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The Hidden Burden of Caregiving: Exploring Mental Health, Financial Challenges, and Social Support Policies for Families of Autistic Individuals

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ABSTRACT: The family often has to take on much more than just household duties, including health care management, educational advocacy, financial management, and long-term support planning for an autistic person. While care can be a fulfilling and meaningful experience, substandard services and inequitable social resources can lead to psychological distress, economic hardship,p and social exclusion. This critical review analyzes the multiple burdens facing family carers of autistic children, adolescents and adults, highlighting issues of mental health, financial difficulties, informal support and social protection policy. This observational, systematic review and intervention research evidence shows that certain caregiver populations are at increased risk for parenting stress, depressive symptoms, anxiety, employment disruption, and an unmet need for support. Individual support needs, co-occurring conditions, household income, gender inequalities, service accessibility, and stigma experiences all impact these outcomes. Financial pressures can occur as a result of direct healthcare costs, education costs, transportation, job loss, and caregiving. Social support, respite services, easily accessible healthcare, and psychological interventions can help to reduce some of the selected difficulties, but they are not consistently effective or available. The current literature is still limited in scope because of the variety of caregiver measures used, the cross-sectional nature of the studies, the lack of autistic adult representation, and the lack of policy assessments in low-resource environments. Future research should include longitudinal family studies, service design that includes caregivers, economic evaluations, and culturally responsive interventions. Unpaid caregiving must be valued in sustainable policy responses, and the mental health, economic well-being, and social engagement of caregivers must all be safeguarded. Empowerment of families and autonomy of autistic people are complementary goals in a just and human rights-based approach to care throughout the lifespan.

1. INTRODUCTION

1.1 Background and Significance

Autism is a lifelong condition that affects social communication and social interaction and has restricted or repetitive patterns of social and sensory experiences, as well as patterns of behavior, interests, or activities. People with autism vary greatly in communication style, intellectual functioning, adaptive functioning, health, and support needs.

Some autistic people have some independence and do need some support; others have significant needs for help with communication, personal care, education, healthcare or daily activities. Support needs can also vary from one developmental phase to another and environmental context to context.

Family members are often key to coordinating these supports. Parents, siblings, grandparents, partners, and other family members can help with appointments, planning for education, emotional support, transportation, administrative matters, and daily activities.

Such contributions are often overlooked in planning and economic assessment in health care.

It is important to note that the problems of caregiving should not be blamed solely on autism. Services that are not accessible, discriminatory, insufficient financial support, and isolated service systems can significantly raise the demands on families.

Hayes and Watson conducted a meta-analysis which did find that parenting stress was higher for parents of autistic children than for parents of typically developing children and higher than in comparisons included for parents of children with other disabilities (Hayes & Watson, 2013).

The results from groups, however, should not be assumed to represent any person or family with autism.

1.2 Understanding the Hidden Burden of Caregiving

Hidden burden is the burden and needs of caregiving that are not fully reflected in traditional health indicators or cost accounting. These can include lost opportunities for employment, disrupted sleep, emotional strain, administrative work, loss of recreation and social opportunities. Some also have apprehensions in relation to future housing, finances and access to support. These roles can build up over time, especially when there is no formal service or the service is poorly coordinated.

However, there are positive aspects to caregiving experiences. Close relationships, advocacy successes, learning more about disability, and participation in their family members' lives may be described. A balanced review should acknowledge the challenges for the person caring for the autistic person as well as the strengths of the family without suggesting that the autistic person is an "extra burden.

1.3 Rationale and Objectives

Healthcare policies and programs are increasingly acknowledging care provider well-being as a critical aspect of family-oriented healthcare. However, mental health services, disability benefits, education and employment policies are often delivered and managed separately, with families having to work through the various support mechanisms.

In a recent scoping review, the study identified that caregiver mental health was linked to parenting practices and family functioning, and that social support and self-stigma were relevant contexts (Lopes et al., 2026). The results of this study support a more comprehensive strategy that takes into account the well-being of the caregivers in addition to the rights and needs of people with autism.

The purpose of this review is to explore the psychological and economic stressors associated with caregiving, to examine social and structural factors that impact family wellbeing across the lifespan, to assess interventions in support of family caregiving, and to review policy options for enhancing family wellbeing throughout the lifespan.

1.4 Scope and Review Approach

This review article is a critical narrative review of 25 relevant publications found in the PubMed database. Selected literature comprises meta-analyses, systematic reviews, observational studies, qualitative studies, and policy-related studies. High-income country evidence and low- and middle-income country evidence is taken into account, with a focus on disparities in service infrastructures and financial protection. This is not a systematic review, and consequently no detailed search protocol was used, nor has a formal risk-of-bias assessment, nor a pooled meta-analysis been undertaken.

2. CONCEPTUALIZING CAREGIVING IN FAMILIES OF AUTISTIC INDIVIDUALS

2.1 Caregiving Across the Lifespan

Caregiving responsibilities change throughout childhood, adolescence, and adulthood. Families can arrange developmental assessments, communication assistance, education, and health care appointments during early childhood.

School-age caregiving frequently involves working in partnership with teachers, making plans for accommodations, facilitating communication, and addressing challenges that arise with inaccessible environments. Adolescence brings in other issues such as preparation for adulthood, mental health, sexuality education, and autonomy and social participation.

Families can also continue to provide support to autistic adults who have significant support needs in relation to their daily support needs, health, work placement and planning, housing, and legal and financial matters. These shifting roles illustrate the need not to restrict caregiving studies to the study of parents of young children.

2.2 Objective and Subjective Caregiver Burden

There can be two types of caregiver burden: objective and subjective. Objective burden refers to the measurable burden, for example, the time spent giving support, cost, travel, and lost time at work. Subjective burden relates to perceived stress, emotional fatigue, doubts, and the impact of caregiving. These dimensions are related but different.

Differences in social support, financial security, health, coping resources and service availability may result in differing degrees of distress for two families receiving similar amounts of practical support. Moreover, high levels of caregiving involvement do not inevitably equate to poor wellbeing. So it is important to take into account family preference, contextual resources and family difficulties due to support needs or due to preventable systemic barriers when interpreting burden.

2.3 Ecological and Family-Systems Perspectives

One ecological theory places caring within the system of individual, family, community, institutional and policy environments. On an individual basis, the factors that should be considered are the autistic's support needs, preferences, and the physical and psychological health of the caregiver.

The division of labour within the family can vary by employment, gender, family size and resources. Factors at the community level include informal support networks, schools, transportation, and social attitudes. Institutional factors include eligibility for services, system of health care system, disability compensation, and educational support policies. This is helpful as it encourages consideration of the social context of caregiving experiences rather than individual coping alone.

3. Mental Health Challenges Among Family Caregivers

3.1 Parenting Stress and Emotional Exhaustion

Caregiver stress can develop when the demands of care require more resources, time,e and support than are available. Families might experience challenges in arranging multiple services, responding to conflicting professional recommendations, obtaining school accommodations, and managing multiple health issues. The unpredictable availability of services could also add to uncertainty.

When the caregiver feels forced to keep explaining and explaining children's needs, or defend them, this can also add to the stress. The level of distress is not only dependent on the autistic person's characteristics, however. This could also be financial stress, discrimination, caregiver health, and the quality of formal care.

In a sample of 152 parental caregivers, daily stressors, coping self-efficacy, and household income were found to be the best predictors of various domains of QOL (Turnage et al., 2025). This indicates that working toward better care provider wellness should be aimed at enhancing personal coping mechanisms as well as external factors.

3.2 Depression and Anxiety

Caring for a patient with depression and anxiety is a significant issue. Some factors that may be contributing are chronic stress, sleep disruption, financial insecurity, social isolation,n and lack of clarity around future support.

A systematic review and meta-analysis of 40 studies with 13,853 caregivers yielded a pooled prevalence of DE symptoms around 45% (Xin Rong et al., 2025). This estimation suggests high psychological vulnerability in the populations studied. But this does not mean that this is the rate of clinically identified depressive disorder in all caregivers. There were variations among the included studies in sampling, assessment tools, thresholds, and geographic context.

In this context, screening for psychological distress might be warranted in family services, especially if family members report ongoing challenges. Evaluation and treatment should be personalized.

3.3 Sleep Disruption and Physical Health

Caregiving can impact sleep in several ways, including helping with sleep at night, working irregular hours, stress, and arranging activities around work or other family needs. Many people with autism will have problems with sleep or health issues that could also need extra family support.

Low levels ofcaregivers's sleep can impair their focus, ability to manage emotions, physical well-being and work productivity. Limited exercise, preventative health care and rest opportunities can, over time, lead to general health inequalities. However, not all families of autistic children have sleep problems.

Research needs to separate the sleep problems that are directly related to the support needs of children from those that are related to poverty, working hours or the mental health of the carer. Accessible sleep assessment, co-ordinated health care, flexible working and suitable respite care are all practical considerations that could be made.

3.4 Psychological Resilience and Coping

Resilience is the ability to cope or to restore functionality in the face of adversity. Stable relationships, good financial stability, access to accurate information,n and opportunities for meaningful participation may help to foster caregiver resilience. There are multiple coping strategies,s and these are unique to the person and the situation.

Problem-solving approaches can include arranging services, obtaining information, or requesting accommodations. Strategies for dealing with emotional distress can involve counseling, peer support,mindfulness-based interventions,s or other strategies. Resilience should not be the excuse to withdraw formal support, however. Giving responsibility for becoming more resilient to the caregiver without providing a different form of services/supports that can be afforded may lead to a shifting responsibility away from institutions.

3.5 Mental Health Interventions

Caring for a loved one who is stressed, anxious, or depressed can be supported with psychological interventions. These methods range from cognitive behavioural therapy, mindfulness-based interventions, psychoeducation and structured group support.

A systematic review and network meta-analysis in 2024 of 69 intervention studies and 4,213 parents showed a benefit for mindfulness-based interventions on parenting stress, and cognitive behavioral therapy on anxiety and depression outcomes (Mo et al., 2024). Yet another meta-analysis of randomized trials found that parents' stress and some psychological measures improved after mindfulness-based interventions (Peng et al., 2025). Overall, these findings are encouraging, but must take into account intervention heterogeneity, length of follow-up, usefulness, and methodological quality. Practical and financial support should not be the only mode of treatment and should complement psychological treatment.

4. FINANCIAL CHALLENGES AND THE ECONOMIC BURDEN OF CAREGIVING

4.1 Direct Healthcare and Intervention Expenditure

Money issues are a significant part of family caregiving experiences. Direct costs include diagnostic evaluations, consultations, communication support, occupational therapy, mental health services, medications for co-occurring medical issues, assistive technologies, and more.

The actual costs can be very different depending on the individual's needs, the funding system in place for healthcare in their country, and the availability of publicly funded support. Some families get a lot of support from public services, while others may have to wait a long time for their support or may have to pay for private providers of support.

In a literature review, Liao and Li found that, across studies in 10 countries, financial difficulty and negative job outcomes were found to be significant risk factors for mothers (Liao & Li, 2019). But it's important to remember that costs do not mean a rigid cost to a person's finances for the diagnosis of autism. These show the interaction between the needs of the individual and the systems that address those needs.

4.2 Educational and Developmental Support Costs

Services related to education can involve special education services, transportation, communication devices, tutoring, school accommodations, and additional assistance. In certain contexts, families are expected to cover costs for services that are provided in private that are not available in the public education system. They can be high if kids need a range of support and if schools are under-resourced.

In a study on the economic costs of childhood autism in the United States, it was estimated that non-healthcare costs were a significant portion of the societal costs, especially educational costs (Lavelle et al., 2014). The study is an example of the need

to analyze the broader economic impacts of insufficient support. Investment in public education can have the potential to lower the amount people spend on education in their homes and offer them greater learning opportunities and participation.

4.3 Employment Disruption and Lost Income

Caregiving can impact work by having a negative effect on hours worked, employment status, absenteeism, and/or leaving the workforce. These can occur if support services are in operation while parents are at work, if there is no transport, or when there is no consistent support available for families. Households relying on a single income could be particularly affected by work disruption. The employment interference was significantly higher in families of preschool children in urban China compared with various comparison families in a study (Ou et al., 2015).

The loss of employment can have repercussions beyond the actual loss of income. Decreased working participation could impact career advancement, retirement plans, professional growth, and financial self-sufficiency. Policies that offer flexible working arrangements and consistent care services, for example, can then offer benefits other than short-term financial support.

4.4 Gender Inequality and Unpaid Care Work

Unpaid caregiving is often shared unequally in the home. While the arrangements for care vary from family to family and culture to culture, mothers may feel more inclined to cut back on employment or take on the role of service coordinator. This imbalanced distribution can help to accentuate gender pay gaps and lower economic wellbeing.

Costs of unpaid care are rarely included in traditional cost calculations. A family could report moderate amounts of direct spending, yet provide a great deal of unpaid support that would come with publicly funded services or private services bought at cost. Unpaid care does not imply that family members are expected to offer care for all time. Rather, it helps to develop policies that safeguard caregivers' financial independence, health,h and employment status.

4.5 Financial Consequences of Co-occurring Intellectual Disability

There may be co-occurring intellectual disability, epilepsy, mental health issues, and other support needs in individuals with autism. These can have an impact on the kind and level of support needed.

A study that looked at the financial and employment effects of having an autistic child in the family showed increased financial problems and disruption to employment if autism was combined with intellectual disability (Saunders et al., 2015). This indicates a need to tailor service funding to individual needs, and not only diagnostic categories. However, the intensity of support needs to be identified as part of the assessment and planning process – not by assuming what is capable.

4.6 Health Insurance and Financial Protection

The level of insurance coverage and public financing arrangements can significantly impact household spending. Even if families have insurance, there can be financial barriers due to coverage limitations, deductibles, co-payments, a shortage of providers,s or reimbursement procedures. Out-of-pocket expenditure was found to be different in families of autistic children in the USA, depending on the type of insurance they had, said Parish and colleagues (Parish et al., 2015).

A companion study of insurance mandates revealed that mandates shifted more of certain autism-related service costs towards insurance companies, but families utilizing high levels of services nonetheless incurred significant expenses (Candon et al., 2018). The results indicate that not all nominal coverage results in affordable access. To achieve effective financial protection, service availability, eligibility, and payment, as well as individual household spending, must be taken into account.

4.7 Financial Burden in Low-Resource Settings

In situations where there are fewer public disability services and more out-of-pocket healthcare spending, financial problems might be especially difficult to manage. Families need to travel a long distance to receive services, pay privately for the evaluation, and/or sacrifice work hours to receive services.

A preliminary study of 80 families in a tertiary care center in urban India found that there was significant cost involved with diagnosis, intervention, education,n and child care. About 71% of those families who participated in the study were found to have made more than the study threshold of catastrophic healthcare expenditure (CHE) (Sakhardande et al., 2026). This estimate

should not be extrapolated to the population of all families with autistic children in India because of the small sample size and facility-based nature of the sample.

The results do, however, signal the possible financial ramifications of restricted public assistance. A scoping review of African studies also revealed expenditure on healthcare, transport, lost productivity, and social exclusion as key issues in caregiving (Anthony et al., 2026). Such observations are one of the reasons for the need for context-specific financial support and community services that are available.

5. SOCIAL ISOLATION, STIGMA, AND FAMILY RELATIONSHIPS

5.1 Social Stigma and Discrimination

Stigma may be experienced by autistic people and their families in the form of stereotyping, exclusion, negative judgment, and/or discriminatory treatment. Criticism about parenting skills, disabilities and disability support needs, and exclusion from community activities may be faced by caregivers. These events can make it easy to stay out of social situations and decrease the desire for help. Evidence of significant associations between stigma and the mental health of informal caregivers was found in a systematic review of stigma and mental health in relation to autism (Papadopoulos et al., 2018). But stigma is not only a problem for the individual care provider.

Institutional practices, services, and social environments that discriminate against autistic people and their families can have a direct impact on their lives. So, in order to reduce the stigma, there is a need for a change in public attitudes and institutional arrangements.

5.2 Social Isolation and Reduced Participation

Limited recreational, friendship, community, and personal interest opportunities may be experienced by caregivers. These conditions may occur when an appropriate support service is not available, public spaces are not accessible, or caregivers are overworked or short on time and money. Others may choose not to attend social events out of fear of misunderstanding or discrimination experienced in the past by some families. But low engagement does not necessarily mean that someone is socially isolated.

There are variations in families' preferences for social interaction, and autistic people may have different sensory or social preferences. Support services shall allow for meaningful participation based on individual preferences and not in a conventional sense of social behavior.

5.3 Family Relationships and Marital Dynamics

Relationships between partners, children, grandparents and other family members may be affected by caregiver responsibilities. Money, division of responsibilities, and disagreements over services can cause conflict. Shared advocacy, understanding, and effective communication can, on the other hand, build stronger relationships.

The impacts are not consistent. The family relationships are interwoven with existing conditions, family communication, support networks, and wider social and economic context.

Policies and interventions must thus not presume that autism automatically leads to marital problems or family dysfunction. When families seek help, counselling and family-focused support can be helpful to provide a better understanding of the situation, as well as practical planning and allocation of roles.

5.4 Siblings and Extended Family Members

Siblings can be involved in day-to-day helping, emotional support, advocacy, and family activities. This depends on the age and circumstances of the household, the support needs of the autistic person, and the distribution of responsibilities. The child's psychological impact on siblings needs to be considered, and siblings do not necessarily suffer similarly from the disability of another. Extended family members may also be able to offer significant support.

A systematic review and meta-synthesis of 42 studies resulted in the identification of emotional, practical, financial, and informational support from grandparents and other family members. It also documented experiences of misunderstanding and

lack of support (Li et al., 2025). The findings suggest that extended-family involvement is protective, but cannot be assumed to be available and/or beneficial in all families.

5.5 Cultural and Socioeconomic Influences

The development of ideas, beliefs, and values is shaped by cultural and socio-economic influences. Cultural beliefs affect the way autism is perceived, the way families look for help, and the services they can get. Some beliefs about developmental differences may contribute to a heightened sense of stigma in some communities. These challenges can be exacerbated by socioeconomic disadvantage, which limits people's access to information, transportation, and professional services.

A systematic review of stigma among ethnic minority caregivers identified several forms of stigmatisation: social stigma, self-stigma, and service utilisation problems (Pang et al., 2023). Culturally responsive services should, therefore, be designed in collaboration with families and autistic people, not from stereotypic notions of cultural groups.

6. SOCIAL SUPPORT NETWORKS AND CAREGIVER WELL-BEING

6.1 Informal Social Support

Informal supports are the help and interaction of family, friends, neighbors, community organizations, and peer groups. This can include emotional reassurance, transportation, temporary assistance, information sharing, or assistance with household tasks. Social support can help to decrease isolation and increase caregivers' ability to address practical issues.

Family structure, geographical mobility, social attitudes and economic resources, however, affect the availability of support. A caregiver can have many social contacts and yet have no one available to give them practical support. Therefore, network size alone is not necessarily the best measure of the quality and reliability of support.

6.2 Parent and Peer Support Groups

Peer Support Groups are opportunities for caregivers to share their experiences, talk about services, and discuss strategies for navigating education and healthcare systems. These groups could be used to address feelings of isolation and to provide information. Online communities can help to extend access to families outside of specialist centres. Peer groups are, however, not all equal in quality, availability and relevance.

There may be some caregivers who feel the available groups don't fit their situation or require one-on-one care. Peer support should therefore be provided on the basis of its being an option, not a standard approach. Other information disseminated via informal networks should also be separated from formally validated clinical advice.

6.3 Formal Family Support Services

Formal Services such as Respite, Counseling, Case Management, Family Education, transportation assistance, and community-based support. The unmet health care and family-support needs of a sample of 263 caregivers in Delaware were found to be significant in a needs-assessment survey conducted. Respite, counseling, support groups, and childcare assistance were reported as gaps (Srinivasan et al., 2021). The results highlight the need to consider the family's needs independently of the clinical services delivered to autistic persons. A family can utilize an intervention and not get support for transportation, employment, or the mental health of caregivers.

6.4 Respite Care

Respite services are temporary services provided to help caregivers rest, work, participate in personal activities, or access other services. Respite can be provided in the home, in the community, or in special facilities. It is useful only if the quality of the service is good, the cost is reasonable, it is easily accessible, and the autistic person feels comfortable and respected.

Respite does not just mean "family away from the autistic individual. The right programs can enable activities of interest, continuity, and individual choice. In a longitudinal study of caregivers of youth with neurodevelopmental disabilities, respite was still salient 19 years later in adult years (Tafolla et al., 2025). But there is limited evidence related to long-term mental health ANd economic outcomes.

6.5 Accessibility of Support Services

Support programmes do not always make services accessible to families. Some barriers are waiting lists, difficult eligibility, cost of transportation, language or cultural differences, and provider availability/limitation, and provider cultural responsiveness.

The qualitative review of underserved families was systematic and revealed that accessibility, service diversity, and stigma were important factors influencing the use of support (Wallace-Watkin et al., 2022). Increasing access is important not only in terms of quantity but in terms of quality. Systems also need to be more user-friendly and responsive to different family situations, as well as be held accountable for fulfilling unmet needs.

7. CAREGIVING ACROSS DEVELOPMENTAL TRANSITIONS

7.1 Early Diagnosis and Service Navigation

The time leading up to the autism assessment can be a time of uncertainty, of a lot of information gathering and of making complex decisions about services. There can be a sense of relief for some families when an assessment process can shed light on their child's attributes and how support can be provided. Others suffer from lengthy wait times, conflicting information, or access to unskilled personnel.

Other administrative tasks can also arise out of a diagnosis, such as insurance, school, and disability services. Family-centered assessment should thus give accessible information, realistic explanations of available supports, and opportunities for the expression of priorities, by caregivers and autistic persons. The goal should be to help provide support, not to imply that all individuals with autism need the same supports.

7.2 School-Age Caregiving and Educational Advocacy

Family coordination needed for educational involvement may be significant. Teachers can communicate with caregivers, request accommodations, attend planning sessions, and assist in addressing challenges in areas of sensory environment or social inclusion.

If schools do not have the proper resources, families may take on tasks that are shared with the schools. This can lead to further time pressures, job insecurity and disruption. Teacher training, accessible communication, individualised adjustments and clear complaints procedures should thus be provided as part of inclusive education policies. The educational success of an autistic student should be measured based on the student's learning, well-being, participation, and goals.

7.3 Transition to Adulthood

The move from puberty to adulthood can be particularly difficult as education, health and disability support systems often change at the same time. Assessing and coordinating adult healthcare, vocational support, housing, financial support and community involvement may be required for families.

Wolpe and colleagues found that four themes emerged in qualitative research about the transition to adulthood: service navigation, limited opportunities, financial pressures, and caregiver well-being (Wolpe et al., 2023). This is a sign of the challenges that lie ahead, meaning that transition planning must start prior to the end of childhood services. Planning should also include taking account of the autistic person's preferences, ways of communicating, right to make decisions, and desire for independence.

7.4 Unmet Needs in Adulthood

Autistic adults are also often under-represented in service research, especially as they have significant communication or daily support needs. A large survey of 5,792 caregivers revealed that service use and unmet needs varied by age group, and there were significant gaps in services for young adults (Song et al., 2022). The results of this study contradict the notion that the need for support decreases post-childhood. Employment, housing, relationships, health, mental health, community involvement and support for the future may all be issues that have to be resolved with adult services. Support needs to be tailored to the individual's needs and not be based on an arbitrary age cutoff.

7.5 Families of Individuals with Extensive Support Needs

Some autistic people need help with everyday activities, communication, health care, and safety. Those families who have someone in their household with a high level of need can have the most complex coordination challenges. Unmet needs of

caregivers of adolescents and adults with profound autism included social opportunities, primary healthcare that was autism-informed, life-skills support and autism-related behavioral assistance (Ferguson et al., 2024). The results underscore the need for sufficient resources and personalised services. However, terms for the level of support should not cloud the person's autonomy, preferences, relationships, or rights in decisions.

7.6 Aging Caregivers and Long-Term Planning

Caregivers, as they get older, may suffer from illness, lower earnings, or worry about what will happen to them when they grow older. Long-term planning may relate to housing, supported decision-making, finances, legal safeguards and continuity of health services. These can be especially acute if the parent of an autistic adult is a very old person. Planning, however, should not presume that an autistic adult cannot make decisions.

Supported decision-making arrangements should keep the person as independent as possible, and provide them with the support they need. Governments and service providers should create long-term support systems, rather than relying on unpaid family work for an undetermined period.

8. SOCIAL SUPPORT POLICIES AND PUBLIC HEALTH INTERVENTIONS

8.1 Family-Centered and Rights-Based Service Models

Social support policies should acknowledge the needs of the autistic person and those of the caregivers but note that they are not necessarily the same. A family-centered approach takes into account the well-being of the caregiver, the family situation, and the need for practical assistance. A rights-based approach also focuses on autonomy, dignity, accessibility and participation of the autistic person in decision-making.

Such methods are complementary when used properly. The family might need respite support, and the autistic person might need to have a choice in the place, what they do, and who supports them. Policies must therefore not be understood as contradictory, to the extent of setting up alternatives between the support of carers and the rights of autistic people.

8.2 Financial Assistance and Disability Benefits

Direct financial support to cover disability costs and minimize economic impacts on unpaid caregiving. There are several potential mechanisms: disability benefits, caregiver allowances, subsidized services, tax relief, and transportation support. The policy design will be informed by the national financing systems and social protection systems.

Means-tested programs can be used to divert resources to lower-income households, but can also create administrative complexities and exclusionary eligibility requirements. The implementation of universal or broadly accessible services can reach out to stigma reduction and better coverage but need sustainability funding. It is important to review policy in terms of spending by families, using services, poverty risk reduction, and employment outcomes.

8.3 Employment Protection and Flexible Work Policies

Conflict between childcare and work can be minimised through employment policies. Possible approaches include leave policies, flexible work schedules, foreseeable leave options, remote work arrangements (where possible), and protecting against caregiver employment discrimination. Flexible work, however, is no substitute for concrete community services.

Even if flexible hours are offered, a caregiver might still not be able to work if they do not have the right support available. Other factors that should be taken into account include retirement funds, advancement, and future financial stability. Caregivers' economic engagement should be maintained, and the goal should not be that someone in the family gives up on a permanent basis.

8.4 Accessible Healthcare and Integrated Service Coordination

Fragmented service systems add to the burden of families. Adopting an integrated care coordination approach can eliminate the need to repeat information, request referrals, and go through multiple eligibility processes. These could involve standalone care coordinators, planned service agreements, easily accessed services and systems of appointments, and better communication between healthcare services, education and social care.

Previous studies of health-related experiences of autistic children identified that there was increased family financial and occupational strain and that a coordinated primary care system might be able to minimize some of these challenges (Kogan et al., 2008). But service integration should be measured in the following measurable terms: waiting time, unmet needs, family satisfaction, and caregiver time.

8.5 Community-Based and Culturally Responsive Services

Bringing assistance to the family can help to decrease geographical and financial barriers through community-based services. Local support centers, community health workers, peer networks, mobile services, and telehealth are all potential options.

Telehealth could enhance the availability of certain counselling and/or consultation services, including in areas with low levels of service provision. However, digital interventions demand secure access, privacy protection, effective communication, and proper clinical supervision. There should also be community services to accommodate linguistic, cultural, and socioeconomic differences. Development projects without meaningful community participation can be unsuccessful in reaching intended beneficiaries' priorities.

8.6 Anti-Stigma and Inclusive Social Policies

Interventions against stigma need to target discriminatory attitudes and institutional barriers toward autistic people and their families. While public awareness campaigns can enhance knowledge, they do not always lead to the change of discriminatory practices.

So, promoting inclusive education, accessible public services, employment protections, and disability rights enforcement is crucial. A recent systematic review of stigma and quality of life for autistic adults and their families found that psychological well-being, relationships, work, and health-care experiences were all negatively associated with stigma (Liu et al., 2026). These results suggest interventions at individual, community, and structural levels.

8.7 Priorities for Low- and Middle-Income Countries

Policy solutions need to reflect the diverse sides of public funding, public workforce, transportation systems, and service offerings. Where resources are lacking, increased support and simple assessment services might be important.

It is possible to alleviate the unmet needs through training of primary health care workers, establishment of referral mechanisms, provision of inclusive educational opportunities and reinforcement of community-based assistance. But policies should not be based only on low-cost volunteer or unpaid family labour. There is a need to ensure that sustainable programmes are adequately funded, that staff are appropriately trained, that they are held accountable and that autistic people and their families are meaningfully engaged.

9. CRITICAL EVALUATION OF EXISTING SUPPORT SYSTEMS

9.1 Individual Interventions Versus Structural Support

Common interventions for caregivers focus on stress management, mindfulness, and/or coping strategies. They can be helpful, especially if caregivers are psychologically distressed, and can be used in conjunction with the other methods mentioned above. However, interventions aimed at only individual coping may not address the structural conditions that are causing distress.

For a caregiver who may be facing financial difficulties due to insufficient service coverage, the need for financial support and low-barrier care may be more pressing than the need for further education on stress management. Likewise, if a family is finding themselves discriminated against on an ongoing basis, they may also need institutional changes in addition to psychological support.

The public health response should therefore attempt to distinguish between problems that can be tackled through individual intervention and those which can be tackled through policy and service delivery changes.

9.2 The Gap Between Policy Entitlement and Service Access

There are many jurisdictions that have disability-related rights or support entitlements. However, there can be waiting lists, eligibility requirements, a lack of workers, and confusing paperwork. The effectiveness of a policy is not automatically assumed when the policy is in place.

Assessment should cover the availability, timeliness, and impact of support for eligible families, to ensure that well-being and participation are enhanced. Administrative burden should also be included as a relevant outcome, as it is an intake of time navigating services, which is a type of unpaid caregiving.

9.3 Economic Evaluation of Family Support

Costs of caregiver assistance should be considered with respect to possible benefits for households and public services. For instance, a respite or community resource that is accessible could allow for employment participation, decrease distress for caregivers, and provide continuity of care. Such are benefits, however, that must be measured and not assumed.

Direct cost, unpaid care time, lost income, caregiver health and outcomes significant to the autistic person should be included in economic evaluations. Minimising public expenditure is not the only definition of cost-effectiveness. A policy can be more costly but have a significant impact on family autonomy, equity and long-term outcomes.

9.4 Participatory Policy Development

The involvement of autistic people and family carers in the design and review of services must be meaningful. They might have different priorities, especially when it comes to independence, privacy, how they'd like to be cared for, and who does what. Participatory methods can uncover issues that traditional service evaluations don't.

But consultation should not be restricted to those who are convenient to attend meetings and able to fill out the usual questionnaires. Equitable participation is important for accessible communication, adequate compensation, and representation of persons with high support needs.

10. LIMITATIONS OF EXISTING EVIDENCE

The available literature on the family caregiving experience offers significant support for the psychological, financial, and social difficulties of the families of children with autism, but several methodological weaknesses in the literature limit interpretation. Many studies employ a cross-sectional design, which makes it hard to discern the effect of caregiving conditions on mental health outcomes, or whether existing vulnerabilities affect outcomes.

The burden of a caregiver is also not consistently measured. Comparability is restricted across studies by the use of various instruments for measuring stress, depression, financial hardship, social support, and quality of life. Recall bias, recruitment procedures, and social norms can impact self-reported outcomes.

Another issue is that mothers of autistic kids are overrepresented. Fathers, siblings, grandparents, partners, autistic caregivers, and families of autistic adults are still largely under-researched. Studies with individuals with wide communication and/or support needs are also scarce.

Evidence is mainly located in countries with high development levels, notably those with relatively well-established systems for health and disability services. Results might, therefore, be difficult to extrapolate to the rural population and low-resource areas.

Unpaid caregiving time, long-term employment impacts, and retirement-related losses are often not included in economic studies. Yet others include both public costs and household costs in their estimate, without separating out the views.

Intervention research frequently involves small sample sizes, brief follow-up times, and diverse programs. There are still weak assessments of the effectiveness of respite services, monetary compensation, employment safeguards, and integrated support policies.

One additional limitation of this review is that it is narratively designed, and 25 PubMed-indexed references were selected. It is not a systematic review or formal meta-analysis.

Standardization of outcomes, representative sampling, longitudinal design, and participatory approaches which reflect the priorities of autistic people and of diverse family caregivers should be incorporated into future research.

11. FUTURE PERSPECTIVES

Future research and policy development should take a lifespan perspective that considers the different needs of autistic people and their families throughout their lives. Longitudinal studies have a special value in providing insights into the change in caregiver mental health, work, income, and social functioning from early childhood to adulthood and aging.

Fathers, siblings, grandparents, partners, and other informal carers need to be more represented. Families from a variety of socio-economic, cultural, and geographical backgrounds should also be included in studies, especially in LMIC countries.

The focus of research needs to expand to the interplay between the needs of the individual and structural variables, including health care financing, the availability of education, social protection, and employment. This might aid in separating out difficulties with caring tasks from avoidable strains caused by poor services.

Unpaid care time, lost earnings, retirement impacts, and the potential gains of community support services should be included in economic assessments. Comparisons of caregiver allowances, respite programs, flexible employment policies, and/or coordinated healthcare could yield better data to support resource allocation.

Digital technologies can impact appointment coordination, facilitate telehealth access, and enhance information sharing. However, their effectiveness needs to be evaluated in conjunction with digital exclusion, privacy, affordability, and accessibility.

To enable better development of services, participatory research should be a core component of the participation of autistic people and family carers. This collaboration will help ensure the autonomy and individual preferences of caregivers are not compromised.

Future interventions should also measure positive outcomes such as relationships, participation, resilience, and quality of life.

Sustainable progress will require policy integration that takes a holistic approach to mental health, covering financial protection, accessible services, inclusive education and long-term arrangements, in a cross-lifespan policy approach.

12. CONCLUSION

The family caregiving process is a critical support area for autistic people throughout childhood, adolescence, and adulthood. But the social, psychological and economic impacts of unpaid care work are underutilized in many health care and social protection policies.

Some family caregivers are found to have higher parenting stress, depressive symptoms, anxiety, disrupted employment status, and financial difficulties. These outcomes are affected not just by the individual support needs, but also by issues of service accessibility, household resources, gender inequalities, social attitudes and institutional barriers.

Healthcare, education, transportation, and assistance can be a significant cost burden on household budgets. Other costs, such as lost earnings, lower productivity, and potential long-term employment issues, also add to the economic fragility.

A lack of community acceptability and support can lead to isolation and psychological pain. Reliable informal networks, suitable respite care, accessible medical and mental health care and evidence-based psychological interventions, on the other hand, can help the caregiver's well-being.

However, any coping measure is no replacement for structural reforms. Financial protection, employment rights, service coordination, inclusive education and continuity of support into adulthood are all areas that should be covered by effective policies.

A rights-based approach should be based on the understanding that the rights of autistic people and of the people who care for them are different, but also interrelated. Support for families should reinforce, not limit, the autonomy, dignity and participation of autistic people.

Longitudinal data, a variety of caregivers, and policy evaluation methods are needed for future research.

In the end, the minimization of the hidden burden of caregiving demands a transition from the use of unpaid family care to a coordinated and fair system that provides sustainable well-being for autistic people and their families, with care that is provided for them and is adequately funded.

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AUTHOR CONTRIBUTIONS

Adrika Singhal: Conception and Design

Adrika Singhal: Literature review and analysis

Adrika Singhal: Manuscript Drafting

Adrika Singhal: Review and editing.

CONFLICT OF INTEREST

The author declares no conflicts of interest to disclose.

ETHICS STATEMENT

This manuscript is a literature-based review of previously published research and does not involve the recruitment of human participants, collection of primary patient data, or experimentation on animals. Therefore, institutional ethics committee approval and informed consent were not required for the preparation of this review.

DATA AVAILABILITY STATEMENT

Data supporting the findings of this study are available from the corresponding author upon reasonable request.

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