alternative narratives allow for reframing the experience and projecting possible futures based on agency and hope.

Likewise, the social model of disability offers a critical framework for questioning explanations that attribute the difficulties experienced by people with ASD exclusively to their neurodivergent condition. From this perspective, disability emerges in interaction with environments that are not transformed to accommodate functional diversity, shifting the focus to the social, cultural, and institutional barriers that limit full participation (Oliver, 2017). Applied to ASD, this approach understands why families identify inclusion not as an individual responsibility but as a social debt that requires sustained structural transformations.

Empirical literature in Latin American contexts supports these theoretical approaches. Recent studies have documented that families of individuals with ASD face high levels of stress, uncertainty, and emotional overload, particularly in relation to the future and the transition to adulthood, as well as a lack of ongoing institutional support (Rojas & Vázquez, 2020). In turn, research focused on parental well-being highlights the protective role of formal and informal support networks, which help reduce isolation and strengthen collective coping strategies (Pineda & Hernández, 2022).

In the educational and social spheres, various studies show a persistent gap between regulatory frameworks for inclusion and everyday institutional practices. This coincided with the approaches of the United Nations Educational, Scientific and Cultural Organization (UNESCO, 2020), which emphasized the need to move toward educational and social systems that recognize diversity as a value and not as an exception, preventing the responsibility for inclusion from falling disproportionately on families.

Based on this theoretical and empirical framework, a gap was identified in studies that explore in depth the future expectations of parents of people with ASD, integrating dimensions of autonomy, support networks, stigmatization, and inclusion from a systemic and narrative perspective. In response to this gap, the present study set out to understand how parents of individuals with ASD construct their expectations for the future in relation to autonomy, social inclusion, support networks, and experiences of stigmatization within their sociocultural context. By recovering parental narratives, this work provided evidence that dialogues with the state of the art and contributes to both theoretical reflection and the design of family interventions and public policies sensitive to the experiences of families.

Based on the above, the following research question arises: How do parents of children with ASD construct their expectations for the future in relation to autonomy, social inclusion, support networks, and experiences of stigmatization within their sociocultural context? Therefore, the objective was to understand the perceptions and expectations for the future of parents of people with ASD, identifying the meanings attributed to autonomy, inclusion, support networks, and social stigma from a systemic and inclusive perspective.

2. METHOD OF RESEARCH

The study adopted a qualitative interpretive approach, aimed at understanding the subjective and relational meanings that families attribute to their experience with ASD. It drew on systemic family therapy, which assumes that individual experiences can only be understood in relation to the family, social, and institutional systems in which they are embedded (Walsh, 2020), and the social model of disability (Oliver, 2017). This approach explores the complexity of parental discourses without reducing them to isolated variables, privileging context, interaction, and the social construction of meaning (Denzin & Lincoln, 2018).

A narrative-phenomenological design was used, which is suitable for exploring lived experiences and parental narratives through which mothers and fathers interpret the present and project the future and inclusion, allowing access to the meaning that families give to their journey with ASD (White & Epston, 2019). This design makes it possible to recover parental voices as carriers of situated knowledge, allowing us to understand how expectations, fears, and hopes are shaped in contexts marked by unequal inclusion and social stigma (White &

Epston, 2019). The scope is exploratory-comprehensive, as it deepens the understanding of a little-explored phenomenon from the perspective of families, without any claim to generalization, providing input for systemic intervention and the design of inclusive policies (UNESCO, 2020). This scope was consistent with qualitative studies that seek to highlight experiences, identify structural tensions, and generate input for systemic intervention, the design of inclusive policies, and future research (Oliver, 2017; UNESCO, 2020).

2.1. Participants

Participants were selected through intentional convenience sampling, based on accessibility and relevance to the context, through links with a civil association dedicated to caring for people with ASD. This type of sampling was consistent with qualitative studies aimed at gaining a deep understanding of specific experiences, rather than statistical representativeness (Patton, 2015).

Participants were adults over the age of 18, mostly mothers, fathers, and/or primary caregivers of children or adolescents diagnosed with ASD. Exclusion criteria included refusal to sign the informed consent form or not being part of the population linked to the association. The initial approach was made through institutional mediation, which facilitated ethical, gradual, and respectful contact with the families, as well as access to suitable spaces for conducting fieldwork.

2.2. Data collection instruments

The information was gathered through in-depth semi-structured interviews, conducted individually. From a systemic and narrative perspective, this type of interview articulated guiding principles with the necessary openness for participants to construct their narratives, favoring the emergence of relational meanings, family tensions, and processes of re-signification associated with the diagnosis of ASD (Kvale & Brinkmann, 2015).

Semi-structured interviews are particularly relevant for qualitative research in the field of family and inclusion, as they enable a contextualized understanding of experiences without reducing them to rigid or predetermined categories (Patton, 2015).

2.3. Procedure

The research process began with formal contact with the civil association, followed by a presentation of the study's objective and the ethical conditions for participation to interested individuals. Subsequently, individual interview sessions were arranged with those who agreed to participate voluntarily. The interviews were conducted at the association's facilities, lasted between 40 minutes and an hour and a half, and were audio-recorded with express authorization to ensure the accuracy of the record.

After the fieldwork phase, the audio recordings were carefully transcribed, preserving the meaning of the discourse and the narrative style of the participants. At the same time, an iterative process of analytical reading, theoretical reflection, and comparison with the specialized literature was carried out. This allowed for progressive advancement in the construction of analytical categories consistent with the interpretive approach of the study (Braun & Clarke, 2021; Ricoeur, 1991).

2.4. Data analysis

The information was analyzed using a reflective thematic analysis, aimed at identifying patterns of meaning, discursive regularities, and significant themes present in the parental narratives. This analytical approach favored a reflective stance on the part of the research team and recognizes the situated nature of the knowledge produced (Braun & Clarke, 2021).

The analysis did not seek to fragment the families' experiences, but rather to understand them in all their complexity, taking into account the interaction between personal, family, and sociocultural dimensions linked to disability, inclusion, and the future of people with ASD. This type of analysis is particularly suitable for studies that explore relational and contextual phenomena from a systemic perspective.

2.5. Ethical considerations

The study was conducted under strict ethical principles. Written informed consent was obtained, ensuring that participants were provided with clear information about the study's objectives, its voluntary nature, the anonymity of their participation, and the possibility of withdrawing if they deemed it necessary. Likewise, the information was handled exclusively for academic and research purposes.

The research process adhered to the guidelines of the Code of Ethics of the Mexican Psychological Association, emphasizing professional responsibility, non-maleficence, and care in addressing sensitive narratives related to diagnosis, uncertainty, and emotional burden in families (Sociedad Mexicana de Psicología, 2010).

3. RESULTS

The results are presented based on a reflective thematic analysis of parental narratives, from a systemic, inclusive, and critical perspective. The analytical categories emerged from recurring meanings, emotions, and social demands associated with the future of children with ASD. Each category was supported by expanded textual vignettes as empirical evidence and accompanied by an interpretive analysis in dialogue with contemporary theoretical references.

3.1. Autonomy as a vision for the future

The results in this category showed that autonomy is conceived as an ideal for future security rather than as an isolated individual goal. From a systemic perspective, independence is linked to the permanence of the parental bond, revealing a paradox between the desire to let go and the need to protect (Walsh, 2020; White & Epston, 2019).

> I hope my son will be independent, that he will know how to cope with problems and, above all, control his temper... I am afraid of how he will cope with his diagnosis as an adult (P1).

> My fear is that he will become completely independent by the time I am gone, that he will be able to live a comfortable life (P2).

> I would like him to be able to fend for himself, to have the ability to discern between what he can and cannot do (P6).

> Always hoping that my daughters will develop their independence... the greatest satisfaction is knowing that she can do many things on her own (P8).

> That in the future he won't depend on me so much (P13).

3.2. Fear, uncertainty, and prolonged parental responsibility

Fear emerged as a structuring emotion in the absence of sustained social support. Drawing on family resilience, these fears coexist with active coping strategies (Walsh, 2021). The social model allows us to understand that uncertainty is intensified by structural failures rather than by the condition itself (Oliver, 2017).

> It's such a big responsibility... my fear is that he won't be able to live comfortably when I'm gone (P2).

> That's my worst fear: that he won't know how to say no and something will happen to him (P6).

> I'm afraid of how he's going to cope with the outside world (P3).
>
> If he grows up and doesn't become independent, or if we aren't there when he needs us (P13).
>
> We have to be emotionally well ourselves in order to be well for our children (P8).

3.3. Inclusion as a social and educational obligation

Inclusion was understood as a collective responsibility. From the social model of disability, exclusion resides in environments that do not transform themselves to accommodate diversity (Oliver, 2017; UNESCO, 2020).

> More inclusion in schools and with teachers (P1).
>
> That there be openness in schools, in public places, in workplaces (P5).
>
> Teachers should be trained and greater attention should be paid to children with ASD (P10).
>
> It is essentially teaching society that these conditions exist (P10).
>
> Include information about ASD in textbooks so that children are aware of it from an early age (P4).

3.4. Support networks and sense of community

In this sense, community networks emerge as resilience mechanisms that reduce isolation and strengthen shared care (Walsh, 2020).

> That there would be support groups, more than anything else, to talk to people who will understand you (P1).
>
> Bringing an association like this civil association closer to where we live (P2).

> Don't let them feel alone, we are more (P8).
>
> We need to support each other, build our network (P9).
>
> More socialization and support programs (P12).

3.5. Social emphaty, recognition, and fighting stigma

Narratives challenge deficient discourses and call for cultural change based on rights and dignity, from a narrative and inclusive perspective (White & Epston, 2019).

> Empathy, because sometimes people make comments out of ignorance (P6).
>
> That people would be a little more empathetic (P11).
>
> Let there be no more bullying, so that there is no discrimination (P13).
>
> People downplay it because ASD is not visible (P4).
>
> Don't point fingers or label them (P1).

4. DISCUSSION

The findings of this study deepened our understanding of how parents of individuals with ASD construct expectations for the future that are shaped by the tension between the desire for autonomy and the persistence of structural conditions that limit social inclusion. In line with previous research, the results showed that projections for the future are not shaped by isolated individual aspirations, but rather by a relational process deeply linked to the permanence of the parental bond, the availability of support, and social recognition (Rojas & Vázquez, 2020; Walsh, 2020).

Autonomy, identified as a central theme in parental narratives, takes on new meaning as a source of security and well-being in anticipation of the future absence of primary caregivers. This finding coincided with that of Walsh

(2021), who argued that, in contexts of prolonged adversity, families reorganize their expectations by prioritizing continuity of care and relational protection. From a narrative perspective, these expectations can be understood as stories of hope that seek to counter social discourses that associate ASD with permanent dependence or disability (White & Epston, 2019).

In relation to the category of fear, uncertainty, and prolonged parental responsibility, the results showed that fear does not operate as a paralyzing emotion, but rather as a form of anticipatory awareness of the fragility of social support systems. This finding is consistent with studies that document high levels of emotional burden in families of people with ASD, particularly in relation to the transition to adulthood and the lack of sustained institutional guarantees (Pineda & Hernández, 2022). From the social model of disability, this uncertainty cannot be attributed exclusively to the neurodivergent condition, but rather to the absence of accessible environments and public policies that effectively accompany the entire life cycle (Oliver, 2017).

Inclusion, understood by families as a social and educational obligation, emerges as a cross-cutting theme that links experiences of everyday exclusion with explicit demands for structural change. The results coincided with research conducted in Latin American contexts that points to a persistent gap between the regulatory frameworks for inclusion and actual practices in educational institutions and community spaces (Vidal Esteve, 2024). In this regard, the findings reinforce the idea that inclusion continues to be sustained, to a large extent, by individual and family efforts, which deepens inequalities and reproduces disproportionate burdens on caregivers.

On the other hand, support networks and a sense of community are key protective factors in reframing the family experience. The possibility of sharing experiences with other families, accessing civil associations, and building local support networks appears to be a fundamental resource for reducing isolation and strengthening collective resilience processes. This result was consistent with the literature that emphasizes the role of formal and informal networks in promoting parental well-being and redistributing care (Walsh, 2020; Pineda & Hernández, 2022).

Finally, the category referring to social empathy, recognition, and the fight against stigma highlights the persistence of social discourses and practices that render ASD invisible or minimize it, especially when it does not conform to visible stereotypes. From a narrative perspective, these parental demands can be interpreted as attempts to challenge hegemonic narratives that pathologize difference, promoting an understanding based on rights, dignity, and recognition of neurodiversity (White & Epston, 2019). This finding was in line with the approaches of UNESCO (2020), which emphasize the need for profound cultural transformations so that inclusion transcends the discursive level.

Overall, the study's results provided empirical evidence that expands the state of the art by integrating, from a systemic and narrative perspective, dimensions of autonomy, fear, inclusion, support networks, and stigmatization in the construction of future expectations. The scientific novelty of the work lay in making these experiences visible through the voices of families, highlighting their relational and contextual nature, as well as pointing out the urgency of public policies and intervention strategies that comprehensively support people with ASD and their families throughout the life cycle.

5. CONCLUSIONS

This study revealed that the future expectations of parents of individuals with ASD are deeply rooted relational constructs, shaped by the tension between the desire for autonomy and the perception of an insufficiently inclusive social and institutional environment. Far from conceiving of the future solely as an individual project for people with ASD, parental narratives articulate it as a shared process, in which the permanence of care, security, and social recognition take center stage.

The findings showed that autonomy is redefined by families, not as a separation from the family system, but as a guarantee of well-being and dignity in the event of the absence of primary caregivers. This redefinition revealed a systemic interpretation of development, in which independence is built gradually, relationally, and contextually, rather than as a normative or standardized requirement. In this sense, parental expectations engage critically with social models that continue to associate ASD with permanent dependence, challenging these narratives through everyday experiences of agency and capacity.

Likewise, fear and uncertainty emerge as structuring emotions that cannot be understood solely from an individual or family perspective. The results showed that these emotions intensify in contexts where social, educational, and community support is fragile or discontinuous. From this perspective, the emotional burden on parents is linked more to structural failures of inclusion than to the neurodivergent condition itself, reinforcing the approaches of the social model of disability.

Inclusion was conceived by families as a collective responsibility that had not yet been fully assumed. Demands for greater teacher training, institutional openness, and social awareness were a direct criticism of the gap between regulatory frameworks and actual practices. In this sense, the study reinforced the need for intersectoral public policies that provide sustained support to people with ASD and their families throughout the life cycle, preventing inclusion from depending exclusively on family efforts.

Support networks and a sense of community emerged as key elements for family resilience, enabling the redistribution of care, emotional validation, and the construction of shared knowledge. These findings underscored the importance of strengthening community spaces and civil associations as support mechanisms that mitigate isolation and promote collective well-being.

Finally, parental narratives revealed an explicit demand for social empathy and recognition, aimed at challenging stigmatizing discourses that render ASD invisible, especially when it does not conform to visible stereotypes. This symbolic struggle for recognition highlights the cultural dimension of inclusion and the urgency of social transformations that recognize neurodiversity as an integral part of the human condition.

In terms of scientific contribution, this study contributed to the field of systemic family therapy and ASD studies by highlighting future expectations from the perspective of families, integrating relational, emotional, and structural dimensions that have rarely been addressed in a coordinated manner in Latin American literature. However, the results raised new questions about how these expectations change over time and in different sociocultural contexts, highlighting the need for longitudinal and comparative research to explore these dynamics in greater depth and strengthen the design of systemic and inclusive interventions.

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