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When Care Becomes a Life: Role Engulfment and Caregiver Irreplaceability Among Family Caregivers of Autistic People in China

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Abstract

This qualitative study examines how long-term family caregiving for autistic people can become concentrated in one person and reshape that caregiver's identity and participation. Semi-structured interviews with 13 primary family caregivers recruited through an autism support center in China were supplemented by two months of participant observation. Thematic analysis identified three overlapping experiences of role engulfment: loss of self, deferred self, and limited preservation of self. Across accounts, the primary caregiver's perceived irreplaceability developed through uneven family divisions of care, employment and financial constraints, and the accumulation of individualized knowledge about an autistic family member's support needs. Daytime and age-limited services offered valued assistance but often left families responsible for continuity of support, particularly as autistic people approached adulthood. Three caregivers entered paid work as autism support assistants, gaining income and social contact while continuing unpaid care at home. These findings suggest that support planning should attend to caregivers' opportunities for roles beyond caregiving, distribute practical knowledge among trusted supporters, and improve continuity of individualized services across the life course. The proposed process requires examination in more diverse family and service settings.

Keywords: Autism; family caregivers; role engulfment; developmental disabilities; caregiver identity; long-term support

Introduction

Autism is a neurodevelopmental condition associated with diverse patterns of communication, sensory experience, routines, and support needs. Autistic people differ substantially in the types and intensity of support they want or require across childhood, adolescence, and adulthood (Hirota & King, 2023). Families may provide practical assistance, coordinate schooling and rehabilitation services, respond to distress, and plan for future living arrangements. This work can be valuable and meaningful, yet access to sustained support from relatives and services is uneven. Studies of autistic people and their families have documented constrained employment, social participation, and well-being among caregivers, particularly mothers (Davy et al., 2022; Huang et al., 2024; Marsack-Topolewski & Church, 2019; Stuart & McGrew, 2009). Studies from mainland China describe family adjustments and challenges around service use and daily life (Feng et al., 2025). In China, gender inequalities in parental employment have also been documented: a national online survey reported employment exit among 54.3% of mothers compared with 2.8% of fathers caring for autistic children (Zhao et al., 2024).

A developmental-disability perspective must consider both the autistic person's changing support arrangements and the opportunities available to other family members. Research has examined the division of caregiving labor (Hartley et al., 2014), parents' experiences of caring for autistic adult children (Ljungberg, 2025), and the contribution of extended family members (Li et al., 2025). In this journal, studies of family navigation and access to services have shown why families' perspectives matter in designing useful supports (Burke et al., 2024), while research on culturally diverse families has examined how everyday routines accommodate autistic children's needs within available resources (Zakirova-Engstrand & Wilder, 2026). Yet practical support needs do not, by themselves, explain why one family member may become responsible for almost all care or why that individual can find it difficult to sustain identities beyond caregiving.

The concept of role engulfment offers a way to examine this relationship between long-term support provision and caregiver identity. In caregiving research, role engulfment describes the progressive dominance of the caregiver role as other social roles, activities, and possibilities contract; in some cases it involves a felt "loss of self" (Skaff & Pearlin, 1992). It differs from caregiver burden: burden emphasizes perceived demands and consequences, whereas role engulfment concerns the narrowing of a person's social roles, identity, and agency over time. The process need not be uniform. Some caregivers may experience the disappearance of valued roles, others may postpone them, and still others may preserve activities whose timing and purpose remain organized around caregiving (Cooper, 2021). These possibilities have implications for evaluating family support beyond caregiver stress alone.

Understanding why role engulfment persists also requires attention to a less visible process: the concentration of caregiving expertise. Familiarity with an autistic person's communication, preferences, routines, and support needs can be indispensable to good support. However, when only one family member has time to acquire and share this knowledge, other potential supporters may have fewer opportunities to participate. The experienced caregiver may then appear increasingly difficult to replace. This study uses perceived caregiver irreplaceability as an interpretive concept, not as a claim that autistic people inherently require a single caregiver. Moreover, time-limited services may help during particular hours without providing continuity of support or enabling other trusted supporters to develop caregiving knowledge. Research on navigating adult disability services points to the importance of such transitions for autistic young people and their families (Espinosa et al., 2026).

Drawing on interviews with 13 primary caregivers and observation at one autism support center in China, this study asks: (1) How do long-term caregiving arrangements shape caregivers' participation, anticipated futures, and sense of self? (2) How do family division of labor, accumulated caregiving knowledge, and access to formal support contribute to the perceived irreplaceability of the primary caregiver? (3) What do these experiences suggest for disability-related family support across the life

course? By distinguishing role engulfment from support needs alone, the study seeks to identify family and service arrangements that may enable both autistic people and caregivers to pursue meaningful lives and relationships.

Method

Design, Setting, and Participants

This qualitative study was conducted in connection with an autism support center in one locality in China. The center offered a setting in which family caregivers regularly accompanied autistic family members and interacted with service staff. The study combined semi-structured interviews with a two-month period of participant observation to examine reported experiences alongside everyday practices in this setting. Recruitment used purposive sampling to identify adults with sustained primary responsibility for an autistic family member. Eligibility criteria specified that their child had an autism diagnosis, that they provided primary family care, and that they were willing and able to discuss their experiences. The two grandparent caregivers were included as primary family caregivers of their autistic grandchildren.

The sample comprised 13 caregivers: 10 mothers, one father, one grandfather, and one grandmother. Their autistic family members were aged 7-23 years. Participants differed in employment background and current care arrangements; three mothers were working as autism support assistants at the center. Table 1 summarizes the characteristics recorded in the study. Support needs were described by caregivers and the center as lower, moderate, or higher; these are contextual descriptors rather than standardized diagnostic or functional assessments. The study did not rely on an independent assessment of co-occurring intellectual disability.

Table 1. Participant Characteristics

Caregiver	Age	Autistic relative age	Previous occupation	Current occupation	Reported support needs
Mother A	39	7	Property management	Full-time caregiver	Higher
Mother B	46	16	Factory worker	Full-time caregiver	Moderate
Mother C	49	22	Factory worker	Autism support assistant	Lower
Mother D	49	11	Finance staff	Full-time caregiver	Higher
Father E	53	11	Casual worker	Casual worker	Higher
Mother F	45	21	Self-employed	Autism support assistant	Moderate
Mother G	42	9	Nurse	Autism support assistant	Moderate
Mother H	47	17	Factory worker	Full-time caregiver	Higher
Mother I	38	8	Accountant	Full-time caregiver	Moderate
Mother J	41	10	Food-service worker	Food-service worker	Moderate
Grandfather K	69	19	Farmer	Full-time caregiver	Lower
Grandmother L	67	13	Farmer	Full-time caregiver	Moderate
Mother M	45	19	Casual worker	Casual worker	Lower

Note. Support-needs categories reflect caregiver and center reports, not an independently administered clinical measure. Descriptors are presented for sample characterization only; they do not establish co-occurring intellectual disability.

Data Generation

Interviews explored changes in family care arrangements following autism diagnosis, everyday tasks, employment, social networks, leisure, personal aspirations, and plans for the future. Particular attention was given to how participants negotiated time and responsibilities and how they understood their roles beyond caregiving. Interviews were audio-recorded with informed consent and transcribed. Identifying details were removed and caregiver pseudonyms are used in the findings.

Researchers also attended the support center two to three times weekly over approximately two months, with observation sessions lasting around two to four hours. Observations included interactions between caregivers and autistic family members, conversations among caregivers, and contact with staff. Fieldnotes were written during and expanded after observations. The observational materials served to contextualize accounts of routines and service use; they were not treated as independent behavioral or diagnostic assessments of autistic participants.

Analytic Approach and Interpretation

Interview transcripts and fieldnotes were examined through repeated reading, initial coding, cross-case comparison, and progressive refinement of themes. Coding attended to caregiving responsibility, employment, participation, division of family labor, access to services, future expectations, and sense of self. The present interpretation relates these themes to role engulfment and to the concentration of caregiving responsibility and practical expertise. The three identity patterns are analytic descriptions of overlapping experiences, not mutually exclusive diagnoses or sequential stages. Similarly, the proposed feedback between care experience and perceived irreplaceability is an interpretive account based on cross-sectional, retrospective narratives rather than a longitudinally demonstrated causal process.

Participants' expressions have been preserved in quoted translations even where their wording reflects medicalized or deficit-oriented views. Such quotations report caregivers' perspectives rather than clinical conclusions endorsed by the authors. The analytical narrative refers to autistic people in neurodiversity-affirming, support-needs-based language. The study did not interview autistic family members as a separate participant group; conclusions therefore concern caregivers' reported experiences, not autistic people's own preferences or views.

Findings

Three interrelated findings organize the analysis: the expansion of everyday and anticipated caregiving, the family and service conditions that make a primary caregiver appear difficult to replace, and the contrasting effects of caregiving on identity and paid work. The order highlights how support arrangements and role outcomes intersect rather than suggesting that every family follows a single trajectory.

Caregiving Organizes Everyday Life and Anticipated Futures

"My time is no longer mine": time, employment, and social participation

Caregiving schedules in these families often required repeated trips to schools and support programs, household work, and assistance at home. The accounts emphasize how the need to coordinate multiple settings made caregivers' time difficult to organize around other commitments:

> I basically have to get up very early every morning, at 5:50.... Although all these years of rehabilitation have made a big difference, there are still many things that require a parent. Even washing and getting ready need adult supervision, so there is basically no time in the morning. My child eats lunch here, but I also have a younger child who needs to eat at home. In the afternoon, after I pick him up from school, I still have to wait until 5:45 for the younger one to finish school.... After I get home and finish cooking dinner, it is usually after 10 at night before I can finally rest. (Mother B)

> Every day I have to get up two hours before my child's classes to make breakfast, do the laundry, and clean the house. Then I accompany him at school. When school finishes at noon, I go home and cook lunch. If I am accompanying him at school, there is really no free time all day. On the afternoons when we have an inclusion class, I can rest for about two hours. (Mother I)

These routines suggest that respite depended on time bounded by schooling or service hours; caregivers described limited control over when they could rest or pursue their own activities.

As caregiving became increasingly embedded in everyday life, caregivers' occupational roles were also constrained. Mother A, for example, had previously worked in property management near her home, with

a stable income and social insurance. She left paid employment after it became clear that her child would require ongoing support:

> After I had this child and found out about this problem, I stopped working and looked after him full-time. At first, I accompanied him in class and attended lessons with him. (Mother A)

Unlike Mother A, who left paid employment soon after her child's diagnosis, Mother C had more than a decade of previous employment experience. However, repeated travel to other cities to seek assessment and rehabilitation services disrupted this occupational trajectory:

> Before my child was diagnosed, I worked in a shopping center. Before that, I had worked in a cotton textile factory in Xinjiang. After the factory closed, I worked in the shopping center for 13 years. After the diagnosis, I took him everywhere for rehabilitation. We first traveled elsewhere for the diagnosis, and then came back to look for a local rehabilitation center. (Mother C)

Mother F described the effect of caregiving on a family business previously run by both parents. The changes were not simply a reduction in working hours: they involved a new division of paid work and everyday support within the household:

> Before our child was diagnosed, my husband and I ran a business together. After the diagnosis, neither of us had the energy to keep the business going, and gradually it became impossible to continue. We used to work on it together, but then we simply could not manage it anymore. In the end, only he continued working outside as a driver, while I stayed home to look after our child, asking around about rehabilitation centers and taking him for rehabilitation training. (Mother F)

Caregivers described reduced social interaction and leisure as well as changes to paid work. Mother A said that friends and relatives no longer invited her out as often after her child's diagnosis. Mother D recalled interests in calligraphy, painting, and later-life learning but said she no longer had time for these activities. The accounts point to restrictions on choice as well as the amount of time spent caring.

Grandparent caregivers had also reorganized work and residence. Grandmother L stopped farming and moved to the city to assist with long-term care. Grandfather K reported moving from another province and leaving agriculture; in his words, "All year round, I did nothing else -- I just looked after him." These experiences show that sustained caregiving could restructure later life as well as parental employment.

Some caregivers remained employed but could not easily choose their hours or pursue advancement. Mother M had continued casual work and hoped for a permanent position, yet explained:

> Sometimes I really want to work harder. I really want to move from being a casual worker to having a permanent position, but I simply do not have extra time to put into work.... My time is no longer mine. It all belongs to my child. (Mother M)

"What retirement could we possibly have?": the future of support

Many participants anticipated caregiving beyond childhood, including into their own later life. In these accounts, retirement was not necessarily understood as a period of increased autonomy. Rather, the future was organized around uncertainty about the autistic person's access to trusted, sustainable support and about caregivers' own ability to continue providing it (Ljungberg, 2025; Marsack-Topolewski & Church, 2019).

When asked about retirement, some participants did not regard it as a transition toward greater control over their own time. Rather, retirement represented a shift from combining paid work and caregiving to another period of continuing care:

> What retirement could we possibly have? When you have a child like this, how can there be retirement? You just look after him from childhood until old age. (Mother H)

Father E repeatedly emphasized exercise and maintaining his health in order to extend the period for which he could continue supporting his child:

> I need to keep myself healthy so that we can live a few more years. Honestly, if we stay healthy and live one more year, that means one more year we can look after him. That is all we can do. There is no other way. (Father E)

For Father E, remaining physically healthy was described primarily as a way to continue providing support. This links a usually individual goal, personal health, to the continued availability of a family caregiver.

Where families could not identify reliable long-term alternatives, some participants spoke about the future cautiously or avoided making plans. Their immediate hopes often concerned everyday living skills and safe support arrangements:

> I don't dare think about what the future will be like. Because of my child's abilities.... If he could at least manage daily life at home by himself, I would already be happy. Right now he cannot take care of himself, so I don't dare think about what the future might be like. (Mother A)

> I don't dare think about the future now. I just take one day at a time. You never know what will happen tomorrow. (Mother C)

> It is hard to say. We just take things one step at a time. (Grandfather K)

> We really cannot imagine the future. Right now, we just hope that after rehabilitation training he will have some basic ability to take care of himself. When I am gone, if he does not starve and knows that he can use money to buy things, that would already be my greatest hope. (Father E)

These accounts express concern about future continuity of support rather than evidence that adult autistic people invariably cannot live outside parental homes. Participants were uncertain about which people or services would be available when their own capacity changed.

Future uncertainty was sharpened by the possibility that caregivers themselves would age, become disabled, or die.

> When children like ours grow older, we will be old as well, and we will not have the strength to hold them back. Even now, when he sometimes loses his temper, I cannot physically restrain him, let alone in the future. (Mother C)

Such concerns reveal the fragility of an arrangement in which individualized practical knowledge and responsibility have become concentrated in one person.

Grandmother L hoped other relatives would share support in the future; Mother F placed particular hope in the availability of a long-term service arrangement:

> When I think about the future, my only wish now is that, after I am gone, there will be an institution that can take my child in and care for him long-term. As long as there is a stable institution willing to accept and care for him, I can leave this world with peace of mind. Things are manageable now because I am here looking after him closely. But when I am old and no longer here, we can only rely on the government and professional institutions to take him in. (Mother F)

Becoming the "Only One": Family Care and Perceived Irreplaceability

Uneven division of care and concentrated expertise

Support needs alone cannot explain how caregiving responsibility becomes concentrated in one particular family member (Hartley et al., 2014). Participants described a combination of household earning arrangements, limited participation from other relatives, and unequal familiarity with the autistic family member's routines. Over time, these circumstances contributed to a perception that the primary caregiver could not easily be replaced.

In households needing income to pay for living costs and support services, other family members often had to prioritize paid employment. The responsibility for providing ongoing support was then delegated to a parent or grandparent:

I can't go back to my hometown in another province, because the child is like this and someone has to look after him all year round. If I leave, there is no one to look after him. And if his parents don't work, how is the whole family supposed to live? (Grandfather K)

> Even where other family members, such as grandparents, were able to provide some assistance, this support was often limited to shopping, cooking, or temporary supervision. They were less able to take on sustained responsibilities such as coordinating services, providing behavioral support, or managing safety-related needs:

The child's grandparents are already in their eighties, so there is nothing we can do. We just have to rely on ourselves. They are old and cannot help very much, right?... No one else can really manage him. Even

my parents or brothers and sisters cannot tolerate him. At most, they can come and have a look, buy some food or things for us. That is about it. Looking after him every day would be impossible. (Father E)

Some relatives could help with food, shopping, or brief supervision but were not expected to provide sustained support. Participants sometimes distinguished these forms of assistance from the more individualized tasks they undertook themselves:

> My mom sometimes helps us with daily things. For example, she sometimes buys groceries for me. But she is already in her seventies, she has quite a temper, and sometimes she spoils the child, so I tell her not to look after him. (Mother A)

These accounts suggest that support from extended family members was often temporary, supplementary, and relatively low in intensity, while the most sustained and intensive caregiving responsibilities remained concentrated in the family member who knew the autistic person best (B. Li et al., 2026; Marsack & Perry, 2018). This concentration of care could then be reinforced by expertise accumulated through years of caregiving, further increasing the primary caregiver's apparent irreplaceability.

Autistic people differ considerably in their communication, sensory profiles, sources of distress, everyday routines, behavioral support needs, and safety-related needs. Responding effectively to such needs may depend substantially on knowledge developed through long-term familiarity. The longer one family member provides care, the greater their accumulated knowledge of the autistic person's preferences, routines, distress signals, and support needs. Conversely, the less other family members participate in caregiving, the fewer opportunities they have to develop this knowledge. Caregiving expertise and caregiving responsibility may therefore become concentrated in the same individual (B. Li et al., 2026; J.-L. Li et al., 2025).

Participants described how repeated care increased the primary caregiver's familiarity with the autistic person, while the limited participation of others left them with fewer opportunities to learn. Knowledge and responsibility thus tended to accumulate together. This is an interpretive account of the interviews, not a finding that other relatives lacked the capacity to learn.

Caregivers' concerns about others' ability to respond to unfamiliar situations strengthened these arrangements. Mother D said, "Other people don't understand autism. I wouldn't feel safe leaving him with anyone else." Mother H described fear about her daughter's safety in public and when left alone:

> She has absolutely no awareness of how to protect herself. Think about it -- mentally she is only 20 months old! A girl with such poor ability to protect herself is extremely vulnerable if she goes out alone. I have to stay with her all the time. When I go grocery shopping or run errands, I take her with me. If it is raining heavily, I lock her at home. (Mother H)

Father E also expressed distrust of formal alternatives to family care:

> I've heard that many older people die in nursing homes. They pay a lot of money and still die there. There have been several cases even in our city. How could I possibly feel reassured? And those nursing homes are for normal people. My child's behavior is quite erratic - could they really look after him properly? So for now we can only rely on ourselves. There is no other way. (Father E)

This concentration was also shaped by gender. Mothers often reduced or left paid work while fathers remained primary income earners, a pattern consistent with prior research on divisions of care (Hartley et al., 2014; Huang et al., 2024).

Mother A explained that her husband was the main earner and therefore had little time for hands-on support. Mother B reported:

> I don't work. I look after the child full-time, and his father is the only one working. The pressure on the two of us is enormous, honestly. When he was first diagnosed, we thought that even if we had to sell everything, we could get him treated. We never realized that the child would be like a bottomless pit. We still had a lot of debt from all those years of paying for rehabilitation. (Mother B)

These accounts suggest a possible reinforcing process: household earning requirements reduce opportunities for shared support; the primary caregiver accumulates specialized knowledge; other relatives gain less experience; and the caregiver becomes less willing or able to delegate. The process is socially contingent rather than an inherent property of autism or of the autistic person.

Formal supports help, but discontinuities leave responsibility at home

Whether families could share support also depended on the availability and suitability of services. Participants acknowledged help from community programs, subsidies, schools, and specialist services (Zou et al., 2025). These accounts are important counterexamples to any suggestion that formal support was universally absent:

> Over all these years, I know how much help our family has received from society. Whether from the community, the government, or schools, they have all helped us a lot. That is the truth. It has been very, very good. (Mother B)

> We applied for subsidies for children in difficult circumstances.... I am very grateful for the government subsidies. The neighborhood committee also regularly comes to visit us and check on how we are doing. (Mother D)

> We parents really thank this autism support center. Being able to receive training nearby is very important to us. Traveling long distances for rehabilitation is too exhausting financially and physically, so we really need an affordable private rehabilitation center like this.... After years of systematic training here, the child's behavior has become much more regulated. He can get along peacefully with other people without disturbing them, which I never imagined before. The

> director often invites experts to train us parents in professional knowledge. The child's progress would have been impossible without the center's professional support. (Mother C)

A few services had also attempted to provide structured employment-related activities for autistic adolescents and adults. Mother C described stationery assembly, food sales, and used-clothing recycling:

> These jobs make very little profit, but the main point is to give the children something to do and somewhere to go. (Mother C)

Participants described useful daytime support while also reporting that services operated during particular hours or developmental periods. For these families, assistance during a program did not necessarily lead to shared responsibility during evenings, weekends, or transitions into adulthood.

For example, Father E described paying for a daily program that afforded several hours of relief. When the program ended, responsibility returned to the household. This distinction between temporary assistance and continuity of support is central to interpreting the reported care arrangements.

Uncertainty was particularly apparent as autistic relatives approached adulthood. Grandmother L anticipated lifelong reliance on parents; Mother F said there was "nowhere suitable for them to go."

Participants described eligibility boundaries and gaps in services as their autistic relatives grew older. Mother H, for example, said that subsidized rehabilitation in her locality ended at age 16. This report illustrates an experienced transition problem; it should not be treated as a uniform nationwide age limit. Other Chinese studies similarly describe challenges in developing sustained support for autistic adults (Wang & Guo, 2026; Zou et al., 2025).

Caregivers also reported difficulty finding suitable adult and residential settings. Some described negative interactions with existing institutions or fear that available settings could not meet their relative's support needs:

> Public welfare institutions generally do not want to accept older special-needs children with poor behavioral abilities. When my child was younger, we went to a public special institution, but they would not accept him. On the one hand, he was already relatively old; on the other hand, his behavior was difficult to control, so the public institution was unwilling to take him. (Mother F)

> Psychiatric hospitals are also unwilling to accept autistic children. Compared with people with schizophrenia, autistic children are developmentally delayed in many areas and cannot take care of themselves, so hospitals find them difficult to manage. One hospital admitted him once and then refused to take him again. Now, when my child loses his temper, I cannot even restrain him myself. There is no emergency support available at all. We can only rely on private rehabilitation centers for professional care. (Mother D)

Taken together, these accounts identify an apparent mismatch between episodic service provision and the continuous responsibilities described by families. They do not establish that every local service lacked the relevant capacity or that the institution-related allegations were independently verified.

Where services were unavailable, age-limited, or not trusted, the primary family caregiver remained the person expected to coordinate everyday support. For caregivers who already had restricted opportunities to share expertise and responsibility, this reinforced a sense of being indispensable.

Identity Consequences: Loss, Deferral, and Limited Preservation of Self

The same caregiving arrangements were associated with different accounts of identity. The following patterns describe how other roles and possibilities were experienced rather than categorizing participants into fixed or mutually exclusive types.

Several caregivers described their lives as increasingly organized around care, leaving little scope for activities they had previously valued. Their experiences resembled the loss of self discussed in role-engulfment research (Skaff & Pearlin, 1992).

Mother D described long-term caregiving as leaving her with 'no life of my own':

> It is unbearable. From the moment I open my eyes in the morning until my child falls asleep late at night, all my time is spent looking after him. I have completely lost myself. I have no life of my own. Ordinary people simply cannot understand this kind of suffering. Sometimes I even think being in prison would be easier than this. (Mother D)

Mother H described this contraction of self as entering a 'frozen period', in which previous interests and forms of social participation had gradually disappeared and everyday life had become almost entirely organized around caregiving:

> I used to enjoy listening to music and reading. Sometimes I liked going out to sing and dance. Now I no longer have the opportunity to do those things -- and even if I did, I would not want to anymore. I feel as though I have entered a frozen period. I do not want anything anymore. I feel as though I have been frozen inside a block of ice. (Mother H)

Other caregivers retained aspirations for a life beyond direct caregiving but imagined pursuing them only if a less dependent arrangement of support became available. In these accounts, identity was not necessarily lost; it was postponed.

Mother B described plans that remained conditional on her child's future support arrangements:

> Everyone has dreams, but because of my child, there is nothing I can do. I have spent the first half of my life on this family and on my child. If he improves in the future and can leave us, then at least I still have things I want to do. I can go and do them. I can have my own dreams and pursue them. (Mother B)

A third pattern involved maintaining selected interests or work while fitting them around caregiving. Mother J explained that she sometimes attended leisure activities with her child:

> I used to like reading, listening to music, and square dancing. If I have time now, I still go, but I take my child with me. My time is still centered more around my child. (Mother J)

Father E similarly maintained exercise but understood this partly as preparation for continuing to support his child. The distinction between preserved and engulfed roles was therefore not simply whether an activity continued, but whether caregivers could participate in it on their own terms.

Role preservation was often limited rather than absent. Time, space, and the meaning of activities could still be determined by caregiving obligations.

Across the participants, loss of self, deferred self, and limited preservation of self capture different ways that personal roles were narrowed, postponed, or reorganized. The sample does not establish their prevalence in the wider population.

The three patterns are not fixed stages. They may coexist or change when family involvement, the autistic person's preferences and support arrangements, employment, or access to services changes. Longitudinal research would be required to trace such changes directly.

Paid Autism-Support Work: Partial Role Reconstruction

Three mothers used experience gained through years of caregiving to undertake paid work as assistants in autism services. Their accounts offer a limited but informative example of how family-support organizations can recognize expertise developed by caregivers.

Mother C, for example, had left her previous employment after her child's diagnosis and spent many years providing full-time care before moving from accompanying her child in classes to working as an assistant at the service center:

> I am especially grateful to the director for giving us parents the opportunity to become assistants. In the beginning, there was only the model where parents accompanied their children throughout classes, and there was no income at all. It is only in recent years that assistant positions have been created. Now we can earn a salary, which at least reduces some of the financial pressure on the family. (Mother C)

For Mother C, paid employment offered a recognized role and some income derived from knowledge previously used without remuneration at home.

Mother F similarly described the conversion of unpaid family care into paid work as providing some economic relief:

> I work here as an assistant and can earn a small amount of money every month, and I am already very grateful for that. Since I have to bring my child here for rehabilitation anyway, being able to earn a small, subsidy-like wage at least helps with household expenses. I am already very satisfied. (Mother F)

Work at the center could also expand social contact by bringing caregivers into regular relationships with professionals and other families.

Mother G, for example, had previously described herself as introverted, having few friends and little contact with others. After becoming a daily-living support worker at the center, she developed more regular relationships with staff members and other parents:

> The daily-living teachers and assistants do things like cooking and helping the children with everyday activities. Since I became an assistant, I have actually made a few more friends. (Mother G)

These positions allowed the caregivers to participate in a service organization as workers rather than solely as family members accessing its programs. However, the employment opportunities described were closely tied to autism-related services and sometimes to the caregiver's own child attending the center.

Thus, occupational participation did not always represent a separate domain of identity. Paid tasks overlapped with unpaid family support, and the obligations of care continued after the working day.

This was particularly evident for Mother F:

> When I go home, I still have to look after my own child. His hands-on abilities are poor, so when he cooks, I have to stand beside him and help.... I have absolutely no time that belongs to myself. The work at the center is already exhausting, and when I go home there are still all kinds of things to deal with. I cannot let go of either side. (Mother F)

Mother F's account shows this tension: wages and colleagues were valuable, while daily care work continued at home. Employment alone would therefore be an incomplete indicator of recovery of non-caregiving roles.

The contrast illustrates a partial, context-dependent form of role reconstruction. Service-linked employment may create income, friendships, and recognition; it may also intensify the total amount of time spent providing care when alternatives remain limited.

In these three cases, paid disability-related support work and unpaid care coexisted. The term "dual care work" summarizes that overlap; because only three participants held these jobs, the study cannot generalize its effects across parent-worker programs.

Discussion

Role Engulfment as a Family-Support Outcome

The findings show why support for autistic people and caregiver outcomes should be considered together without treating autism-related support needs as a sufficient explanation for caregiver role engulfment. Three overlapping experiences - loss of self, deferred self, and limited preservation of self - extended beyond perceived stress to encompass opportunities for paid work, friendships, leisure, and imagining the future. Research on autism caregiving has documented employment and participation costs (Davy et al., 2022; Huang et al., 2024); this study adds an identity-oriented perspective on how these constraints may

become organized across life domains. The patterns are tentative analytic descriptions from one setting, not a validated typology.

The most important interpretive contribution is the proposed relationship between individualized caregiving knowledge and perceived caregiver irreplaceability. Attentive knowledge of a particular autistic person's routines and preferences is valuable and often necessary. It can nevertheless become concentrated when household work arrangements and inadequate alternatives leave the same individual continuously on duty. Other relatives then have fewer opportunities to learn support routines, which may strengthen both their reluctance to help and the primary caregiver's reluctance to delegate. This possible reinforcing process locates perceived irreplaceability in family and service arrangements rather than as an inevitable consequence of disability. It also suggests that reducing the concentration of care requires more than advising an individual caregiver to ask for help.

Implications for Disability-Related Support and Services

First, family support and respite planning should evaluate whether another trusted person or service can reliably assume responsibility, rather than count the existence of a program as sufficient support. Families may need predictable hours of respite, support options outside daytime programming, and opportunities for other caregivers to develop practical familiarity with the autistic person's communication, preferences, routines, and sources of distress. Such arrangements should be collaborative and attentive to autistic people's own choices, not merely aimed at making care easier for adults around them. Previous work in this journal on family navigators and navigating adult services suggests that service information and transition support may be important complements (Burke et al., 2024; Espinosa et al., 2026).

Second, caregivers' uncertainty about adulthood and later life points to the importance of early, sustained planning for adult day opportunities, supported living where desired, employment support, and alternative support arrangements. Participants often valued existing schools, subsidies, and support centers; the issue was the reliability of support across times of day and changes in eligibility. Caregivers could also benefit from practical coordination among providers, including planning before services end rather than only after a crisis emerges. These are practice implications derived from reported experiences, not effectiveness claims about an intervention tested in this study.

Third, support for caregivers should include meaningful opportunities to preserve interests, paid work, and social relationships that are not dictated entirely by care obligations. The three mothers who became autism support assistants reported gains in income and social contact, but their work also extended care into the workplace. Programs drawing on family expertise should consider compensation, training, appropriate employment protections, and possible routes to work not dependent on continued service use by the worker's own family member. A narrow employment outcome could obscure persistent role engulfment.

Strengths, Limitations, and Future Research

The combination of interviews and observations situates caregiver narratives in an actual service setting, and the inclusion of caregivers of school-aged children, young adults, and grandparents offers varied points along the life course. Nonetheless, all participants were recruited through one center in one Chinese locality, which likely favored families already engaged with formal services. The sample was small and mostly mothers; only one father, two grandparents, and three paid support assistants were interviewed. The findings cannot represent families outside services or all Chinese caregivers. Information about autism-related support needs was based on caregiver and center accounts, not standardized assessment, and co-occurring intellectual disability was not established. The study also did not collect autistic family members' own accounts or perspectives from non-primary relatives. Retrospective interviews and a cross-sectional observation period cannot demonstrate that the proposed knowledge-concentration feedback loop develops in the stated sequence.

Future research could follow families longitudinally across transitions in education, work, and adult services; include autistic people as research participants and decision-makers; compare families with different support arrangements; and examine whether distributing support knowledge and creating dependable respite or adult services changes caregivers' opportunities for life beyond care. Such studies could test and refine the mechanisms suggested here.

Conclusion

For the primary family caregivers in this study, role engulfment was associated not simply with the provision of long-term support but with its sustained concentration in one person. Caregivers described forms of lost, deferred, and restricted identity alongside family divisions of labor and gaps in reliable alternatives. Support arrangements that share practical expertise and enable continuity into adulthood may help prevent caregiver identity from becoming narrowly organized around care while respecting autistic people's preferences, autonomy, and support needs.

Statements and Declarations

Competing Interests. The authors declare no competing interests.

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Ethics Approval. Ethical approval was granted by the authors' university. The identifying institution is provided separately for double-anonymous review.

Consent to Participate. Informed consent was obtained from all interviewed caregivers, and interviews were audio-recorded with their consent.

Data Availability. Interview transcripts and observation fieldnotes are not publicly available because of potentially identifiable and sensitive family information, consistent with the confidentiality conditions described in the source manuscript.

Use of Generative AI. OpenAI ChatGPT (including GPT-6) assisted with the language, organization, and developmental editing of an author-written manuscript to prepare this journal-specific version. AI was not used to generate participant quotations, collect interviews, or carry out an independent reanalysis of raw participant data for this revision. The human authors are responsible for checking the accuracy of all claims, translations, citations, and final text.

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