ISSN 2616-5783 Vol.9, Issue 7: 1-8, DOI: 10.25236/AJHSS.2026.090701

Caregiving Challenges and Support Strategies for Older Caregivers of Adults with Disabilities in the Context of Population Aging

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Abstract: *In the context of population aging, changing family structures, and the growing long-term care needs of adults with disabilities, particularly those with intellectual and developmental disabilities, older parents, spouses, and other relatives are increasingly assuming long-term caregiving responsibilities for adult family members with disabilities. These families constitute a distinct group within long-term care systems. Drawing on relevant literature and policy documents, this paper examines the caregiving challenges faced by older caregivers and proposes potential support strategies. It identifies major pressures related to declining physical health, financial and time constraints, emotional burden, and barriers to service access. It then analyzes four underlying factors: the long duration of caregiving relationships, declining family caregiving resources, the undervaluation of unpaid care work, and weak coordination between services for older adults and disability services. Finally, it recommends strengthening caregiver identification and assessment, community support and respite care, future care planning, and institutional coordination. The paper argues that this issue should not be treated solely as a private family matter; rather, it is a long-term care challenge shaped by demographic change, weakened family support, and the development of public services.*

Keywords: *Population Aging, Older Caregivers, Adults with Disabilities, Long-Term Care, Caregiving Burden, Social Support*

1. Introduction

Population aging has become a long-term challenge for many countries in the twenty-first century. According to the United Nations Department of Economic and Social Affairs, the number of people aged 65 years or older is expected to more than double, rising from 761 million in 2021 to 1.6 billion by 2050 [1]. This trend suggests that population aging is no longer confined to a limited group of high-income countries. Rather, it is a structural change occurring across countries with different income levels, welfare systems, and family cultures. As population age structures continue to change, demand for long-term care will grow, placing additional demands on families, communities, and public service systems.

At the same time, disability has become an increasingly important long-term policy concern. The World Health Organization estimates that approximately 1.3 billion people experience significant disability, representing 16% of the global population, equivalent to about one in six people [2]. Persons with disabilities face challenges not only in health care but also in rehabilitation, education, employment, community life, and long-term care. The World Health Organization's Global Report on Health Equity for Persons with Disabilities notes that persons with disabilities continue to experience persistent health inequities. They may die earlier, have poorer health and functioning, and be more affected by health emergencies than the general population. These inequities are linked to unfair conditions, including barriers within health systems and limited access to services [3].

In this paper, the term "families with older caregivers of adults with disabilities" refers to families in which older parents, spouses, or other relatives continue to provide long-term care for adult family members with disabilities. Among these families, aging parents who care for adult children with intellectual or developmental disabilities constitute a particularly important group and are a central concern of this paper. In many cases, caregiving begins when the child is young and continues through education, rehabilitation, daily living support, medical care, and into adulthood. Over time, this long-term caregiving relationship becomes deeply embedded in family life. However, as parents or other

ISSN 2616-5783 Vol.9, Issue 7: 1-8, DOI: 10.25236/AJHSS.2026.090701

caregivers grow older, their physical strength, income, social networks, and emotional capacity may gradually decline, while the care needs of the adult family member with a disability may continue.

Recent studies no longer treat this issue solely as an internal family responsibility. Instead, they examine it from the perspectives of social support, service transitions, and future care planning. Research on family caregiving for older adults indicates that caregiving outcomes vary considerably and are closely related to the intensity of care and the level of suffering experienced by the care recipient [4]. Therefore, the caregiving burden in families with older caregivers cannot be understood solely by considering the duration of care. It must also be analyzed in relation to the needs of the care recipient, the circumstances of the caregiver, and the support available outside the family. This paper draws on a review of relevant literature and policy documents. It follows a framework that links challenges, mechanisms, and support strategies rather than treating family strain solely as a problem of individual or family capacity.

2. Major Caregiving Challenges

2.1 Physical Strain and Daily Care Demands

Older caregivers are affected by age-related changes in health and functional capacity. As they age, they may experience chronic illnesses, reduced physical strength, sleep problems, and limited mobility. They may also require increasing support for health management and daily living. However, in families with older caregivers, caregivers often find it difficult to attend to their own needs. Adult children or spouses with disabilities may still require assistance with eating, bathing, community mobility, medication management, rehabilitation, and emotional support. In many families, daily life is organized around these care tasks. From the stress-process perspective, caregiver stress is shaped by caregivers' socioeconomic characteristics and resources, primary stressors directly related to caregiving, and secondary role and intrapsychic strains. Coping and social support may intervene at multiple points in this process [5].

The physical burden on older caregivers can accumulate over many years of caregiving. For families of persons with intellectual or developmental disabilities, caregiving responsibilities often span multiple stages, including education, rehabilitation, daily living, medical management, social participation, and future care arrangements. When the main caregiver reaches older age, earlier caregiving tasks do not necessarily become less demanding. Instead, they may be compounded by the caregiver's declining health, the increasing care needs of the family member with a disability, and unclear future arrangements. This makes the caregiving burden more prolonged and complex.

In addition to physical strain, long-term care also consumes family time and financial resources. Family caregiving is typically unpaid, but medical and rehabilitation costs, nursing supplies, assistive devices, transportation, and accompaniment services all create direct expenses. In addition, caregivers may leave employment or reduce their working hours, resulting in opportunity costs. Families therefore face both visible and hidden long-term costs. Eurofound notes that aging populations, declining fertility rates, and changing family structures are reshaping care needs and the provision of care. Nearly half (45%) of the EU population provides unpaid care, and 10% balance multiple caregiving responsibilities simultaneously [6]. These figures indicate that unpaid care is widespread in the EU.

Long-term caregiving also limits older caregivers' opportunities for self-care. In families that require continuous or round-the-clock supervision, caregivers often have little time to attend medical appointments, rest, or participate in community life. In the absence of trusted, affordable, and reliable respite care, older caregivers may gradually withdraw from social contact. Their health management and social support networks may also weaken.

2.2 Emotional Burden and Long-Term Uncertainty about Future Care

In addition to physical strain and care costs, families with older caregivers face sustained emotional pressure. This pressure arises not only from day-to-day emotional demands but also from long-term uncertainty about future care arrangements. Parents who have cared for adult children with disabilities for many years often face a central question: if they can no longer provide care because of aging, illness, or death, how will the family member with a disability maintain a stable daily life and receive social support in a familiar environment? The anticipated risk of care interruption makes emotional pressure not merely a short-term response but a persistent state of psychological tension.

ISSN 2616-5783 Vol.9, Issue 7: 1-8, DOI: 10.25236/AJHSS.2026.090701

In this context, a strong sense of emotional responsibility helps maintain stable family care, but it may also reinforce a tendency to preserve existing arrangements. Some older caregivers are concerned about the quality of institutional care, the continuity of services, and the ability of family members with disabilities to adapt to a new environment. They therefore prefer to continue home-based care and may be reluctant to seek alternative care arrangements. As caregivers grow older and their health declines, preserving existing arrangements may increase uncertainty about future care. When a sudden health event occurs, the family may be forced to respond urgently and without adequate preparation.

Research has shown that perceived social support is associated with greater progress in long-term care planning and lower caregiver burden. However, fewer than 40% of caregivers reported receiving social support [7]. As parents age, these families require more systematic support for future care planning to reduce the risk of crisis interventions following parental death or when parents can no longer provide care [8]. This suggests that many caregivers do not consistently receive or perceive adequate social support. A lack of social support may not only increase the current caregiving burden but also weaken a family's ability to develop future care plans. As a result, concerns about who will take over care may persist for a long time.

2.3 Barriers to Service Access and Unclear Service Entry Points

The challenges faced by families with older caregivers are also reflected in uncertainty about service access. Unlike families whose needs fall primarily within either services for older adults or disability services, these families usually have overlapping needs. Older caregivers need health management, support services for older adults, and respite care. Adult family members with disabilities need rehabilitation, day care, assistive devices, opportunities for social participation, and long-term living arrangements. However, services are often designed separately according to target populations and departmental responsibilities. When a family has complex needs, it may not know which assessment to complete first, which department to contact, or who should coordinate the services.

Unclear service entry points increase the time and effort required to seek assistance. Older caregivers may have to consult community workers, hospitals, disabled persons' federations, civil affairs departments, service providers for older adults, and social organizations repeatedly. They may need to explain the family situation several times and submit supporting documents more than once. Even when a family receives subsidies or services, this support may not address the practical demands of continuous care. For example, the family member with a disability may receive rehabilitation services or financial allowances, while the older caregiver may still lack time for rest, medical care, and respite. An older caregiver may be covered by services for older adults, while day care, behavioral support, or future living arrangements for the family member with a disability may still not be addressed in an integrated manner.

Difficulties in accessing services can also lead to an underestimation of the risks faced by older caregivers. Current assessments often focus on the functional status and service needs of the family member with a disability. They may fail to assess, at the same time, the main caregiver’s health, caregiving capacity, psychological stress, and available backup care arrangements. In families in which older parents care for adult children with disabilities, continuity of care depends not only on the needs of the person with a disability but also on whether the caregiver can continue to provide daily care. If a caregiver has worsening chronic illness, declining physical strength, emotional exhaustion, or no other family member available to share caregiving responsibilities, and these risks are not identified early, the family may seek temporary assistance only after the caregiver suddenly becomes ill, is hospitalized, or can no longer provide care.

3. Institutional and Social Mechanisms Underlying These Challenges

This section further examines how these challenges arise. In general, they are not simply caused by insufficient family caregiving capacity. Rather, they are shaped by the long duration of caregiving relationships, shrinking family caregiving resources, the undervaluation of unpaid care work, and weak coordination between services for older adults and disability services.

3.1 Long-Term Caregiving Relationships and Extended Family Life Cycles

Improvements in health care and living conditions have enabled more adults with intellectual and developmental disabilities to live into adulthood and older age. This is a positive outcome of social

ISSN 2616-5783 Vol.9, Issue 7: 1-8, DOI: 10.25236/AJHSS.2026.090701

development, but it also extends family caregiving relationships. For families of persons with lifelong disabilities, such as intellectual and developmental disabilities, care does not end in childhood or adolescence. As family members with disabilities grow older, care increasingly includes health management, participation in community life, housing support, medical decision-making, and future care arrangements. A scoping review on aging well with a lifelong disability suggests that support should be based on a multilevel perspective involving micro-level individual and relational support, meso-level system and community support, and macro-level government policy and disability-rights measures [9].

These long-term caregiving relationships distinguish families with older caregivers from conventional elder-care arrangements. In conventional elder-care arrangements, older adults are usually the main care recipients. In families with older caregivers, older parents, spouses, or relatives may simultaneously have their own care needs and remain the primary caregivers of adult family members with disabilities. When caregivers reach advanced age, the care needs of the family member with a disability do not naturally decrease. Instead, these needs may overlap with the caregiver's declining health, unclear arrangements for continuity of care, and limited external support. As adults with intellectual and developmental disabilities increasingly outlive their caregivers, many families still lack adequate preparation and support for future long-term care planning [10]. Therefore, the length of the caregiving relationship is not simply a matter of time. It also reflects a mismatch among family life cycles, caregiving responsibility cycles, and public support cycles.

3.2 Shrinking Family Caregiving Resources and the Undervaluation of Care Work

As caregiving cycles lengthen, the resources available to families may decline. These resources include not only the number of family members but also relatives' proximity, time to participate in care, caregiving skills, and ability to provide long-term financial and emotional support. With low fertility, smaller families, and increased population mobility, the number of siblings is decreasing. Adult children or younger relatives may live far away because of work, marriage, or migration. The traditional arrangement in which several relatives share care is becoming less common. Tasks such as accompanying family members to medical appointments, supporting rehabilitation, providing supervision, and organizing daily living support are therefore more likely to fall on one older parent or spouse.

Long-term reliance on family care is also reinforced by the normalization and undervaluation of unpaid care work. Parents caring for children and spouses caring for partners are often regarded as fulfilling moral duties within the family. However, when care lasts for many years or even decades and clearly affects a caregiver's health, income, labor market participation, and quality of life, it extends beyond ordinary family assistance and has broader public and social implications. Eurofound notes that when formal care services are under strain, unpaid carers become increasingly crucial but may remain unrecognized and unsupported. Unpaid caregiving is often driven by obligation rather than choice, shaped by societal norms and the limited availability of affordable, high-quality formal care services. It can reduce labor-market participation, cause financial strain, lead to social isolation and loneliness, and affect carers' physical and mental health [6]. Although these data come from the EU context, the report helps explain how unpaid care becomes normalized and how care costs remain hidden in families with older caregivers.

When care work has long been regarded as an internal family matter, the needs and circumstances of older caregivers can easily be overlooked. External service systems may identify whether a family member with a disability needs rehabilitation, subsidies, or assistive devices. However, they may not identify who provides long-term care, the volume and intensity of care tasks performed each day, whether the caregiver can still manage the work physically, or whether other family members can assume caregiving responsibilities. Consequently, caregivers are essential to sustaining family care, but their own needs may not be sufficiently recognized in existing assessments. The undervaluation of care work makes it difficult to identify family caregiving strain early and keeps the effects on caregivers' health, opportunity costs, and psychological well-being within the private family sphere.

3.3 Mismatch between Service Categories and Whole-Family Needs

The needs of families with older caregivers clearly cut across service categories. Older caregivers need health management, support services for older adults, respite care, and psychological support. Adult family members with disabilities need rehabilitation, day care, assistive devices, opportunities

ISSN 2616-5783 Vol.9, Issue 7: 1-8, DOI: 10.25236/AJHSS.2026.090701

for social participation, and long-term living arrangements. However, service systems often operate according to separate target groups and departmental responsibilities. Services for older adults primarily focus on daily living assistance, health management, and age-related care needs. Disability services mainly focus on rehabilitation, allowances, assistive devices, and social participation. Medical services focus on disease treatment and health management, while social assistance mainly targets financial hardship. This classification is useful for administrative purposes, but it can create a structural mismatch between need identification and service responses for families that include both older caregivers and adult family members with disabilities.

The problem is not merely the insufficiency of service provision. A classification system based on separate service users can also obscure the family-based nature of care continuity. In practice, older caregivers may come into contact with services for older adults or medical systems, but their long-term caregiving role may not be included in the assessment. Family members with disabilities may enter the disability service system, but the health risks, respite needs, and future transition pressures of the main caregiver may not be identified at the same time. As a result, a single family's needs may be fragmented into separate aging, disability, medical, or social-assistance issues. Integrated mechanisms for assessing care sustainability from a whole-family perspective remain limited in many settings.

Under this institutional logic, families are often left to coordinate services independently. Older caregivers must manage their own age-related health needs while also seeking rehabilitation, care, day activities, or long-term living arrangements for family members with disabilities. When services lack information sharing, active referral, and case coordination, families must understand policies, find resources, and repeatedly explain their circumstances. Therefore, the caregiving challenges of families with older caregivers do not arise solely within the family. They are shaped by the long caregiving cycle, reduced family resources, undervalued care work, and categorical service systems. Only by understanding these mechanisms can the discussion of reconstructing the support system move beyond simply adding separate services.

4. Directions for Reconstructing the Support System

Population aging, changing family structures, and the continuing care needs of adults with disabilities have made long-term care an important issue for public service systems in many countries. A distinctive feature of families with older caregivers is that the older caregiver's own needs for age-related support and health care overlap with the continuing care needs of the adult family member with a disability. It is difficult for these families to sustain care through internal resources alone. The World Health Organization categorizes core long-term care interventions for older people and carers into health care, palliative care, and social care and support, and identifies person-centered integrated care as a facilitating factor for coordinated service delivery [11]. In China, rapid aging, the large number of persons with disabilities, and changing family structures make this issue more urgent. The National Bureau of Statistics of China reported that, at the end of 2025, China had 323.38 million people aged 60 and above, accounting for 23.0% of the national population. Of these, 223.65 million were aged 65 and above, accounting for 15.9% [12]. The 2006 Second China National Sample Survey on Disability estimated that China had 82.96 million persons with disabilities, accounting for 6.34% of the total population [13]. Based on the challenges and mechanisms discussed above, and in light of the trend toward integrated long-term care and China's practical needs, this paper outlines directions for reconstructing the support system in three areas: caregiver identification and risk assessment; community support and respite services; and future care planning and institutional coordination. The framework is shown in Figure 1.

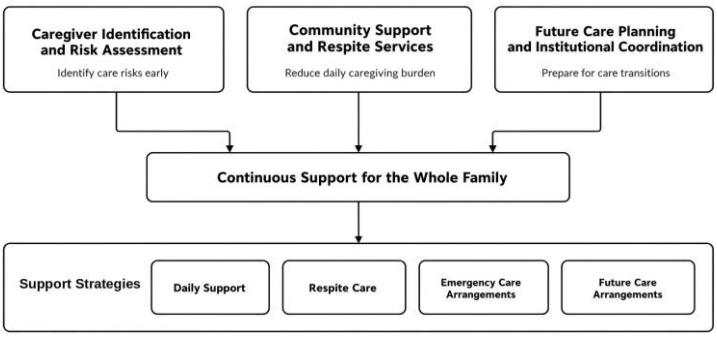

Figure 1: Framework for Reconstructing the Support System for Families with Older Caregivers.

ISSN 2616-5783 Vol.9, Issue 7: 1-8, DOI: 10.25236/AJHSS.2026.090701

4.1 Caregiver Identification, Assessment, and Risk Classification

The first step in reconstructing the support system is formally identifying older caregivers within service systems. Many caregivers remain invisible within these systems for a long time and often become visible only when a family crisis occurs. A better approach is to assess the main caregiver alongside the functional status and service needs of the person with a disability. The assessment should include the caregiver's health status, time spent on daily care, financial strain, psychological stress, available backup care arrangements, and future care arrangements. In this way, caregivers can be recognized as service users with assessable needs and a legitimate claim to support, rather than remaining "invisible supporters."

The purpose of this assessment should go beyond simply recording difficulties. It should identify high-risk families in advance. Communities and relevant organizations can pay particular attention to caregivers of advanced age, caregivers who provide care alone, families in which the care recipient requires round-the-clock supervision, families without clear care-continuity arrangements, and families in which the caregiver already has a serious illness, emotional exhaustion, or weak social support. Through risk classification, families can be grouped according to general support needs, priority follow-up needs, and urgent intervention needs. Home-based services, community referrals, psychological support, and respite care can then be arranged accordingly. In this way, the service system can move from passive crisis response to proactive risk identification and continuous follow-up.

4.2 Community Support and Respite Services

In practical terms, cash subsidies can partially reduce the financial burden on families, but they cannot replace caregiving work. For families with older caregivers, more practical forms of support include services that can be integrated into daily life, such as day care, short-term residential care, home nursing, rehabilitation guidance, behavioral support, transportation assistance, and psychological support. Respite care is especially important. It gives older caregivers time to attend medical appointments, rest, and manage personal affairs. It also helps family members with disabilities gradually become familiar with support settings outside the home, which can prepare them for later service transitions and long-term arrangements.

Community support should also reduce barriers to service access. Older caregivers often need clear, accessible, and practical information rather than complex policy explanations: what services are available, how to apply, how much they cost, whom to contact in an emergency, whether short-term care is available, and whether services can be accessed on a trial basis. A study of caregiver support services for family caregivers of persons with intellectual disabilities in Singapore found that targeted family support services can enhance caregivers' well-being. The use of specific support services was associated with greater satisfaction, coping capacity, and resilience [14]. Therefore, community support should not merely provide a list of resources. It should rely on case follow-up, service coordination, and ongoing support to help families reduce the daily caregiving burden.

4.3 Future Care Planning and Institutional Coordination

Future care planning should become an important part of support for families with older caregivers. It concerns not only where the family member with a disability will live in the future, but also who can serve as the main contact person, guardian, or designated support person; how financial resources and property will be arranged; how medical decisions will be made; who can take over in an emergency; and how communities, institutions, and social organizations can remain involved. Lindahl et al. identify several major domains of future planning, including housing, legal planning, identification of primary caregiver(s), financial planning, day-to-day care, medical management, and transportation [10]. This shows that future planning is a comprehensive process.

When future care planning is undertaken, the views and preferences of persons with disabilities should be respected to the greatest extent possible. Although some persons with intellectual or developmental disabilities may need supported decision-making, this does not mean they should passively accept arrangements. A better approach is to use accessible communication methods to involve them in discussions, help them gradually become familiar with possible future service settings, and reduce the disruption associated with sudden transitions. For older caregivers, future planning can also turn long-term uncertainty into arrangements that can be discussed, prepared, and implemented.

ISSN 2616-5783 Vol.9, Issue 7: 1-8, DOI: 10.25236/AJHSS.2026.090701

This can reduce the risk that a family will have to make urgent decisions after the caregiver suddenly becomes ill, becomes unable to provide care, or dies.

Institutional coordination is essential for making future planning practical. China has piloted and expanded long-term care insurance in recent years, but challenges remain in financing arrangements, insurance coverage, the supply of long-term care services, and the size and professional capacity of the long-term care workforce [15]. For families with older caregivers, institutional coordination should not remain a general call for interdepartmental cooperation. It should be translated into practical arrangements for assessment, information sharing, referral pathways, and the division of responsibilities. More specifically, communities can establish a family-based comprehensive assessment and case-management mechanism. This mechanism can link services for older adults, disability services, medical rehabilitation, social assistance, long-term care insurance, and services provided by social organizations. At the service-delivery level, a continuous support chain should be developed, ranging from daily care and respite care to emergency care arrangements and future care planning. Only when caregiver identification, community services, and future planning are placed within a single support framework can families with older caregivers move from managing long-term care alone to sharing care responsibilities with communities and public systems.

5. Conclusions

With population aging, changing family structures, and the continuing care needs of adults with disabilities, families with older caregivers have become a group that should not be overlooked in long-term care systems. Older caregivers face their own declining health and age-related support needs while continuing to assume primary responsibility for adult family members with disabilities. Their situation lies at the intersection of aging, disability care, and changes in family support capacity. This paper acknowledges the emotional value and moral significance of family care while emphasizing that, when caregiving relationships last for many years or even decades, family care is no longer solely a private matter. It should be supported by public services and social support systems.

From the perspective of challenges and mechanisms, the pressures faced by families with older caregivers are long-term, complex, and structural. Even when older caregivers have declining physical capacity, limited financial resources, and weak social support, they may still need to provide daily care, accompany relatives to medical appointments, support rehabilitation, and offer emotional support. They therefore face multiple pressures, including physical strain, time constraints, emotional concerns, and difficulties in accessing services. These challenges cannot be explained simply as a lack of caregiving capacity within individual families. They are shaped by long-term caregiving relationships, changing family caregiving resources, the undervaluation of unpaid care work, and weak coordination between services for older adults and disability services. In this sense, the issue is a long-term care challenge shaped by the interaction of family responsibility, demographic change, and service systems.

Therefore, future support systems should shift from temporary relief and stand-alone subsidies toward proactive identification, continuous support, and early planning. Services for older adults, disability services, and community services should jointly assess older caregivers' health status, care intensity, psychological stress, available backup care arrangements, and future care arrangements so that high-risk families can be identified early. Day care, home-based services, respite care, psychological support, and emergency care arrangements should be developed to provide meaningful daily relief. Future care planning and institutional coordination should also be strengthened. Housing, guardianship support, financial security, medical decision-making, service transitions, and long-term support should form part of a continuous plan. For China, as population aging deepens, family structures change, and community services continue to develop, a family-centered support network backed by community services and institutional coordination will be important for addressing the challenges faced by families with older caregivers. Only when the contributions and needs of older caregivers are recognized, future care for adult family members with disabilities is planned in advance, and care responsibilities are shared among families, communities, and public systems can the dignity of older caregivers and the security and well-being of adults with disabilities be better protected.

Acknowledgements

This research is supported by the Guangzhou Philosophy and Social Sciences Development Project (Project No. 2025GZGJ51).

ISSN 2616-5783 Vol.9, Issue 7: 1-8, DOI: 10.25236/AJHSS.2026.090701

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