

BUILDING A BETTER ONTARIO FOR CAREGIVERS

by Making Caregivers Matter in the Community Systems They Navigate

The 2024 Ontario Caregiver Coalition Survey of Caregivers: Policy Brief #6

"Everytime I'm referred, they deny. And then professionals don't know what to do. It's frustrating."

September 2026

ABOUT THE ONTARIO CAREGIVER COALITION

The Ontario Caregiver Coalition (OCC) is the voice of caregivers in Ontario. We advocate for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health system. Our members include both caregivers from across Ontario and organizations that support them. For more information about the OCC and our work, please see our website at www.ontariocaregivercoalition.ca, or follow us on social media.

BUILDING A BETTER ONTARIO FOR CAREGIVERS: POLICY BRIEF SERIES

This Policy Brief, developed by the Ontario Caregiver Coalition (OCC) and informed by OCC's 2024 Ontario Caregiver Survey, is the sixth and final in a series of Policy Briefs that will guide our advocacy for policy change.

The OCC's 2024 Ontario Caregiver Survey sought to explore policy priorities among Ontario caregivers. The Survey was in the field from January 31, 2024, until March 12, 2024, and received 612 responses from Ontario caregivers. The results of the Survey should be interpreted understanding that the respondents included a relatively small proportion of participants who identified as ethno-culturally diverse (18%) or Indigenous (4%). Nor did the Survey collect information on participants' education and socio-economic status, nor on respondent's location in the province of Ontario.

The policy recommendations presented in each Policy Brief are based on the views expressed in the Survey by caregivers, as well as literature reviews, environmental scans, and key informant interviews.

We would like to extend our thanks to all of the many members and friends who worked to design, distribute and complete our 2024 Ontario Caregiver Survey. Your passion for supporting unpaid caregivers and your commitment to change are inspiring, and make the impossible possible!

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MAKING CAREGIVERS MATTER IN THE COMMUNITY SYSTEMS THEY NAVIGATE

"Absolute mind boggling rules & regulations to follow, paperwork that is time consuming, usually requires me to take online training sessions to figure out how to get funds reimbursed. then the housing…there's no way to make a long term plan for a safe home environment for my adult disabled person. The agencies offer unrealistic seminars that in the end are not either realistic & more importantly affordable for most."[1]

Caregivers play an essential role in supporting those they care for to remain where they want to be — in the community. To make this possible, caregivers must often organize a mix of supports around a care recipient. This might include accessible housing, help with activities of daily living, measures to ensure safety and security, specialized services such as physiotherapy or behavioural supports, transportation, medical care, and activities to support social inclusion. All this must be pulled together in an environment where community services are limited and fragmented. Simply ensuring daily assistance with bathing, dressing, and eating for a loved one may require a caregiver to interact with multiple agencies, each with its own eligibility requirements and processes. It is most frequently the caregiver's role to ensure that services are located and coordinated, and paperwork completed. This aspect of the caregiver's role is often poorly understood by those who have not undertaken it. It is also one of the most exhausting, time-consuming and frustrating aspects of the role.

The Ontario Caregiver Coalition calls on the Ontario government to ensure community supports are designed to include caregiver needs and perspectives by:

1. Ensuring caregiver needs are systematically identified, assessed and addressed as part of assessing the needs of care recipients;
2. Including caregivers in the design of the systems that they must use and navigate;
3. Providing good conditions of work for paid care providers, as a precondition to ensuring quality and consistency of care;
4. Investing in transition supports to avoid crisis approaches and enable future-planning;
5. Moving towards system integration and coordination, together with professional case management;
6. Strengthening investment in services in the community, including home care, community services, developmental services, and mental health and addictions supports.

[1] All quotes are from caregivers who responded to the Ontario Caregiver Coalition's 2024 Caregiver Survey

WHY IS IMPROVING ACCESS TO SUPPORTS IN THE COMMUNITY FOR CARE RECIPIENTS A PRIORITY FOR CAREGIVERS?

"[We need] more flexible and available options in the community to address complex needs of loved one."

Almost all Ontarians who are living with a disability or who are aging prefer to live in the community rather in more institutionalized settings. For example, the National Institute on Ageing's (NIA) 2025 Ageing in Canada Survey found that only 3% of older Ontarians wanted to age in a long-term care home or residence, with 81% preferring to age in their own homes, and smaller numbers either unsure or anticipating moving in with a family member. As the NIA comments, "This preference reflects more than comfort or familiarity; it speaks to the importance of independence, belonging and connection to community."[1] The importance of inclusion and participation for persons with intellectual and developmental disabilities has long been a foundation stone of the community living movement, based on the understanding that connection to community is central to a life of meaning and autonomy. Governments have recognized this aspiration — as well as the cost-savings associated with care in the community — with policies aimed to allow persons with disabilities to remain in the community, and older adults to age in place.

Yet inclusion in the community for older persons and persons with disabilities requires a network of surrounding supports. Caregivers are essential to the achievement of this goal, but caregivers cannot themselves provide all of the supports that community inclusion often requires. Inclusion in the community for older persons and persons with disabilities requires a network of supports to attend to their medical, social, and practical needs, as well as for some, support with the activities of daily living. Government provides these supports through developmental services, which are funded by the Ministry of Children, Community and Social Services, and home and community care, funded by the Ministry of Health through Ontario Health atHome, as well as various programs funded through the Ministry for Seniors and Accessibility.

Access to supports in the community was a top concern of caregivers in the OCC's 2024 Caregiver Survey. Caregivers told us that publicly funded home and community care services are overstretched, often providing limited and minimal support, while private services are often beyond their financial reach. Developmental services entail long waitlists and complicated processes. Long-term planning seems impossible, as families and systems must constantly respond to crises.

The Ontario Community Support Association (OCSA) has pointed out that, while the Ontario government has made important investments in home and community care in recent years, an aging population, and caregiver burnout means that demand continues to grow rapidly. Just to keep 76% of people aged 75 or older at home and in community, we need to provide for an additional 23,000 home and community care clients annually. According to OCSA, "At some Community Support Service organizations, waitlists for personal support services have increased almost 8 times in size this year. Many organizations have seen their waitlists triple in size or grow to nearly 4 times the size of their funded program."[2]

According to Community Living Ontario's 2026 Pre-Budget Submission, at present, there are 53,000 individuals waiting to access developmental services. In fact, there are more individuals on waitlists for these services than there are people who actually receive them. These services are often provided only in crisis situations, such as when the caregiver dies or becomes too frail or disabled to provide care, leaving most individuals on waitlists for years. While direct funding programs such as Passport have allowed individuals to pay for services such as support workers, funding allocations have not kept up with the cost of inflation. Community Living Ontario points out that while the average full Passport allocation is $11,200 a year, just over half of all those eligible for developmental services receive the full amount, meaning that most are receiving very modest levels of support.[3]

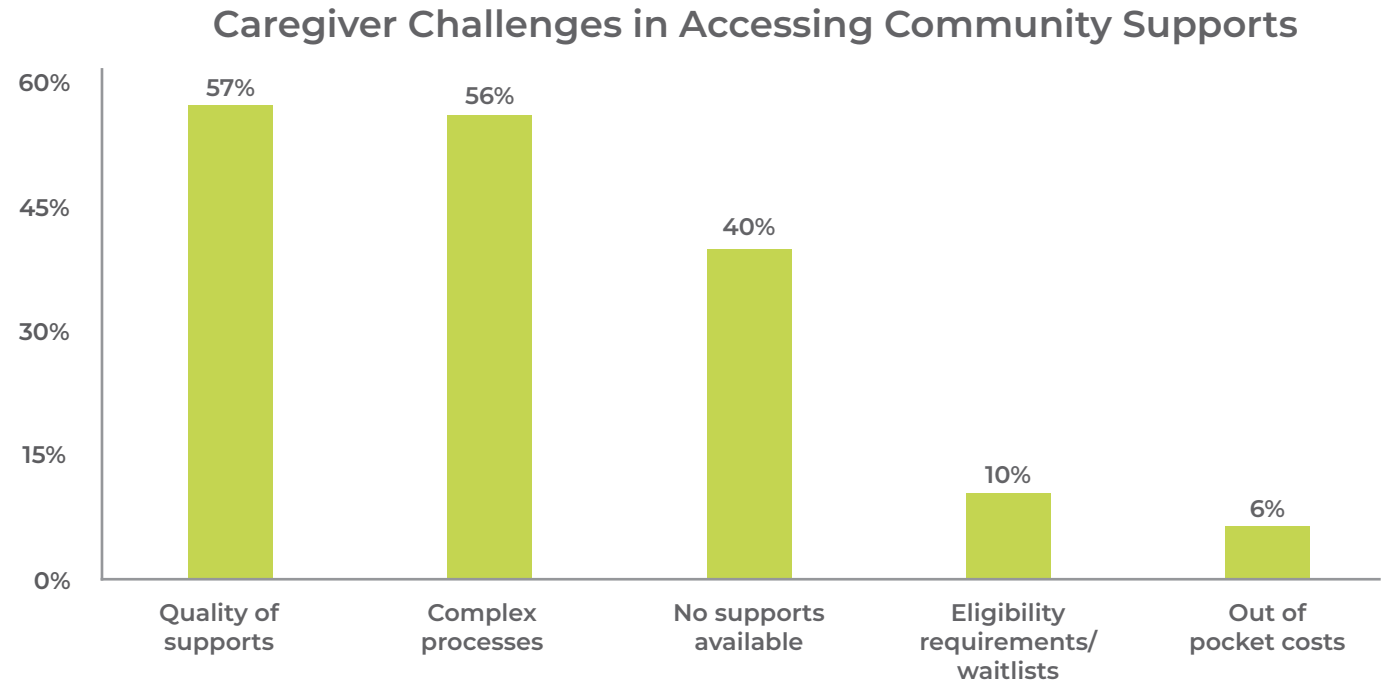
And not only is there a shortage of services in the community for older persons and persons with disabilities, but it can be hard to find and access the services that exist, adding a navigational and administrative burden to caregiving, and disadvantaging those families that are less equipped to navigate complex systems, whether because of linguistic, knowledge or resource barriers.

Without access to these services, caregivers struggle to maintain employment, care for their own physical and mental health, and provide the kind of dignified and secure lives that they strive to create for those they care for. They pay out of pocket for costs of care, adding to their financial strain. The lack of services in the community underlies or exacerbates all of the caregiver concerns that have been covered in this policy brief series: financial distress, inability to take a break, mental health challenges, and struggles to balance work and care. Ensuring a strong foundation of supports in the community must be a primary goal of any policy framework that seeks to support caregivers in their vital role.

WHAT BARRIERS DO CAREGIVERS FACE IN ACCESSING SUPPORTS IN THE COMMUNITY FOR CARE RECIPIENTS?

"As a caregiver the time spent both investigating and navigating support options is extensive. When added to day-to-day care obligations, plus employment and other family obligations it is not sustainable."

According to the 612 caregivers who completed the OCC's 2024 Caregiver Survey, the second most common challenge faced by caregivers is navigating systems and finding services and supports for the person they care for. Over half of respondents reported challenges in accessing supports for their person, including help with activities of daily living, developmental services, mental health and addiction services, community services such as meals or social activities, and specialized supports such as speech or occupational therapy. Two of every three caregivers were relying on informal resources such as family, friends and other caregivers, rather than system level resources.



Respondents to the Survey identified a range of challenges in accessing supports, including the quality of services and supports, complex and poorly organized access processes, a lack of appropriate supports, restrictive eligibility requirements and long waitlists, and unaffordable out of pocket costs.

Example of Access Barriers: Accessing Adult Day Programs in Ontario

Accessing a publicly funded adult day program generally requires an assessment by a health care professional whose job it is to determine whether the person in need of care meets adult day program eligibility criteria. Assessment processes require a strong understanding of both day program requirements and the needs and capabilities of the person seeking a referral. Without highly trained personnel, either eligible individuals are not referred, or individuals are referred to programs which cannot meet their needs. Caregivers in such cases must decide whether to appeal the decision or seek alternative services, in either case taking on an increased administrative burden and deferring access to appropriate supports. Further, many day programs do not provide transportation as part of their services, leaving this as an additional responsibility for caregivers, who must either provide or arrange transportation themselves. Finally, where an individual has been admitted to a day program, the family may remain reliant on home and community care to assist with preparing the individual to attend the program, so that shortfalls or unreliability in these programs can have a cascading effect for the caregiver.

WHY IS IT SO DIFFICULT TO ACCESS THESE SUPPORTS?

"Who is the point person that can even inform the caregiver that specialized supports in the home exist (that is, IF these specialized supports actually exist)? An informal caregiver is usually so busy with caregiving activity, they have little if any time to figure out what services are available and how to access them."

Depending on who they are caring for, caregivers navigate within different systems, which are often managed by different institutions and overseen by different ministries. Caregivers may be interacting with acute care, palliative care, home and community care, mental health and addictions, developmental services, or other systems. Often they are interacting with multiple systems, and with a mix of public, private, for-profit, and non-profit institutions. Responsibility for these systems may lie with the Ministry of Health, the Ministry of Long-Term Care, the Ministry for Seniors and Accessibility, or the Ministry of Children, Community and Social Services. A striking feature of the OCC's 2024 Caregiver Survey was the similarity in challenges faced by caregivers across all of these different systems and institutions.

In all of these systems:

Caregivers are both essential and invisible. It is widely acknowledged that care recipients would have extensive difficulty in navigating systems and managing care on their own. In many, if not most cases, it would be impossible. Health, developmental services, mental health and addictions services, and the senior care system are wholly dependent on the unpaid efforts of family

and friends for the effective delivery of services. And yet the experiences of caregivers in carrying out their role rarely receives attention or support. Services are generally not designed or delivered with the needs of caregivers in mind. And at times service design is an active barrier to provision of support by caregivers — for example, when visitor policies restrict caregiver access to the person they are caring for. Professionals within the system understand their role to be providing services to the care recipient, and it is only when the caregiver is in such extreme crisis, that care in the community is at the point of collapse, that professional attention may turn to ensure the sustainability of the caregiving role. A recent review of instruments for assessing caregiver needs found that while numerous assessment tools exist, relatively few are designed to understand caregiver-defined support needs, instead focusing on caregiver burden, distress, or preparedness. The utility of these tools for care planning, care transitions or system integration is therefore limited.[4]

Caregivers are responsible for piecing together a fragmented system. Providing care for someone living with acute illness, frailty, or a disability generally requires managing a range of needs that might include housing, activities of daily living, social and emotional supports, medical and other health needs and more. Very frequently, this involves pulling together a mix of services and supports, some of which are provided through publicly funded systems, some of which are privately purchased. Each system has its own requirements and administrative processes, and must be learned, navigated, and managed. For something as seemingly straightforward as accessing home care for daily living requirements such as dressing and toileting, caregivers may find themselves interacting with multiple agencies, each of which has its own processes, and managing complex schedules. Frequently, it is the caregiver themselves that must manage communication between all of the agencies involved in care, because the systems themselves do not have coordination mechanisms. Thus, caregivers take on reams of repetitive paperwork, as well repeating the same concerns and stories to multiple providers, sometimes at significant emotional cost.

It is difficult to overstate the complexity, stress, and time burdens that caregivers may experience in navigating and advocating within all of these systems. As one caregiver commented, "I need an administrator to manage the 'business' of supporting my daughter: recruitment, screening, hiring, training, supervision of support workers; financial management; life planning; ensuring support is provided according to person-centred, social role valorization, and core competency principles."

Navigation tools may be helpful, but they still require caregivers to do the actual work of contacting service providers, managing eligibility and admission requirements, monitoring waitlists, and coordinating the potentially conflicting requirements of multiple service providers. While some care coordination does exist, too often it becomes a form of de facto gatekeeping. Families must wait for access to care coordinators in order access services, and coordinators may find it necessary to try to manage demand for services, rather than to problem-solve or advocate on behalf of the family.

Caregivers are unable to plan for the future in a system driven by crisis response. Care transitions are inevitable, as care recipients transition from hospital to home (and often back again), from community into residential care, from the child and youth system into adult systems, among other transitions. As caregivers age or themselves develop illnesses or disabilities, alternative care arrangements must be developed. Caregivers are often encouraged to plan ahead — for example, to tour long-term care homes and join waitlists for a parent with dementia, or to develop a circle of care for a young adult with a developmental disability. Transition-planning supports for adults with disabilities whose primary caregivers are aging or becoming unable to care found that most of these supports consisted of voluntary tools and educational resources, rather than more structured supports.[5]

Yet because our systems are under stress, they are dominated by crisis response, driving out capacity to plan ahead. For example, in Ontario, about half of all admissions to long-term care transition directly from hospital as crisis placements,[6] and in some long-term care homes, particularly in urban areas, almost all admissions are directly from hospital.[7] As a result, educational resources and voluntary tools are often of little use, as planning ahead and waitlisting may be futile.

Parents of children with developmental disabilities have long raised concerns that the lack of community housing options leaves them unable to plan for the future of their children and living in fear of what will become of their children when disability or death leaves parents unable to continue to provide care. As one caregiver emphasized, we need to "[o]pen more community living housing so we don't have to wonder if our adult children with disabilities will be homeless when we are gone!"

Often, when a placement does become available, caregivers and the person they care for are given very short windows of time in which to make a decision and take up a placement.

The inability to plan for the future is a major source of distress for caregivers, and ultimately leads to higher system costs as disproportionate resources are dedicated to crises and the fallout from those crises.

Caregivers must design their lives around an unreliable system, operating as a safety net for the care recipient. In many of the systems that caregivers rely on, the working conditions of paid care staff have led to an ongoing human resource crisis, resulting in staff shortages and continual turnover. Ontario will need 33,200 more nurses and 50,853 more personal support workers (PSWs) by 2032, highlighting the urgent need not only to recruit more workers into the sector, but also to retain the experienced workforce already providing care.[8] Workforce shortages and wage disparities continue to threaten sector stability. Community PSWs and nurses earn $3.50–$10 per hour less than their hospital or long-term care counterparts, contributing to recruitment and retention challenges. While recent wage investments have helped reduce turnover among home care providers by close to 50%, vacancies remain at 12%, and Community Support Services (CSS) and Independent Living

(IL) providers report average turnover rates of 18%.[9] Without sustained investment in recruitment and retention, workforce instability will continue to undermine the reliability and continuity of home and community care.

These kinds of pressures tend also to lower the skill level of the workforce, as some workers leave the sector before developing the range of expertise needed to perform some of these tasks at a high level, and others develop burnout. Staff shortages and turnover mean that services may be unreliable, or that continuity of care is difficult to achieve. Caregivers describe having to continually orient new workers. Care for those who are frail, vulnerable or have disabilities often requires relationships of trust, which cannot develop when workers are constantly changing. Last-minute cancellations or scheduling changes leave caregivers scrambling to find alternatives, reschedule plans, or provide care themselves. Caregivers have described the unreliability of home and community care services as a key factor pushing them out of the labour force. Effectively, the conditions of work for paid care providers are both the conditions of care for care recipients, and the conditions of life for unpaid caregivers. The fates of care recipients, care providers, and caregivers are inextricably linked.

In addition to providing 'hands-on' care, caregivers are acting as case managers, system navigators, patient advocates, trainers, quality assurance managers and system safety nets. They are, in effect, taking on key system roles. Many caregivers have neither the knowledge, the skill set, the resources or the time to take on what is effectively a significant, high-stakes job. However, there may appear to be no alternative, and so caregivers may feel forced to continue until they reach the point of collapse. The negative consequences for the care recipient, the caregiver, and for health and social services systems were outlined in our first policy brief, Listening to the Voices of Caregivers.

WHAT ARE THE IMPACTS OF A LACK OF ACCESSIBLE SUPPORTS IN THE COMMUNITY?

"It is exhausting and triggering to have to navigate, advocate and tell our story over and over."

The lack of accessible supports in the community for older persons and persons with disabilities has real costs for Ontario's health care, long-term care, and social systems. As one example, the lack of early intervention and appropriate community-based options, including assisted living, supportive housing, and group homes connected to mental health and social services, has increasingly positioned long-term care as a setting absorbing unmet needs from across the system.[10] The Ontario Caregiver Organization notes that almost one in five caregivers report having taken a care recipient to a hospital emergency room because they needed respite they could not access otherwise. This resulted in

an estimated 1.9 million ER visits last year for caregiver respite, at an estimated cost of $643 million in 2024–25.[11] As noted earlier in this brief, the vast majority of Ontarians who are aging or living with disabilities want to remain in community, rather than in an institutional setting. However, under investment and ineffective system design is pushing individuals who could have remained in the community into institutional settings. Given the higher costs of institutional care, and the demand pressures on these institutions, this is a negative outcome from a system perspective as well as an individual one.

It is important to remember that these system trends and statistics are made up of many thousands of individual stories. Behind these trends are individuals who could have continued in their communities had appropriate supports been offered, but who instead are living the much more restrictive lives available in institutional settings; of families struggling with the pressures of acting as a system safety net and living from crisis to crisis; and of caregivers sacrificing their health, financial security, and personal hopes to ensure dignity for a loved one.

Maya's Story

Maya is a single mother residing with her 21-year-old son Ethan, who lives with a developmental disability. Her son is in the last year of high school and she is worried about that dreaded "cliff" that is imminent, as her son transitions out of high school and transitions into the adult developmental services system, where he will face long waitlists and limited services. Maya has attended transition sessions hosted by the local school board, but she feels lost. Ethan receives ODSP and $5,000 of Passport funding. Ethan is non-verbal and incontinent.

Maya works two jobs — she has a full-time job working at the local daycare of her son's school and working during the weekends at a local Tim Hortons. She is the primary caregiver for her son and has been very fortunate until now that her mother has been helping her on evenings and weekends when Maya has to work. Maya's father passed away several years ago. More recently, Maya's mother was admitted to the hospital, leaving Maya scrambling to find care for her son after school and on weekends. She has called Developmental Services Ontario and has pleaded with them to help increase Passport funding for her son so she can hire someone to help take care of Ethan. Maya has been advised that there is no additional funding for Ethan. Maya is worried that she will now have to quit one of her jobs.

MOVING TOWARDS AN ACCESSIBLE AND MEANINGFUL SYSTEM OF COMMUNITY SUPPORTS

"We need more direction about when it is time for a nursing home and how long it will take. We need a little longer to make a move, not just 2 or 3 days. We need better communication with workers providing support, like a weekly review or bi-weekly. We need the same caregiver to go each day, or at least not a different person daily."

To solve the problem requires a fundamental shift in approach. We must begin by recognizing caregiving as a fundamental pillar of society, on which we all depend for lives of dignity and inclusion. **Recognizing caregiving as essential, we must design formal care systems in a way that embeds caregiver voices, needs, and perspectives in their design.** To do so, these systems, including acute care, developmental services, home and community care, and mental health and addiction services must:

1. Recognize caregivers as an essential element of systems of care by systematically assessing and addressing their needs for support;
2. Include caregivers in the design of systems and processes that they are expected to use — this must go beyond simple representation on a Committee to genuine engagement and co-design of services;[12]
3. Place a priority on the reliability, consistency, and quality of supports in the community by recognizing that the conditions of work for health workers are the conditions of care for care recipients, as well as the conditions under which caregivers must live and carry out their essential roles;
4. Enable proactive approaches and planning, recognizing that most care recipients will transition between systems at some point, and that the needs and capacities of caregivers will also change;
5. Move towards system integration and coordination, together with professional case management;
6. Invest in services in the community, including home care, community services, accessible housing, developmental services, and mental health and addictions supports, to reduce waitlisting and more closely tailor services to needs.

Starting Points for Creating Community Services that Support the Caregivers Who Navigate Them

There are promising models and initiatives that can be built upon the design community systems that include and support the caregivers on whom they rely.

The **Ontario Caregiver Organization** has created an Essential Care Partner Support Hub that provides guidance and resources to help health care organizations adopt caregiver-inclusive practices.

The **Ontario Community Support Association** has recommended policy changes to enable the expansion of Healthy Aging Community Care Hubs that integrate medical, social, and wellness-oriented services to enhance the overall health and quality of life of people with complex or chronic needs. These Hubs emphasize coordination and collaboration between professionals, and allow for a focus on wellness and prevention.

Recent Ontario government budgets have recognized the importance of investments in home care. As **Care Watch** has emphasized, future investments in home and community care should enhance base rates as well as service expansion, to ensure that staff are properly compensated, thus reducing turnover and improving consistency of care.

Community Care for Central Hastings has a **Regional Care Planning** model that centralizes intake and coordinated care planning approach, so that clients and caregivers can access assessment, navigation, and service coordination across multiple community support providers. Similarly, **Access CSS** provides care coordination and navigation through a Regional Care Coordination Access model that allows coordinated access and referral pathways across multiple community support providers.

VHA Home HealthCare has developed an Interprofessional Collaboration Competency Framework that provides an approach to support communication and collaboration between health care providers of different disciplines as they care for shared clients, one that specifically addresses the particular contexts and challenges of the home care sector.

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