Setting the Balance of Care in Northwestern Ontario:

Opportunities and Challenges for Aging in Place

> *"I had one lady; she had 17 people walk into her door. Now some of them were family but the rest of them were service providers in one day."*
>
> - Homecare Provider in Northwestern Ontario

HEALTH SYSTEM PERFORMANCE RESEARCH NETWORK (HSPRN)

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Introduction and Overview

A growing number of people in northwestern Ontario (much like other parts of the world) require access to home and community care services as they age (1, 2). Homecare plays an important role in meeting the daily living needs of people in their natural environments. Ideally, homecare can also substitute for more expensive care in hospitals and long-term care facilities. Finding the appropriate balance between care in the home and care in institutional settings for older adults with care needs is not always easy to achieve. To that end, our team has been working closely with care providers and managers across Ontario for over ten years to better understand the characteristics of vulnerable older adult populations who are at risk of long-term care placement and explore opportunities for them to age in place (1-4).

This report highlights our most recent study of this nature in northwestern Ontario (NWO). The study had 3 core objectives: 1) to examine the characteristics of adults waiting for long-term care in Northwestern Ontario; 2) to work with local care managers and providers to design and estimate the costs of packages of community care for clients waiting for long-term care and 3) to outline the factors that need to be addressed to make it easier for care providers and managers to mobilize and deliver home and community care for older adults in their communities.

The report is divided into 3 sections, corresponding to the aforementioned objectives. Section 1 outlines the characteristics of adults waiting for long-term care in Northwestern Ontario. Comparisons are made between the most urbanized area (Thunder Bay) to the rest of the region (comprised of various rural and remote communities). Data from the Resident-Assessment Instrument for Home Care (RAI-HC) were analyzed to characterize the population. Section 2 outlines the types of services and delivery models needed for adults to avoid or delay, long-term care admission from the perspectives of providers and care managers in Northwestern Ontario. Section 3 provides a thematic analysis of the conversation that care providers engaged in as they designed the care packages. They outlined barriers and facilitators to optimal home and community care provision. These thematic findings are presented as the "fundamentals" of home and community care. Before addressing the 3 study objectives we provide a summary of the population health profile of residents in NWO below.

Context

NWO is the largest geographic region in Ontario, covering approximately 47% of Ontario's landmass, but home to less than 2% of the population (231,000). Approximately 16% of the population in NWO is 65+ which is higher than the Ontario average and expected to increase to 22% in the next ten years (5). The rapidly aging population is shaped in part, by out-migration of younger adults who are leaving the region to seek employment in larger urban centers (1, 2). Compared to the Ontario average, people in NWO have higher rates of premature and preventable mortality, higher rates of obesity, and a higher incidence of chronic conditions, including diabetes, hypertension and arthritis (5). The life expectancy of residents of NWO is approximately 2.5 years lower than the average Ontarian (ibid). In terms of health services utilization patterns, NWO has high rates of emergency department and hospital utilization for health issues that could be treated in the community (i.e., ambulatory care sensitive conditions) (ibid). NWO also has the highest proportion of hospital patients who are occupying beds unnecessarily due to a lack of available supports in alternate settings (6).

Much like other parts of the province, NWO has a lengthy waiting list for long-term care. While some older adults have such high needs that warrant long-term care facility admission, others, could potentially receive care in the community, assuming it were available, properly integrated, managed, and aligned with the needs of the client and their caregiver(s).

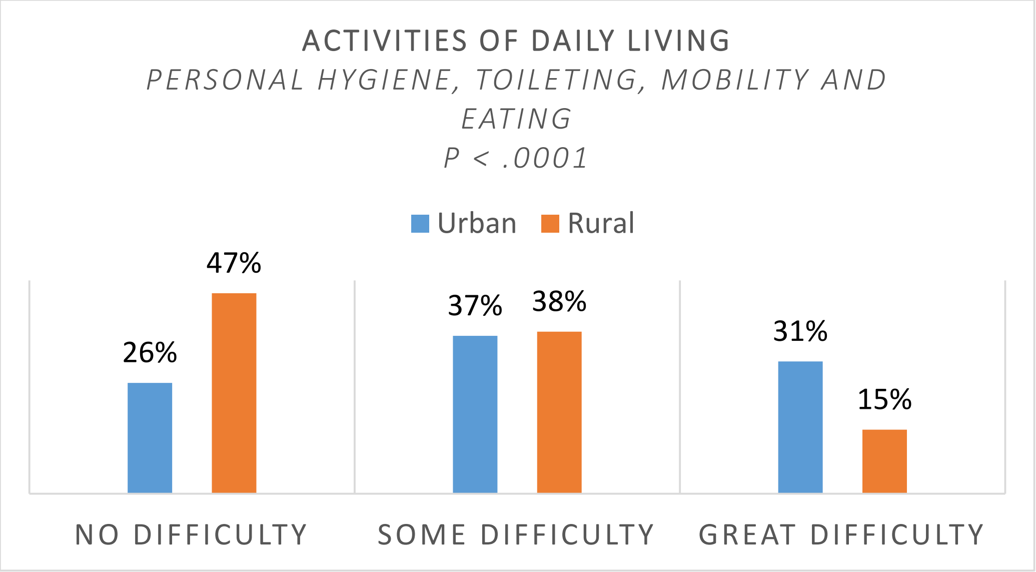
In our previous research we found considerable opportunity to support many persons (up to one half of wait-listed persons in rural parts of NWO) in their homes and communities (2). Even in Thunder Bay, where there is considerably greater infrastructure compared to the surrounding rural and remote areas, it seemed that some people were at premature risk of admission due to lack of access to homecare (1, 2).

PART 1:

What are the characteristics of people on the wait-list for long-term care in Northwestern Ontario? Are there differences between people waiting in Thunder Bay compared to the rest of the region?

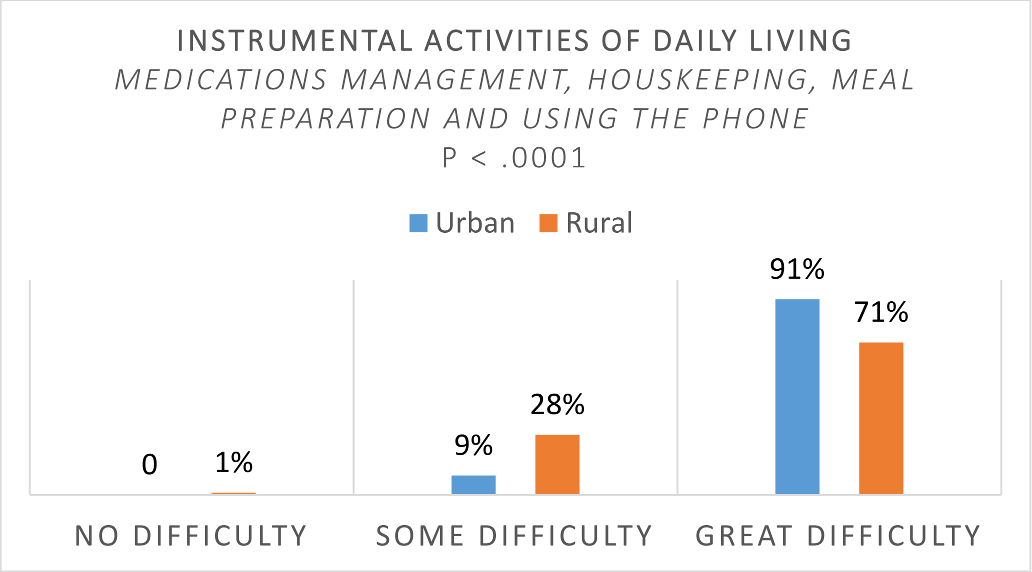
As of 2014 when the data were provided, 973 people were on the wait list for long-term care in Northwestern Ontario~ **680 people were waiting in Thunder Bay and 287 were waiting in the surrounding Region**. 6 people on the wait-list had an unknown location and could not be classified into the urban or rural categories. Using RAI-HC data, we compared people who were wait-listed in Thunder Bay (i.e., urban) to people who were wait-listed outside of Thunder Bay in the surrounding North West Region (i.e., rural). Four key variables were used for the comparison: activity of daily living impairment, instrumental activity of daily living impairment, cognition and presence of an informal (unpaid) caregiver in the home (such as a family member). Statistical tests (t-tests and chi-square) were run to assess differences between urban (Thunder Bay) and rural areas (Region).

Figure 1: Activities of Daily Living



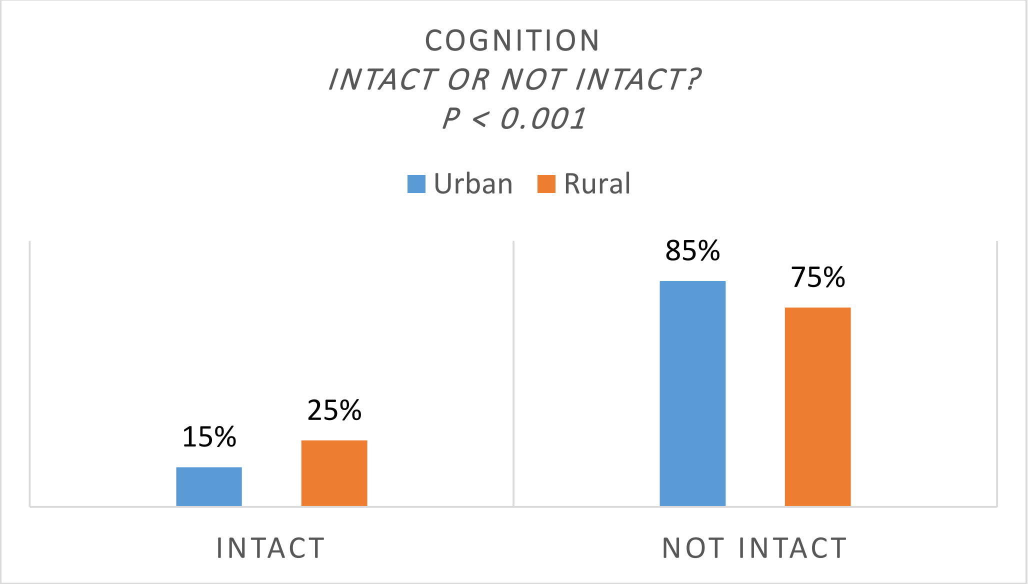
As seen in Figure 1, people waiting for a long-term care bed in Thunder Bay (i.e., urban) had significantly greater difficulties with activities of daily living compared to their counterparts in the region (i.e., rural). Furthermore, between one quarter and almost one half of people waiting in Thunder Bay and the Region respectively had no ADL impairments in personal hygiene, toileting, mobility and eating.

Figure 2: Instrumental Activities of Daily Living



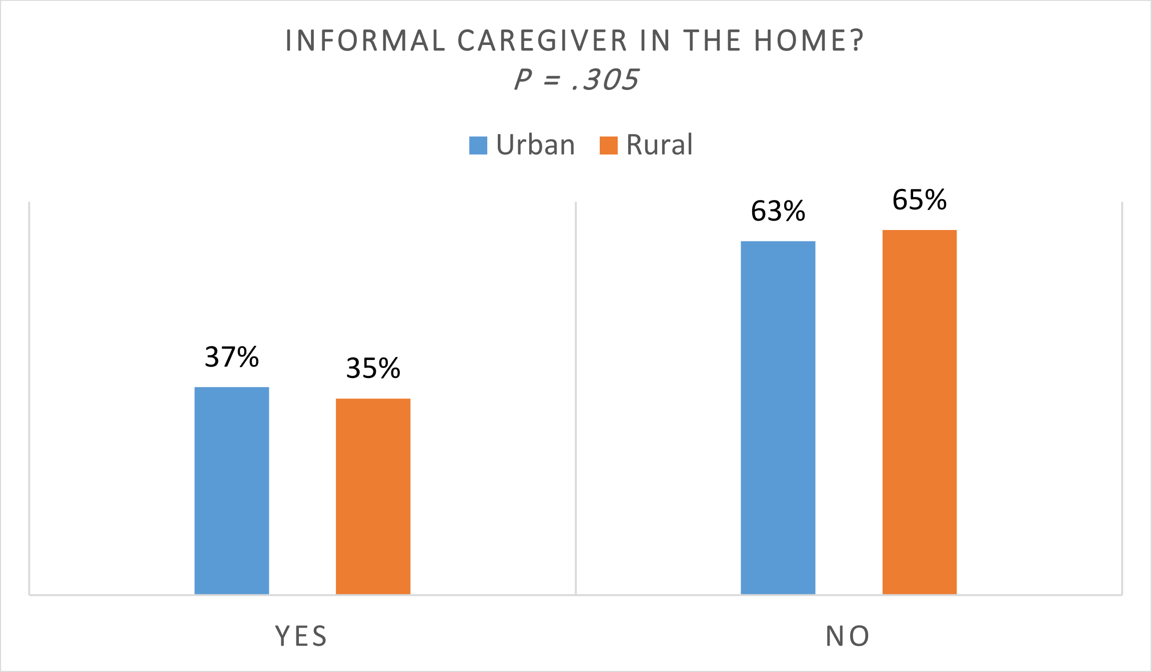
As seen in Figure 2, people waiting for a long-term care bed in Thunder Bay had significantly greater difficulties with instrumental activities of daily living (IADLs) compared to their counterparts in the region. Furthermore, the majority of people on the wait-list (in both Thunder Bay and the Region) had great difficulty with IADLs.

Figure 3: Cognition



As seen in Figure 3, people waiting for a long-term care bed in Thunder Bay had significantly greater cognitive difficulties compared to their counterparts in the region. Furthermore, between 15% and one quarter of older adults in Thunder Bay and the Region respectively were cognitively intact. Among individuals who were “not intact” they were, for the most part, experiencing mild-moderate levels of impairment; less than 10% were severely impaired.

Figure 4: Presence of a Caregiver



As seen in Figure 4, just over one third of people on the wait-list in both Thunder Bay and the Region lived with a primary informal caregiver.

In summary, similar to our previous analysis (1, 2), people wait-listed in Thunder Bay showed higher impairments overall; suggesting a higher threshold for placement compared to the region. Furthermore, compared to our previous analysis, it seemed that people in both Thunder Bay and the Region on the wait-list were showing overall greater impairments.

Based on their characteristics (ADLs, IADLs, cognition and presence of a caregiver), clients were stratified into one of 36 groups. Each of the 36 groups were given a name (alphabetically, strictly for organizational purposes). The highlighted groups represent those that were written up into vignettes (i.e., detailed stories) and presented to an expert panel of care providers. The expert panel was tasked with designing community care packages for each of the vignettes (see Section 2). A more detailed description of our methodology can be found elsewhere (2).

Table 1: Groups

Stratification	Confusion	ADL Difficulty	IADL Difficulty	Live with Caregiver?	% Thunder Bay Waitlist N = 680	% Region Wait List N = 287
#1 Appleton	Intact	No	No	Yes	0	0
#2 Bruni	Intact	No	No	No	0	.7
#3 Copper	Intact	No	Some	Yes	.4	2.4
#4 Davis	Intact	No	Some	No	2.2	7.7
#5 Eggerton	Intact	No	Great	Yes	.6	.7
#6 Fanshaw	Intact	No	Great	No	1.3	1.4
#7 Grimsby	Intact	Some	No	Yes	0	0
#8 Hamilton	Intact	Some	No	No	0	0
#9 Islington	Intact	Some	Some	Yes	.1	.3
#10 Jones	Intact	Some	Some	No	.7	.7
#11 Kringle	Intact	Some	Great	Yes	.4	3.5
#12 Lambert	Intact	Some	Great	No	2.6	5.6
#13 Moore	Intact	Great	No	Yes	0	0

#14 Nickerson	Intact	Great	No	No	0	0
#15 Opus	Intact	Great	Some	Yes	.4	0
#16 Pringle	Intact	Great	Some	No	.1	.3
#17 Quinn	Intact	Great	Great	Yes	2.1	1
#18 Rogers	Intact	Great	Great	No	4	1
#19 Smith	Not Intact	No	No	Yes	0	0
#20 Thompson	Not Intact	No	No	No	0	0
#21 Upperton	Not Intact	No	Some	Yes	.7	.7
#22 Vega	Not Intact	No	Some	No	3.5	12.2
#23 Wong	Not Intact	No	Great	Yes	4.4	5.9
#24 Xavier	Not Intact	No	Great	No	12.4	15.7
#25 Yeung	Not Intact	Some	No	Yes	0	0
#26 Zeleny	Not Intact	Some	No	No	0	0
#27 A. Armour	Not Intact	Some	Some	Yes	.3	1
#28 B. Biloski	Not Intact	Some	Some	No	.3	1.7

#29 C. Cameron	Not Intact	Some	Great	Yes	13.4	12.2
#30 D. Daniels	Not Intact	Some	Great	No	18.5	12.9
#31 E. Edwards	Not Intact	Great	No	Yes	0	0
#32 F. Fish	Not Intact	Great	No	No	0	0
#33 G. Gallo	Not Intact	Great	Some	Yes	.1	0
#34 H. Hogan	Not Intact	Great	Some	No	.1	.7
#35 I. Innis	Not Intact	Great	Great	Yes	13.4	6.6
#36 J. Johns	Not Intact	Great	Great	No	17.6	4.9

Similar to our previous analysis (1, 2), the lower needs groups (e.g., Copper and Davis) were more heavily populated by people waiting in the Region, while the higher needs groups were more heavily populated by people in Thunder Bay (e.g., I.Innis and J.Johns). These differences may be due to the greater community infrastructure available in Thunder Bay compared to the outer region, allowing people to 'age at home' longer before being placed for long-term care.

PART 2:

What resources are required to support older adults (at risk of long-term care admission) in their homes and communities?

The highlighted groups detailed above in Table 1 were written up as case "vignettes" (see Appendix A) and presented to a group of 10 care providers (i.e., expert panel) who worked in various organizations across the health and social care continuum in NWO (homecare, rehabilitation, hospital, mental health, supportive housing and other community supports). The expert panel was tasked with designing community care packages for each of the vignettes.

When care managers designed care packages they indicated that it was important to consider delivery models that facilitated greater integration of services, care continuity and ease of access. As noted by one care manager, having “17 providers show up at your door” is not a feasible and sustainable way to provide homecare. As can be seen in figure 5 below, a number of ways to provide personalized, integrated care were suggested.

Such models ranged from **supported self-management** where families and providers co-design care using set budgets; to housing with care models (like supportive housing) where care is provided “under one roof.” Ideally, as needs increased, supportive housing would become ***enhanced*** through further adaptations (lifts, and other home adaptations). However, it was cautioned, that supportive housing should continue to be used as a prevention model and be targeted to people *early* in their care trajectory in order to maximize its potential to prevent or slow down decline. **Day programs** could also be adapted to include needed medical care on-site, particularly for moderate-high needs clients. Finally, as noted at the bottom of the figure, these models would ideally be situated within geographically based “hubs” comprised of a network of providers who leverage local resources and work closely with clients and families over time.

Figure 5**: Types of Integrated Delivery Models**

The “hub” models suggested by the expert panel emulate the community based hub models that were defined in a recent planning document by the Ontario government. Here community hubs were defined as “a central access point for a range of needed health and social services, along with cultural, recreational, and green spaces to nourish community life. A community hub can be a school, a neighborhood centre, an early learning centre, a library, an elderly person’s centre, a community health centre, an old government building, a place of worship or another public space. Whether virtual or located in a physical building, whether located in a high-density urban neighborhood or an isolated rural community, each hub is as unique as the community it serves and is defined by local needs, services and resources.” (7).

Community based hubs were also endorsed by the Ministry of Health and Long-term Care in its 2014 Mandate Letter (8). In the Mandate Letter the Minster of Health elicited a call to action for a cross ministerial (health, education, municipal affairs and housing) developments of geographically based, ground up initiatives to support the health and wellbeing of citizens.

Community based hubs, to some extent, share some commonalities with Ontario’s Health Links. Health Links are geographically based groups of providers in Ontario who are tasked with working together to better coordinate care for heavier users of the health care system. The key difference is that Health Links are intended to focus on the top/high cost utilizers of health resources (9) while hub models appear to take a life course approach by leveraging the capacity of communities to keep people healthier over the long-term and not just pick them up once already quite complex.

While the above types of integrated service delivery models were emphasized by the expert panel during the review of case vignettes, in the absence of these options in daily practice, the panel members discussed the list of services required for each of the vignettes. Similar to past research in this region as well as all across Ontario, services for both activities of daily living as well as instrumental activities of daily living were deemed vital and recommended for all vignettes. The issue in current practice is that many IADLs (transportation, paying bills, shopping, making meals, and yard maintenance) are typically not part of publicly funded homecare services in Ontario, or may not be available at all in the most remote locations. The need to broaden the “basket of services” to included non-clinical supports such as IADL care was also highlighted in the Report of the Expert Group on Home and Community Care (10).

In addition to identifying needed services, care providers spoke at length about programs and services that currently work well in NWO, but need additional capacity. For instance, highly commended were the caregiver respite programs, particularly in-home visits, as well as Supportive Housing (except long wait lists prevented access for many). New emerging innovations that held promise included the Alzheimer Societies First Link Program (connecting early stage dementia patients and their caregivers to services and following them throughout their care trajectory). It was noted that the First Link “philosophy” -- connecting people early to services-- could be applied beyond the Alzheimer’s population. Other successful programs included IADL supports for low income populations, home visits from nurse practitioners for housebound seniors, and virtual visits (through a tablet) for home based palliative care patients and their providers enabled through Ontario's Telemedicine Network (11). These were just a few examples of new and innovative emerging programs that could potentially be scaled up and spread to other jurisdictions.

To view the detailed care packages, see Appendix A.

PART 3:

What would make it easier for care managers and providers to mobilize and deliver home and community care?

Providers face many difficulties when mobilizing and delivering homecare to clients in need. As the expert panel members designed the care packages (detailed in Appendix A) they discussed the issues and challenges faced in daily practice. Through this discussion our team generated key insights, described as the *fundamentals* of home and community care. This was achieved by audio recording and transcribing the expert panel meeting verbatim (approximately 6 hours of tape) and thematically analyzing the content using qualitative descriptive methods [1]. Trustworthiness of data was addressed by having two reviewers independently code the transcripts, and then meeting to discuss, compare and reach final consensus on themes. Both reviewers used NVivo software to organize their findings. Furthermore, member checking (presenting themes back to participants) and making needed changes thereafter ensured that the findings adequately captured the views of the participants.

The themes were organized into 4 overarching categories: Capacity and Roles of Care Providers; Organization and Structure of Care; Orientation/Focus of Care; and Accessibility and Knowledge of Care.

I. Capacity and Roles of Care Providers

Personal Support Worker Role Optimization

The expert panel discussed the role of providers in the homecare sector, with special attention to the role of Personal Support Workers (PSWs). In Ontario, PSWs are unregulated care providers who provide the bulk of formal homecare in the province. Stated was the importance of valuing and optimizing the PSW role through standardized education, professional regulation, adequate reimbursement and a greater scope of practice. It was thought that by increasing scope of practice, PSWs would not have to "break the rules" in order to provide good client care. One provider noted:

> *"But my point is if we all had to feel every day that we are sneaking around doing something that we think is right but we can only do it because we can secretly… I mean that's not a way to do your job every day. Yet, I think both [care manager] and I can speak to the fact that yes, they're doing that bath quick and getting that person for a*

> *walk in the house, out of the house. They're doing laundry when that's not on the ticket of what they're supposed to be doing."*

Also emphasized was the suboptimal conditions in which PSWs work, including tight, back-to-back appointments and a lack of subsidized transportation to get between appointments.

Ongoing Navigation

The expert panel strongly emphasized the need for, and importance of, ongoing system navigation. The system navigator would "connect the dots" along the clients care trajectory and mobilize the team of care providers required. Coordination would occur virtually or over the phone, but ideally, face to face, particularly for people with heavier care needs. A care provider noted:

> *"…if there can be system navigation built in somehow so that there's one person that they know. They built that relationship with them over time so when you get them here [at a stage with higher levels of need], they're already in the system and you can follow through and check on them. Even if they're doing well, to check in on them…"*

Also discussed was the importance of knowing the expanse of the client's social network. For example, making note of the people that the client regularly interacted with – such as the bank teller, grocer, postal worker, etc. These naturally embedded supports would, ideally, know how to connect to the care coordinator if they detected a health change in the client. A provider stated:

> *"…you've got people that are delivering the mail…if they see someone, we have to give them somehow [the] okay to phone 911 or phone somebody and say, you know what, something is wrong with this person, they're not picking up their newspaper..."*

Consistent Care Providers

It is not uncommon for homecare clients to see many different providers when receiving homecare services. Even if receiving one type of service (e.g., bathing support from a PSW), there is no guarantee that they will see the same provider twice. This is in stark contrast to other types of care, such as primary care, where clients may be rostered to one provider and/or interdisciplinary team. Providers noted that by having an ongoing relationship with a client and their family, it would likely increase the comfort and safety for all players involved, help providers flag early signs of decline, decrease duplication of assessments and treatments as well as mitigate the stress associated with provider changeover.

> *"Our greatest problem here with my patients is consistency. So I have a couple that have a consistent PSW. And they're the ones that identify changes in their medical condition prior to family members."*

In the absence of consistent staff, clients and families have to continuously reorient new providers to their homes and routines.

> *"And it's stressful for them [clients/families] if they have to show somebody around the house or the routine every time."*

As the care providers resorted to creating "line by line" care packages, one participant summed up:

> *"If there is someone different going in there every single day then none of this stuff is going to work."*

Teamwork

The providers emphasized the importance of teamwork—described as a collection of providers who know and support the client and family, and rely on each other to step in and provide support as needed. A member of the expert panel noted:

> *"And the other part of that too is not just knowing your client but knowing the other healthcare professionals that I work with so we work as a team in that hub…"*

They noted that being part of a team would take the pressure off any one individual care provider having to know all the answers:

> *"…between the team, they would know about every single service in [city]. So then it's not always just up to one person…"*

A participant also acknowledged that even they, as experts, didn't know the full array of services available:

> *"So it goes back to us [providers] not knowing what services we have. It does. I mean if we don't know, how are they supposed to know?"*

In summary, enhancing the capacity of care providers to provide holistic care (e.g., particularly PSWs who provide the bulk of professional homecare), striving for care consistency, working as part of a team to trade-off on tasks and share knowledge, as well as proactively and continually coordinating care were emphasized.

B. Organization and Structure of Care

Pool Services/ Substitute and Cluster Care

The providers discussed a need for greater flexibility in how they delivered care to their clients. For instance, pooling services together—through therapeutic bundles (i.e., a team of allied health professionals who respond flexibly to the changing needs of clients) was put forth as a potentially useful strategy. For example, instead of allotting a block of physiotherapy appointments to clients, the type of care provider attending to the client would depend on the need of the client on a given day. One of the participants noted:

> *"The other thing you could do to complicate things, but you could do like social work, OT and PT, you could lump them and then depending on the client's need, you can kind of use that money to really make it [work]…"*

The providers also discussed the idea of clustering care which would entail a network of providers working within specific geographic areas/ neighborhoods. The providers suggested that geographically based teams and clients would allow providers to see many people in one building or neighborhood within a given day. The clustered model would potentially enhance capacity to respond to the fluctuating and unpredictable needs of clients. This is similar to a supportive housing model where on-site providers can respond to clients in the building on an as needed basis. Formally situating providers as a geographic team or "hub" is something that could also yield incredible gains in underserviced areas.

Providers also talked about a need to horizontally substitute services and/or providers. For example, if a client needed bathing support, this need could be addressed through the installation of a bath seat or grab bar, or through the assistance of a PSW. Similarly, nutrition and meal support could be met through congregate dining (bringing someone to a group dining activity), bringing meals *to* them, or take-away dinners provided after a visit to a day program. All in all, the providers discussed the importance of flexibility when providing care so that clients could choose the appropriate/preferred service and have it delivered in a way that aligned with their preference.

Create a Flexible Funding Model

The providers discussed the limitations of the current funding structure for homecare, which reimburses organizations and providers by units of care (by visit or by hour). They discussed the potential merits of a capitated-funding model or remuneration by client type/ case complexity. Reimbursing providers/organizations by day (with the amount in accordance with case complexity) instead of by visit was also suggested. A participant noted:

> *"…rather than per visit, you go in and see as many clients as you can within a day… if we billed you out per day versus per visit, we could actually probably see 8 or 9 people."*

Providers also talked about allocating budgets at the discretion of clients and their families. This would take the form of a personal budget managed by a formal care provider (such as a care coordinator) who would discuss options with clients and their families who would essentially select from a menu of options or suggest service preferences. This type of funding model is akin to personal budgets in the UK (12). One of the participants stated:

> *"…so they say you've been assessed to get [amount] per month. How do you want to use it? These are what the costs of the services are, and you choose the package."*

The providers noted that when additional funds were introduced into the home and community care sector, they were often directed in response to a crisis (such as hospital issues), representing a "Band-Aid solution". Discussed were the challenges of "new" and "one time funding" which officered no guarantees for sustainability and made it difficult to plan new programs and interventions or to spread and scale up successful ones.

In summary, geographically based teams, pooling and substituting services supported through flexible remuneration schemes were recommended.

C. Orientation/ Focus of Care

Provide Proactive as Opposed to Reactive Care

The providers discussed the importance of "catching people early" in their illness trajectory in order to mitigate unnecessary hospitalizations, emergency room use and long-term care admissions. Identifying people upon diagnoses or very early stages of decline by a primary care provider would allow them to subsequently be "rostered" to a care coordinator.

A participant noted:

> *"…by the time they get to where you are, they've already gone over the cliff…if you consider once the diagnosis starts or as clients start aging, if we had the support system in place that was very proactive…"*

Another participant talked about the importance of recognizing early warning signs:

> *"…when you're working with these clients in the community, you see it. You see where it's falling down. And a lot of it is maybe just not advocating for themselves until they finally can't do it anymore, and then they end up in the system."*

Support and Involve the Caregiver

The providers emphasized that the informal caregiver was an essential part of the unit of care, whether they lived in the home with the care recipient or not:

> *"Just because [caregiver] doesn't live in the home… they still need to be a piece of this puzzle too."*

A participant went on to say:

> *"Treating the family. You treat the family. You don't just treat the patient anymore because it's such dynamics within it. And then if you get others, like kids involved, and stuff like that, it's complex."*

In summary, orientating care towards prevention and early detection and focusing on the client *and* their caregiver was deemed important.

D. Accessibility and Knowledge of Care

Improve Access and Eligibility

A key challenge noted by the provider participants was timely access to care. Services such as transportation tended to be particularly problematic, had to be booked quite far in advance and often involved some form of co-payment. A participant noted:

> *"Like right now I have a client who needs to get to [the grocery store] to get a few things. It's really hard to get her services that don't cost a lot or you don't have to book like 2 weeks ahead…"*

Access to homecare was also challenged by stringent caps on hours:

> *"…the program[s] that are offered for this type of person isn't enough hours to maintain them in their home. So we don't have a choice but to keep them in hospital because the environment is not going to be safe for them for discharge."*

Eligibility criteria for certain programs were also quite strict, particularly (as noted above) for caregiver respite, a program comprised of in-home support and activities for care recipients, including overnight care. In order to qualify for these services, the caregiver and patient had to live in the same household:

> *"And I know I've had so many things where I've tried to fight for it. Even if a caregiver is there like all day, every single day, they don't qualify because they don't live there."*

Providers also noted that by the time services become available it was often too late:

> *"And then sometimes your wait lists are long at those places. So people might be eligible and good to go to supportive housing, and then they're on the wait list for a really long time and end up declining so much that by the time their name comes up, they're not eligible."*

Another key access challenge was in relation to homebound clients, an issue that became exacerbated during the long winter months. It was recommended that services such as primary care be brought to the person, through a visiting provider (e.g., nurse practitioner).

Alternatively, the use of electronic tablets was suggested as a way to engage with a provider virtually. At the time of the study, NWO had a pilot program that consisted of technology based visits (through the use of a tablet to facilitate on going check-ups between providers and clients), but was restricted to palliative populations.

In summary, timely access to care, providing care in flexible ways (bringing care to people) and relaxing stiff eligibility criteria were recommended.

Enhance Education/Information

The provider participants discussed the importance of educating caregivers- both formal and informal- of ways to identify "red flags" and mitigate unnecessary decline.

> *"So what about education in the system to make sure that the team knows what the red flags are? You know, like just to make sure that it's cohesive….a bit of training."*

The providers also discussed the importance of adequately training personal support workers, particularly on ways to deal with the fluctuating needs of clients. One participant noted:

> *"Education of the PSWs too because they are not regulated. And when it gets a little bit complex, and I know we are not there yet, but they don't always get it. And if you don`t have that consistency."*

Similarly, educating informal caregivers on the execution of certain tasks to increase their confidence and willingness to engage in more complex care was noted:

> *"I feel like lots of caregivers don't want to take on more of a caring role because they don't know how to do a lot of stuff. Then even with ER visits and going to the ER because they are not educated enough to know what else to do. So maybe if there was some sort of education program that they could have on like the meds, then they might feel okay about administering the medication if they know about them."*

Finally, educating others in the client's circle of care was discussed:

> *"Police are a big part of it too because, no offence, but they don't always respond properly to those clients even if they are mildly cognitively impaired…..so I think some education and understanding within those hubs [geographically based care networks] with the police and the EMS and first responders."*

In summary, educating the circle of care (including intimately involved family caregivers and formal providers to those on the periphery, such as first responders) to handle complex cases and recognize tipping points was emphasized.

Conclusions

In this report we shared the results of our most recent study in Northwestern Ontario. We addressed key questions including: “Who is waiting for long-term care?” “How can the community potentially support them?” and “What needs to be in place to make this happen?”

Similar to our previous work in this region (1, 2) and across Ontario (3, 4) we found that some people have such high needs that there appeared to be no safe alternative to a long-term care facility placement. On the other hand, for others, we questioned why they were on the wait-list at all. Did they need to be there? What could be leveraged in the community to support them and their families to successfully age in place? Based on our analysis we suggest that home and community care, if nothing else, needs to be flexible, consistent, proactive and integrated.

Flexible Care

Publicly funded homecare in Ontario, as well as other Canadian jurisdictions, is characterized by stringent eligibility criteria, capped hours (with some exceptions for complex cases) and specifications on the types of services that can be provided. In this study as well as our previous work across Ontario; IADL support (assistance with transportation, meals, medication management, housekeeping and maintenance, etc) was deemed critical, yet continues to be the hardest to mobilize and access (often involving a co-payment or lacking in availability).

Flexibility is also required in the provision of care, including the tasks that providers are expected to do. For instance, providers discussed scopes of practice—with particular reference to the role of the PSW—discussing that a more formalized, regulated role would help, but ultimately providers need the time and capacity to provide care that does not position them to “break the rules” in order to meet the needs of their clients and families. While it was recognized that going above and beyond the call of duty already occurred, there is a need to recognize and support the role of PSWs in a more formalized way (longer visits allotted, appropriate compensation including support for travel, which occurred in some cases and not others). Recent wage increases for PSWs in Ontario is a step in the right direction but more is to be done to truly support them in their important role.

Consistent Providers

It is necessary for clients to be supported by consistent and familiar providers. Provider turnover rates can be high, particularly when contracts change, leaving clients and families left to reorient unfamiliar people to their routines. A familiar and consistent provider or team can facilitate shared understanding of client care needs, a better care experience for the family, as well as earlier identification of cues that may be indicative of decline. For example, in the Toronto Central CCAC, high needs/complex clients are assigned a “quarterback” ~ a consistent care coordinator who works closely with a primary care provider, client and family in designing care, following up on care needs, and bringing in other members of the care team when needed. Partnerships with Emergency Services allow for ongoing communication in the event of hospitalization and quick reconciliation of medications (13).

Proactive and Integrated Approach

Providers emphasized the importance of catching people early in their illness trajectory in order to monitor and support them over time, and potentially mitigate premature decline. The whole notion of early detection and prevention is embedded as a standard of care in Denmark. Since 1998, all municipalities in Denmark have been required by law to offer each resident (75+ years of age) two preventive homecare visits each year (14, 15) allowing care providers to flag concerns and mobilize care prior to a crisis situation occurring. Another example is the Ontario Alzheimer Society's 'First Link' initiative which begins at a person's diagnosis of dementia, and provides clients and families with education and support throughout the course of their dementia trajectory.

The expert panel noted that the primary care provider could play a role in identifying clients at early stages of decline and linking them to home and community care. There are many existing exemplar models of tightknit primary care and homecare integration that support clients and their caregivers. These models are characterized by many of the features recommended by providers in this study. For instance, care coordination, access to a team and ongoing follow-up are key components of these models. The Guided Care Model in the United States includes care coordination and ongoing assessment by a Guided Care Nurse who connects with the family *and* client as they move across the care continuum (from the primary care clinic, to the home, hospital, etc). The Guided Care Nurse conducts comprehensive assessments, organizes services including care for the caregivers and aims to flag early warning signs of decline [7]. Other US models have similar features including the Geriatric Resources for Assessment and Care of Elders (GRACE) model which hinges on a collaborative care model led by a nurse and social worker who provide ongoing management and care and frequently consult with a broader team of providers including the client's family physician [8]. The well-known Program of All Inclusive Care for the Elderly (PACE) model, is largely run out of a day program where an interdisciplinary team, including a primary care physician provides care and ongoing follow-up for PACE attendees (16, 17).

Such integrated care would include funding arrangements that facilitate seamless care across care boundaries. This aligns with Ontario's current experimentation with bundled payments (18), where groups of providers across hospital and home determine a single payment to support care for patients across these two settings (19). Providers in our study talked about ways to put patients and families at the centre by using personal budgets as a way for patients and families to integrate their needs and preferences into care plans. Improved integration with primary care and funding reform were both key components of the recent Report of the Expert Group on Home & Community Care (10).

In summary, much can be done to improve the home and community care sector in Ontario and beyond. Many people continue to be at risk of long-term care placement, even with care needs that could potentially be met in the community. Ongoing resource constraints in the home and community care sector combined with a lack of capacity to integrate services across boundaries, prevent providers from doing what they wish to do—keep their clients and families safely in the community with access to appropriate supports. These supports include things that are traditionally included in publicly funded homecare packages such as bathing and mobility support but also supports for the “smaller” and perhaps “less traditional” things like housekeeping, meals and socialization. We also have an opportunity to leverage what already works well in northwestern Ontario, including and not limited to: caregiver respite programs, Alzheimer’s First Link, supportive housing and virtual home visits. The insights from this report adds to a growing evidence base on the “needed ingredients” for home and community based care improvement and can potentially help Northwestern Ontario and other like jurisdictions set priorities for their growing senior population.

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Appendix A- Vignettes and Care Packages

Detailed below are the vignettes and care packages designed by the expert panel. The vignettes reflect a mix of clients with low, moderate and high needs; some of whom lived with caregivers and others who did not. After the packages were created, the research team calculated the weekly public (i.e., government) cost of the packages and compared these package costs to the weekly public cost of long-term care. The most up-to-date local unit cost data were used: the CCAC average unit costs were provided by the North West CCAC and all other service costs (community support service unit costs) were provided by the North West LHIN. The long-term care cost data were obtained online and verified by the North West LHIN: the per diem subsidy from the government was equal to the total funding /resident/day ($160.75) less the basic co-pay ($56.93) as of September 2014 = $103.82 / day.

A few caveats need to be considered: since these cost data are averages (across the whole region), these findings need to be interpreted with caution and would vary depending on the specific community in which the client is seeking care. Furthermore, although packages include care for caregivers (as well as the client) it does not consider personal (out-of-pocket costs) or opportunity costs (e.g., time taken from work and other activities) borne by the client or caregivers. Since only a sub-sample of vignettes were explored the team did not calculate diversion rates.

Copper- Case Vignette
"Copper is cognitively intact and functionally independent in all activities of daily living (ADLs) with the exception of bathing (limited assistance is required). Copper has no difficulty using the phone, some difficulty with transportation, managing medications and preparing meals; great difficulty with housekeeping. Copper has a live-in caregiver (a spouse) who provides advice/emotional support and assistance with instrumental activities of daily living (IADLs)."

Cognition- Intact (short-term memory recall is good; procedural memory is good (can perform all or most tasks in a multi-task sequence); makes consistent/reasonable/safe decisions; can express ideas without difficulty and understand others; does not display any behavioral/verbal problems- e.g. wandering)
ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).
IADL- No difficulty using the phone; some difficulty with transportation, managing medications and preparing meals (needs some help, is very slow/fatigues); great difficulty with housekeeping (little or no involvement in the activity is possible).
Caregiver (in home?)- Yes, the caregiver is a spouse who provides advice/emotional support and assistance with IADLs.

Copper Care Package
Estimated *Weekly* Public Cost: $395.46

Service	Frequency/ week	Cost per Unit ($)
System Navigation/ Check-In	2 visits (hours) per year	25.00
Use of Seniors Centre (55+ Program) or Day Program	2 days/ week	75.00
Medical House Calls/ Education Check-In (may include use of Tablet for electronic access)	1/quarter (from Nurse-Led Clinic)	57.25
In-Home Caregiver Respite	2 hours/week	25.00
Meals on Wheels	5 meals/ week	10.00
Transportation	2 round trips/ week	18.00 (one-way)
Security Checks/Reassurance	5 times/ week	7.00
CCAC Occupational Therapy	2 visits (1 initial and 1 follow-up) / quarter	139.87
CCAC Personal Support	1 visit/ week	27.72
Self-Management program (CCAC)		
		LTC Cost- $726.74 / week

Davis- Case Vignette

“Davis is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Davis has no difficulty using the phone; some difficulty with transportation, managing medications and preparing meals; great difficulty housekeeping. Davis does not have a live-in caregiver. Davis’ caregiver is an adult child who lives outside of the home. This caregiver provides advice/emotional support and assistance with IADLs.”

Cognition- Intact (short-term memory recall is good; procedural memory is good (can perform all or most tasks in a multi-task sequence); makes consistent/reasonable/safe decisions; can express ideas without difficulty and understand others; does not display any behavioral/verbal problems- e.g. wandering)

ADL- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).

IADL- No difficulty using the phone; some difficulty with transportation, managing medications and preparing meals (needs some help, is very slow/fatigues); great difficulty with housekeeping (little or no involvement in the activity is possible).

Caregiver (in home?)- No. Has an adult/child caregiver living outside of the home who provides advice/emotional support and assistance with IADLs.

Davis Care Package
Estimated *<u>Weekly</u>* Public Cost: $506.69

Service	Frequency/ week	Cost per Unit ($)
System Navigation/ Check-In	2 visits (hours) per year	25.00
Day Program- Frail Seniors	2 days/ week	75.00
Training and Education for Staff and Family	Initial + 1 follow-up	20.00
Community Respite Bed	3 weeks/year	80.57
Friendly Visiting	1x/week	7.00
Red Cross/Volunteer Services/Seniors Helping Seniors (used home maintenance cost)	1x/week	20.00
Meals on Wheels	5 meals/week	10.00
Transportation	3 round trips/ week	18.00 (one-way)
Security Checks/Reassurance	5x/week	7.00
CCAC Occupational Therapy	Initial and 1 follow-up	139.87
CCAC Personal Support	3.5 hours/ week	27.72
		LTC Cost- = $726.74 / week

Quinn- Case Vignette

"Quinn is cognitively intact but requires assistance with all ADLs (limited assistance required when eating; maximal assistance when bathing and engaging in personal hygiene activities; totally dependent on others with locomotion in the home and toileting). Quinn also requires assistance with all IADLs (great difficulty with transportation, using the phone, managing medications, preparing meals, and housekeeping). Quinn has a live-in caregiver." Quinn's caregiver is a spouse who provides advice/emotional support and assistance with IADLs. Many of the caregivers in this category also provide assistance with ADLs.

Cognition- Intact (short-term memory recall is good; procedural memory is good (can perform all or most tasks in a multi-task sequence); makes consistent/reasonable/safe decisions; can express ideas without difficulty and understand others; does not display any behavioral/verbal problems- e.g. wandering).

ADL- Limited assistance required when eating (highly involved in activity but requires some assistance/guided maneuvering); maximal assistance required when bathing and engaging in personal hygiene activities (client performs less than half of the tasks for these activities and may require a 2 person assist); totally dependent on others with locomotion in the home and toileting (entire task performed by others).

IADL- Great difficulty with transportation, using the phone, managing medications, preparing meals and housekeeping (little or no involvement in the activity is possible).

Caregiver (in home?)- Yes. The caregiver is a spouse who provides advice/emotional support and assistance with IADLs. Many of the caregivers in this group also provide assistance with ADLs. Half of the caregivers in this category are experiencing health decline and will not be able to continue caregiving activities.

Quinn Care Package
Estimated *Weekly* Public Cost: $1194.89

Service	**Frequency/ week**	**Cost per Unit ($)**
System Navigation/ Check-In	2 visits (hours) per year	25.00
Day Program (for higher needs)	2 days/ week	75.00
Meals on Wheels	5 meals	10.00
Transportation	2 round trips	18.00 (one-way)
Medical House Calls/ Education Check-In (may include use of Tablet for electronic access)	1/quarter (from nurse-led clinic)	57.25
"Rehab Bundle" OT, PT, SWK or PSW as needed	1x/week	126.72 (average across all provider type unit costs)
CCAC Personal Support	18 hours per week (twice per day)	27.72
Short Stay Respite	4 weeks/year	80.57
In-Home Respite	8 hours per week + 9x48 hours blocks/ year	25 for day + 140 for overnight
		LTC Cost- $726.74 / week

Rogers- Case Vignette

"Rogers is cognitively intact but requires assistance with ADLs (supervision required when eating); maximal assistance with personal hygiene activities; and is totally dependent on others with locomotion in the home, toileting and bathing. Rogers also requires assistance with all IADLs (some difficulty using the phone and great difficulty with transportation, medications management, meal preparation and housekeeping). Rogers does not have a live-in caregiver. Rogers has an adult child caregiver who lives outside of the home. This caregiver provides advice/emotional support and assistance with IADLs."

Cognition- Intact (short-term memory recall is good; procedural memory is good (can perform all or most tasks in a multi-task sequence) some difficulty making decisions in new situations only; can express ideas without difficulty and understand others; does not display any behavioral/verbal problems- e.g. wandering).
ADL- oversight and cuing needed when eating; maximal assistance needed with personal hygiene activities (client performs less than half of the tasks for these activities and may require a 2 person assist); totally dependent on others with locomotion in the home, toileting and bathing (entire task performed by others).
IADL- Some difficulty using the phone (needs some help, is very slow/fatigues), great difficulty with transportation, medications management, meal preparation and housekeeping).
Caregiver (in home?)- No. Adult child caregiver lives outside of the home. This caregiver provides advice/emotional support and assistance with IADLs

Rogers Care Package
Estimated *Weekly* Public Cost: $573.20

Service	Frequency/ week	Cost per Unit ($)
System Navigation/ Check-In	4 visits (hours) per year	25.00
Meals on Wheels	5 meals	10.00
Transportation	3 round trips/ week	18.00 (one-way)
"Rehab Bundle" OT, PT, SWK or PSW as needed	1x/ week	126.72 (average across all provider type unit costs)
Medical House Calls/ Education Check-In (may include use of Tablet for electronic access)	1/quarter (NP Clinic)	57.25
CCAC Personal Support	14 hours per week	27.72
		LTC Cost- $726.74 / week

Wong- Case Vignette

"Wong is not cognitively intact but independent in most ADLs (locomotion in the home, personal hygiene activities and toileting). Needs help setting up when eating and requires limited assistance required when bathing. Wong experiences some difficulty with transportation and phone use and great difficulty with meal preparation, medication management and housekeeping. Wong has a live-in caregiver." Wong's caregiver is a spouse who provides emotional support and assistance with ADLs and IADLs.

Cognition- Not Intact (short term memory and procedural memory problem. Decision-making is consistently poor/unsafe, cues/supervision required at all times). Has difficulty finding words or finishing thoughts but if given time no prompting is required. Usually understood by others (misses some part/intent of message but comprehends most conversation with little prompting). Does not display any behavioral/verbal problems- e.g. wandering).
ADL- Independent in locomotion inside the home, personal hygiene activities and toileting. Set-up help required when eating and limited assistance required when bathing (highly involved in activity but requires some assistance/guided maneuvering).
IADL- Some difficulty with transportation and using the phone; great difficulty with meal preparation, housekeeping and managing medications (little or no involvement in the activity is possible).
Caregiver (in home?)- Yes (spouse) - provides advice/emotional support and assistance with ADLs and IADLs.

Wong Care Package
Estimated Weekly Cost: $696.00

Service	**Frequency/ week**	**Cost per Unit ($)**
System Navigation/ Check-In	4 visits (hours) per year	25.00
Day Program- Alzheimer’s	2 days/ week	75.00
Referral to First Link		
Meals on Wheels	5 meals/ week	10.00
Transportation	3 round trips/ week	18.00 (one-way)
Friendly Visiting	1 visit/ week	7.00
Security Checks	1x/week	7.00
Caregiver Support- Paid Staff	8 hours per week + 9x48 hour blocks/year	25 for day + 140 for overnight
CCAC Occupational Therapy	Initial + 1 follow-up	139.87
CCAC Personal Support	3 hours/ week	27.72
Short Stay Respite	3 months/ year	80.57
		LTC Cost- $726.74 / week

Xavier- Case Vignette

"Xavier is not cognitively intact but independent with locomotion in the home and toileting. Xavier requires set-up help when eating and engaging in personal hygiene activities and requires limited assistance when bathing. Xavier experiences some difficulty using the phone and great difficulty with housekeeping, meal preparation, managing medications, and transportation. Xavier does not have a live-in caregiver. Xavier's caregiver is an adult child who lives outside the home. This caregiver provides advice/emotional support and assistance with IADLs."

Cognition- Not Intact (short term and procedural memory problem). In specific situations, decision become poor or unsafe and cues/supervision are necessary at those times. Has difficulty finding words or finishing thoughts but if given time, little or no prompting is required. Misses some part/intent of message, but comprehends most conversation with little or no prompting. Does not display any behavioral/verbal problems- e.g. wandering).

ADL- Independent with locomotion inside the home and toileting. Set-up help required when eating and with personal hygiene activities. Limited assistance required when bathing (highly involved in activity but requires guided maneuvering).

IADL- Some difficulty using phone (needs some help, is very slow/fatigues), great difficulty with housekeeping, meal preparation, managing medications and transportation (little or no involvement in the activity is possible).

Caregiver (in home?)- No. Adult child caregiver lives outside of the home and provides advice/emotional support and assistance with IADLs

Xavier Care Package
Estimated *Weekly* Public Cost: $888.83*

Service	**Frequency/ week**	**Cost per Unit ($)**
System Navigation/ Check-In	6 visits (hours) per year	25.00
Day Program- Alzheimer’s	2 days/ week	75.00
Referral to First Link		
Alzheimer Society- Minds in Motion Program	8 week program	*Cost Data Not Available*
24 hour response (Pendant/alert)	Pendant/alert (GPS Lifesaver)	
Meals on Wheels	5 meals	10.00
Transportation	2 round trips/ week	18.00 (one-way)
Friendly Visiting	1 visit/ week	7.00
Security Checks	1x/day	7.00
Caregiver Support- Training, Education, Counselling	1x/month	35.00
“Rehab Bundle” OT, PT, SWK, PSW as needed	4 visits total/quarter	126.72 (average across all provider type unit costs)
CCAC Personal Support	3x/day incl morning to prep for day program	27.72
Behavior Support (BSO) in the home		
*Not all cost data available so cost likely higher than estimate provided.		**LTC Cost- $726.74 / week**

I.Innis- Case Vignette
I.Innis is not cognitively intact and requires assistance with all ADLs (extensive assistance required when eating; maximal assistance required with locomotion in the home and personal hygiene activities; totally dependent on others when toileting and bathing). I. Innis also experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). I.Innis has a live-in caregiver. This caregiver provides advice/emotional support and assistance with ADLs, IADLs."

Cognition- Not Intact (short term and procedural memory problem; never/rarely makes decisions; ability is limited to making concrete requests; responds adequately to simple, direct communication).
ADL- extensive assistance required when eating (client perform only 50% of tasks on own, full performance required by others for part of tasks); maximal assistance required with locomotion in the home and personal hygiene activities (client performs less than 50% of subtasks on own) ;totally dependent on others when toileting and bathing
IADL- Great Difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation) - little or no involvement in activity is possible.
Caregiver (in home?)- Yes. Caregiver is a spouse who provides advice/emotional support and assistance with ADLs and IADLs. Some signs of health decline of caregiver are evident.

I.Innis Care Package
Estimated *Weekly* Public Cost: $1199.66

Service	Frequency/ week	Cost per Unit ($)
System Navigation/ Check-in	2 hours (visits) per month	25.00
Meals on Wheels	5 meals/ week	10.00
Medical house calls (NP Service + check in)	1/quarter (NP Clinic)	57.25
Transportation	2 round trips/ week	18.00 (one-way)
First link referral		
Psychogeriatric Program Assessment	Initial	80.00
Security Checks/Reassurance and a Med Alert	5x/ week	7.00
Caregiver Support-Counseling, Training, education	1x /month	35.00
Caregiver Support- Paid Staff	8 hours per week in home, 9x48 hr blocks / year	25.00 for day + 140.00 for overnight
"Rehab Bundle" (OT, PT, SWK, PSW as needed)	1x/week by most appropriate provider	126.72 (average across all provider type unit costs)
CCAC Personal Support	21 hours/ week	27.72
Short Stay Respite	3 months/year	80.57
		LTC Cost- $726.74 / week

J. Johns- Case Vignette

"J. Johns is not cognitively intact and requires assistance with all ADLs (supervision when eating; maximal assistance with personal hygiene activities; totally dependent on others with locomotion in the home, toileting and bathing). J.Johns has great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). J. Johns does not have a live-in caregiver."J. Johns has a caregiver outside of the home who provides advice, emotional support and assistance with IADLs.

Cognition- Not Intact (short term memory and procedural memory problem. Decisions consistently poor or unsafe, cues/supervision required at all times. Has difficulty finding words or finishing thoughts, prompting usually required. Responds adequately to simple, direct communication). Does not display any behavioral/verbal problems- e.g. wandering).
ADL- Oversight, encouragement and cuing needed when eating; Maximal assistance required with personal hygiene activities (client completes less than 50% of subtasks and may require a 2 person assist). Totally dependent in locomotion in the home, toileting and bathing (full performance of activities by others).
IADL- Great Difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in activity is possible).
Caregiver (in home?)- No (caregiver is a non-spouse relative who lives outside of the home and provides advice/emotional support and assistance with IADLs).

No Care Package- requires 24/7 Live in Support