Cultural Perceptions of Autism, Diagnostic Instruments, and Healthcare Resources in Romania: A Situational Analysis

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Abstract

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition characterized by difficulties in social interaction, communication, and restricted or repetitive behaviors. Although ASD is highly prevalent worldwide, most research has been conducted in high-income countries, leaving low- and middle-income countries underrepresented. This thesis analyzes the interaction between social norms and their impact on treatment selection and diagnostic processes for children diagnosed with autism in Romania. Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, both peer-reviewed studies and gray literature were reviewed in English and Romanian. Data was extracted, translated, and qualitatively synthesized to identify patterns across healthcare practices, treatment availability, and cultural perceptions. Findings reveal that Romanian families navigate a paradox of high awareness but limited access: while many therapies exist, services remain unevenly distributed and financially burdensome. Stigma strongly influences both family experiences and professional practices, leading to diagnostic delays, school exclusion, and concealment of diagnoses. Recent policy changes, including a 2023 national reform providing reimbursement for autism therapies, represent progress. However, systemic barriers such as corruption, regional disparities, and limited professional training persist. Thus, ASD in Romania emerges not only as a clinical condition but also as a cultural and structural phenomenon. For children with autism and their families, meaningful change will come only when policies are implemented fairly, professionals are equipped to provide help, and fragmented services are unified into a reliable system.

Keywords: Autism spectrum disorder, Romania, stigma, healthcare

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition, characterized by challenges with social interaction and communication, the presence of restricted or repetitive behaviors, and heightened sensory sensitivities (American Psychiatric Association, 2013). Beyond these primary characteristics, many children with ASD also experience difficulties with emotional regulation, which can lead to an irritable disposition or temper tantrums (Totsika et al., 2010).

The global prevalence of ASD has gradually increased, with current estimates suggesting that around one in 44 children are affected by this condition (Maenner et al., 2021). Alongside attention-deficit/hyperactive disorder (ADHD), ASD is one of the most common neurodevelopmental disorders (Federico et al., 2024). This rise in prevalence signals a growing need to support families who struggle with the psychological and caregiving demands of raising children with autism. According to Estes et al., (2009) parents of children diagnosed with autism consistently report higher levels of parenting stress and psychological distress compared to parents of typically developing children and even those caring for children with other disabilities.

Although ASD is highly prevalent (Maenner et al., 2021), most research on this condition is conducted in high-income countries. As a result, low- and middle-income countries are still underrepresented (Durkin et al., 2015; Elsabbagh et al., 2015; de Vries, 2016). According to de Vries (2016), this imbalance persists despite the demographic pattern that an estimated 90% of individuals with ASD likely live in low- and middle-income countries. It is important to note that, this estimate reflects the population distribution and not a diagnostic prevalence (WHO, 2011; Elsabbagh et al., 2012). This pattern of distribution reveals a deeper structural gap: individuals with ASD that live in environments with lower resources remain largely invisible. The absence of tools, research infrastructure, and clinical

services highlights the need to examine how these global patterns emerge within particular cultural contexts. This thesis therefore focuses on Romania.

Romania is a post-communist country located in the Eastern Europe, with a population of approximately 21.9 million inhabitants (National Institute of Statistics, 2023). Since joining the European Union in 2007, the country has undergone a rapid economic development. However, structural gaps are still present. They are particularly present in: education, public health, and mental healthcare (Kovess-Masfety et al., 2016; Petre et al., 2023; Petrescu, 2019). Furthermore, religion is of great importance in Romania, with the majority of the population (86.3%) identifying as Christian Orthodox (National Institute of Statistics, 2023). This prevalence gives Orthodox beliefs significant influence over societal views on morality, parenting, and disability. Lastly, Romania is also characterized by a collectivistic culture (David, 2015), where the needs of the group often outweigh those of the individual, which sometimes reinforces bias (Someki et al., 2018).

Prior to 1989 in Romania, children with ASD were classified under the broader category of intellectual disabilities. This meant they received assessments in clinics, day-care centres, and hospitals, along with pharmacological treatments (Dobrean, 2010), which did not address the core symptoms and challenges faced by children with autism. During this period, Romania did not have any autism-specific screening tools, even though such instruments had been developed internationally since the 1960s (Rimland, 1964, 1968). However, diagnostic tools like the ADI-R and ADOS-G became available in Romania in the 2010s (Dobrean, 2010). Furthermore, the CS-TSA (Chestionarul de Screening pentru Tulburări de Spectru Autist) was developed by David et al. (2013), with support from the Ministry of Health, to help general practitioners improve early detection of ASD. While this tool showed promising psychometric properties, diagnoses are still typically made after the age of three, and intervention delays of one to two years are common (Salomone et al., 2016). Moreover, even

when a diagnosis is delivered, parents report that professionals rarely explain the condition clearly, leaving them confused and unsupported while navigating their child's needs. This is a pattern also observed among families of children with disabilities more generally in Romania (Collins & Coughlan, 2016).

Despite notable shifts in both laws and societal norms, a diagnosis of ASD can still bring significant emotional unease for Romanian parents (Toth, 2015). Many struggle with the diagnosis: 38% of parents reported feeling that the diagnosis should be kept as a secret, while 19% of parents still hide it from certain individuals (Toth, 2015). Furthermore, an ASD diagnosis impacts not only the family system but also broader social relationships, by altering how others perceive and interact with the family. This dynamic introduces additional emotional burden, one that is further solidified by social stigma. Thornicroft et al. (2007) define social stigma as encompassing ignorance (lack of knowledge), prejudice (negative attitudes), and discriminatory behaviors. Stigma can intensify a range of difficulties for families with autistic children, including public misunderstandings of their child's behavior, inappropriate remarks from others, social exclusion, and even mistreatment in public settings. More than half of parent's report experiencing mistreatment in public spaces such as parks, stores, or public transport due to their child's behavior (Toth, 2015). Additionally, for parents of children belonging to ethnic minorities, such as the Roma community, the stigma associated with ethnicity often overshadows the diagnosis of ASD, reinforcing discrimination and exacerbating prejudice (Toth, 2015).

Beyond stigma, caregivers of children with autism struggle in the medical sector as well. The medical sector in Romania is divided into private and public sectors. The Minister of Health (Ministerul Sănătății) oversees the public sector that the majority of Romanians use (Petre et al., 2023). However, parents of Romanian children sometimes pay additional fees to doctors to access their services, which often functions as a form of bribery. Nevertheless,

individuals always have the option of choosing private healthcare if they have the financial means to do so. Based on a survey about perceived corruption in the public health system, one in every five respondents (20.5%) considers corruption to be the main problem in the Romanian medical system (Farcasanu, 2010). The primary reasons cited for this corruption are the societal norm of giving or receiving bribes (73.4%) and the lack of penalties (70.9%) (Farcasanu, 2010).

Kovess-Masfety et al. (2016) conducted a project called School Children Mental Health in Europe (SCMHE), which aimed to develop a set of indicators to efficiently monitor the mental health of primary school children across European Union countries. Romania participated in this project as well, and it was found that the majority of children (90.4%) with psychiatric needs primarily had contact with a general practitioner. Furthermore, Rahbar et al. (2021) found that Romanian general practitioners have a limited understanding of mental health disorders, including ASD. This lack of knowledge can negatively impact the health and well-being of individuals affected by these conditions.

This is the first situational analysis that aims to investigate the intricate interaction between social norms and their impact on treatment selection and diagnostic processes for children diagnosed with autism in Romania. This study aims to offer insights into the lasting effects on policy formulation, clinical protocols, and societal perspectives regarding ASD in Romania. The specific research questions to be addressed are as follows:

1. What are the cultural norms related to autism in Romania?
2. What treatments are offered for children with autism in Romania by healthcare practitioners?
3. How does stigma influence healthcare practitioners in diagnosing children with autism?
4. Are the treatments for autism covered by health insurance?

Method

This study adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021). Originally published in 2009, the PRISMA guidelines were designed to address several conceptual and practical advancements in the science of systematic reviews (Moher et al., 2009). Due to further advancements in the methods for identifying, selecting, evaluating, and synthesizing primary studies, an essential update was released in 2020. The PRISMA 2020 statement includes an explanation and elaboration, a flow diagram, and a checklist with seven sections containing 27 indicators, some of which have sub-items (Liberati et al., 2009; Page et al., 2021). The PRISMA statement aims to enhance the transparency and scientific quality of systematic reviews and meta-analyses. Many journals endorse PRISMA and reference it in their author guidelines (Moher et al., 2009). In psychology, adherence to these guidelines by researchers, clinicians, authors, and reviewers will elevate the scientific approach and improve practice by enhancing the quality of evidence (Swartz, 2015).

Eligibility criteria

This situational analysis makes use of data collected through diverse methodologies. Both qualitative and quantitative studies were eligible, including interviews, surveys, and observational research. The inclusion criteria specified studies that: involved children under 18 years of age with a diagnosis of ASD, were conducted with Romanian participants, and were published in English or Romanian. Exclusion criteria were: studies not involving Romanian participants, studies targeting populations over 18 years of age, studies published in other languages.

Data sources

This situational analysis employed a deliberately broad search strategy to maximize retrieval of literature concerning autism in Romania. The primary database was PsycINFO, where searches were conducted using both English and Romanian terms. PubMed was also screened, though it offered no additional Romania-specific studies, as most results were biomedical in focus (e.g., neuroimaging, biomarker studies) and beyond the scope of this analysis. Google Scholar and ResearchGate were consulted but not used systematically due to their lack of filtering mechanisms and inclusion of large volumes of non-peer-reviewed content.

Given the scarcity of peer-reviewed research on systemic issues such as healthcare access, diagnostic practices, and stigma, gray literature was deliberately included. Sources comprised Romanian government websites (e.g., Ministry of Labour, Family, Youth and Social Solidarity; National Institute of Statistics; National Institute of Public Health), NGO publications (e.g., Romanian Angel Appeal), and purposeful Google searches. One such search identified a doctoral thesis from Queen's University Belfast focusing on autism and discrimination in Romania. Even though not available on PsycINFO, this thesis provided unique data and was therefore included. The October 23 policy announcement on reimbursement for autism therapies was also included, as it was directly relevant to the research question examining treatment reimbursement. (Ministry of Labour, Family, Youth and Social Solidarity, 2023).

Search strategy and selection criteria

The following keywords were employed: "Children" AND "Autism, "OR "Autism spectrum disorder," OR "ASD," OR "Autistic, "AND "Romania, "AND "Healthcare," AND "Stigma," OR "Prejudice," OR "Discrimination." Moreover, searches were conducted in the Romanian language using the following keywords: "Copii" AND "Autism," OR "Tulburare

de spectru Autist," OR "TSA," AND "Sistemul de sănătate," AND "Stigma," OR "Discriminare," OR "Prejudecată."

Translation

The translation process for the Romanian articles involved several steps to ensure accuracy and fidelity to the original text. Initially, a translation software, such as ChatGPT (OpenAI, 2023), was employed to translate Romanian documents into English. Following this, the researcher (A.G.B), who is a native Romanian, conducted a thorough proofreading of the translated content, making necessary amendments to enhance accuracy and readability. Furthermore, the revised English translation was re-submitted to ChatGPT (OpenAI, 2023) to be translated back into Romanian. This back-translation step (Brislin, 1970) was implemented to verify the accuracy of the English version by comparing it with the original Romanian text. If the back-translated Romanian version closely matched the original document, the English translation was considered accurate. Finally, the completed English translation was submitted to the project supervisor for final review and proofreading. This multi-step translation process ensured that the English version of the articles closely reflected the content and nuances of the original Romanian texts.

Data Collection and Extraction

All search results were exported into Excel. Titles and abstracts were screened by the author to exclude studies not meeting the inclusion criteria. Full texts of potentially relevant studies were then reviewed in detail, and the selection process is illustrated in Appendix A, which presents the PRISMA diagram. Furthermore, the extracted data from each source included is provided in Appendix B, while an expanded exclusion breakdown is present in Appendix C, which documents the reasons for exclusion, with categories including: robot-assisted interventions, quasi-autism institutional deprivation cohorts, ADHD-focused research, and therapy efficacy trials. The pattern of exclusions itself highlights an imbalance

in the autism research present in Romania, with systemic and cultural factors underrepresented relative to intervention studies.

Data syntheses

Following a comprehensive search across multiple databases using the specified keywords, titles, and abstracts of the retrieved studies were screened by the author to identify relevant studies. Studies that met the initial screening criteria were retrieved in full text and assessed for eligibility based on predefined criteria. Given the diversity of study designs and outcomes, a narrative synthesis was chosen to integrate findings from both qualitative and quantitative studies. This approach facilitated a comprehensive understanding of the complex interactions between stigma, cultural norms, and healthcare for children with autism in Romania. Through a thematic analysis of qualitative data, themes related to cultural norms, stigma, and healthcare practices were identified. This process involves coding the data via Excel and grouping the codes into overarching themes. The primary codes identified were discrimination, available treatments, and healthcare policies. Furthermore, healthcare tools were categorized into: behavioral intervention, developmental or relationship-based interventions, speech and language therapy, occupational therapy, and parent training. Additionally, discrimination was divided into parent-specific discrimination and child-specific discrimination.

Results

Stigma and Acceptance

Society

Research reveals diverse findings regarding social acceptance of families with children diagnosed with ASD. Munteanu (2014) emphasizes that a well-functioning family relies significantly on both intra-familial and extra-familial support. Intra-familial support was defined as the interaction, cohesion and adaptability among family members. By contrast,

extra-familial support referred to available resources outside of the family, such as: professionals, schools, legislations (Munteanu, 2014) In this study, 66.6% of Romanian parents reported openly discussing their child's diagnosis with friends, family, extended family, and professionals. However, 23.3% of grandparents expressed high levels of stress and denial, 16.6% reported sadness and shock, and another 16.6% felt uninvolved or unaware. Importantly, a significant number of parents (53.3%) noted that grandparents primarily focused on helping (Munteanu, 2014).

In contrast, Toth (2015) found that around 25% of parents experienced discriminatory behavior from friends, neighbours, or public authorities. Such discrimination happened in different forms, such as: offensive looks, insults, and verbal abuse, which prompted many parents to conceal their child's diagnosis. Approximately 38% of parents felt pressured to hide the diagnosis from specific individuals, with 16% initially hiding it from close relatives and 19% continuing to do so. Stigma was particularly pronounced in public spaces: more than 50% of parents reported mistreatment in parks, stores, or public transport. Nearly two-thirds reported experiencing mistreatment in their communities because of their child's autism, highlighting the pervasive stigma these families endure (Toth, 2015).

Rusu et al. (2023) added quantitative evidence: affiliate stigma correlated significantly with both shame ($r = .59$, $p < .01$) and parental stress ($r = .13$, $p < .01$). Parents of children with moderate ASD reported the highest stress levels ($M = 48.58$, $SD = 11.99$), compared with mild ASD cases ($M = 39.24$, $SD = 9.77$). Furthermore, parents who continued therapy during COVID-19 reported lower stress ($M = 43.31$) than those who did not ($M = 47.23$, $p < .05$).

Psychological Impact on Parents

Tiba et al. (2012) explored cognitive vulnerability: negative parental emotions correlated with irrational beliefs ($r = .48$, $p < .01$), negative automatic thoughts ($r = .44$, p

= .02), and problem behaviors (r = .47, p = .01). Positive emotions were inversely associated with irrational beliefs (r = –.55, p < .01) and negative metacognitions about positive emotions (r = –.40, p = .03). This suggests that irrational beliefs block positive emotions and reinforce stress in parents of children with autism.

Collins and Coughlan (2016) conducted a qualitative study which is not autism-specific. Although this study did not focus specifically on autism, it was included because children with ASD are legally classified as persons with disabilities in Romania (Law 448/2006), and thus families face similar systemic barriers. The authors highlight Romanian mothers' experiences after receiving a disability diagnosis. Themes included: uncertainty, accidental discovery, and distrust in professionals due to misdiagnosis or inappropriate medication. Mothers reported bureaucratic marginalization during annual disability commission evaluations, which caused stress, stigma, and feelings of neglect.

Family

Romanian families display both resilience and strain in caregiving roles. Munteanu (2014) found that 90% of families engaged in free activities with their children, and 73.3% continued therapies independently at home. However, 20% reported high stress, and 10% required constant supervision. Grandparents played a significant role: 53.3% of families reported strengthened relationships, while 16.6% saw little change. Gender roles varied, with 60–70% of parents sharing caregiving, while 30–40% believed mothers should take primary responsibility (Munteanu, 2014).

Toth (2015) also noted that a diagnosis of autism often strains social and familial bonds, with one-third of parents reporting negative changes in family life and interactions. Eight percent experienced separation or divorce post-diagnosis, and 12% reported a decline in marital satisfaction. Additionally, 10% encountered distancing from extended family or friends, and 7% reported that close relationships were severed entirely. Social isolation is also

a reality: one in six parents chose to withdraw socially. Despite these challenges, 46% of parents reported strengthened familial relationships, although 14% felt their relationships had deteriorated (Toth, 2015).

Media Representation

The "Give Me a Chance!" campaign, a year-long initiative aimed at raising public awareness about autism in Romania, utilized a wide range of media platforms (Pasco et al., 2014). It included one television spot, three audio spots, and ten press releases. Additionally, 16,000 posters and 30,000 informational flyers were distributed to schools and parents, complemented by eight 25-minute radio interviews with autism professionals on Radio Itsy-Bitsy, a station targeting parents and children. To further encourage public engagement, six events were organized for community participation and education (Pasco et al., 2014).

Treatments and Therapies

Salomone et al. (2016) conducted a survey about the interventions children with ASD received across 18 European countries, including Romania. Among the 1,680 participants, 62 were Romanian parents of children with ASD aged seven or younger. The study found that 80% of Romanian children with ASD received behavioral interventions, while 25.8% participated in developmental or relationship-based interventions. Additionally, 67.7% received speech and language therapy, 37.1% underwent occupational therapy, 21% engaged in other educational or psychological interventions, and 56.5% participated in parent training.

Munteanu (2014) surveyed Romanian families' knowledge about ASD services and therapies. Parents reported awareness of physiotherapy, occupational therapy, speech and language therapy, early intervention, therapeutic listening, PECS (Picture Exchange Communication System), ABA (Applied Behavior Analysis), music therapy, animal-assisted therapies (e.g., horse-riding, therapy dogs), sensory integration, art therapy, TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children), and

medication. Between 66.6% and 86.6% of families reported using various interventions, and only 10% indicated a lack of information. The first specialized school for children with autism, offering both preschool and elementary education, opened in Cluj-Napoca in 2013. Some organizations, such as Casa Faenza Community Centre, provided dedicated support. Interestingly, 63.3% of parents surveyed felt that the diagnostic system required no further improvements (Munteanu, 2014).

In contrast, Toth & Mareș (2015) conducted a large survey (*N*=728 parents) regarding the needed services for parents with children with ASD. The key findings are as follows: 84% had consulted a family doctor before diagnosis, 75% visited a psychologist, and 66% saw a psychiatrist. However, 64% reported therapy expenses as a significant financial burden. 58% felt they lacked sufficient services in their county, and 67% rated available therapies as insufficient. The most accessed therapies were speech therapy (66%) and ABA (42%).

Diagnostic Processes

Policy Innovation

Although a number of screening tools for ASD are available internationally, Romania lacked an assessment instrument tailored specifically for its population. In response, the Romanian Health Ministry initiated the development of the Chestionarul de Screening pentru Tulburări de Spectru Autist (CS-TSA), a screening questionnaire designed exclusively for use by Romanian general practitioners (David, 2015). This decision was driven by two main considerations: first, no ASD screening tools had been validated for the Romanian context, and second, the Ministry recognized that a favourable implementation setting within Romania's healthcare system would maximize the tool's effectiveness. By focusing screenings within GP practices, which maintain regular contact with families, the Ministry aimed to align ASD detection efforts with the structure of Romania's healthcare and social services. The primary objective of the CS-TSA was to facilitate early ASD detection by

providing a practical screening option to identify developmental anomalies that may indicate autism. With ASD diagnosis on the rise and high costs associated with comprehensive evaluations, this tool was developed to offer a preliminary assessment, allowing for timely referrals to mental health professionals. Modelled after the Checklist for Autism in Toddlers (Baron-Cohen, Allen, and Gillberg, 1992), the CS-TSA was carefully adapted to meet Romania's specific needs (David, 2015).

Parental Evaluations

Feedback on diagnostic adequacy was mixed. Among parents surveyed, 63.3% believed the current process required no changes. Others expressed the need for quicker diagnosis (3.3%), more centres and early intervention options (20%), additional professional training (26.6%), and better awareness and information dissemination (3.3%) (Munteanu, 2014).

Lebeer et al. (2011) found that Romanian assessment practices emphasized deficiencies rather than functioning. Official evaluation sheets focused on general function (70%), language (60%), cognitive functions (50%), social skills (30%), and motor skills (20%). School psychologists sometimes conducted over 1,000 assessments per year, resulting in superficial evaluations.

Bejarano-Martín et al. (2019) examined detection and diagnosis across the EU, Romania being included. Families reported raising concerns at 18.3 months on average, while diagnoses were confirmed at 36.4 months, and interventions began at 42.2 months. Around 20% of families received no information at diagnosis. Speech therapy and parental training were the most recommended interventions, but significant delays, greater than six months were common.

Guillon et al. (2022) reported on 2,032 families across Europe, including 28 from Romania. Families consistently rated detection and diagnosis processes less positively than professionals, particularly regarding how their concerns were addressed and the adequacy of information provided. The overall pattern emphasizes dissatisfaction with diagnostic delays and limited professional communication across the participating countries, including Romania.

Delays in Diagnosis

In Romania, most ASD cases are identified only when children enter kindergarten or early schooling. This delay in diagnosis significantly hinders timely interventions, which are crucial for improving long-term outcomes for affected children. One contributing factor to this delay is the limited awareness and understanding of ASD-specific characteristics among both practitioners and the general public (David et al., 2013). Furthermore, Munteanu (2014) highlights that the average age for diagnosis in Romania is 36 months, with the diagnostic process taking an average of 4.6 months. Parental report reveals that most ASD diagnoses occur when children are between two and three years old. However, approximately 25% of diagnoses are made only after age four. Intensifying this issue, many children with ASD also present with co-occurring developmental challenges: 65% experience delays in language development, nearly half exhibit delays in mental development, and around 40% are diagnosed with ADHD or hyperkinetic syndrome (Toth, 2015).

Parental Concern

Munteanu (2014) also examined parental concerns. Families worried primarily about their child's future and capabilities related to communication, learning, and improvement, and less about service availability or independence. Over half focused on what they could personally do to help their child. Immediate emotional reactions included uncertainty about next steps (23.3%), need for more information (46.6%), panic (26.6%), sadness (23.3%), and

existential questioning (43.3% asked “why me/why my child?”). These responses illustrate the profound psychological impact of diagnosis and the centrality of support in this phase.

Insurance Coverage

In September 2023, the Ministry of Labour, Family, Youth and Social Solidarity announced a reimbursement reform for therapies available for individuals with ASD. Starting with the 1st of October 2023, approximately 13,471 children and 2,660 adults diagnosed with ASD became eligible for coverage through the National Health Insurance House (CNAS). The program reimburses up to two therapy sessions per day, limited at 40–44 sessions per month, at a rate of 135 RON for a 50-minute session. Eligible providers include: specialists in clinical psychology, psychotherapy, educational psychology, special education, and counselling. This policy marks the first systematic nationwide insurance support for ASD therapies in Romania.

Discussion

This study examined how cultural perceptions, systemic infrastructure, and healthcare policy shape the experiences of children with ASD and their families in Romania. Given the country's unique post-communist social context and persistent institutional challenges, a situational analysis was conducted to explore four research questions: What are the cultural norms related to autism in Romania? What treatments are offered for children with autism in Romania by both healthcare and non-healthcare practitioners? How does stigma influence healthcare practitioners in diagnosing children with autism? Are the treatments for autism covered by health insurance? This section discusses the findings in relation to each question, connecting them to prior literature, systemic factors, and sociocultural realities. While the Results section followed a bottom-up approach, where themes were extracted from the available data, the Discussion adopts a top-down approach, interpreting these findings in relation to the research questions.

Cultural Norms Related to ASD in Romania

In Romania, perceptions of ASD are shaped by a complex interaction of cultural norms, stigma, and silence. For many families, a diagnosis does not provide relief; it often introduces pressure to conceal it. Toth (2015) reported that a significant number of parents initially concealed their child's ASD diagnosis from close relatives, and many parents continued to hide it more broadly. This concealment was not always motivated by shame of the child, but by fear of social rejection and discriminatory treatment. In public spaces, children's atypical behaviors are frequently misinterpreted, resulting in parental blame, verbal abuse, or exclusion (Toth, 2015). Mothers in particular described feeling harshly judged, suggesting that gender roles amplify stigma in caregiving contexts (Toth, 2015).

Stigma in Romania is not only external but also internalized. Rusu et al. (2023) found that affiliate stigma was strongly correlated with both shame and parental stress. Mediation analyses demonstrated that shame fully mediated the relationship between stigma and stress, highlighting this affective dimension as a critical mechanism. These findings indicate that stigma functions not only as social pressure but also as a psychological burden, which reinforces cycles of stress and negative cognitions.

Similarly, Tiba et al. (2012) showed that negative parental emotions correlated with irrational beliefs and automatic thoughts, while positive emotions were inversely associated with such beliefs. Together, these studies suggest that stigma in Romania is not only a social barrier but a factor that reshapes parental emotional and cognitive patterns, with implications for both family functioning and mental health.

The cultural context further complicates these dynamics. Romania's collectivistic values can serve as both a resource and a liability. On one hand, families report strong intrafamilial support, with many grandparents primarily focused on helping parents that have

children diagnosed with ASD (Munteanu, 2014). On the other hand, collectivistic expectations to "appear normal" and "not stand out" can intensify isolation when children deviate from social norms (David, 2015; Someki et al., 2018). Furthermore, this tension is even more pronounced for Roma families, where ASD is often misinterpreted as "ethnic misbehavior" rather than neurodevelopmental difference (Toth, 2015). Thus, the stigma of autism is filtered through the lens of ethnic bias, resulting in discrimination which leaves Roma children doubly excluded.

Even though efforts to reduce stigma exist, their impact has remained modest. The "Give Me a Chance!" campaign sought to increase awareness through media engagement (Pasco et al., 2014). However, the limited timing of the campaign restricted how much it could influence public awareness. Furthermore, almost all parents reported little or no knowledge of autism prior to their child's diagnosis (Toth & Mareș, 2015), highlighting significant gaps in public awareness of ASD. Following diagnosis, many parents reported reactions similar to grief, such as: denial, anger, shock, and despair (Toth & Mareș, 2015). Collins and Coughlan (2016) add that Romanian mothers often describe uncertainty and distrust in professionals, shaped by experiences of misdiagnosis, inappropriate medication, and bureaucratic marginalization.

In conclusion, the cultural environment in Romania frames a diagnosis of ASD as both a personal and collective challenge. Stigma manifests socially through discrimination, psychologically through shame and stress, and structurally through misdiagnosis and limited awareness. While intrafamilial support offers resilience, broader societal attitudes continue to isolate families, particularly those from minority groups, such as the Roma community. Future initiatives must extend beyond short-term awareness campaigns and prioritize sustained and culturally grounded interventions that address both social stigma and its psychological consequences. Moreover, targeted support for Roma families and professional

training to reduce diagnostic bias are essential to reducing the stigma and misinformation that families face.

Treatment Availability and Accessibility

In Romania, the availability of ASD focused therapies is marked by a paradox: a wide variety of interventions exists, yet access remains inconsistent and unevenly distributed. Salomone et al. (2016), found that most Romania parents of children with autism reported access to behavioral interventions, speech therapy, and occupational therapy. Developmental or relationship-based interventions were less common, while more than half of families engaged in parent training. These findings suggest a broad therapeutic portfolio, at least in principle.

Munteanu (2014) similarly reported high levels of parental awareness of available therapies, including ABA, TEACCH, sensory integration, music therapy, art therapy, physiotherapy, animal-assisted interventions, and speech and occupational therapies. Most families reported using such services, and only a few indicated a lack of information. Specialized institutions have also emerged, such as the first autism-specific school in Cluj-Napoca (opened in 2013), and community centres like Casa Faenza, which provide assessment and intervention services.

However, national data reveal a more complex reality. Toth & Mareș (2015), reported that many parents identified costs as a significant financial burden, while others noted insufficient services in their counties and overall dissatisfaction with the quality of available therapies. The most accessed therapies were speech therapy and ABA, suggesting reliance on a limited range of interventions despite the reported awareness of a broader set of options. Furthermore, regional disparities remain significant: families in urban areas have access to NGO-run programs such as Autism Transylvania and the Romanian Angel Appeal (RAA),

while families in rural areas often report minimal or no services. Teachers, who are the first line of support outside the family, also face significant constraints. Toth (2015) found that while most children would benefit from classroom assistants, only a small proportion actually received this support, reflecting both systemic underfunding and a lack of trained professionals.

These findings reveal a structural contradiction: parents are aware of many therapies and often use them, yet the quantity and quality of interventions remain far below international recommendations. A national assessment indicated that children typically receive only two to three hours of therapy per week, far below the evidence-based standard of 20 or more. Families cope by compounding together services from multiple sources: the majority rely on public providers and NGOs, but no single system is sufficient to meet these needs (Toth & Mareș, 2015).

In conclusion, the available ASD treatment in Romania is paradoxical: awareness is high, NGOs provide essential support, and specialized schools exist, but systemic gaps in funding, training, and regional coverage severely limit access. Future efforts must focus on scaling NGO innovations into sustainable public frameworks, increasing funding for classroom assistants, and ensuring equal access across rural and urban regions. Without such structural integration, Romania risks maintaining a dual system in which only certain families, those with financial means or geographic advantage, can access comprehensive care.

Influence of Stigma on Diagnosis and Education

Stigma in Romania does not always look like open rejection; it often manifests through diagnostic and educational delays. Although the Ministry of Health developed the CS-TSA, a screening tool tailored for general practitioners, usage has been uneven, and many professionals remain hesitant or undertrained in its use (David, 2015). As a result, children are

typically diagnosed around 36 months of age, with nearly one quarter not receiving a formal diagnosis until after age four (Munteanu, 2014; Toth, 2015). Furthermore, Bejarano-Martín et al. (2019) reported that concerns were first raised by parents at 18 months on average, yet children were only diagnosed at 36 months, with interventions beginning around 42 months. Guillon et al. (2022) further demonstrated that Romanian families rated the diagnostic process significantly less positively, particularly regarding the adequacy of information provided and responsiveness to parental concerns. These findings align with earlier observations by Lebeer et al. (2011), who noted that Romanian evaluations emphasized deficiencies over function. School psychologists were often responsible for an extremely high number of assessments, which can limit the depth, validity and reliability of their evaluations. When psychologists are pressured to process around a thousand assessments annually, evaluations risk becoming checklists of deficits rather than comprehensive assessments of a child's functioning and support needs.

Stigma interacts with these limitations in ways that sustain social exclusion. Some families reported concealing the diagnosis to avoid rejection in schools, while others were turned away after disclosure (Toth, 2015). This means that stigma shapes not only social interactions but also access to education and services. Schools often lack resources to accommodate children with ASD: a significant of children with ASD were not enrolled in school at all, and among of those enrolled, only a small proportion had access to a classroom assistant, despite more children needing one (Toth & Mareș, 2015). These findings indicate that institutional under capacity translates into educational exclusion which reinforces stigma through systemic failure rather than individual prejudice. Ethnic minority families face additional barriers. For Roma children, autism is frequently misread as ethnic misbehavior rather than neurodevelopmental difference, leading to higher discrimination and reduced access to services (Toth, 2015).

Toth (2015) found that while many teachers were willing to support children with autism, they lacked the professional preparation to do this effectively. This aligns with global observations that stigma operates across multiple levels: ignorance, prejudice, and discrimination, each reinforced by institutional gaps (Kassam et al., 2011; Thornicroft et al., 2007).

In sum, stigma in Romania is both social and structural. It shapes the timing of diagnosis, the willingness of professionals to engage with families, and the extent to which children are welcomed in schools. Delays are not only a function of resource scarcity but also of avoidance driven by stigma and exclusion. Future efforts must focus on strengthening professional training, ensuring accountability in schools, and addressing the discrimination faced by Roma families. Without tackling these systemic forms of stigma, legislative reforms alone will remain insufficient to guarantee timely diagnosis and inclusive education.

Insurance coverage for autism therapies in Romania illustrates the gap between formal policy and lived reality. Historically, families have paid the majority of therapy costs, with surveys indicating that the majority identified expenses as a significant financial burden and a significant proportion paid entirely out of pocket (Toth & Mareș, 2015). For many families, this financial pressure has severe consequences: more than half reported that caregiving responsibilities forced one parent, most often the mother, to leave employment or reduce working hours Thus, reducing household income.

Corruption within the healthcare system further complicates affordability. Farcașanu (2010) found that many Romanians identified corruption as the main problem in the medical system, with informal payments to physicians functioning as both expected and normalized. For families seeking autism therapies, this creates a double burden: not only must they cover therapy fees, but they may also face additional, informal payments to access public-sector

care. This undermines trust in the healthcare system and forces many families to rely on NGOs or private providers, reinforcing inequality between those who can afford additional expenses and those who cannot.

Insurance and Affordability

In September 2023, Romania introduced a major reform aimed at reducing this discrimination. The Ministry of Labour, Family, Youth and Social Solidarity announced that children and adults diagnosed with ASD became eligible for reimbursement through the CNAS Beginning October 2023, the program allows up to two therapy sessions per day, limited at 40–44 sessions per month, reimbursed at a rate of 135 RON for a 50-minute session. Eligible providers include specialists in clinical psychology, psychotherapy, educational psychology, special education, and counselling. This reform represents the first systematic nationwide insurance support for autism therapies in Romania.

However, significant questions remain regarding implementation. The reform does not specify which therapies are reimbursed, leaving ambiguity about whether families can access coverage for behavioral, speech, or occupational therapies. Additionally, given the prevalence of informal payments and uneven service distribution, the risk remains that reimbursement will not translate into fair access. Previous studies suggest that even when parents are aware of available therapies, fewer than half receive any reimbursement, reflecting structural barriers (Munteanu, 2014; Toth & Mareș, 2015).

In conclusion, while the 2023 CNAS reform marks an important systemic milestone, it is insufficient on its own to guarantee equal access. Financial barriers, corruption, and service shortages continue to constrain choices. Future policy must ensure transparency in which therapies are covered, enforce accountability in reimbursement, and provide targeted support to rural and underrepresented communities. Without these measures, Romania risks

implementing a policy that exists on paper but fails in practice, leaving families to choose between therapy and financial survival.

Structural and Systemic Gaps

Autism care in Romania is constrained less by the absence of laws than by the absence of coordination and accountability. Families often describe systemic failure as the cumulative weight of many small absences rather than a single point of collapse (Toth & Mareș, 2015; Petrescu, 2019). Educational, health, and social care systems operate in parallel, but rarely together: schools are mandated to include children with autism, yet teachers report limited training; doctors are responsible for diagnosis, yet lack time and knowledge; NGOs provide specialized support, yet are dependent on donor cycles and inconsistent funding. As a result, parents are left to coordinate services that do not coordinate with one another.

Data on the scope of the problem remain incomplete. Romania has no national prevalence study for autism (National Institute of Public Health, 2023), and Roma children are particularly underrepresented due to social marginalization and distrust of institutions (Toth, 2015). What is not counted is not funded, and what is not named is not served. These statistical gaps not only obscure the true scale of need but also perpetuate inequalities in policy attention and resource allocation.

Even where inclusion is formally mandated, implementation is weak. Nearly half of children report being mocked at school, one in four are not enrolled at all, and one in three have been physically assaulted by peers (Toth & Mareș, 2015). Families frequently encounter barriers to obtain shadow teachers and adapted materials, leaving inclusive education more aspirational than attainable. As a result, children with autism experience exclusion within the very systems designed to ensure their rights.

Corruption further compromises systemic trust. Petrescu (2019) documented misused funds, nepotism, and a broader pattern of institutional unreliability, raising concerns about the credibility of official data and the sustainability of reforms. Informal payments, previously identified as part of the norm in the healthcare system (Farcașanu, 2010), persist as hidden costs for families. These dynamics erode public trust and limit the effectiveness of policy interventions, even when well-intentioned.

In conclusion, the systemic gap in Romania is reflected by fragmentation, underfunding, and weak enforcement rather than a complete absence of initiatives. NGOs play an indispensable but insufficient role in filling these gaps, often substituting for state services. Future directions must include coordinated national prevalence studies, cross-sectoral integration of health and education, and transparent monitoring mechanisms to reduce corruption and ensure that reforms reach the families they are designed to support. Without such measures, Romania risks perpetuating a cycle in which families carry the burden of systemic dysfunction with little reliable institutional support.

Limitations and Future Directions

This situational analysis examined how cultural perceptions, diagnostic practices, stigma, and healthcare infrastructure shape the experiences of children with autism and their families in Romania. Utilizing both national and European data, the findings reveal a pattern of progress constrained by systemic fragmentation, cultural stigma, and institutional unreliability. As a Romanian researcher, my position is both a strength and a limitation. It allows me to interpret cultural silences, bureaucratic practices, and familial expectations from lived experience, but it also requires careful reflection to avoid normalizing systemic failures and introducing my own biases.

Furthermore, this situational analysis was constrained by both methodological and contextual factors. The limited number of Romanian peer-reviewed studies restricted the empirical depth of the findings, while the NGO reports illustrate how funding priorities can influence the methodological consistency. Moreover, no included study examined regional differences in depth, making it difficult to identify disparities between rural and urban settings or between counties.

Translation and back-translation procedures were carefully used, however subtle semantic nuances may have been lost, and the interpretation of results relied on the researcher`s subjective judgment, introducing a potential source of interpretive bias. Furthermore, the analysis focused on three main variables: stigma, availability of treatment, and reimbursement, leaving unexplored the influence of additional factors such as parental education, socioeconomic status, or minority identity.

Lastly, while peer-reviewed studies provide structured insight into how systems are designed to function, parent-driven online communities, such as Facebook groups and online forums, reveal how families navigate those systems in everyday life. The data from these informal sources were excluded to preserve methodological accuracy, but their absence narrows the representation of lived experience. Future research should incorporate first person perspectives alongside institutional data to bridge the gap between documented policy and lived reality.

Given these limitations, efforts to improve autism care in Romania must operate across multiple levels. At the policy level, transparent monitoring of the CNAS reform is needed, alongside clarity on reimbursed therapies, expanded funding for classroom assistants, and the integration of NGO innovations into sustainable state frameworks. In research, national prevalence studies are essential, with particular attention to Roma communities and

rural regions, while future work should also consider social media discourse as a source of raw, unfiltered insight into public attitudes toward autism. In practice, greater professional training for teachers, general practitioners, and psychologists is required to reduce diagnostic delays and support inclusive education. Finally, systemic accountability must be prioritized, with anti-corruption safeguards in healthcare and education to rebuild public trust and ensure that policies genuinely benefit the families they are designed to serve.

This thesis demonstrates that autism in Romania is not only a medical diagnosis but a social and structural phenomenon. Families navigate stigma in public, exclusion in schools, delays in healthcare, and gaps in insurance coverage. Progress is visible in new policies and the dedication of NGOs, but systemic failures continue to shift the burden of care onto parents who become therapists, case managers, and advocates by necessity rather than choice. The challenge that Romania faces is not only to pass laws, but to ensure that laws live in classrooms, clinics, and communities. Real reform requires cultural humility, institutional transparency, and a commitment to inclusion. The future of autism care in Romania depends on whether families remain isolated coordinators of fragmented systems, or whether the state and society step forward to share the burden. Only then can children with autism, and their families, be seen not as problems to be managed, but as citizens entitled to dignity, support, and belonging.

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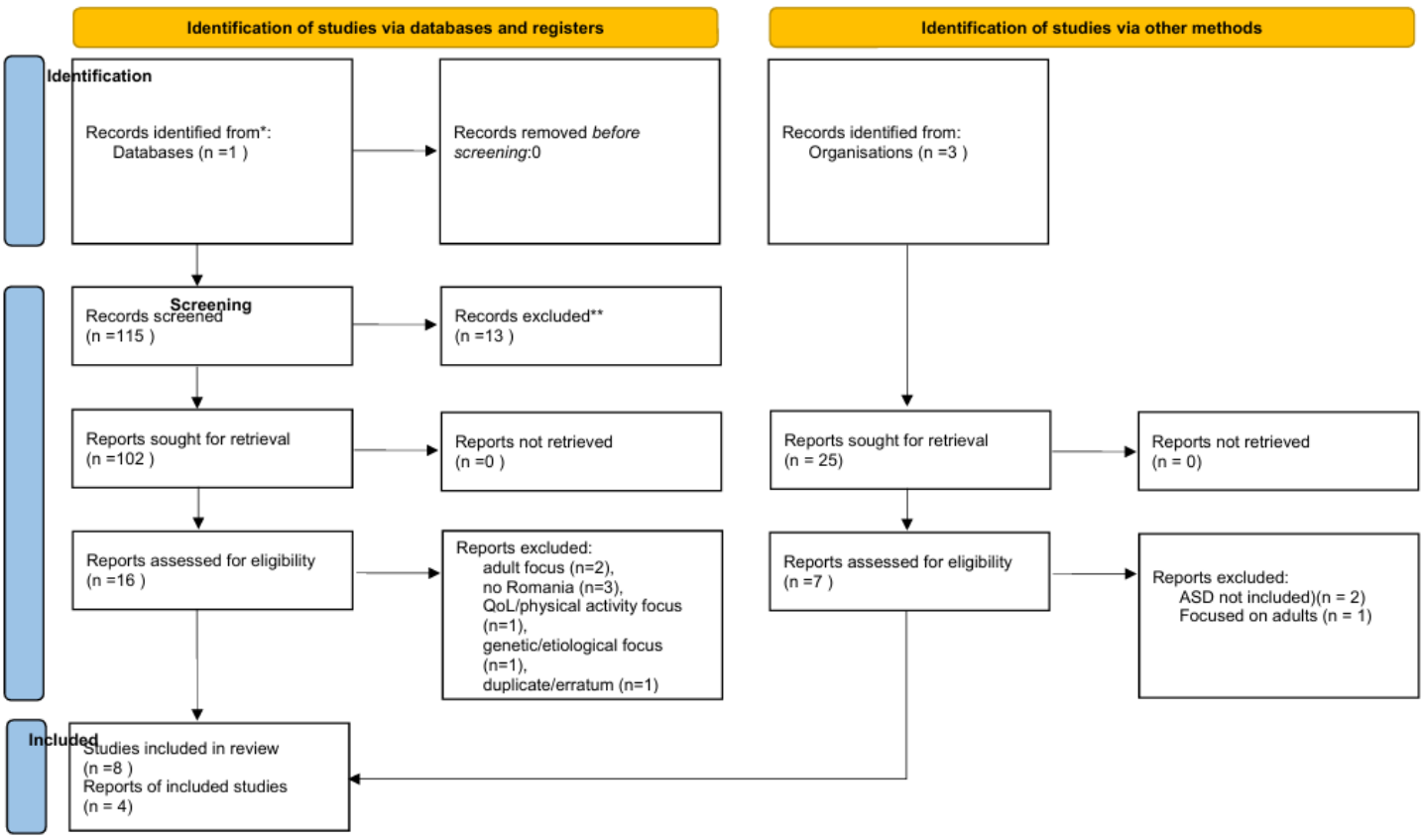
Appendix A

PRISMA Flow Diagram



Appendix B

Extracted Data from Reviewed Articles

Table 1

Overview of Studies on ASD Assessment, Diagnosis, and Services Provided in Romania

Authors	Year	Total Sample	Romanian Subsample	Objective	Key Findings
Bejarano-Martin et al.,	2019	2032	28	To compare family and professional perspectives on early ASD detection and intervention across the EU.	Families described significant gaps between first concerns and intervention onset, reflecting systemic delays in early detection and limited post-diagnostic guidance.
Collins & Coughlan	2016	8	-	To explore Romanian mothers' experiences following a disability diagnosis.	Mothers described uncertainty, miscommunication, and bureaucratic difficulties during annual disability assessments, revealing gaps between policy promises and lived experience.
David et al.,	2013	132	-	To validate the Romanian Screening Questionnaire for Autism Spectrum Disorders (CS-TSA	The study established the first Romanian screening tool for autism, showing adequate reliability and validity for use by general practitioners to enable early detection.

Guillon et al.,	2022	2032	28	To examine parental satisfaction with ASD detection and diagnosis processes across Europe.	Families across Europe expressed low satisfaction with the diagnostic process, due to delayed referrals and limited professional guidance.
Lebeer et al.,	2011	166	Not specified	To assess how European diagnostic systems for developmental difficulties support or hinder inclusion.	Romanian assessment practices are medicalized and test-oriented, with overburdened professionals relying on static psychometric tools rather than developmental evaluation.
Ministry of Labour, Family, Youth and Social Solidarity	2023	-	-	To introduce nationwide reimbursement for ASD therapies under the National Health Insurance House (CNAS).	The 2023 reform extended therapy coverage to over 13,000 children and 2,600 adults with ASD, funding up to 44 sessions per month.
Munteanu	2014	54	30	To explore family functioning and support systems among Romanian families raising children with ASD	Families displayed resilience through close routines and strong caregiving networks but relied heavily on family resources in the absence of professional support.
Pasco et al.,	2014	1005	-	To evaluate a three-year national initiative improving autism diagnosis, training, and	The project expanded Romania's autism foundation through national professional training, 40 new treatment centres,

				public awareness.	and a large-scale awareness campaign.
Rusu et al.,	2023	196	-	To examine how affiliate stigma and shame relate to parental stress in families of children with ASD.	Shame mediated the link between social stigma and parental stress, showing how societal attitudes amplify emotional burden for Romanian parents.
Salomone et al.,	2016	1680	62	To map early intervention, use for children with ASD across Europe.	Romanian parents most often accessed behavioural and speech therapies. However, service availability and fairness are inconsistent, reflecting structural obstacles for early interventions.
Tiba et al.,	2012	27	-	To analyse cognitive vulnerability factors in parents of children with ASD	Irrational beliefs and negative metacognitive patterns reduced positive affect and resilience. Representing the cognitive mechanisms underlying parental distress.
Toth	2015	129	-	To document experiences of stigma and discrimination among Romanian families of children with ASD.	Families frequently encountered public and institutional discrimination, leading many to conceal their child's diagnosis. Stigma impacted social and marital relationships

					which reinforced isolation.
Toth & Mareș	2015	728	-	To evaluate parental access to ASD services and perceived service needs in Romania.	Most families consulted multiple specialists before diagnosis and faced financial difficulty. Parents reported therapy shortages, regional disparities, and uneven quality.

Note. This table summarizes all peer-reviewed, NGO, and governmental sources included in the situational analysis. Several studied covered European countries, including Romania. Thus, the sample is divided into Total Sample and Romanian Subsample. A dash (–) in the Romanian Subsample column indicates that the study was conducted exclusively in Romania, and the entire sample is represented in the Total Sample column. The Ministry of Labour, Family, Youth and Social Solidarity (2023) source does not report a sample size, because it represents a governmental policy announcement.

Appendix C

Detailed selection criteria for scientific articles and gray literature

Table 2

Expanded Exclusion Breakdown – Scientific Literature

Topics	Nr of articles	Example study type
Robot-assisted therapy (incl. VR)	15	Social robots, VR-based interventions
Therapy/intervention efficacy only	11	Occupational therapy, ABA, LC-SMA
Quasi-autism / non-ASD population	19	Institutional deprivation, "retarded children" (1989)
ADHD-focused	10	ADHD measurement
Adult services / >18 years	5	Autistic adult services, adult diagnosis experiences
Neuroimaging / brain volume	3	MRI, cortical thickness
Biological/biomarker focus	1	Blood zinc/copper levels
Brain electrical activity	1	Blood zinc/copper levels
Behavioral/symptom comparisons	2	Emotional or cognitive differences
Theory of Mind/Executive functions	2	ToM and EF testing
Fetal Alcohol Spectrum Disorder	1	FASD-focused study
Maternal smoking	1	Prenatal smoking as risk factor
ASD + Epilepsy	2	ASD with Epilepsy comorbidities
HIV	1	ASD and HIV comorbidity
Environmental neurotoxicology	1	Pollution/chemical exposure studies

Medical comorbidities	1	Impact of chronic illness on learning
Bipolar Disorder	1	Bipolar, not autism-related
Not Romanian-only	5	Meta-analysis without Romania-only data

Note. This table represents the exclusion categories applied during the screening of peer-reviewed scientific literature. Number of articles indicate the number of studies excluded in each category, and the examples illustrate typical study types that did not meet the inclusion criteria.

Table 3

Expanded Exclusion Breakdown – Gray Literature

Topics	Nr of articles	Example study type
Refugees/immigrant language programs	3	Teaching Romanian language to refugees/immigrants
General Education	1	Collection of non-formal educational adventures
Online psychoeducation (adolescence)	1	Digital resources used by adolescents
Tuberculosis related reports	7	TB prevention/intervention reports
Medical (non-ASD)	3	Generic medical initiatives without autism focus
Teaching/teacher training	2	Reports on general teaching practices
Children rights	2	Reports on diversity, not autism-specific
Diversity	3	Reports on diversity, not autism-specific

Note. This table represents the exclusion categories applied during the screening of gray literature sources. Number of articles indicate the number of documents excluded in each category, and the examples illustrate typical document types that did not meet the inclusion criteria.