European Journal of Social Sciences Studies
ISSN: 2501-8590
ISSN-L: 2501-8590
Available on-line at: www.oapub.org/soc

DOI: 10.46827/ejsss.v11i5.2083
Volume 11 | Issue 5 | 2025

HOW DO PARENTS OF AUTISTIC ADULTS IN THE ARAB SECTOR IN ISRAEL PERCEIVE THEIR ROLE IN SUPPORTING THEIR CHILDREN DURING THEIR ADULTHOOD LIFE AFTER SCHOOL?

Rawd Brejieh
Girne American University (GAU),
Cyprus

Abstract:
This research explores how parents of autistic adults living in the Arab sector in Israel understand and enact their roles of caregiving during the transition to adulthood after school. The research was undertaken due to the increasing need to understand the lived experiences of parents caring for an autistic adult child, where support during the transition to adulthood is often not present at all, and especially to families living in under-resourced and culturally different communities. As a new addition to the literature, the research contributes by illustrating the cultural, emotional, and structural complexities influencing parental support for their autistic children living in Arab communities. Thematic analysis was used as part of a qualitative, phenomenological methodology, which included data collected from semi-structured interviews and focus groups conducted with 40 Arab parents. The findings demonstrated that parents provided emotional, financial, and practical holistic support to their autistic adult child, but were also confronted by systemic negligence, cultural stigma, and economic struggle. In conclusion, the care being offered by parents is dependent on their family resources, with few professional services available, and often, the services available are not culturally appropriate. Links were made in the recommendations for research and practice about establishing and developing systems to provide culturally appropriate, accessible community-based supports and transition programs, for autistic adults living in the Arab sector of Israel. In theoretical terms, the research adds to the understanding of caregiving in minority communities; in practical terms, the research shows an urgent need to create and enact inclusive policies that integrate family voices into the autism care structure.

Keywords: Autism Spectrum Disorder (ASD); Arab parents; autistic adults; caregiving; transition to adulthood; Arab sector in Israel; cultural stigma; family support; parental perceptions; services

1. Introduction

This research will investigate how the parents of autistic adults in the Arab sector in Israel see and enact their role in supporting their child in adulthood after the end of formal schooling. The main research question was: *"How do parents of autistic adults in the Arab sector in Israel perceive their role in supporting their children during their adult life after school?"* To narrow the focus of the study and to relate the main research question to the research approach, five sub-questions were prepared to address the various aspects of the support parents provide their young adult sons/daughters. Using a qualitative, phenomenological method, data collection included semi-structured interviews and focus groups with 40 parents. This study found that parents remain the primary, often intensive, caregiver, since parents are responsible for emotional, financial, and practical assistance in the absence of local professionals. In outlining their experiences, this study adds to the literature about family care, caregiving in the context of autism, and services available to parents and their children in minority communities in Israel.

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by persistent impairment in social communication, restricted interests, and repetitive behaviors (American Psychiatric Association, 2013). ASD is a lifelong disability that is increasingly prevalent both globally and nationally (Blaxill *et al.*, 2022; ALUT, 2023). The focus of this study is on autistic adults from the Arab sector in Israel and the parental caregiving practices they engage with in transitioning from school. The transition period involves challenges related to identity, autonomy and social inclusion (Scheef & Mahfouz, 2020; Paraskevi, 2021) but is rarely part of formal support. In Arab communities, caregiving is mediated by certain cultural values, including family loyalty, stigma of disability and social/economic disadvantage (Shattnawi *et al.*,2020; Al-Oran & Khuan, 2021). This research explored the lived experiences of parent caregivers caught in the middle of intersecting values and responsibilities.

This study has wider-reaching implications because it examines a population that is not well represented in the academic literature and policy plans related to autism: Arab families of autistic adults in Israel. It identifies important gaps in services to highlight the emotions and practical load parents face, as well as reveal culturally specific styles of caretaking. The phenomenological methods permitted rich insights into parents' experiences, feelings, perspectives, and needs (Tavakol & Sandars, 2025; Alhazmi & Kaufmann, 2022), in addition to revealing reliance on family members because of a lack of services that were accessible and culturally relevant to them. The need for government-funded and community-based transition services was indicated. Based on the findings, this study recommends that inclusive and culturally relevant support systems should be developed, and the views of parents should be considered during future planning of services. This research also serves a theoretical purpose in relation to caregiving and autism, and a practical purpose for policy-makers, educators, and health practitioners who engage with the service needs of minority and underserved communities.

2. Literature Review

2.1 Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a lifelong condition that occurs among people of all races, ethnicities, and social groups. Individuals with ASD will demonstrate ongoing challenges in social interaction and communication - either verbal or nonverbal. Some individuals will also show restricted and repetitive behaviors, interests, or activities (American Psychiatric Association, 2013). In the last thirty years, evidence suggests a dramatic increase in the number of individuals diagnosed with ASD (Blaxill *et al.*, 2022). ASD is a common neurological condition and is characterized by differences in social communication and repetitive behaviors (American Psychiatric Association, 2013). There is a range in the presentations that make up autism symptoms (Hull *et al.*, 2020), as individuals with autism have their own individual strengths and interests (Davey, 2020). For many autistic individuals, autism is not just their clinical symptomology it is a way of being that is a key component of their identity (Biklen, 2005). With that, there is significant diversity within the autism community.

The CDC (2021) stated that the global prevalence of ASD is estimated to be 1 in 44 children. These children will face barriers to learning, including limitations in speech development and possibly language skills (Sun *et al.*, 2019). Furthermore, children may demonstrate difficulty with social interaction (Huang *et al.*, 2017), as well as difficulty with adaptive behavior (Towle *et al.*, 2014). It is also estimated that approximately 50% of individuals with ASD will also be diagnosed with Attention-Deficit Hyperactivity Disorder (ADHD) (Dellapiazza, 2021). Furthermore, Dellapiazza (2021) found that children diagnosed with both ASD and ADHD experience greater social problems, aggressive and oppositional behaviors, and greater internal problems such as anxiety and mood disorders. ASD's complex symptoms greatly inhibit a child's development socially and in their behavior (Jaisle *et al.*, 2023).

2.1 The Prevalence of Autism

In 2023, Israel's population was nearly 10 million, with Jews at 73%, Arabs at 21% (including Muslims, Christians, and Druze), and the last 5% representing other ethnicities. The population growth rate is currently 2%, and it is one of the highest growth rates in developed countries (Central Bureau of Statistics, 2023).

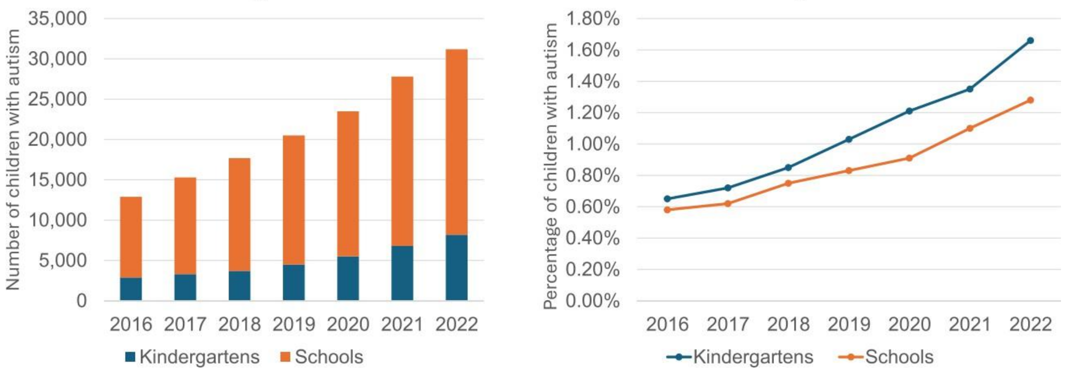
In recent years, studies on the global prevalence of autism have not been consistent. A systematic review included 71 studies reporting from 34 countries from 2012 to 2021 and found a median prevalence of 1% for children (Zeidan *et al.*, 2022). Salari and others (2022) published a meta-analysis of 74 studies from the years 2008 to 2021 and found a combined autism prevalence of 0.6%. Talantseva and others (2023) reviewed 85 articles from 1994 to 2019 and provided the range of prevalence rates, including the United States, which had the highest with 1.12%. Higher prevalence rates tend to correlate with high socio-demographic index (Solmi *et al.*, 2022). In Israel, the estimated autism prevalence in children and teens during 2021-2022 was approximately 1.13%, (ALUT, 2023), which is consistent with the United States (Talantseva *et al.*, 2023). Reports of ASD prevalence in Arab countries ranged from a low of 0.2% to a high of 1.49%. The wide range of ASD prevalence likely resulted from the heterogeneity of methodologies and inclusion criteria between studies (Qoronflesh *et al.*, 2019). Data collected in 21 countries in North Africa/Middle Eastern showed an age-standardized prevalence rate of 0.3% in 2019 with the country breakdown showing the highest in Iran (0.37%), and the United Arab Emirates (0.33%) and the lowest in Syrian Arab Republic (0.28%), Yemen (0.29%) and Libya (0.29%) (Ebrahimi *et al.*, 2023). The reported prevalence of autism among 0-14-year-olds in Oman was 0.2% (Al-Mamri *et al.*, 2029). However, autism was reported to be higher in the Middle Eastern countries, similar to Israel, such as the Kingdom of Saudi Arabia (0.59%), (Qoronflesh *et al.*, 2019) Qatar 1.1%,18 Egypt (1%), Jordan (0.92%), and Lebanon (1.49%) (Ferman & Segal, 2024).

The male-to-female ratio in Israel is 4:1 (ALUT, 2023), which is consistent with global ratios (Loomes *et al.*, 2017). The prevalence rate in North Africa and Middle Eastern countries showed that males with autism were 2.9 times more likely to be diagnosed in 2019 than females. The proposed explanation for the relative dearth of females receiving a diagnosis of autism is related to overlooking, misdiagnosis, or a higher risk of a later diagnosis (Ebrahimi *et al.*, 2023).

In Israel, autism prevalence mirrors global trends, with a notable increase in recent years (Figure 1). Davidovitch et al. (2020) studied data of 879,029 children born in the years 1999-2017, indicating a notable increase in Autism incidence by age 8. The prevalence rate has increased by 128% at an average of 23% per year (ALUT, 2023). The estimates of the continued growth of individuals with Autism will continue to grow.

Surveys of the Israeli education system have shown a steady increase in the number of students identified with Autism and the rate of Autism students in relation to the overall student body, particularly for kindergarten and preschool-aged students (Ferman & Segal, 2024).

Figure 1: Change in the number of students with autism in kindergartens (ages 3–6) and schools (ages 6–21) from 2016 to 2022



Source: (Ferman & Segal, 2024)

2.2 Parenting of Autism Spectrum Disorder (ASD) Individuals

Raising a child with autism spectrum disorder (ASD) can be exhausting for parents. ASD children usually struggle with communicating, and for some of them, can use crying or screaming to express what they want (Azzam & Joseph, 2021). This demonstrates only one difficulty experienced by many parents in both home and public settings. Mothers tend to experience parenting a child with autism more than fathers since they are often viewed as the primary caregiver (Shattnawi *et al.*, 2020). In addition to communication struggles, ASD children with ASD are less aware of social cues that can make socializing difficult. Parents are called on to meet their child's needs in the education and medical community (Al-Oran & Khuan, 2021). When some of these behaviors become unpredictable, they can undoubtedly make it hard for families to establish daily routines. Regardless of the challenges, many of these parents find creative ways to support their child's growth and development, and seek out information, attend support groups, and leverage therapy to help mitigate the demands of being a parent of an ASD child (Chau & Furness, 2023).

Several studies indicate that parents of children with autism spectrum disorder (ASD) often experience more stress from parenting, more mental health issues, and worse physical health than parents of typically developing children, as well as parents of children with other disabilities. In addition, ASD has been shown to affect family systems and marriage (Alkhateeb *et al.*, 2022). Furthermore, there is strong evidence of a relationship between the level of distress parents' experience and the severity of their child's emotional and behavior issues, along with numerous other factors that may exacerbate the stress parent experience, including overwhelming caregiving demands, inadequate parenting coping skills, inadequate support, financial issues, as well as parental expectations and understanding of ASD (Ilias *et al.*, 2018; Papadopoulos, 2021).

2.3 Autistic Individuals' Adulthood Life After School

Youth (both autistic and non-autistic) who are transitioning from school to adulthood are participating in a very complex psychological task. It involves potentially mixing several different emotions and the need to accommodate their self-concept based on their new adult roles (Chun *et al.*, 2022). An individual signs their transition to adulthood through completing school. Post-transition, there could be numerous pathways, such as entering employment, transitioning into further education or working, and changes to household, community, and social participation (Schneider *et al.*, 2016). There is no clearly defined point at which transition planning begins. Nevertheless, it is suggested that transition preparation and planning ideally should start as a young person starts to become a teenager (Ross-Lévesque *et al.*, 2024). Young people who are well prepared to facilitate the change in identity and adjust to their new social roles can have a more successful transition to post-school life (Scheef & Mahfouz, 2020). However, even with transition planning, the autistic young people transitioning from school are likely to face extra obstacles (Crane *et al.*, 2021). There is an increasing likelihood that an autistic young person, who appreciates order and structure, is entering a period that requires pastoral care to create and adapt to their various new routines. This may be difficult to navigate without appropriate support (Paraskevi, 2021). Participating in the sometimes-complex social negotiations that exist within a new social context may be difficult for some autistic people (Nuske *et al.*, 2019). This is because, as they become uncomfortable in their new context, it may not be a place that is accommodating towards, or upholds, their preferences and methods of social communication (Richter *et al.*, 2020).

3. Material and Methods

This study used a qualitative research design, and more specifically, a phenomenological approach. A phenomenological approach was chosen because it could research the actual, lived, experiences and subjective experiences of parents of autistic adults within the Arab sector, in Israel (Bouzioti, 2023). The phenomenological lens is suitable for research that intends to explore how people understand and interpret their particular roles, especially in complex social situations such as caregiving for autistic adults (Tavakol & Sandars, 2025). As Alhazmi and Kaufmann (2022) maintain, phenomenology is important for getting to the essence of individuals' experiences, which fits well with understanding the ambiguous support roles for parents. Creswell (2018) and Flick (2018) concurred with the belief that qualitative methods can be appropriate for illuminating participant meaning at a deeper level and participant behaviors within specific, socio-cultural contexts.

The main data collection tool for this research study was the semi-structured interview. This method allowed a level of structure with guided questions, as well as freedom for the participant to explain their thoughts and perspectives in detail, while maintaining the same questions to be used for every interview (Hossain, 2024). The semi-structured interviews focused on exploring, indicating, and demonstrating the types of support parents provide, the methods/strategies employed when facilitating transitions to adult roles, and the impediments parents encountered within their caregiving responsibilities. The focus groups were an additional data-gathering tool for this study to help elicit data and supportive reflective discussion among parents. In addition to semi-structured interviews, focus groups provided parents with the opportunity to reflect upon or share information together in group discussions (Adler *et al.*, 2019). The combination of one-on-one semi-structured interviews with focus groups provided an added level of reliability from the qualitative data being offered, as well as more depth (Busetto *et al.*, 2020).

The target population of the study comprised parents of autistic adults who are living in the Arab sector in Israel. The study based its identification of participants utilizing purposive sampling to identify participants who could be rich, relevant and diverse in thinking about the research questions articulated (Memon *et al.*, 2025). Purposive sampling is a non-probability sampling strategy that is often associated with qualitative studies to guarantee that participants have the relevant traits to the research we are conducting (Bryman, 2017). The final sample consisted of 40 parents; 20 conducted face-to-face semi-structured interviews, and the other 20 parents participated in focus groups with a total of 4 groups, where each group consisted of 5 parents. The sampling strategy provided a total sample size and maintained diversity of participants across different levels of socio-economic status and culture while keeping the group manageable (Andrade, 2021).

Data was analyzed using thematic analysis, a representative approach that is both rigorous and flexible, to identify, analyze and report themes within data. In moving through analysis of the data, the researchers found it was helpful to pull out recurring and important ideas from participant stories (Sundler *et al.*, 2019). This was important to maintain a focus on the experiences of the individuals in the study (Naeem *et al.*, 2023). Thematic analysis allowed for a systematic process of coding and interpretation in both interview transcripts and focus group transcripts; this facilitated triangulation and improved the rigor of the overall findings (Finlay, 2021). The analytic process was iterative and reflexive, allowing emergent themes to dictate later stages of analysis while being responsive to contextual factors of participants' cultural and emotional aspects of their experiences.

4. Results

The findings of this study provide a nuanced understanding of perceptions and practices among Arab parents in Israel when assuming a support role for their adult autistic children, subsequent to formal schooling. The in-depth thematic analysis produced five main themes that involve the complexity of caregiving in a socio-culturally specific context: emotional, financial, and practical support; individualized strategies to develop independence; many challenges related to limited professional services; cultural, social, and economic context; and endemic reliance on family-based support networks due to structural deficits.

4.1 Theme 1: Emotional, Financial, and Practical Support Provided by Arab Parents to Their Autistic Adult Children

Parents in the Arab sector in Israel see their role as central in holistic support for their adult autistic children, encompassing emotional, financial, and practical aspects. One mother said, *"He still relies on me for everything: meals, talking to people, and just calming down when he gets anxious."* Another parent explained, *"We pay for everything because he can't work and we don't get enough support from the government."* These are in line with the study by Alkhateeb et al. (2022), who found that parents of people with ASD are more likely to experience significant financial and emotional stress. Parenting also means advocating for the adult, which, as Azzam and Joseph (2021) noted, can require such high levels of mediation related to communication problems that parents may see communications as becoming completely dependent on resolving needs in collaborative ways so that caregivers reliably act on behalf of a person with ASD, both publicly and in the home. Even when caring becomes a heavy lift, many parents remain deeply committed to multi-faceted support and wellbeing for their child through caregiving (Samuel *et al.*, 2025).

4.2 Theme 2: Parental Strategies and Approaches for Promoting Adulthood Transition and Independence Among Autistic Adults in the Arab Sector

The Arab parents in the study utilized a multitude of individualized strategies to prepare their autistic children for life after school, overall, despite being underprepared due to a lack of institutional support. *"We teach her daily things slowly, how to make tea, how to go to the shop. But it is step by step and always close to me,"* one father said. Another participant added, *"We tried to get her working in the family shop so she can be around people, but we always worry about how other people treat her."* These strategies indicate a somewhat hesitant attempt at independence while remaining closely engaged. This is consistent with Scheef and Mahfouz (2020), who identified that in some cultures where there is limited transition support publicly, parents take an early responsibility for identity development and social role adjustment for their autistic children and youth. Crane *et al.* (2021) also noted the barriers autistic individuals face when moving into adult roles, confirming this parental need to act as steady guides.

4.3 Theme 3: Challenges Experienced by Arab Parents in Supporting Autistic Adults Post-School Life

The transition from school to adulthood can be especially difficult for parents. Respondents reported emotional stress with no options or services and fears about the future. One mother stated, *"When he left school, we were on our own. No programs, no plans. It was just us."* Another father stated: *"There are no blueprints -- no one tells you what happens next. We just carry on."* The frustrations felt by parents are consistent with results from Paraskevi (2021), who emphasized that autistic individuals do not know what to expect in unstructured adult environments. Parents, too, have to experience the uncertainty without professional support. Additionally, the emotional upheaval experienced by participants also tracked with Ilias and others (2018), who found parental distress was related to extensive caregiving burdens and limited resources to cope. The parents in this study were also worried about long-term care of their children and were anxious about care without help from formal state assistance, or when they die.

4.4 Theme 4: Impact of Arab Cultural, Social, and Economic Contexts on Parental Support for Autistic Adults

Cultural beliefs and socio-economic limitations were critical in establishing parental support. One parent said, *"In our culture, children stay with their parents— but with autism, it's not just tradition, it's necessity."* Another parent said, *"We don't talk about autism too much in the community, so there is little time for people to judge when my child acts differently."* These comments illustrate the unique ways traditional family values support and restrict care. Stigma around disability in Arab society often leads families to socially withdraw, as presented by Shattnawi *et al.* (2020), which adds social isolation on top of care.

Financial stress can also lead to barriers in accessing therapies or private services, as is often the case in impoverished, especially Arab families (Al-Oran & Khuan, 2021). Although some cultural norms promote family loyalty and quality care, they also restrict the ability to get care outside the family unit and limit the ability to openly discuss the struggles of caregiving (Alkhatib *et al.*, 2024; AboJabel & Abo-Rass, 2025).

4.5 Theme 5: Resources and Support Systems Valued by Arab Parents in Assisting Their Autistic Adult Children's Adulthood Journey

The Arab parents in this study spoke of a significant dependence on family networks when professional services are lacking. For example, one father stated, *"We don't have therapists or programs in our area, so we do most things at home—his siblings do a lot with him, especially his older sister."* Another parent stated, *"My husband and I take turns with our son. There is no professional parent support around us who understands autism, so only the family supports him."* These statements highlighted the significant role that families played in dealing with the obligations and demands of raising an autistic adult. This situation supports the findings of previous studies that highlighted that many Arab families will fill the professional gaps with informal care due to cultural expectations and access to service gaps (de Leeuw *et al.*, 2024; Saleh, 2024; Wang *et al.*, 2025). Since there are limited autism resources in the Arab sector of Israel, many families have no choice but to rely on their own internal supports. As noted by Papadopoulos (2021), the lack of accessible, culturally relevant, and comprehensive professional services creates increased stress for caregivers and challenges opportunities for the retention of autistic adults. Participants requested state-funded services to create inclusive, community-based services that are relevant to the Arab population.

5. Discussion

This research addresses the diverse and affect-laden situations of Arab families in Israel as they integrate their autistic adult children into the adult world after school. By analyzing parents' experiences phenomenologically, this research explored and reflected on how parents consider their roles, the strategies they employ, the various barriers they encounter in the task of caring, and the supports they utilize. The findings of this research provide further evidence to understand how culturally-technically-specific, institutional gaps and family obligations intersect with parental roles of caregiving.

To start, the findings showed that Arab parents were looking after their autistic adult children in some or all areas of life and provided ongoing emotional, financial, and logistical support. Clubbing any domestic support ontologically together, therefore, it does not undermine the seriousness of the role parents play. The finding further resonates with the research of Alkhateeb et al. (2022), which indicated that parents of children with ASD do not have a fair share of social burden for care that's already impacted their emotional health and physical wellbeing. Not only did these parents manage the emotional regulation of their children, their daily routines, but also their financial stability when their autistic adult children were unable to secure gainful employment. Again, the findings reflected the work of Azzam and Joseph (2021) and the task of communicating, which, if unable, would place great weight on parents or caregivers because their autistic adult lost the ability to address daily tasks to be fulfilled independently. It is clear that parents' ongoing caregiving ideally could be seen as an extension of infancy and childhood once parents undertake to support and act semi-independently. There was no opportunity for other care in public space, so whether 5, 16, or 40 years, dependency remains without the social infrastructure for integration into the adult world.

In addition, parents had an active role in moving their child into adulthood, demonstrating this in an effort to teach their children basic life skills and the attempts to create social experiences for youth through family or community areas. Most of these strategies demonstrate an astuteness around the relative importance of autonomy, but these strategies are limited in that there is little in the way of institutional support structure, echoing the idea that Scheef and Mahfouz (2020) presented about programming existing toward early transition planning to support autistic youth transition to adulthood. Unlike examples focusing on transition services with a supporting structure, parents' approaches in this study for transition planning are constrained by the absence of direct support systems in the educational structure, and the reliance on informal and largely unstructured means to come up with their own approaches (based around cultural norms). Crane and others (2021) stated how autistic individuals experience significant barriers to transitioning into adult forms of roles and responsibilities when there are absent or poorly constructed supporting systems. This reinforces the need to understand parental approaches not as simply an aspect of cultural practice but as forms of adaptation to a structure of appeasement.

The findings also indicated that the transition out of the education system left many parents staring into the void for service support, resulting in feelings of disillusionment and despair. Many parents felt a very real sense of abandonment as there were no identifiable components, pathways, or available programs for their child's developmental and skill work outside of formal schooling. Paraskevi's (2021) findings greatly support these concerns with their earlier identification of the difficulties faced by autistic individuals when transitioning to the less structured imposed adult environment. Ilias and others (2018) sent these difficulties further with their insistence that parental distress is directly related to resources from government structures, as well as parental distress as a by-product of chronic caregiving. When parents had no reliable pathways for systems to take over caregiving support responsibilities, parents held the agency of increasingly complex ways and navigated developmental pathways for their children's social constructions. This dynamic also places significant emotional responsibility (the unknown) and existential pressures long-term for families who are facing imagined futures for their child in their absence.

Culture and socio-economic conditions were important considerations that influenced caretaking practices. Parents indicated that it was a cultural expectation in the

Arab tradition to care for the autistic adult in the family. This aligns with Shattnawi and others' findings (2020) that Arab parents experience greater social pressures associated with caring for a child with a disability in the home, and Al-Oran and Khuan (2021), who identified social stigma surrounding disability in Arab cultures. Financial difficulties were frequently mentioned as barriers to private or professional services. These findings indicate that socio-economic conditions and cultural norms can have overlapping and intersecting effects on parental roles, in that cultural expectations reinforce family loyalty simultaneously as they reinforce isolation and non-use of external support services.

The study further found that families typically relied on internal resources, particularly siblings and extended family members, as a means to provide care and companionship for the autistic adult in the absence of professional support. This is consistent with recent findings by de Leeuw and others (2024) and Saleh (2022), who found that Arab families engaged in informal networks to fill the voids and gaps created by inadequate levels of public services. It is worth noting that this reliance on family-based care was likely not the family's option of choice, but was necessitated due to coping in a situation where access to autism-specific services was severely limited or culturally inappropriate. Papadopoulos (2021) noted similar findings in situations of lack of professional services or the absence of culturally appropriate services; the burden on family caregivers increased disproportionately, with little relief or recognition from formal systems. This further reinforces the need for inclusive and community-based programs targeted towards Arab families to allow equitable pathways to resources and services.

6. Conclusion

The present study has examined how Arab parents in Israel conceptualize and undertake their roles in supporting their autistic adult children after the formal schooling context, and has demonstrated that these parents enact broadly considered support in emotional, practical and financial terms. Notably, these parents not only undertook the role of caregiving but also became a moral voice, teacher and emotive bastion for their children. It is evident from their accounts of caregiving that they employed familial and cultural obligations in their respective roles of caregiving, as there was limited or no organized state support, reflecting a strong commitment and motivation to continually provide caregiving assistance. These findings work in synergy with previous research indicating that parental roles can remain deleterious in-home environments with parents of autistic individuals, particularly if the state does not provide adequate supports (Alkhateeb *et al.*, 2022; Azzam & Joseph, 2021).

The synthesis of data indicated a number of key takeaways. Firstly, support for autistic adults in the Arab sector continues to be familial. Secondly, parents had different approaches for facilitating autonomy despite systemic gaps. Thirdly, cultural approaches both enabled and constrained parental and family caregiving roles. The use of informal networks, such as siblings, was a realistic approach to compensating for unviable professional support, de Leeuw and others (2024) and Papadopoulos (2021). The interplay of cultural aspirations, economic barriers, and structural negligence subsequently becomes one of the most salient issues and perpetuates the need for community-based services that address the cultural context and are user-friendly. Many parents were open about their anxieties concerning the future of their child's care, especially without the formal transition plans and long-term support.

Nevertheless, several questions are still present. What would effective transition programs look like, developed in culturally appropriate ways? How can service delivery models be adapted to serve underserved populations, in this case, the Arab sector in Israel? To what degree are policymakers aware of the lived realities of caregivers? Future research needs to look at the long-term outcomes of autistic adults in these communities, including intervention models that apply cultural relevance in tandem with professional knowledge. There is an urgent need for increased engagement and investment in inclusive and sustainable care systems that view family caregivers as coexisting with public services rather than actors filling the needs that public services can provide. Ultimately, the dignity and development of autistic adults demand public action that is coordinated, caring, and culturally contextualized.

Creative Commons License Statement

Conflict of Interest Statement

The author declares no conflicts of interest.

References

AboJabel, H., & Abo-Rass, F. (2025). Attitudes of Arab family caregivers in Israel toward robot-delivered care for ADL-dependent (activities of daily living-dependent) older people: Identifying ethical and social issues. *Bioethical Inquiry, 22*, 415–430. https://doi.org/10.1007/s11673-024-10414-3

Adler, K., Salanterä, S., & Zumstein-Shaha, M. (2019). Focus group interviews in child, youth, and parent research: An integrative literature review. *International Journal of Qualitative Methods, 18*, 1–15. https://doi.org/10.1177/1609406919887274

Alkhateeb, J.M., Hadidi, M.S. & Mounzer, W. (2022). The Impact of Autism Spectrum Disorder on Parents in Arab Countries: A Systematic Literature Review. *Front. Psychol, 13* (*955442*). https://doi.org/10.3389/fpsyg.2022.955442

Alkhatib, R. N., Dukmak, S. J., El-Dahiyat, F., & Abojadi, A. A. (2024). Developing the first Arabic quality of life for parents of children with autism (QoLA) scale: Translation, cultural adaptation and psychometric validation. *Middle East Current Psychiatry, 31*(33). https://doi.org/10.1186/s43045-024-00344-7

Alhazmi, A.A. & Kaufmann, A. (2022). Phenomenological Qualitative Methods Applied to the Analysis of Cross-Cultural Experience in Novel Educational Social Contexts. *Front Psychol,13.* https://doi.org/10.3389/fpsyg.2022.785134

Al-Mamri, W., Idris, B., Dakak, S., Al-Saidi, A., Al-Shibani, T., Al-Harthi, I., Al-Mamari, W., & Al-Adawi, S. (2019). Revisiting the prevalence of autism spectrum disorder among Omani children: A multicentre study. *Sultan Qaboos University Medical Journal, 19*(4), e305–e309. https://doi.org/10.18295/squmj.2019.19.04.005

Al-Oran, M. & Khuan, L. (2021). Predictors of parenting stress in parents of children diagnosed with autism spectrum disorder: A scoping review. *The Egyptian Journal of Neurology, Psychiatry and Neurosurgery, 57(1).* https://doi.org/10.1186/s41983-021-00345-w

ALUT – The Israeli Society for Children and Adults with Autism. (2023). *Autism in Israel – Status Report 2021–2022*. Tel Aviv: ALUT. Retrieved from https://www.alut.org.il [in Hebrew]

American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders. 5th ed.* Arlington, VA: American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596

Andrade, C. (2021). The inconvenient truth about convenience and purposive samples. *Indian journal of psychological medicine, 43(1),* 86-88. https://doi.org/10.1177/0253717620977000

Azzam, M., & Joseph, R. A. (2021). Parenting a child with autism spectrum disorder: perspective of Jordanian mothers. *J. Transcult. Nurs, 32,* 474–483. https://doi.org/10.1177/1043659620970634

Beenstock, M., Pinto, O., & Rimmerman, A. (2021). Transition Into Adulthood with Autism Spectrum Disorders: A Longitudinal Population Cohort Study of Socioeconomic Outcomes. *Journal of Disability Policy Studies, 32*(3), 159-170. https://doi.org/10.1177/1044207320943590

Blaxill, M., Rogers, T., & Nevison, C. (2022). Autism tsunami: the impact of rising prevalence on the societal cost of autism in the United States. *J. Autism Dev. Disord, 52*, 2627–2643. https://doi.org/10.1007/s10803-021-05120-7

Biklen, D. (2005). *Autism and the myth of the person alone*. New York University Press. Bouzioti, D. (2023). Introducing the phenomenological model of performance practice (PMPP): Phenomenological research design and the lived experience in performance. *International Journal of Qualitative Methods, 22.* https://doi.org/10.1177/16094069231211142

Bryman, A. (2017). *Social Research Methods (4th ed).* Oxford: Oxford University Press. Retrieved from https://ktpu.kpi.ua/wp-content/uploads/2014/02/social-research-methods-alan-bryman.pdf

Busetto, L., Wick, W., & Gumbinger, C. (2020). How to use and assess qualitative research methods. *Neurological Research and Practice,* 2, Article 14. https://doi.org/10.1186/s42466-020-00059-z

Centers for Disease Control and Prevention. (2021). *Data and statistics on autism spectrum disorder*. https://www.cdc.gov/ncbddd/autism/data.html

Central Bureau of Statistics. (2023). *Statistical Yearbook for Israel 2023*. Israel: Central Bureau of Statistics. Retrieved October 15, 2023, from https://www.cbs.gov.il/he/publications/Pages/2023

Chau, W. & Furness, P. (2023). Happiness in Parents of Children with Autism Spectrum Disorder: A Qualitative Study. *American Journal of Qualitative Research, 7 (1)* 168-190. Retrieved from https://www.ajqr.org/download/happiness-in-parents-of-children-with-autism-spectrum-disorder-a-qualitative-study-12950.pdf

Chun, J., Kuo, H. J., Curtiss, S. L., Lee, G. K., Lee, H., & Awadu, J. (2022). The interplay of supports and barriers during the transition to adulthood for youth on the autism spectrum. *Disability and Rehabilitation.* https://doi.org/10.1080/09638288.2022.2112097

Crane, L., Davies, J., Fritz, A., O'Brien, S., Worsley, A., Ashworth, M., & Remington, A. (2021). The transition to adulthood for autistic young people with additional learning needs: The views and experiences of education professionals in special schools. *British Journal of Special Education, 48*(4), 509–529. https://doi.org/10.1111/1467-8578.12372

Creswell, J., Poth, C. (2018). *Qualitative inquiry and research design: Choosing among five approaches (4th ed).* Sage. Retrieved from https://collegepublishing.sagepub.com/products/qualitative-inquiry-and-research-design-4-246896

Davey, L. (2020). Using the special interests of autistic children to facilitate meaningful engagement and learning. *Good Autism. Practice, 21(1),* 43–64. https://www.bild.org.uk/wp-content/uploads/2020/01/Davey-GAP-May-2020.pdf

Davidovitch, M., Slobodin, O., Weisskopf, M. G., & Rotem, R. S. (2020). Age-specific time trends in incidence rates of autism spectrum disorder following adaptation of DSM-5 and other ASD related regulatory changes in Israel. *Autism Research, 13*(11), 1893–1901. https://doi.org/10.1002/aur.2420

de Leeuw, A., Happé, F., & Hoekstra, R. A. (2020). A conceptual framework for understanding the cultural and contextual factors on autism across the globe. *Autism Research, 13*(7), 1029– 1050. https://doi.org/10.1002/aur.2276

Dellapiazza, F., Audras-Torrent, L., Michelon, C., & Baghdadli, A. (2021). Clinical characteristics of children with ASD and comorbid ADHD: Association with social impairment and externalizing and internalizing behaviours. *Research in*

Developmental Disabilities, 113, 103930–103930. https://doi.org/10.1016/j.ridd.2021.103930

Ebrahimi, M. S., Amiri, Z., Shobeiri, P., Khazaei, S., Rabiee, N., Gholamaliee, B., & Moradi, Y. (2023). Burden of autism spectrum disorders in North Africa and the Middle East from 1990 to 2019: A systematic analysis for the Global Burden of Disease Study 2019. *Brain and Behavior, 13*(7). https://doi.org/10.1002/brb3.3067

Ferman, S., & Segal, O. (2024). The face of autism in Israel. *Neuropsychiatric Disease and Treatment, 20*, 1677–1692. https://doi.org/10.2147/NDT.S437518

Finlay, L. (2021). Thematic analysis: The 'Good', the 'Bad' and the 'Ugly'. *European Journal Qualitative Research in Psychotherapy, 11,* 103-116

Flick, U. (2018). The Concepts of Qualitative Data: Challenges in Neoliberal Times for Qualitative Inquiry. *Qualitative Inquiry, 25*(8), 713-720. https://doi.org/10.1177/1077800418809132

Hull, L., Petrides, K. V., & Mandy, W. (2020). The female autism phenotype and camouflaging: A narrative review. *Review Journal of Autism Developmental Disorders, 7(1),* 306–317. https://doi.org/10.1007/s40489-020-00197-9

Huang, A. X., Hughes, T. L., Sutton, L. R., Lawrence, M., Chen, X., Ji, Z., & Zeleke, W. (2017). Understanding the self in individuals with Autism Spectrum Disorders (ASD): A review of literature. *Frontiers in Psychology, 8,* 1422–1422. https://doi.org/10.3389/fpsyg.2017.01422

Hossain, MS., Alam, K. & Ali, S. (2024). Phenomenological Approach in the Qualitative Study: Data Collection and Saturation. *ICRRD Journal, 5(2),* 147-172. https://doi.org/10.53272/icrrd.v5i2.4

Ilias, K., Cornish, K., Kummar, A. S., Park, M. S., and Golden, K. J. (2018). Parenting stress and resilience in parents of children with autism spectrum disorder (ASD) in Southeast Asia: a systematic review. *Front. Psychol. 9,* 280. https://doi.org/10.3389/fpsyg.2018.00280

Jaisle, E.M., Groves, N.B., Black, K.E. & Kofler, M.J. (2023). Linking ADHD and ASD Symptomatology with Social Impairment: The Role of Emotion Dysregulation. *Res Child Adolesc Psychopathol. 51(1),*3-16. https://doi.org/10.1007/s10802-022-00982-6

Knott, E., Rao, A.H., Summers, K. & Teeger, C. (2022). Interviews in the social sciences. *Nat Rev Methods Primers, 2 (73)*. https://doi.org/10.1038/s43586-022-00150-6

Loomes, R., Hull, L., & Mandy, W. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child and Adolescent Psychiatry, 56*(6), 466–474. https://doi.org/10.1016/j.jaac.2017.03.013

Memon, M. A., Thurasamy, R., Ting, H., & Cheah, J.-H. (2025). Purposive sampling: A review and guidelines for quantitative research. *Journal of Applied Structural Equation Modeling, 9*(1), 01–23. https://doi.org/10.47263/JASEM.9(1)01

Naeem, M., Ozuem, W., Howell, K., & Ranfagni, S. (2023). A Step-by-Step Process of Thematic Analysis to Develop a Conceptual Model in Qualitative Research.

International Journal of Qualitative Methods, 22. https://doi.org/10.1177/16094069231205789

Nuske, H. J., McGhee Hassrick, E., Bronstein, B., Hauptman, L., Aponte, C., Levato, L., Stahmer, A., Mandell, D. S., Mundy, P., Kasari, C., *et al.* (2019). Broken bridges—New school transitions for students with autism spectrum disorder: A systematic review on difficulties and strategies for success. *Autism, 23*(2), 306–325. https://doi.org/10.1177/1362361317737922

Papadopoulos, D. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: a qualitative study. *Brain Sci. 11,* 309. https://doi.org/10.3390/brainsci11030309

Paraskevi, G. (2021). The inclusion of children with autism in the mainstream school classroom: Knowledge and perceptions of teachers and special education teachers. *Open Access Library Journal, 8*. https://doi.org/10.4236/oalib.1107855

Qoronflesh, M. W., Essa, M. M., Alharahsheh, S. T., Al-Farsi, Y. M., & Al-Adawi, S. (2019). Autism in the Gulf states: A regional overview. *Frontiers in Bioscience, 24*(2), 334–346. https://doi.org/10.2741/4721

Richter, M., Flavier, E., Popa-Roch, M., & Clément, C. (2020). Perceptions on the primary-secondary school transition from French students with autism spectrum disorder and their parents. *European Journal of Special Needs Education, 35*(2), 171–187. https://doi.org/10.1080/08856257.2019.1581401

Ross-Lévesque, É., Martin-Roy, S., Julien-Gauthier, F., Jacob, S., Grandisson, M., St-Pierre, M.-C., Dahan-Oliel, N., Lamontagne, M.-È., & Desmarais, C. (2024). Transition to adulthood of youth with disabilities: Mapping declared practices to recommended practices. *British Journal of Special Education.* Advance online publication. https://doi.org/10.1111/1471-3802.12652

Salari, N., Rasoulpoor, S., Rasoulpoor, S., Shohaimi, S., Hosseinian-Far, A., Khaledi-Paveh, B., & Mohammadi, M. (2022). The global prevalence of autism spectrum disorder: A comprehensive systematic review and meta-analysis. *Italian Journal of Pediatrics, 48*(1), 112. https://doi.org/10.1186/s13052-022-01310-w

Saleh, A. (2024). *Autism, adolescence, and sexual health education in the Arab world: Safeguarding through behaviour analysis* (Doctoral dissertation). Queen's University Belfast. Retrieved from https://pure.qub.ac.uk/en/studentTheses/autism-adolescence-and-sexual-health-education-in-the-arab-world/

Samuel, P. S., Marsack-Topolewski, C. N., & Chan, K. T. (2025). Quality of life of family caregivers of adults with autism: Role of caregiver burden, health, and social support of compound and noncompound caregivers. *Families in Society: The Journal of Contemporary Social Services*, 1–20. https://doi.org/10.1177/10443894241306145

Shattnawi, K., Bani, W., Al-Natour, S., Al-Hammouri, M., Al-Azzam, M. & Joseph, R. (2020). Parenting a Child with Autism Spectrum Disorder: Perspective of Jordanian Mothers. *Journal of Transcultural Nursing*. https://doi.org/10.1177/1043659620970634

Scheef, A. & Mahfouz, J. (2020). Supporting the post-school goals of youth with disabilities through the use of a transition coordinator. *Research in Educational Administration and Leadership*, 5(1), 43–69. https://files.eric.ed.gov/fulltext/EJ1253134.pdf

Schneider, B., Klager, C., Chen, I.-C., & Burns, J. (2016). Transitioning into adulthood: Striking a balance between support and independence. *Policy Insights from the Behavioral and Brain Sciences, 3*(1), 1–8. https://doi.org/10.1177/2372732215624932

Solmi, M., Song, M., Yon, D. K., Koyanagi, A., Smith, L., Kim, J., Fusar-Poli, P., & Jacob, L. (2022). Incidence, prevalence, and global burden of autism spectrum disorder from 1990 to 2019 across 204 countries. *Molecular Psychiatry, 27*(10), 4172–4180. https://doi.org/10.1038/s41380-022-01630-7

Sun, I. Y., Cortez, A. C. M., & Fernandes, F. D. M. (2019). Learning disabilities in children with autism. In S. Misciagna (Ed.), Learning disabilities: Neurological bases, clinical features and strategies of intervention. *IntechOpen., 8923,* 12-21. https://doi.org/10.5772/intechopen.89234

Sundler S. J., Lindberg E., Nilsson C., Palmér L. (2019). *Qualitative thematic analysis based on Descriptive Phenomenology* (pp. 733–739). Wiley Nursing Open. https://doi.org/10.1002/nop2.275

Talantseva, O. I., Romanova, R. S., Shurdova, E. M., Idrisov, B. M., & Muhamedrahimov, R. J. (2023). The global prevalence of autism spectrum disorder: A three-level meta-analysis. *Frontiers in Psychiatry, 14,* 1071181. https://doi.org/10.3389/fpsyt.2023.1071181

Tavakol, M., & Sandars, J. (2025). Twelve tips for using phenomenology as a qualitative research approach in health professions education. *Medical Teacher*. https://doi.org/10.1080/0142159X.2025.2478871

Towle, P. O., Vacanti-Shova, K., Shah, S., & Higgins-D'alessandro, A. (2013). School-aged functioning of children diagnosed with autism spectrum disorder before age three: Parent-reported diagnostic, adaptive, medication, and school placement outcomes. *Journal of Autism and Developmental Disorders, 44(6),* 1357–1372. https://doi.org/10.1007/s10803-013-1997-2

Wang, X., Cui, Y., Wang, M., & Fan, X. (2025). Experiences of Social Support among Foreign Parents Raising Children with Autism Spectrum Disorder in China: A Cross-Cultural Study. *International Journal of Disability, Development and Education*, 1–20. https://doi.org/10.1080/1034912X.2025.2500325

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research, 15*(5), 778–790. https://doi.org/10.1002/aur.2696