

CONSTRUCCIÓN DEL CONOCIMIENTO EDUCATIVO: ESTUDIOS EMPÍRICOS, EXPERIENCIAS Y ANÁLISIS TEÓRICO

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EDITORIAL
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Construcción del conocimiento educativo: estudios empíricos, experiencias y análisis teórico

María Soledad Villarrubia Zúñiga, Paula González García,
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Índice

Presentación.....	9
Competencias de directivas y su presencia en los planes de estudio de los Grados de Infantil y Primaria	11
<i>Jesús Enrique Albertos San José y Miguel Ángel Comas</i>	
Educación, género y memoria: mujeres en la narrativa escolar de la historia chilena del siglo XIX.....	23
<i>Humberto Álvarez Sepúlveda</i>	
La mentoría entre iguales como una estrategia para mejorar la motivación de estudiantes universitarios nuevos	35
<i>Paola Salomé Andrade Abarca y Bryan Israel Gómez Flores</i>	
Percepción, conocimientos y prácticas del profesorado universitario español con respecto al trabajo en equipo.....	44
<i>Yordan Todorov Apostolov</i>	
Negociación y consenso estratégico como habilidades determinantes en la construcción de discursos efectivos	53
<i>Claudine Benoit Ríos</i>	
Uso de TIC y plataformas digitales en la educación universitaria y certificación ambiental: una revisión sistemática	65
<i>Augusto Cahuapaza Morales</i>	
Learning environments and inclusion: a case study of transposition of the Reggio Emilia approach in Swedish schools.....	74
<i>Capelli Letizia, Drure Eloise y Muzzi Chiara</i>	
Hacer papel, hacer comunidad: un taller de papel artesanal como acto pedagógico y relacional.....	85
<i>Isabel Carralero Díaz y Antonio Navarro Fernández</i>	
Evaluación crítica de propuestas didácticas generadas por inteligencia artificial sobre patrimonio bibliográfico y documental	96
<i>Verónica Mateo-Ripoll y Antonio Carrasco-Rodríguez</i>	
La IA en el aula de ILE a un nivel A1 en Bangladesh: percepción y resultados	109
<i>Stefania Chiapello</i>	

Competència (socio)lingüística al grau de Llengua i Literatura Catalanes: una experiència d'innovació docent	119
<i>Elga Cremades</i>	
Desarrollo de la competencia investigadora en educación superior: una experiencia de investigación participativa.....	129
<i>Lucrezia Crescenzi-Lanna y Belén Gutiérrez-de-Rozas</i>	
Minicongreso de las Ciencias en línea con estudiantes del grado de Educación Infantil	141
<i>María José Cuetos Revuelta y Natalia Serrano Amarilla</i>	
Impacto de la musicoterapia en el desarrollo integral de la persona	150
<i>Amparo de Dios Tronch</i>	
El aprendizaje cooperativo como herramienta fundamental para el aprendizaje de la Educación Musical.....	161
<i>Amparo de Dios Tronch</i>	
Activando la motivación del alumnado universitario a través del “efecto espejo”: del “yo estudiante” al “yo profesional”	171
<i>Fernando de Llano Paz y Alejandro Manuel Fernández Castro</i>	
University Go, diseño de una propuesta de Red Social para el aprendizaje colaborativo y la comunicación en la Universidad de Málaga.....	181
<i>Salvador Doblas Arrebola y Gonzalo Pascual Ramos Jiménez</i>	
Fans as translators: para-institutional training and translational capital in manga and anime translation	191
<i>Salomón Doncel-Moriano Urbano</i>	
Impacto de una formación en primeros auxilios en mujeres migrantes cuidadoras informales	202
<i>Felipe Santiago Fernández Méndez, Alejandro Afonso Izquierdo, Iván Pérez Heras, José Manuel Díaz González y Maryurena Lorenzo Alegría</i>	
Transferencia de conocimiento y educación musical por medio del proyecto expositivo <i>Cantantes líricas gallegas de los siglos XIX y XX</i> : génesis y desarrollo	213
<i>María del Carmen Fernández-Morante, Francisco Javier Garbayo Montabes y María del Carmen Lorenzo Vizcaíno</i>	
Educación, fronteras y narrativas: por una pedagogía contra la exclusión.....	224
<i>Massimiliano Fiorucci y Giorgio Crescenza</i>	

When the home learns to breathe again: a qualitative case study on family adjustment and school inclusion in neurodevelopmental disorders	234
<i>Antonios Fodelianakis</i>	
Innovación docente en contratación de proyectos mediante simulación profesional con Scrum Learning.....	244
<i>José Luis Fuentes-Bargues, Alberto Sánchez-Lite, Fernando Grande-González y M.ª Carmen Gonzalez-Cruz</i>	
Nuevos formatos de aprendizaje de la teoría de conceptos umbral	252
<i>Andrés García Ramos, Miguel Howe León y Celeste Armas Bacci</i>	
<i>Learning Paths</i> : aprendizaje y bienestar estudiantil en lugares más allá del aula	261
<i>Isabela García Senent y Carmen Sánchez-Ovcharov</i>	
Percepción del uso de ChatGPT en Educación superior y retos para el alumnado	270
<i>María Yolanda González Alonso</i>	
Conocimiento, esfuerzo y capacidad de no rendirse como herramientas en nuevas experiencias de innovación docente implementadas en grado universitario	279
<i>Rosalía González Brito</i>	
Addressing bullying perpetration among Serbian adolescents: the role of school safety dimensions.....	289
<i>Adrijana Grmuša</i>	
Concepciones del patrimonio etnológico en el profesorado en formación inicial de Educación Primaria.....	300
<i>Aitana Guardiola Moreno, Ariadna Garrigós Aunión y Santiago Ponsoda López de Atalaya</i>	
Repensar la enseñanza: del enfoque tradicional al protagonismo del alumnado en el aprendizaje	310
<i>Jorge Heliz Llopis y Carmen Mañas Viejo</i>	
Educación a distancia en responsabilidad social y sostenibilidad: percepción de estudiantes universitarios	323
<i>Diana Hernández Cruz</i>	
Los conceptos umbral en la concepción del proceso de enseñanza-aprendizaje en educación superior y su implicación en el diseño de las asignaturas	333
<i>Miguel Howe León, Juan Fraile RuizMartina, María Loitegui y Noemy Martín-Sanz</i>	

Investigación relacionada con la aplicación de la metáfora biológica del árbol del conocimiento en la cooperativa COOPSERSAN, Colombia.....	342
<i>Karen Melissa Hurtado Arciniegas y Doris Rosero-García</i>	
Innovación educativa con tecnologías emergentes en la universidad: el proyecto EmTech4HE como experiencia transformadora	351
<i>Nahia Idoiaga Mondragon y Idoia Legorburu Fernandez</i>	
La Semana de la Innovación en el Aprendizaje como una buena práctica que fomenta el cambio en profesores universitarios	361
<i>Martina María Loitegui, Belén Obispo-Díaz y Andrés García Ramos</i>	
La temática ético-social en la formación continua del profesorado universitario	371
<i>Francisco Javier Malagón Terrón</i>	
La actitud proactiva docente frente a la investigación educativa: desafíos y oportunidades para su aplicación en el aula	383
<i>Mireya Mallén Berdejo y Cristina Borau Viu</i>	
Del aula al laboratorio: competencias críticas y profesionales a través del Aprendizaje Basado en Proyectos en Periodismo.....	393
<i>Luz Martínez Martínez, María Arteaga Ros y Luis Felipe Solano Santos</i>	
Prácticas de liderazgo medio: contribuciones al Desarrollo Profesional Docente en centros de formación técnico profesional en Chile.....	406
<i>Óscar Maureira Cabrera y Manuel Pineda Torres</i>	
Las TIC en la enseñanza de la geometría: análisis temático y de frecuencia de descriptores.....	419
<i>Alexander Maz-Machado y María Josefa Rodríguez-Baiget</i>	
La formación política en las infancias: un análisis de la afiliación y el control sobre el entorno como capacidades humanas	431
<i>Leidy Ximena Mesa y Guillermo Meza Salcedo</i>	
La representació de les violències masclistes en les novel·les d'Irene Solà i d'Andrea Abreu: anàlisi de cas per a una proposta didàctica.....	442
<i>Carla Mira Anton</i>	
Estilos de vida pospandemia de estudiantes universitarios. Una mirada transatlántica.....	452
<i>Luis Moral Moreno</i>	

Rethinking architectural education: uncertainty, error and laziness as (unexpected) learning assets for creativity	465
<i>Sandra Neto</i>	
College UFV: una experiencia formativa en el aula universitaria, con personas extranjeras	477
<i>Belén Obispo-Díaz, Natalia Sarrión Rubio de la Torre y Noemy Martín-Sanz</i>	
Decálogo para la introducción del consentimiento en la Educación Infantil.....	489
<i>María Isabel Olmedo Corral, Carmen Mañas Viejo y Jorge Heliz Llopis</i>	
Posturas paradigmáticas en la formación en fisioterapia: una revisión de alcance.....	499
<i>Karen Pascal Mamani</i>	
MOSL4L: towards a framework for learner-based and context-sensitive technology enhanced language learning	512
<i>Timothy Read, Juan-José Magaña y Elena Barcena</i>	
Futuros docentes ante la autoevaluación con grados de certeza	522
<i>Ana Remesal y Horacio F. Vidosa</i>	
Desafíos éticos de la inteligencia artificial generativa en la educación: un análisis de la literatura académica.....	533
<i>Sebastián Reyes Alvarado y Laura Hernández Dager</i>	
El enfoque <i>student voice</i> y el <i>cuaderno de bitácora</i> como dispositivo de formación innovador para el desarrollo profesional del profesorado universitario y una educación democrática. Una reflexión teórica.....	544
<i>Roberta Rosa</i>	
John D. Caputo: las buenas razones de la religión sin religión y el Dionisos rabino que nadie vio venir	554
<i>Encarnación Ruiz Callejón</i>	
Aprendizaje de la música tradicional a través de un proyecto que combina el análisis, la creación y la práctica musical.....	564
<i>Facundo San Blas y Ángela Buforn</i>	
Detectar els senyals de les violències masclistes: una experiència a l'aula universitària a través de la literatura	575
<i>Raül Sánchez-Ballester</i>	

Metodologías activas y el aprendizaje colaborativo en el desarrollo del perfil profesional del diseñador gráfico del Centro universitario de arte, arquitectura y diseño.....	585
<i>Aurea Santoyo Mercado, Eva Guadalupe Osuna Ruiz y José Antonio Luna Abundis</i>	
Proyecto PROMESA-EF: codiseño con maestros para desarrollar programas de promoción de la actividad física en la escuela.....	597
<i>Romina Gisele Saucedo-Araujo, Francisco Javier Huertas-Delgado, Emilio Villa-González y Manuel Ávila-García</i>	
La educación ambiental y fiscal como estrategia para fomentar la concienciación ciudadana en la tributación ecológica.....	607
<i>Arantxa Serrano Cañadas</i>	
La guía didáctica como reflejo del pasado y del presente histórico y como medio para una educación musical transformadora: “Cantantes líricas galegas dos séculos XIX e XX”	619
<i>Laura Touriñán-Morandeira, Ilduara Vicente Franqueira y M^a del Carmen Fernández-Morante</i>	
Lengua, historia e hibridismo cultural: tres aplicaciones prácticas de la literatura neomahyarí en la universidad española	632
<i>Rocío Velasco de Castro</i>	
La presencia del franquismo en los proyectos educativos de Canarias: una revisión historiográfica y curricular.....	641
<i>Yago Viso Armada</i>	
Inteligencia Artificial Generativa en la universidad bajo sospecha: percepciones del profesorado y el alumnado sobre sus riesgos.....	563
<i>Montserrat Yepes-Baldó y Marina Romeo</i>	

When the home learns to breathe again: a qualitative case study on family adjustment and school inclusion in neurodevelopmental disorders

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Abstract: This qualitative case study explores the lived experience of a Greek family raising an eight-year-old child diagnosed with Autism Spectrum Disorder (ASD, Level 1) and Attention Deficit Hyperactivity Disorder (ADHD). Drawing on semi-structured interviews with the mother, the research highlights the multifaceted psychological, emotional, and social impacts of neurodevelopmental diagnoses on family life. Five core themes emerged: emotional response to diagnosis, disruptions in family dynamics, daily caregiving challenges, collaboration with school, and interaction with therapeutic services. The findings reveal considerable emotional strain, maternal burnout, social isolation, and structural deficiencies in educational and health systems, including fragmented support and limited school coordination. Despite these challenges, the family demonstrated significant resilience through emotional bonding, therapeutic engagement, and informal support from grandparents. The study underscores the urgent need for systemic reform, emphasizing the importance of coordinated institutional support, psychoeducation for extended family, enhanced school-family cooperation, and sustained public investment in inclusive practices. Ultimately, the paper advocates for a holistic, person-centered approach to neurodevelopmental disorder management that validates caregiver roles while promoting children's functional and emotional well-being.

Keywords: neurodevelopmental disorders, family resilience, autism, inclusive education, caregiver stress.

1. INTRODUCTION

Neurodevelopmental disorders (NDDs) represent a spectrum of complex conditions emerging in early childhood, associated with dysfunctions in the development of the central nervous system (APA, 2013; Fodelianakis, 2023; 2020a; 2020b; WHO, 2010). Their presence profoundly impacts the cognitive, social, communicative, and emotional development of the child (Milathianaki, 2023). Among the most common forms are Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), and Intellectual Disability (ID), each necessitating individualized educational and psychosocial interventions (Pistola, 2019).

Diagnosing such disorders affects not only the child but also the entire family structure, leading to a reconfiguration of roles, relationships, and daily routines (Brown et al., 2013; McManus et al., 2011; Milathianaki, 2022; 2020a; 2020b). The adaptation process often involves emotional stages similar to grief, including denial, guilt, and anger (Pistola, 2019; Wall, 2010), while parental resilience and access to social and institutional resources significantly influence smooth transitions (Resch et al., 2010).

The school environment acquires strategic importance, serving not only as a learning setting but also as a space of either support or additional challenge for the family. The quality of family-school collaboration, the availability of support services, and administrative attitudes significantly shape the child's educational experience (Kilic et al., 2013; Rosenbaum, 2016). Despite improvements in the Greek educational system, many families still experience special education as fragmented and poorly coordinated (Mazzoni et al., 2021; Pistola, 2019).

This study explores the experiences of a Greek family with a child diagnosed with ASD and ADHD. Utilizing a case study approach and semi-structured interviews, the emotional and psychological impacts of the diagnosis, daily challenges, interactions with the school, and family resilience strategies are examined. This methodological approach facilitates an in-depth understanding of personal experiences and amplifies the family's voice, often marginalized in dominant narratives of special education.

The research aims to identify not only challenges but also potential strengths. It emphasizes the importance of institutional support, school collaboration, and psychoeducation for all stakeholders as necessary conditions for successful social and emotional integration. Within an evolving educational landscape, family experiences serve as critical guidance for effectively implementing inclusion.

2. THEORETICAL FRAMEWORK

Neurodevelopmental disorders constitute an increasingly significant area of scientific interest, particularly in relation to social and educational policies, given their implications for school inclusion and family adjustment. NDDs arise from early developmental dysfunctions in the central nervous system and typically present during childhood, persisting throughout life (APA, 2013; WHO, 2010). Diagnostic categories include autism, ADHD, intellectual disabilities, learning disabilities, and speech and communication disorders, each uniquely impacting functionality and requiring individualized educational and psychosocial approaches.

ASD specifically involves difficulties in social interaction, stereotypical behaviors, and a need for stable routines. ADHD is characterized by attention deficits, hyperactivity, and impulsivity. Co-occurrence complicates the clinical picture, necessitating intensive and multifaceted support (Mazzoni et al., 2021; Purpura et al., 2021). In these scenarios, family and school roles are pivotal for social integration and enhancing quality of life.

The family's functioning under an NDD diagnosis has been extensively studied. Researchers such as Pistola (2019) and Wall (2010) highlight that diagnosis can severely disrupt family equilibrium, generating intense feelings of guilt, inadequacy, and isolation, especially among parents. Mothers often assume primary caregiving roles, experiencing psychological exhaustion and burnout, documented in Greek and international research (Craig et al., 2016; Wang et al., 2011). Fathers typically display emotional distance, influenced by social norms or difficulty comprehending the situation.

The impact extends beyond parents, affecting siblings who may feel neglected or prematurely assume caregiving roles, influencing their psychosocial development (Vetri et al., 2020). Grandparents can offer support, contingent upon appropriate psychoeducation and information (Rosenbaum, 2016; Wall, 2010).

Schools are integral to the inclusion process. Inclusion of children with NDDs aligns with international educational guidelines and Greek legislation (Law 3699/2008; ESPA, 2023). However, policy implementation often remains superficial. Dysfunctional

collaboration among general and special educators, insufficient training, and passive administrative involvement undermine inclusion intentions (Kilic et al., 2013).

Parallel support has become a core mechanism in Greece. Nonetheless, special educators frequently operate isolated from general classroom teachers, and coordination among specialists (speech therapists, occupational therapists, psychologists) remains limited, complicating family understanding and support (Mazzoni et al., 2021; Sánchez Amate & Luque de la Rosa, 2024).

Student experiences greatly depend on the school's overall acceptance culture. Proactive administrative leadership facilitates smoother inclusion, whereas passive attitudes and persistent stereotypes hinder genuine integration (McConkey & Collins, 2010).

In conclusion, the theoretical framework underscores the complexity of interactions among families, schools, and support structures managing NDDs. The child is not viewed in isolation but within a system necessitating coordinated, collaborative, and reinforced strategies. Developing coherent educational policies is essential for an authentically inclusive intervention model.

3. METHODOLOGY

This qualitative study employs the case study methodology to deeply explore complex social phenomena such as family daily life with a child with neurodevelopmental disorders (Yin, 2018). The research focuses on a Greek family from a middle socioeconomic background with an eight-year-old boy diagnosed with Level 1 ASD and ADHD. This case was selected to highlight both difficulties and adaptive strategies in a context of multiple challenges.

Data were collected through a semi-structured interview with the mother, chosen due to her central caregiving role. This tool offers flexibility and facilitates exploring subjective meanings attributed by individuals to their experiences (Creswell & Poth, 2018). Conducted face-to-face in a secure, neutral environment, the interview lasted approximately 75 minutes and was recorded with participant consent. Transcription was verbatim, followed by thematic content analysis.

Analysis centered on five key themes identified through interpretative processes: a) emotional response to diagnosis, b) impacts on family functioning, c) daily planning and mother's role, d) relationship with the school, and e) collaboration with external specialists. This thematic structuring facilitated identifying recurrent patterns and diverse experiences shaping the mother's caregiving identity.

Focusing exclusively on the mother is justified by the depth-oriented interpretative intent rather than generalizing findings, aiming instead to deepen understanding of complex psychosocial dynamics. Ethical considerations included confidentiality, voluntary participation, and informed consent. Pseudonyms and modified identifying information ensured anonymity. Results were presented respectfully, aiming for socially sensitive knowledge production.

4. CASE STUDY: GIANNIS AND HIS FAMILY

Giannis is an eight-year-old boy attending the second grade of primary school who has been diagnosed with Autism Spectrum Disorder (ASD, Level 1) and Attention Deficit Hyperactivity Disorder (ADHD). The diagnostic process was lengthy and comprehensive, encompassing classroom observations, referrals, and multidisciplinary assessments. Initial concerns were raised by his first-grade teacher, who observed significant difficulties regarding attention, inadequate social interactions, and challenges

adjusting to the daily school routine. Subsequently, through referral from school services, Giannis underwent evaluation at the Diagnostic, Differential Diagnosis, and Support Center (ΚΕΔΑΣΥ), which confirmed the necessity for supportive interventions, including speech therapy and the assignment of a paraprofessional assistant.

Giannis' family consists of his parents, himself, and his five-year-old sister. Considerable support is provided by the maternal grandparents, who reside nearby and actively participate in daily caregiving routines. His mother has reduced her work hours, explaining that managing Giannis' needs is equivalent to having a second job. The father maintains full-time employment and engages intermittently in therapeutic processes and communication with the school.

Giannis demonstrates relatively advanced verbal expression; however, he encounters substantial difficulties in comprehending and responding to social cues, interacting effectively with peers, and participating in tasks requiring sustained attention. According to his teacher, Giannis frequently leaves his seat without an apparent reason, withdraws when exposed to loud noises, and struggles significantly to complete assigned tasks. Although a support teacher has been appointed, this professional provides assistance for only part of the school day, a limitation that complicates fully addressing Giannis' educational needs. The general education teacher, on the other hand, acknowledges an inability to adequately meet the increased demands for differentiated instruction.

The diagnosis was a critical turning point for the family. Initially, Giannis' mother experienced shock and negative emotions, indicating, "I thought he was just shy and energetic; I couldn't accept the term autism." Over time, participation in parent groups, engagement with therapists, and access to information have gradually facilitated her adjustment. Conversely, the father appears more detached, stating that he is uncertain about how to help and prefers limited involvement.

Giannis' younger sister exhibits pronounced attention-seeking behaviors and increased attachment to her mother, a situation which raises concerns. The mother expresses guilt, stating, "I feel guilty because I spend more time with Giannis, but it's unavoidable," highlighting her internal conflict regarding equitable caregiving among her children.

Although the grandparents contribute significantly to daily activities, they do not fully comprehend Giannis' special needs. As his mother notes, "They believe we are exaggerating and perceive it primarily as an upbringing issue." The lack of adequate psychoeducation within the extended family network appears to hinder family cohesion and effective support.

The family's relationship with the school is ambivalent. Despite the classroom teacher's positive intentions, Giannis' mother expresses dissatisfaction concerning limited communication and inadequate coordination with the support teacher. She emphasizes, "I am informed about what happens at school only when Giannis returns home agitated or isolated." This experience reveals structural limitations within the educational system concerning the comprehensive management of students with disabilities, indicating that collaboration among stakeholders frequently relies on individual initiative rather than systematic institutional approaches.

5. ANALYSIS OF SEMI-STRUCTURED INTERVIEW

The interview with Giannis' mother illuminated crucial aspects of family experience and the adaptive processes associated with parenting a child with neurodevelopmental disorders. Through thematic analysis, five main themes emerged, illustrating not only the

psychological burden and needs of the family but also the systemic complexities inherent in relationships with educational institutions and therapeutic providers.

Emotional Responses to the Diagnosis. The mother described the initial period following the diagnosis as a significant psychological shock, accompanied by denial and feelings of guilt: *"I didn't want to accept it. I kept saying he was just shy and sensitive. I wondered if perhaps there was some mistake in the assessment."* This reaction aligns with the stages of grief documented in the international literature (Pistola, 2019; Mazzoni et al., 2021). Over time, with gradual familiarization with the diagnosis, the mother developed a new perspective: *"The more I learned, the more I realized this wasn't the end, just a different path."*

Impact on Family Life. The mother highlighted substantial disruptions in family dynamics. Her relationship with her husband experienced strain, as most of their energy and attention became centered around their son: *"Our relationship was affected. There was no space for just the two of us."* Additionally, she reported experiencing social isolation and withdrawal from friendships: *"I avoid social gatherings and outings. I don't want to risk upsetting Giannis. We have become socially isolated at home."* Such experiences reflect patterns commonly documented among families with children diagnosed with ASD or ADHD (Wall, 2010; Brown et al., 2013).

Challenges in Daily Organization and Parenting Role. The mother described an intensely demanding daily routine, where her caregiving role consumes all her available energy: *"My day begins and ends with Giannis. I can't remember the last time I slept peacefully. My mind is constantly focused on him."* Concurrently, she expressed concern for her younger daughter, who persistently seeks attention: *"She clings to me constantly. I feel guilty because I spend less time with her."* This internal conflict exemplifies the challenges family systems face when psychological and social resources are limited (Craig et al., 2016; Vetri et al., 2020).

Relationship with the School. Collaboration with the school was marked by notable deficits, particularly concerning communication and coordination: *"I learn about incidents after they've already occurred. Giannis comes home distressed, and nobody from the school has contacted us."* The mother expressed doubts about the existence of genuine cooperation among involved educators: *"I'm unsure if they coordinate with each other or if everyone acts independently."* The lack of systematic and consistent communication, as documented in other studies, represents a frequent shortcoming in the implementation of inclusive practices (Resch et al., 2010; Kilic et al., 2013).

Relationships with Therapeutic Providers and Professionals. While positive experiences exist, notably with certain professionals such as the occupational therapist and parental counselor, the mother expressed frustration due to the absence of coordination: *"Each professional gives different instructions. Nobody seems to have an overall view. We feel lost."* The fragmented service provision and lack of unified guidance emerge as chronic issues in the support of children with neurodevelopmental disorders (Sánchez Amate & Luque de la Rosa, 2024).

Conclusion. Overall, the mother's narrative highlighted numerous challenges she faces as the primary caregiver, emphasizing her need for validation, substantial support, and understanding. Despite the psychological strain, she remains committed to providing her child with a stable and secure environment. Her voice serves as a valuable resource for mental health professionals, educators, and policymakers, contributing insights essential for designing socially sensitive and empirically grounded interventions.

5.1. Emotional and psychological responses

The emotional and psychological experiences of families raising children with neurodevelopmental disorders are inherently complex, multidimensional, and deeply human. The experiences of Giannis' family illustrate the internal transformations and interpersonal consequences associated with managing the diagnosis, highlighting the contradictory attitudes and emotions encountered by parents in their everyday lives.

The mother, who assumed the primary caregiving role from the outset, reported feelings of intense anxiety, constant vigilance, and profound exhaustion: *"I cannot remember the last time I slept peacefully. My mind is always on Giannis, even when I am away from home."* The constant engagement with therapeutic programs, the organization of daily routines, and the necessity of adapting to her child's needs have accumulated substantial physical and psychological stress, frequently resulting in parental burnout (Pistola, 2019; Purpura et al., 2021; Craig et al., 2016).

Additionally, the mother strongly experiences feelings of social isolation. She explicitly mentioned that her social interactions have significantly decreased as she avoids exposing Giannis to situations that might provoke tension or dysregulation: *"Often, we don't leave the house. I fear how he might react. Gradually, our friends distanced themselves."* Such isolation is exacerbated by the limited understanding within their social environment and frequently contributes to emotional depletion (Brown et al., 2013; Kilic et al., 2013).

The relationship between the parents has experienced challenges. The mother expressed a sense that she carries most of the responsibility, whereas the father maintains a distant stance: *"I feel that I carry this burden alone. He withdraws into himself."* Their limited communication negatively impacts family stability. This aligns with findings indicating that fathers often adopt more detached attitudes, either due to societal expectations or their own difficulties coping with the situation (Craig et al., 2016; Wang et al., 2011).

Grandparents' involvement represents a critical pillar of support, yet it comes with its own set of challenges. Although grandparents provide significant practical assistance, they often fail to fully understand the nature of the disorders. As the mother noted, *"They help a lot, but they don't understand... they think we are exaggerating."* Insufficient psychoeducation within the extended family can exacerbate tensions and further burden the parents emotionally (Wall, 2010; Rosenbaum, 2016).

Despite these challenges, the mother described moments of profound connection with Giannis: *"He may not speak much, but when he laughs, I feel like he is telling me, 'I'm okay.'"* Such emotional intimacy acts as a crucial resilience mechanism, enhancing the sense of purpose and meaningful engagement (Romero et al., 2021). The mother's dedication emerges as a fundamental stabilizing factor within the family system, particularly when institutional structures present significant shortcomings.

Overall, the portrayal highlights the necessity for substantial and ongoing parental support through empowerment programs, support groups, and explicit recognition of their complex role. Giannis' family thus represents both vulnerability and dynamism, where everyday difficulties, under appropriate conditions, can transform into opportunities for caregiving, conscious presence, and mutual empowerment.

5.2. Collaboration with school and external agencies

Collaboration among the family, school, and external support agencies emerges as both critical and significantly problematic in Giannis's case. The mother repeatedly expressed disappointment regarding the quality of communication with the educational institution: *"We find out what happened only when Giannis returns home upset. No one has informed*

us beforehand." The absence of timely and systematic communication fosters uncertainty among parents, complicating smooth transitions between the school and family environments (Pistola, 2019; Resch et al., 2010).

Although the support provided through the resource-teacher model (parallel support) is institutionalized as an essential inclusion strategy for students with developmental difficulties, substantial implementation issues are evident. In Giannis's situation, parallel support is only partially provided during school hours, lacking systematic coordination with the mainstream classroom teacher. The mother stated: *"I don't know who is responsible for what. Nobody explains to me what exactly they do at school."* This disconnection between involved professionals corroborates findings from previous studies highlighting inadequate implementation of inclusive educational principles (Kilic et al., 2013; Mazzoni et al., 2021).

Similar difficulties occur in collaboration with therapeutic agencies. Although Giannis attends speech and occupational therapy sessions privately, there is no systematic network or information exchange between professionals and either the school or the family. As the mother mentioned: *"Everyone operates individually. There is no coordinator. We have to transfer information from one specialist to another."* The absence of a coordinated approach represents a longstanding weakness within support systems for children with neurodevelopmental disorders, identified as a critical barrier to effective care (Sánchez Amate & Luque de la Rosa, 2024; Rosenbaum, 2016).

In summary, Giannis's case reveals a deficiency in a unified, well-coordinated support strategy. Although individual professionals exhibit notable efforts, a robust institutional framework to ensure integrated cooperation between school, family, and therapists is absent. The family's experience underscores the need for institutional enhancement of communication, and for establishing stable, transparent, and common channels of action, thus preventing fragmented and disorganized care.

5.3. Systems of resilience

Despite the complex challenges of raising a child with neurodevelopmental disorders, Giannis's family mobilizes essential resilience mechanisms that allow them to manage everyday demands with remarkable adaptability. Resilience, in this context, is not defined by the absence of difficulties but by the capacity of the family system to survive, transform, and continue functioning under conditions of psychosocial stress (Romero et al., 2021; Heward, 2011).

The mother represents a central pillar of this resilience, actively engaging in therapeutic interventions and consistently seeking support through psychoeducation. Her participation in a parental counseling group has deepened her understanding of Giannis's behaviors, enabled calmer responses to crises, and helped develop realistic expectations. She remarked: *"I realized I'm not alone. There are other families experiencing similar situations."*

The strong emotional bond with Giannis also serves as a crucial empowering resource. Despite daily struggles, the mother emphasizes the importance of this relationship: *"He is my child. Nothing matters more than helping him feel well."* This engaged and stable relationship appears to enhance her psychological resilience and safeguard the family system as a whole (Pistola, 2019; Wall, 2010).

Although the father exhibits emotional detachment, the broader family context maintains cohesion largely through the grandparents' involvement. Despite their limited specialized understanding, their consistent physical presence and contributions to practical daily tasks

provide significant support (Rosenbaum, 2016; Wall, 2010). Nonetheless, maximizing their contribution requires targeted psychoeducation to help them better comprehend the child's needs and improve their interaction skills.

The child's inclusion in school, despite implementation shortcomings, establishes a consistent daily routine, indirectly contributing to the family's sense of normalcy. Therapeutic interventions and regular school attendance serve as key pillars of stability (McConkey & Collins, 2010).

Giannis's family experience indicates that even with limited resources, families actively cultivate strategies for adaptation and empowerment. Recognizing and enhancing these strategies should constitute a fundamental objective for mental health professionals and social policy agencies, informing the development of targeted, sustainable interventions.

5.4. Intervention and policy recommendations

The experience of Giannis's family, as revealed through qualitative analysis, clearly highlights the necessity for a multi-level support framework that transcends individual initiatives and integrates strategic institutional interventions. Primarily, systematic psychological support for parents is essential, either through individual counseling or group-based psychoeducational interventions. Parental burnout, repeatedly documented in the international literature (Pistola, 2019; Purpura et al., 2021), constitutes a significant barrier to the long-term care of the child and overall family cohesion.

Furthermore, systematic training and psychoeducation of the family's support network, including grandparents and close relatives, becomes imperative. Enhancing environmental awareness reduces maternal emotional isolation and reinforces collective responsiveness to the child's needs (Rosenbaum, 2016; Wall, 2010).

At the school level, the establishment of systematic collaborative mechanisms between general and special educators, coupled with the active involvement of school leadership in supporting inclusive practices, is strongly recommended (Kilic et al., 2013; McConkey & Collins, 2010). Institutionalizing weekly meetings, maintaining coordinated intervention plans, and appointing a dedicated coordinator within each school could significantly enhance the support framework.

Finally, there is a critical need for government enhancement of care services through funding for therapies, transportation, and adequate hours of parallel support. Without sufficient resources, inclusion remains merely rhetorical. Supporting the family should be regarded as an investment in the child's long-term functionality rather than preferential treatment.

6. CONCLUSIONS

The case of Giannis's family provides a clear depiction of the multi-layered and interconnected dimensions involved in parenting a child with a neurodevelopmental disorder. The diagnosis represents not merely a medical or educational event, but a profound psychosocial experience affecting family relationships, roles, and personal identities (Pistola, 2019; McManus et al., 2011). The mother, as the primary caregiver, faces heightened psychological demands, anxiety, and isolation, yet simultaneously develops strategies of resilience and emotional connection with her child.

The lack of effective coordination between school, specialists, and the family, as well as insufficient utilization of parallel support, exposes structural weaknesses in the Greek educational framework (Kilic et al., 2013; Mazzoni et al., 2021). Nevertheless, the family itself demonstrates significant sources of empowerment, including parental commitment,

proactive information-seeking, and support—albeit limited—from their immediate social environment.

The study of this case underscores the need for a holistic, inclusive, and person-centered approach to caring for children with neurodevelopmental disorders. Responsibility cannot solely rest upon families. Instead, establishing a coordinated, sufficiently trained, and actively engaged support network is necessary, one that reinforces family roles and promotes the child's functionality and quality of life through respect and understanding.

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