

Erie St. Clair (ESC) Balance of Care Project

Windsor-Essex Final Report

Submitted to:
Erie St. Clair Local Health Integration Network

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A. Paul Williams, PhD.	Lead, Balance of Care (BoC) Research & Evaluation Group
Allie Peckham	Research Associate
David Rudoler	Research Associate
Tommy Tam	Research Associate
Jillian Watkins	Research Associate

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We also wish to thank the Erie St. Clair Community Care Access Centre (ESC CCAC), especially Betty Kutcha, Kathryn Leferman, and Brent Semande, for their help in accessing and analyzing the Resident Assessment Instrument – Home Care (RAI-HC) data.

The members of the ESC Community Capacity Plan Advisory Committee, the Windsor-Essex Balance of Care Expert Panel, the Windsor-Essex Balance of Care Think Tank, and Key Informants deserve special mention; they took considerable time out of busy schedules to provide valuable insight into current health care challenges in ESC, and approaches to building community capacity to meet them.

Finally, we want to thank Lucy Brun and Susan MacDonald at Agnew Peckham Health Care & Facility Planners, who connected us with key health care leaders in ESC.

Executive Summary

1.0 Introduction

Following an extensive community engagement process and the recommendation of the Windsor Hospitals Study Task Force, the Board of Directors of Hôtel-Dieu Grace Hospital (HDGH) and Windsor Regional Hospital (WRH) recently agreed on a proposed new vision for hospital care delivery in the Windsor-Essex region. This vision will realize “a new, state-of-the-art single site acute care hospital, within the context of an integrated health system that continues to shift services located within the acute facilities to ambulatory settings, within the community, patients’ homes and other provider settings.”

The Erie St. Clair Local Health Integration Network (ESC LHIN) subsequently commissioned a *Community Capacity Plan (CCP)* to determine the community health service capacity needed to support achievement of clinical change and create a roadmap for restructuring where and how services are delivered.

In late 2013, the *Balance of Care (BoC) Research and Evaluation Group*, based at the University of Toronto, was commissioned to conduct the *CCP Component A*, focusing on services and supports required to maintain people, including growing numbers of older persons, safely and appropriately at home or in other community settings.

2.0 What We Did

We designed a multi-stage, multi-methods approach which accesses the best available quantitative and qualitative data. As in all *BoC Projects*, we wanted to tap into the first-hand experiences and expertise of front-line care providers, as well as the more strategic perspectives of senior health care leaders.

2.1 Community Capacity Plan Steering Committee

We engaged with a Steering Committee of senior health care leaders in Windsor-Essex; it considered “big picture” issues, provided advice on project design, nominated experienced professionals to Expert Panels, and assisted with interpreting findings. The Steering Committee met 3 times including an initial web-enabled meeting on December 12, 2013 to launch the project, and a web-enabled wrap-up meeting on March 27, 2014.

2.2 Review of Key Documents and Reports

We conducted a “rapid review” of key documents describing demand and supply-side factors impacting on the ESC LHIN as a whole; a series of reports detailing health system restructuring in Windsor-Essex; and a number of provincial reports.

2.3 Analysis of ESC CCAC RAI-HC (Resident Assessment Instrument – Home Care) Assessment Data

With assistance from the Erie St. Clair Community Care Access Centre (ESC CCAC) we accessed and analyzed RAI-HC assessment data for all CCAC clients including those waiting for residential LTC and those assessed in hospitals.

2.4 Windsor-Essex Expert Panel

Advised by the Steering Committee and the ESC LHIN, we convened an “Expert Panel” of experienced program managers, care coordinators, case managers and discharge planners from across the care continuum with first-hand knowledge of local needs and an understanding of local service capacity. We presented Panellists with 8 “vignettes” (written as case notes) describing the assessed needs and characteristics of CCAC home care clients and asked them to create ideal “packages” of community-based supports required to maintain clients safely and appropriately at home or in home-like settings.

2.5 Follow-Up Interviews

We conducted follow-up interviews with Expert Panellists (and some additional colleagues) to extend and elaborate their thinking. Interviews averaged about 30 minutes in length.

2.6 Key Informant Interviews

We also interviewed “key informants” nominated by the ESC LHIN to gather additional “high level” intelligence about the current state of home and community care in the ESC LHIN, and approaches to strengthen community-based capacity in the future.

2.7 Think Tank

We organized a half-day Think Tank in Windsor on March 12, 2014 with 18 participants, including a number of CCP Steering Committee members and Expert Panellists. Think Tank participants were asked to consider questions about the design of initiatives to strengthen community capacity in Windsor-Essex.

3.0 What We Found

3.1 Review of Key Documents

ALC is a persistent problem in Erie St. Clair and the top priority for the ESC LHIN¹. In September 2013, 14% of all acute care hospital beds in Ontario were considered ALC; the corresponding rate for the ESC LHIN was 24%². As of January 31, 2014, this rate had dropped to 22.3% suggesting a positive impact from ESC LHIN’s investments in community-based programs.

¹ Erie St. Clair LHIN. (2013). Better care, better experiences, better value: 2013-16 Erie St. Clair Local Health Integration Network Integrated Health Service Plan 3. Government of Ontario.

² Ontario Hospital Association. (2013). Ontario ALC and ER Wait Times by LHIN. April 2008 to September 2013. <http://www.oha.com/CurrentIssues/Documents/2013%20Sept%20%20ALC%20and%20Wait%20Times.pdf>.

ALC is problematic for a number of key reasons:

- **Acute care settings are not designed to meet a patient’s “restorative, supportive or rehabilitative needs...”** Evidence suggests the longer older persons wait in acute care for appropriate placement the greater their risk of cognitive, physical, and emotional decline, and the greater the risk of hospital-acquired infections³
- **ALC diverts scarce resources away from other hospital challenges.** As ALC numbers rise, hospitals lose capacity to meet the needs of acutely ill people, including those admitted through the ED
- **ALC diverts resources away from investments in community-based care options.** Such options are essential to ensure timely hospital discharge, and to support older persons (and their informal caregivers) as independently as possible, for as long as possible in their own homes and communities (long-term care “places”).

The international literature and recent consulting reports in Windsor-Essex have identified a range of approaches to reducing utilization of hospital services. These include:

- **Approaches aimed at avoiding unnecessary hospitalizations** (e.g., hospital at home, minor injury and illness/urgent care clinics; Medical Assessment Units providing rapid assessment, treatment and diagnosis for non-critical medical patients in hospital EDs; ED/in-patient follow-up clinics; single assessment and coordinated care programs for the elderly; intensive case management particularly for persons with complex needs who may become “frequent flyers”)
- **Approaches aimed at reducing hospital re-admissions** (e.g., Comprehensive in-hospital geriatric assessment care; improved discharge processes; enhanced transition programs; community virtual wards; chronic care coordination).

3.2 Analysis of RAI-HC (Resident Assessment Instrument – Home Care) Assessment Data

We analyzed RAI-HC data describing key characteristics and assessed needs of a total of 6,820 ESC CCAC home care clients as of November, 2013; this number included 5,500 individuals who received home care services (“home care referral clients”) and an additional 1,320 home care clients waiting for admission to residential LTC (“LTC wait-list clients”). We observed that:

- **More than eight in ten (81%) individuals waiting for LTC in ESC experienced cognitive challenges.** These individuals had short-term memory problems, consistently made decisions which were poor or unsafe, and required cues/or supervision on a continuous basis; the same proportion (also 81%) in Windsor-Essex also experienced such challenges.
- **About half (51%) of LTC wait-listed individuals in ESC and the same number (51%) in Windsor-Essex experienced high levels of difficulty performing ADL tasks.** These individuals required extensive help with eating, personal hygiene, toilet use and locomotion in the home; less than a fifth (15-16%) could manage on their own.

³ Walker, D. (2011). Caring for Out Aging Population and Addressing Alternate Level of Care.
http://www.homecareontario.ca/documanager/files/news/report--walker_2011--ontario.pdf

- **A large majority (90%) of wait-listed individuals in ESC and Windsor-Essex experienced high levels of difficulty performing IADL tasks.** IADLs include meal preparation, housekeeping, telephone use, and medication management; they required others to perform these tasks for them.
- **About four in ten (40-42%) individuals waiting for LTC had an informal caregiver (often an adult child) living with them in the home.** However, the majority (58-60%) of home care clients lived without a caregiver.

3.3 Expert Panel

Expert Panellists identified a number of different approaches to integrating care which they felt could quickly be adapted to the Windsor-Essex area including:

- **Technology-enabled virtual rounds.** Virtual rounds, using web-based technologies, smart phones, or teleconferencing, could build on existing hospital-based rounds to engage all community-based providers, including primary care providers, and initially be targeted at hard-to-serve populations
- **Enhanced care navigation.** Panellists stated that such navigation was needed to overcome existing gaps within and across sectors (e.g., hospital acute care, primary care, home and community care)
- **Multi-service in-home care provider(s).** Multi-service in-home care providers could reduce the number of different providers visiting the homes of high-needs individuals generating efficiencies for providers and better care for clients and informal caregivers
- **Assertive Community Treatment (ACT) Team models.** The ACT Team model already in place in Windsor-Essex focuses on community-based psychiatric care; it could be extended to serve other high needs populations as well (e.g., dementia care).

3.4 Expert Panel Follow-Up Interviews

Semi-structured follow-up interviews with 11 Panellists from 7 different provider organizations revealed a number of recurrent themes:

- **The transformation from the current “provider-centred” care system to a “person-centred” care system needs to be accelerated**
- **Communication and collaboration can be strengthened**
- **More emphasis needs to be placed on support for IADLs since these are essential to keeping people in their homes**
- **Housing-based care models offer advantages for care integration**
- **Residential LTC should be seen as only one option within a broader continuum.**

3.5 Key Informant Interviews

When asked where the ESC health care system should be in five years, key informants offered a forward-looking vision which emphasizes:

- **Integration:** bring together all of the players in the system
- **Unity:** share roles and responsibilities and work together to provide the best care

- **Client-centred care:** shift to a client-centred care system focusing on what people need and away from the current provider-centred system which focuses on what providers can offer
- **Prevention:** move the focus from acute and post-acute care to prevention and health promotion to reduce risk factors for chronic conditions
- **Support at home:** provide more supports at home to improve care for people and ease pressure on acute care.

Key informants identified barriers to achieving this vision. Among them:

- **Lack of communication:** limited opportunities to talk to others
- **Rigid funding requirements and regulations:** inflexible rules which restrict the ability to collaborate
- **Short-term funding:** one-time and time-limited funding which create uncertainty and work against providers taking a chance.

Key informants noted actions to overcome these barriers:

- **Clear vision and leadership from the top**
- **A mandate to innovate from the ground up.**

3.6 Think Tank

Three main themes emerged reinforcing those heard in earlier Project stages:

- **Collaborate and share.** Accelerate conversations and encourage collaboration across organizations and sectors
- **Build flexible hub models which match local needs and resources.** Community hubs can be established to provide a single point of access for clients and critical mass for providers. Hubs might begin by focusing on a specific needs group (e.g., high needs older persons) and then “radiate” services out to the broader community
- **Manage uncertainties.** While there was much optimism around new opportunities and the need for change, there was also a sense that change would be constrained in an environment of competition for scarce resources and uncertainty about future directions.

4.0 Summary

ALC is a persistent concern and top priority driving change in the ESC LHIN, as it is across Ontario. No longer is ALC seen simply as a hospital problem; it is more accurately understood as a sentinel indicator of health system performance.

Some of the opportunities for Windsor-Essex involve ramping up the volume of key community-based services and programs; *BoC Project* participants pointed to transportation and medication management, and mental health and dementia care.

Other opportunities have to do with scaling-up and spreading integrating mechanisms such as virtual rounds, electronic medical records, inter-disciplinary teams, and intensive care

management/system navigation. A strong message from *BoC Project* participants, especially those on the Expert Panel, is that while particular services and programs need to be enhanced, the real challenge is finding ways to encourage joint working across providers and sectors to serve people who have multiple needs.

Still other opportunities anticipate the emergence of more complex organizations with greater scope to access and manage an array of community-based services including primary care, chronic care, mental health, community supports, and housing. These could be located in different sites including supportive housing/attendant care, adult day programs and community health centres.

The importance of Instrumental Activities of Daily Living (IADLs) emerged as a recurrent theme. Though not health care per se, *BoC Project* participants emphasized that everyday supports like transportation, and the consequent ability to get out to do chores and engage socially can mean the difference between older persons continuing to live independently in the community, or “defaulting” to hospital emergency departments, and becoming ALC. The ESC RAI-HC data confirm that IADLs play a major role in referral to LTC in Windsor-Essex.

IADLs also draw attention to the pivotal role of informal caregivers who provide the bulk of IADL support on a daily basis, and to the consequences if informal caregivers withdraw or are not there to begin with. Across ESC and in Windsor-Essex, only four in ten persons on LTC wait-lists had caregivers living with them. This number should be considered against the 90% of wait-listed persons who were completely dependent on others to perform IADL tasks such as meal preparation, housekeeping, telephone use, and medication management.

5.0 Recommendations

5.1 Accelerate the Conversation

Participants suggested, and we recommend:

- Hosting an annual ‘health fair’ that engages the public and providers (including hospital discharge planners and informal caregivers) to raise awareness of available community resources
- Creating joint working groups across providers and sectors focused on the care of high needs and “hard-to-serve” populations
- Holding open planning forums to encourage broad community engagement and innovative solutions that leverage local resources including cultural organizations and faith groups.

5.2 Make Targeted Investments in Community Infrastructure

BoC Project participants suggested, and we recommend, targeted investments in:

- Transportation
- Medication management

- Enhanced coordination/system navigation.

Participants also suggested, and we recommend, enhanced program capacity in areas impacting directly on population health and ALC rates in Windsor-Essex:

- Mental health
- Alzheimer’s disease and other dementias.

5.3 Encourage Joint Working between Providers and Across Sectors

Participants identified a number of mechanisms which by themselves, or in combination, can facilitate greater collaboration, integration, and joint working. Participants suggested, and we recommend:

- Establishment of inter-disciplinary and inter-organizational teams around the care of high risk and hard-to-care-for populations
- Technology-enabled virtual rounds to build common care pathways for persons with complex chronic needs who are “at risk” of becoming “stuck” in the health care system
- Integrated care plans which follow the individual through their care journey.

5.4 Scale-up and Spread Community-Based Integrating Models

BoC Project participants pointed to the strengths of “hub and spoke” models which lever existing community resources, build critical mass in strategic locations for geographically-defined populations, establish an organizational focus and infrastructure for multi-provider collaborations, and radiate services out into the broader community through satellites and other forms of outreach.

We recommend that hub-and-spoke models be established in some combination of the following settings:

- **Community Health Centres (CHC).** CHCs already have interdisciplinary primary health teams, integrated client records, and experience serving hard-to-serve populations across Ontario; they have strong relationships with other health and social care providers, and they are already taking on clinical programs (such as diabetes management) as these shift from acute care settings.
- **Supportive housing/attendant care.** Data provided by an attendant care/supportive housing provider in ESC Assisted Living Southwestern Ontario (ALSO), suggests that it currently serves many persons at high levels of need, albeit balanced against larger numbers of individuals who have low to moderate needs, but whose levels of need may be expected to increase as they age. Major advantages of such arrangements are the ability to provide 24/7 monitoring (crucial for persons with ADOD), proactive “early warning” of emerging health issues, smoother transitions following an acute care episode, flexible use of staff, and the ability to generate critical mass by using housing facilities to host primary health teams as well as clinics in areas such as medication checks and dementia care.
- **Elderly Persons Centres (EPC)/Adult Day Programs (ADP)/Enhanced Adult Day Programs (EADP)/Alzheimer Day Programs.** According to Sinha, EPCs offer

considerable opportunity to build social networks and provide access to wellness and prevention and care services; he recommends the number and role of EPCs be strengthened across Ontario. While definitions vary, ADPs typically offer a more extended range of supports including transportation, meals, activation, and connections to other needed community services; EADPs, such as those in Central LHIN, partner with CCAC and other providers to offer an extended range of services including foot care and medication checks; Alzheimer Day Programs offer specialized care and respite to older persons and caregivers coping with the disease, including many who are LTC-eligible.

5.5 Support Informal Caregivers

Our final recommendation addresses the formal/informal care divide. In the hospital where the focus is on short-term episodic care, informal caregivers may play a supporting role; in home and community, they are the lead players.

Specifically, we recommend leveraging the success of two innovative caregiver support initiatives in Toronto Central LHIN; these projects provide combinations of counselling, case management, in-kind services, and cash, to “at risk” caregivers of “high needs” children with complex medical needs, and older persons eligible for residential LTC, with the aim of sustaining caregivers, and avoiding or delaying institutional care.

Full Report

1.0 Introduction

Following an extensive community engagement process and recommendations of the Windsor Hospitals Study Task Force, the Board of Directors of Hôtel-Dieu Grace Hospital and Windsor Regional Hospital recently agreed on a proposed new vision for hospital care delivery in the Windsor-Essex region. The vision will realize a new state-of-the-art single site acute care hospital, within the context of an integrated health care system that continues to shift services located within the acute facilities to ambulatory settings within the community, patients' homes and other provider settings.⁴

A range of benefits are seen to flow from this merger including:

- Achieving clinical efficiencies to ensure the community has access to the right care, in the right place at the right time including hospitals and community settings
- Shifting where health care services are provided so that services are provided in the right setting; ensuring services that need to be provided in an acute hospital setting are supported and resourced, and that services for patients in non-hospital settings are developed and implemented; and
- Implementing infrastructure renewal to provide state-of-the-art facilities to support new models of service delivery, across the continuum of care⁵.

Given that the attainment of such opportunities impacts on an array of services and providers beyond the hospital, the Erie St. Clair Local Health Integration Network (ESC LHIN) commissioned a *Community Capacity Plan (CCP)* to:

- Determine the community health service capacity to support achievement of clinical change
- Create a roadmap for restructuring where and how services are delivered; and
- Align with the Ministry of Health (MOH) transformation agenda and ESC LHIN priorities⁶.

The *CCP* has two components:

- *Component A*, focusing on services and supports required to maintain people, including growing numbers of older persons, safely and appropriately at home or in other community settings; and
- *Component B*, focusing on changes required to service delivery models to locate key clinical services outside of the hospital.

⁴ Agnew Peckham Health Care and Facility Planners (Agnew Peckham). (2013). Hôtel-Dieu Grace Healthcare (HDGH) and Windsor Regional Hospital, Stage 1 proposal – Part A, 1.0 Service delivery Model Report.

⁵ Agnew Peckham Health Care and Facility Planners (Agnew Peckham). (2013). (see n.1 above).

⁶ Agnew Peckham Health Care and Facility Planners (Agnew Peckham). (2014). Community Capacity Plan Component B – Overview.

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In late 2013, the *Balance of Care (BoC) Research and Evaluation Group*, based at the University of Toronto, was commissioned to conduct the *CCP Component A*. Work began with a web-enabled meeting of the Community Capacity Plan Steering Committee on December 12, 2013.

This report presents findings from *CCP Component A* (Balance of Care Sub-Project). While *Component A* will ultimately encompass the LHIN as a whole, in its first phase it has focused exclusively on Windsor-Essex, the area most directly impacted by the hospital merger.

We begin by detailing our analytic approach, data and methods. We then present key findings and offer recommendations for strengthening community capacity in Windsor-Essex to support health system transformation and ensure the provision of appropriate, cost-effective community-based care for people, including growing numbers of older persons, with multiple chronic health and social needs and their informal caregivers.

1.1 A Brief Introduction to the Balance of Care Approach

The *BoC* is a policy planning tool adapted from the UK and used by our team in 12 of Ontario's 14 LHINs (as well as in First Nations communities) to assist local providers, planners, policy-makers and other stakeholders in creating local solutions for local needs.

Consistent with the current policy focus on high intensity, high cost users, *BoC Projects* begin by focusing on individuals "at risk" of loss of independence, typically Community Care Access Centre (CCAC) long-stay clients, those waiting for residential long-term care (LTC), and those occupying hospital ALC beds. The *BoC Projects* ask what can be done at the local level to support people in their own homes and communities to avoid or delay hospital or residential LTC and facilitate timely discharge when hospital care is required.

The *BoC* emphasizes that while planners, providers and policy-makers may have little control over changing population needs, they have considerable choice about how to deploy available resources to meet needs. While conventional projections of the care needs of an aging population often assume that a greater number of older persons will require a proportionately greater number of hospital and residential LTC "beds," the *BoC* looks more broadly to the need for long-term care "places," including combinations of community-based services and supports that can be used to maintain persons with long-term needs and their informal caregivers. Such "places" may be located in different sites including adult day programs, supportive housing and assisted living, as well as in the family home.

BoC Projects emphasize that challenges and solutions will have a large local component. For example, older persons living in rural areas often face the "double jeopardy" of fewer formal services and fewer informal caregivers, in turn increasing the likelihood of hospitalization or admission to residential LTC even at relatively low levels of assessed need. To work in rural areas, solutions will have to be adapted to low population density and long distances; for example, instead of using conventional case conferences where participants gather at the same physical location, web-enabled "virtual" rounds and case conferences can facilitate interdisciplinary, inter-organization teams over long distances.

Thus, *BoC Projects* aim to ground discussion in local realities. The most current assessment data are used to look at actual needs at region, sub-region and organization levels. Steering Committees and Expert Panels are tailored to bring together the most experienced front-line providers and senior leaders from across the continuum of care (e.g., hospitals, LTC, supportive housing, community supports, primary care). Projects often “deep dive” into particular challenges; for example, previous projects in the NE and NW LHINs have looked specifically at the potential of supportive housing to maintain older people in the community and “divert” them from LTC wait-lists.

Subject to data availability, the *ESC BoC Project* aimed to:

- Present up-to-date needs profiles of CCAC home care clients (including those waiting for LTC and those assessed in hospitals) in the region as a whole, and in selected sub-regions including Windsor-Essex;
- Gain insight from experienced front-line providers representing organizations across the care continuum about current needs and local capacity and approaches to meet needs in community settings; and
- Gather intelligence from senior leaders around strategic directions and approaches to building community-capacity in the ESC LHIN as a whole, and in Windsor-Essex specifically.

2.0 What We Did

Recognizing the broad scope of the *CCP*, the multiple providers and services that constitute the community sector in ESC LHIN, and the diversity of population needs and characteristics in the region, we designed a multi-stage, multi-methods approach which accesses the best available quantitative and qualitative data. As in all *BoC Projects*, we also aimed to tap into the first-hand experiences and expertise of front-line care providers, in addition to the more strategic perspectives of senior health care leaders.

2.1 Community Capacity Plan Steering Committee

BoC Projects always engage with “Steering Committees” of senior leaders (e.g., executive directors, chief executive officers and general managers) of local organizations including, but not limited to, residential LTC, acute care, primary care, home care, community supports, housing, and mental health. Steering Committees consider “big picture” issues, provide advice on project design, nominate experienced professionals to Expert Panels (see below), and assist with interpreting and disseminating findings.

In the case of the Windsor-Essex Project, the *Community Capacity Plan (CCP) Steering Committee* also served as the *BoC Steering Committee*, ensuring broad representation and a high level of familiarity with issues and opportunities in Windsor-Essex. Steering Committee members included (in alphabetical order):

- Alec Anderson, ESC LHIN
- Dr. Glenn Bartlett, Windsor Essex Community Health Centre

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- Sally Bennett Olczak, Alzheimer Society of Windsor and Essex County
- Lynn Calder, Assisted Living Southwestern Ontario
- Barb Catherine, Chartwell Devonshire Retirement Residences
- Debbie Cercone, City of Windsor, Housing and Children’s Services
- Shelley Dobson, Franklin Gardens Long Term Care Home
- Mark Ferrari, Windsor Family Health Team
- Ralph Ganter, ESC LHIN
- Betty Kuchta, Erie St. Clair Community Care Access Centre (ESC CCAC)
- Sandra Lariviere, ESC LHIN
- Dr. Martin Lees, ESC LHIN, Primary Care Physician Lead
- Mark Lennox, Brentwood Recovery Home
- Randy Mellow, Essex-Windsor Emergency Medical Services
- Hardeep Sadra, Windsor Essex Community Health Centre
- Terry Shields, Leamington District Memorial Hospital
- Dino Villalta, Renal Program at Windsor Regional Hospital
- Andrew Ward, Victorian Order of Nurses Windsor-Essex
- Mary Wilson, Canadian Mental Health Association Windsor and Essex County Branch
- Joyce Zuk, Family Services Windsor-Essex

The *BoC Project* Steering Committee met 3 times including an initial web-enabled meeting on December 12, 2013 to launch the project, and a web-enabled wrap-up meeting on March 27, 2014.

2.2 Review of Key Documents and Reports

We conducted a “rapid review” of key documents describing demand and supply-side factors impacting on the ESC LHIN as a whole; a series of reports detailing health system restructuring in Windsor-Essex; and a number of provincial reports identifying key issues and policy directions. These include:

ESC LHIN-level documents and reports

- Access to Care. LHIN Monthly Alternate Level of Care Performance Summary. Erie-St. Clair LHIN. January 2014.
- Better care, better experiences, better value: 2013-16 Erie St. Clair Local Health Integration Network Integrated Health Service Plan 3 (2013) Erie St. Clair LHIN accessed on-line at <http://www.eriestclairhin.on.ca/Page.aspx?id=13428>
- Erie St. Clair LHIN Dashboard Data (November 2013) accessed on line at <http://www.eriestclairhin.on.ca/Page.aspx?id=14096>
- Ministry of Health and Long Term Care - Health System Accountability and Performance Division (MOHLTC – HSAPD) Quarterly Stocktake Report, Erie-St. Clair LHIN (May 2013) accessed on line at www.eriestclairhin.on.ca/WorkArea/showcontent.aspx?id=14092
- Ontario ALC and ER Wait Times by LHIN, April 2008 to September 2013, Ontario Hospital Association (September 2013) accessed on-line at <http://www.oha.com/CurrentIssues/Documents/2013%20Sept%20%20ALC%20and%20>

[Wait%20Times.pdf](#)

Windsor-specific documents and reports

- Ambulatory Care and Avoidable Admissions Strategies report (July 2013), conducted by the Hay Group
- Hôtel-Dieu Grace Healthcare (HDGH) and Windsor Regional Hospital, Stage 1 proposal – Part A, 1.0 Service delivery Model Report (November, 2013), conducted by Agnew Peckham Health Care and Facility Planners
- Project Charter – Community Capacity Plan (December, 2013), Agnew Peckham
- Program Logic Model: a service delivery model shift to the community (no date), Erie St. Clair Community Care Access centre (ESC CCAC)
- Windsor Hospital Study Final Report (November 2012), Windsor Hospitals Study Task Force, accessed on-line at http://www.wrh.on.ca/Site_Published/AcuteCare/Document.aspx?Body.Id=50441&LeftNav.QueryId.Categories=774
- Windsor Hospital Clinical Efficiency Analysis report (June 2013) conducted by the Hay Group

Provincial documents and reports

- Ontario's Action Plan for Seniors (2013), Ontario Seniors' Secretariat. Accessed on-line at <https://dr6j45jk9xcmk.cloudfront.net/documents/215/ontarioseniorsactionplan-en-20130204.pdf>
- Ontario's Action Plan for Health Care (2012), Ontario Ministry of Health and Long-Term Care, accessed on-line at http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_healthychange.pdf
- Living Longer, Living Well. Highlights and Key Recommendations (January 2013), Dr. Samir Sinha, Provincial Lead, Ontario's Seniors Strategy, accessed on-line at http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/docs/seniors_strategy.pdf
- Caring for Out Aging Population and Addressing Alternate Level of Care (2011), Dr. David Walker, accessed on-line at http://www.homecareontario.ca/documanager/files/news/report--walker_2011--ontario.pdf

2.3 Analysis of ESC CCAC RAI-HC (Resident Assessment Instrument – Home Care) Assessment Data

With assistance from the Erie St. Clair Community Care Access Centre (ESC CCAC) we accessed and analyzed RAI-HC assessment data for all CCAC clients including those waiting for residential LTC. The RAI-HC is a standardized assessment tool used across Ontario to measure home care needs; estimates in one region, or across sub-regions, are comparable to others.

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Because needs vary considerably even among home care clients, *BoC Projects* begin by using four multi-measure indicators of need to stratify individuals into relatively homogenous sub-groups based on:

- *Cognitive performance* including short term memory, cognitive skills for decision-making, expressive communication, and eating self-performance
- *Level of difficulty with ADLs* (activities of daily living) including eating, personal hygiene, locomotion, and toilet use
- *Level of difficulty with IADLs* (instrumental activities of daily living) including meal preparation, housekeeping, phone use, and medication management
- *Presence of an informal/family caregiver in the home.*

Individuals at “lower levels” of need thus present as cognitively intact, able to conduct ADLs and IADLs with little assistance, and have a caregiver living with them; those at higher levels experience significant cognitive limitations, require extensive assistance with ADLs and IADLs, and live alone. Being able to differentiate needs in this way allows for more “granular” consideration not only of needs, but of different approaches to meeting them.

Given the ESC LHIN’s interest in within-region variations, we analyzed the RAI-HC data for:

- The ESC as a whole
- ESC sub-regions: Chatham-Kent, Sarnia-Lambton, and Windsor-Essex.

Based on this analysis, we developed detailed “vignettes” written like case notes, to describe the characteristics and needs of typical individuals in heavily populated sub-groups; vignettes add additional details about the health needs of older persons and caregiver capacity.

2.4 Windsor-Essex Expert Panel

With advice from the ESC LHIN and the Steering Committee, we convened an “Expert Panel” composed of experienced program managers, care coordinators, case managers and discharge planners from across the care continuum with first-hand knowledge of local needs, and an understanding of local service capacity.

Windsor-Essex Expert Panellists included (in alphabetical order):

- Tracey Bailey, Community Support Centre
- Colleen Bussett, Windsor Regional Hospital Ouellette Campus
- Jill Cadarette, Canadian Mental Health Association, Windsor-Essex County
- Lynn Calder, Assisted Living Southwestern Ontario
- Jennifer Chene, Windsor-Essex Community Health Centre
- Rosemary Fiss, Alzheimer Society Windsor & Essex County
- Jonathan Foster, Hôtel-Dieu Grace Healthcare
- Sonja Grbevski, Hôtel-Dieu Grace Healthcare
- Helen Johnson, ESC LHIN Rehabilitation Network Lead
- Christine Laidlaw, Erie St. Clair Community Care Access Centre
- Kathy Macintyre, City of Windsor, Social Services, Housing and Children’s Services

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- Norma Mamaril, Hôtel-Dieu Grace Healthcare
- John Norton, Hôtel-Dieu Grace Healthcare
- Alison Sherwood, Franklin Gardens Long Term Care Home.

In other Ontario *BoC Projects*, Expert Panels have typically met for two full days to consider the needs of persons represented in up to 16 *BoC* vignettes, and to construct “ideal” community care packages needed to maintain them safely and appropriately at home or in home-like settings. As it turned out, the Windsor-Essex panel was available for one day only. Given this time constraint, we selected 8 vignettes representing concentrations of CCAC clients in Windsor-Essex, at low, medium and high levels of need, living with/without a caregiver.

We facilitated the Expert Panel in Windsor on February 18th, 2014. Three *BoC* team members each took detailed field notes and subsequently cross-checked them for accuracy.

2.5 Follow-Up Interviews

We conducted follow-up interviews with Expert Panellists (sometimes alone and sometimes with additional colleagues) to extend and elaborate their thinking. Interviews were conducted via telephone by pairs of *BoC* team members who took detailed field notes and cross-checked them for accuracy. Interviews averaged about 30 minutes in length.

We interviewed (in alphabetical order):

- Jill Cadarette, Canadian Mental Health Association, Windsor-Essex County
- Jennifer Chene, Windsor-Essex Community Health Centre
- Andrea Drummond, Hôtel-Dieu Grace Healthcare
- Rosemary Fiss, Alzheimer Society Windsor & Essex County
- Helen Johnson, Erie St. Clair Local Health Integration Network Rehabilitation Network Lead
- Joe Karb, Hôtel-Dieu Grace Healthcare
- Christine Laidlaw, Erie St. Clair Community Care Access Centre
- Kathy Macintyre, City of Windsor, Social Services, Housing and Children’s Services
- John Norton, Hôtel-Dieu Grace Healthcare
- Lisa Paolatto, Hôtel-Dieu Grace Healthcare
- Jason Petro, Hôtel-Dieu Grace Healthcare.

In these interviews we asked,

- Do you have additional ideas or information that you would like to share?
- How many of your current clients fall into each of the (8 selected) *BoC* vignettes?

Ideally, data provided in response to the second of these questions would allow us to compare the client profiles of different community providers to those of CCAC clients.

2.6 Key Informant Interviews

We also interviewed “key informants” nominated by the ESC LHIN to gather additional “high level” intelligence about the current state of home and community care in the ESC LHIN, and approaches to strengthen community-based capacity in the future (a number of these individuals also participated on the Expert Panel and in follow-up interviews).

We interviewed (in alphabetical order):

- Dr. Glenn Bartlett, Windsor Essex Community Health Centre
- Lynn Calder, Assisted Living Southwestern Ontario
- Debbie Cercone, City of Windsor, Housing and Children’s Services
- Andrea Drummond, Hôtel-Dieu Grace Healthcare
- Jonathan Foster, Hôtel-Dieu Grace Healthcare
- Joe Karb, Hôtel-Dieu Grace Healthcare
- Mark Lennox, Brentwood Recovery Home
- John Norton, Hôtel-Dieu Grace Healthcare
- Lisa Paolatto, Hôtel-Dieu Grace Healthcare
- Jason Petro, Hôtel-Dieu Grace Healthcare
- Hardeep Sadra, Windsor Essex Community Health Centre
- Mary Wilson, Canadian Mental Health Association Windsor and Essex County Branch

Key informants were asked combinations of the following questions:

- Where do you think ESC’s health care system should aim to be in five years?
- What are the main barriers and opportunities to getting there?
- What is needed to build community capacity?
- What are current community-based best practices and innovations?
- What are some quick wins?

Telephone interviews were conducted by pairs of evaluation team members who took detailed field notes and subsequently cross-checked them for accuracy. Interviews averaged about 30 minutes in length, with some lasting 45 minutes.

2.7 Think Tank

We conducted a half-day Think Tank in Windsor on March 12, 2014. There were 18 participants, including a number of CCP Steering Committee members, and Expert Panellists. Due to inclement weather, about half participated by telephone.

Participants included (in alphabetical order):

- Sally Bennett Olczak, Alzheimer Society of Windsor and Essex County
- Dawn Bosco, City of Windsor, Housing and Children’s Services
- Lynn Calder, Assisted Living Southwestern Ontario
- Pete Crvenkovski, Erie St. Clair Local Health Integration Network
- Marthe Dumont, Erie St. Clair Local Health Integration Network
- Sonja Grbevski, Hôtel-Dieu Grace HealthCare

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- Jon Jewell, Victorian Order of Nurses
- Lisa Kolody, Multicultural Council of Windsor Essex County
- Bruce Krauter, Essex-Windsor Emergency Medical Services
- Betty Kuchta, Erie St. Clair Community Care Access Centre
- Sandra Lariviere, Erie St. Clair Local Health Integration Network
- Mark Lennox, Brentwood Recovery Network
- Gertie Mai Muise, Southwest Ontario Aboriginal Health Access Centre
- John Norton, Hôtel-Dieu Grace Healthcare
- Andrea Pelaccia, Windsor Regional Hospital
- Hardeep Sadra, Windsor Essex Community Health Centre
- Ron Sheppard, Erie St. Clair Local Health Integration Network
- Mary Wilson, Canadian Mental Health Association Windsor and Essex County Branch.

We began the Think Tank by presenting a high level summary of findings from our RAI-HC data analysis, Expert Panel session, follow-up interviews and key informant interviews. We then introduced a number of “promising practices” from the literature on integrating care for older persons that potentially could be adapted to Windsor-Essex.

We asked Think Tank participants to consider what should be done to strengthen community capacity in Windsor-Essex:

- Who should be targeted?
 - E.g., top 1-5%; ALC; persons at risk of chronic illness or loss of independence
- What services should be integrated?
 - E.g., primary care; community-based supports; mental health, rehabilitation
- How should services be managed?
 - Coordination; intensive care management; self-management; vertical integration
- Where should services be located?
 - Family residence; supported/assisted living; day programs; primary health care organizations.

We also asked:

- What are main barriers/facilitators to innovation?
- What are quick wins in Windsor-Essex?
- How can existing assets be leveraged?
- What additional investments will be required?
- What’s the likely return on investment?
 - For people (including informal caregivers)
 - For providers
 - For the system?

Think Tank discussion was facilitated using a live Twitter feed projected on screen; in addition to facilitating individual engagement, Twitter keeps an exact record of all comments and feedback for analysis.

3.0 What We Found

3.1 Review of Key Documents

Like those in other jurisdictions, the health system in Erie St. Clair (ESC) faces converging demand and supply-side challenges. Many of these challenges have been well documented in recent reports on ESC and Windsor-Essex and need not be repeated here in any detail. However, it is worth briefly highlighting a number of key challenges that directly impact on the need for, and the capacity to provide appropriate, cost-effective community-based care.

On the demand side, the population of ESC LHIN is aging: in 2012 an estimated 16% of individuals living in the LHIN catchment area were 65 years and older; this number is projected to rise to 19% in 2017, to 22% in 2022 and to 27% in 2032. While recent data from the Canadian Institute for Health Information (CIHI) show that population aging is not, by itself, a major driver of rising health care utilization and costs, since utilization is rising across all age groups⁷, aging is strongly associated with the rise of multiple chronic needs; in ESC LHIN chronic conditions such as arthritis, hypertension, diabetes and cancer are on the rise, and more than half of older persons have two or more such conditions⁸.

On the supply side, the ongoing shift from acute illnesses that can be treated on an episodic basis in institutional settings, to multiple chronic conditions that must be managed over the course of a lifetime “closer to home,” challenges hospital-based, curative health care systems which may not be well equipped to respond.

One outcome is that substantial numbers of hospital beds are occupied by individuals (often older persons with multiple chronic health and social needs) who no longer require acute care, but who cannot be discharged because of a lack of appropriate care alternatives. “Alternate level of care” or ALC beds have emerged as an important indicator of health system performance in Ontario, and a measure of the success (or lack of success) of different health care sectors (e.g., acute care, primary care, long-term care, home and community care) working together to address complex needs.

ALC is a persistent problem in Erie St. Clair and the top priority for the ESC LHIN⁹. In September 2013, 14% of all acute care hospital beds in Ontario were considered ALC; the corresponding rate for the ESC LHIN was 24%¹⁰. As of January 31, 2014, this rate had dropped to 22.3% suggesting a positive impact from ESC LHIN’s investments in community-based programs such

⁷ Canadian Institute for Health Information. (2011). Health Care Cost Drivers: The Facts. https://secure.cihi.ca/free_products/health_care_cost_drivers_the_facts_en.pdf

⁸ Erie St. Clair LHIN. (2013). Better care, better experiences, better value: 2013-16 Erie St. Clair Local Health Integration Network Integrated Health Service Plan 3. Government of Ontario.

⁹ Erie St. Clair LHIN. (2013). Better care, better experiences, better value: 2013-16 Erie St. Clair Local Health Integration Network Integrated Health Service Plan 3. Government of Ontario.

¹⁰ Ontario Hospital Association. (2013). Ontario ALC and ER Wait Times by LHIN. April 2008 to September 2013. <http://www.oha.com/CurrentIssues/Documents/2013%20Sept%20%20ALC%20and%20Wait%20Times.pdf>.

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as Home First (which supports patients to transition to home after hospital care) and Assess and Restore (which supports assessment, activation and restoration of function after an in-patient stay); however, ESC's ALC rate remained second highest in Ontario¹¹.

ALC numbers in Windsor have been higher than those in other areas of ESC. In Q2 of 2013-14, ALC rates across ESC LHIN's five hospitals averaged 19.6%; by comparison, reported rates for the two largest hospitals, Windsor Regional Hospital (WRH) and Hôtel-Dieu Grace Healthcare (HDGH), both located in Windsor, were 23.8% and 25.8% respectively¹². By early 2014, service restructuring had changed the distribution of ALC numbers across these two hospitals: while the ALC rate for WRH declined to 16.0%, the rate for HDG rose to 38.1%¹³.

Given the majority of ALC patients are older persons, and that frail older persons with complex needs including Alzheimer's disease and other dementias (ADOD) are among those most likely to occupy ALC beds, ALC numbers are likely to experience continued upward pressure as the population ages. Other factors will impact ALC rates as well; Ontario data have shown that half or more of persons occupying ALC beds have mental health needs¹⁴.

In 2013, more than half (55%) of ALC patients in ESC LHIN were waiting for placement in a Long Term Care (LTC) facility, in part reflecting their high levels of need, but also high LTC occupancy rates: long-stay utilization in the LHIN's 4,365 LTC beds have consistently approached 99.0%. By January 2014, reported numbers of ALC patients in acute care beds waiting for LTC had dropped by almost half¹⁵, possibly an outcome of concerted efforts on the part of the ESC CCAC and other providers to move ALC patients to community-based care alternatives.

Why is ALC a problem? First, as Walker pointed out in his insightful analysis, acute care settings are not designed to meet a patient's "restorative, supportive or rehabilitative needs..."¹⁶ Evidence suggests the longer older persons wait in acute care for appropriate placement the greater their risk of cognitive, physical, and emotional decline, and the greater the risk of hospital-acquired infections¹⁷.

Second, ALC diverts scarce resources away from other hospital challenges. As ALC numbers rise, hospitals lose capacity to meet the needs of acutely ill people, including those admitted

¹¹ Erie St. Clair LHIN. (2014). Access to Care. LHIN Monthly Alternate Level of Care Performance Summary.

¹² Erie St. Clair LHIN. (2013). MOHLTC-HSAPD Quarterly Stocktake Report.

¹³ Erie St. Clair LHIN. (2014). (see n.3 above).

¹⁴ Butterill, D., Lin, E., Durbin, J., Lunskey, Y., Urbanoski, K. & Soberman, H. (2009). From Hospital to Home: The Transitioning of Alternate Level of Care and Long-stay Mental Health Clients. Centre for Addiction and Mental Health. Toronto, ON. Retrieved from:

http://www.omhf.on.ca/files/file.php?fileid=fileZxrgSZFHTJ&filename=file_ALC_Report_FINAL4.pdf

¹⁵ Erie St. Clair LHIN. (2014). Access to Care. LHIN Monthly Alternate Level of Care Performance Summary.

¹⁶ Walker, D. (2011). Caring for Out Aging Population and Addressing Alternate Level of Care. http://www.homecareontario.ca/documanager/files/news/report--walker_2011--ontario.pdf

¹⁷ Walker, D. (2011). (as n. 2 above).

through the ED; as Ontario moves away from global funding to activity based funding, high ALC numbers could potentially jeopardize a hospital's economic viability.

Third, ALC diverts resources away from investments in community-based care alternatives essential to ensure timely hospital discharge, and to support older persons (and their informal caregivers), as independently as possible, for as long as possible in their own homes and communities (long-term care "places"). Recent provincial reports and policy papers have emphasized the need to improve access to community-based wellness, prevention, support and primary care services, both as a means of enhancing the lives of older persons and as a way of moderating demand for costly and sometimes inappropriate hospital and residential long-term care^{18,19}. As Walker observed, "Seniors want to live in their homes for as long as possible and receive dependable and reliable community supports to meet their social, physical, emotional, nutritional, health professional and caregiver needs."²⁰ According to an Ontario Hospital Association position paper, "the only way to reduce hospital capacity is to keep people out of hospital, which requires investments in the community sectors."²¹

However, particularly in a period of "no new money," the more resources spent on ALC beds, or on discharging ALC patients to community settings after-the-fact, the less resources there are available to invest in community-based prevention and maintenance.

What needs to be done? The *Windsor Hospital Clinical Efficiency Analysis* conducted by HayGroup identified an ALC reduction target of 50% to be accomplished by leveraging a range of community-based opportunities, including conducting greater numbers of in-patient surgical procedures in ambulatory settings²². However, the analysis also noted that "reduction of ALC days is very dependent on access to post-acute services,"²³ not just the provision of acute care in non-hospital settings; further, attention has to be paid to the ongoing management of chronic problems such as dementia, organic mental disorders, and palliative care in community settings, since these are among the top factors contributing to ALC rates in the Windsor area.

A subsequent, and very comprehensive report by the HayGroup, titled *Ambulatory Care and Avoidable Admission Strategies*, presented a range of community-based "approaches to reducing utilization of hospital services" including those aimed at preventing unnecessary in-patient hospital stays²⁴.

¹⁸ Drummond, D. (2012). Commission on the Reform of Ontario's Public Services.

¹⁹ Sinha, S. (2013). Ontario Seniors Strategy: Ontario Action Plan for Seniors.

²⁰ Walker, D. (2011). (as n.2 above).

²¹ Ontario Hospital Association (OHA). (2011). OHA Position Statement on Funding and Capacity Planning for Ontario's Health System and Hospitals.

<http://www.oha.com/Documents/OHA%20Position%20Statement%20on%20Funding%20and%20Capacity%20Planning%20for%20Ontario's%20Health%20System%20and%20Hospitals.pdf>

²² The HayGroup. (2013). Windsor Hospital Clinical Efficiency Analysis.

²³ The HayGroup. (2013). (as n.1 above).

²⁴ The HayGroup. (2013). Ambulatory Care and Avoidable Admission Strategies.

Approaches identified by the HayGroup to avoid hospitalizations include:

- Hospital at home, involving home nursing and physician visits to targeted groups of older patients, as an alternative to hospital stays
- Minor injury and illness/urgent care clinics staffed by multidisciplinary teams as an alternative to hospital ED visits
- Medical Assessment Units providing rapid assessment, treatment and diagnosis for non-critical medical patients in hospital EDs to avoid unnecessary admissions
- ED/In-patient Follow-up Clinics to avoid hospital admissions by assuring patients that they will receive timely follow-up in the community
- Single Assessment and Coordinated Care Programs for the Elderly [(including PACE (Program of All Inclusive Care for the Elderly) and GRACE (Geriatric Resources for Assessment and Care of Elders) models] which use assessments, integrated care plans and multidisciplinary teams, to maintain the health, well-being and functional independence of high needs older persons, and thus avoid or delay hospital and institutional care
- Intensive case management particularly for persons with complex needs who face barriers accessing appropriate health, mental health and support services and thus become hospital emergency department “frequent flyers.”

Approaches aimed at reducing hospital re-admissions include:

- Comprehensive in-hospital geriatric assessment care on admission to hospital to improve health outcomes
- Improved discharge processes encompassing education, follow-up appointments and tests, organization of post-discharge services, medication reconciliation, and onward communication of a discharge plan to the patient and relevant community providers
- Enhanced transition programs to foster improved self-management where appropriate, and better coordination of care by health professions, particularly for high-risk, older persons with chronic illnesses
- Community virtual wards, which employ health technologies and interdisciplinary teams to provide timely, collaborative, coordinated care in the home
- Chronic care coordination, using multi-disciplinary teams to develop needs-based care plans and facilitate smoother transitions for persons with multiple chronic needs.

Why is needed change difficult to achieve? Even when particular approaches have demonstrated success in one jurisdiction, they may still prove difficult to implement in another.

In part, the literature suggests, this may be due to vested interests. As Berwick and Smith noted almost two decades ago, shifts toward more integrated, person-centred care systems, particularly during periods of economic constraint and competition for scarce resources, will almost inevitably face challenges; providers will fight to preserve their autonomy, professional groups will struggle to prove that they alone have the skills needed to deliver particular

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services, and channels for sharing innovations and lessons learned will become narrower as providers move to protect their competitive advantage^{25,26,27}.

Institutions also play a part. For example, the INTERLINKS Project, funded by the European Commission, and conducted across 12 EU countries (Austria, Denmark, Finland, France, Germany, Greece, Italy, Netherlands, Slovakia, Spain, Sweden, the United Kingdom and Switzerland), identified a range of organizational mechanisms (e.g., multi-professional teams, joint working, and service flexibility and adaptability) that can be implemented in different care settings (including nursing homes, assisted living, home and community care, transitory care facilities, and hospitals) to improve the planning and delivery of long-term care services for frail older persons and other high needs populations (such as persons with disabilities and children with medically complex needs). It is important to note that in Europe, long-term care refers to care over the longer term in both community and institutional settings (including hospitals)²⁸.

However, INTERLINKS also clarifies that achieving such goals requires spanning two major divides: the divide between health care and social care (involving different and often incompatible legislation, regulations and funding arrangements); and the divide between formal and informal care (e.g., informal caregivers many not be considered as clients in their own right)²⁹. The first divide speaks to the need to mobilize community-based services and supports (such as meals, homemaking, transportation, and medication checks) which, while not health care per se, can have a direct impact on the health of older persons. The second speaks to the crucial role that informal caregivers (family, friends and neighbors) play in maintaining older persons as independently as possible for as long as possible in their own homes and communities; in addition to providing a range of personal, instrumental and emotional supports, informal caregivers serve as the main interface with the formal care system, accessing and coordinating services on behalf of cared-for persons³⁰.

²⁵ Berwick, D. & R. Smith. (1995). Cooperating, Not Competing, to Improve Health Care. *British Medical Journal* 310: 1349–50.

²⁶ Williams, A. P., Lum, J. M., Deber, R., Montgomery, R., Kuluski, K., Peckham, A., Watkins, J., Williams, A., Ying, A., & Zhu, L. (2009). Aging at Home: Integrating Community-Based Care for Older Persons. *HealthcarePapers* 10(1). Accessed on line at <http://www.longwoods.com/content/21218>.

²⁷ Ham, C. & J. Smith. (2010). Removing the policy barriers to integrated care in England. The Nuffield Trust. 2010. Accessed December 2013 at http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/Removing_the_Policy_Barriers_Integrated_Care.pdf.

²⁸ Leichsenring, K., Billings, J. & Nies, H. eds. (2013). Long-Term Care in Europe: Improving Policy and Practice. Houndmills, Basingstoke, Hampshire: Palgrave Macmillan.

²⁹ Billings J. (2013). The INTERLINKS framework for long-term care of older people in Europe. *Journal of Integrated Care* 21(2): 126-138. Accessed on-line at <http://www.emeraldinsight.com/journals.htm?articleid=17091186>

³⁰ Hollander, M.J., Liu, G., & Chappell, N.L. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly* 12(2), 42-49. Accessed on-line at http://www.leg.bc.ca/cmt/39thparl/session-4/health/submissions/Hollander_Who_Cares_How_Much_2009.pdf

Having illustrated the challenges, INTERLINKS provides a comprehensive listing of “good practices in long term care for older people” which do not require extensive system redesign, and may be implemented in otherwise fragmented systems by leveraging existing community capacity. A recent briefing to the European Parliament highlights the following examples³¹:

- Domiciliary Rehabilitation (Germany): multidisciplinary in-home rehabilitation care for older persons who cannot travel to a rehabilitation centre
- Alzheimer Café (Netherlands): community gatherings which provide information and education, and build connections between older persons with ADOD, caregivers, and providers
- Better Homes, Active Lives (UK): community residences for older persons which offer on-site care managers and tailored levels of care, including specialized services for persons with ADOD
- Acute Geriatric Care Unit (across Europe): specialized units in acute care facilities designed for older persons with multiple needs, which first address acute care needs, and then develop coordinated community care plans once acute care problems have been solved
- Care in the neighbourhood – Buurtzorg (Netherlands): district “block nurses,” who take responsibility for the entire care process (from assessment to formal and informal care provision) of older persons with complex needs who cannot leave their homes.

What does this mean for ESC? These documents and reports suggest a number of important “learnings” that can inform ESC’s thinking and planning going forward:

- First, solutions to hospital problems such as ALC, particularly when linked to the rise of multiple, chronic needs in aging populations, are heavily dependent on the ability to mobilize and connect with resources beyond the hospital walls
- Second, successful community-based approaches to supporting people with multiple chronic needs and their caregivers are quite diverse; they can be located in the family home, in other home-like environments, in community-based clinics, or in the hospital itself, and be tailored to individuals who are more or less capable of managing care on their own; where you start will depend largely on existing resources and capacity. Nevertheless, these approaches combine essential characteristics including a clear point of access, comprehensive assessment, a single care plan, and multidisciplinary teams which continuously monitor and support the individual’s changing needs not only to speed discharge, but to promote wellbeing, manage chronic needs, and proactively avoid hospitalization
- Third, implementing such approaches is never a “slam dunk,” precisely because they may challenge existing interests, and they often have to find ways to work-around existing institutional barriers. Nevertheless, a growing weight of international experience points to the value of “bottom-up” approaches which lever existing community resources and leadership in support of local needs

³¹ The INTERLINKS. (2013). Good practices in long term care for older people in Europe presented at the European Parliament. Accessed on-line at <http://interlinks.euro.centre.org/news>

- Fourth, attention has to be paid to the crucial role of informal caregivers. As a growing international literature emphasizes, informal caregivers provide the bulk of the day-to-day emotional, instrumental and personal care required by older persons; informal caregivers also access and coordinate needed formal care on behalf of cared-for persons who cannot manage on their own. As our team has observed in Balance of Care projects conducted across Ontario, informal caregivers are key to determining not only whether persons with multiple chronic needs can continue to live in the community, but whether they can be discharged home in a timely fashion after an acute care episode.

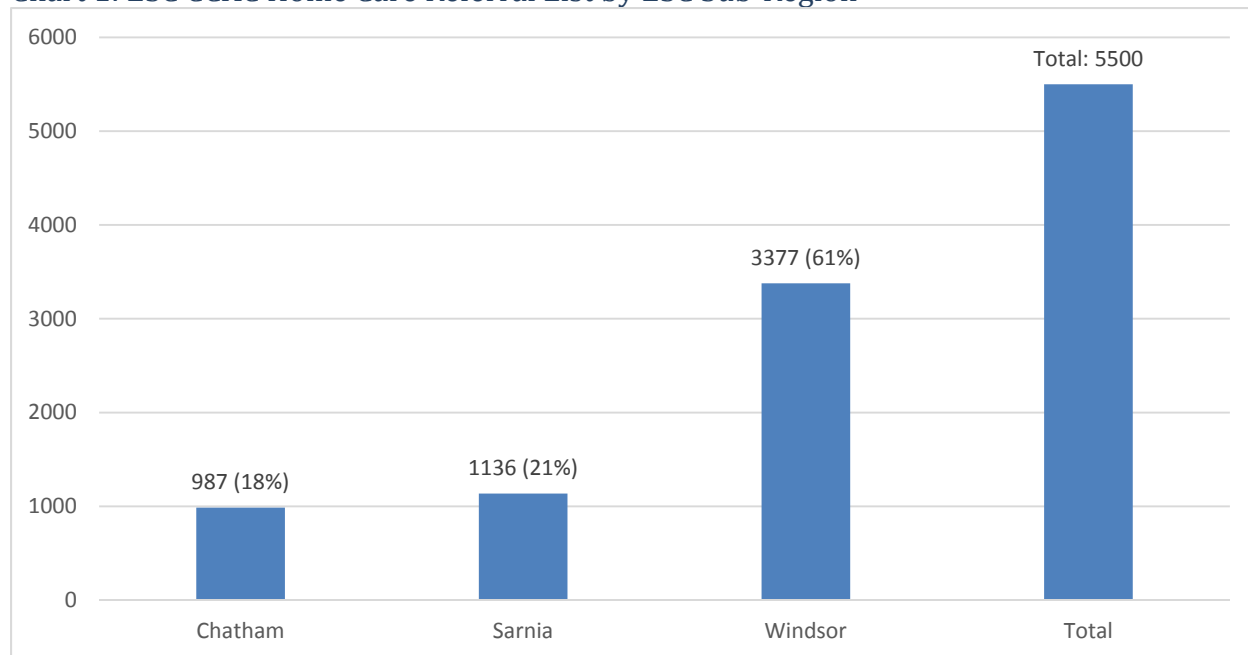
3.2 Analysis of RAI-HC (Resident Assessment Instrument – Home Care) Assessment Data

We accessed and analyzed RAI-HC data documenting key characteristics and assessed needs of a total of 6,820 ESC CCAC home care clients as of November, 2013; this number included 5,500 individuals who received home care services (“home care referral clients”) and an additional 1,320 waiting for admission to residential LTC (“LTC wait-list clients”).

3.2.1 ESC CCAC Home Care Referrals by Region

Reflecting population size, the data in Chart 1 show that the majority of ESC home care referral clients (61%) lived in Windsor-Essex; about a fifth (21%) were located in Sarnia-Lambton, with the remainder (18%) in Chatham-Kent.

Chart 1: ESC CCAC Home Care Referral List by ESC Sub-Region

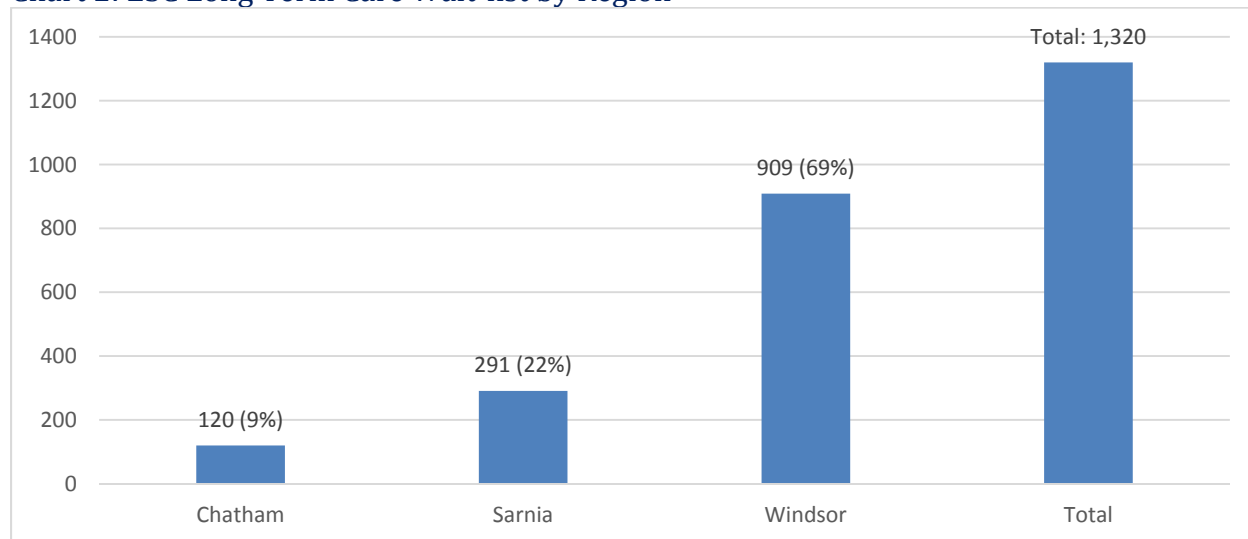


3.2.2 ESC LTC Wait-list by Region

Chart 2 shows that of those individuals waiting for a LTC bed, more than two thirds (69%) were in Windsor-Essex, about a fifth (22%) lived in the Sarnia region, and 9% lived in and around

Chatham. While this distribution is similar to that observed for home care referral clients, individuals in Windsor-Essex appear to be proportionately more likely to be referred to LTC.

Chart 2: ESC Long Term Care Wait-list by Region



3.2.3 Characteristics of LTC Wait-Listed Individuals for ESC and Windsor-Essex

Across Ontario, individuals are referred to residential LTC when their needs exceed local capacity to maintain them safely and appropriately in the community.

As a result, needs thresholds for placement on LTC wait-lists vary depending on local access to, and the capacity of formal and informal care providers to deliver needed care. Where access and capacity are more limited, as in many rural and remote areas of Ontario, the needs “tipping point” for referral to LTC may be relatively low; in urban areas, where community-based support infrastructures are more developed, and where informal caregivers are more likely to be available, individuals at higher levels of need may be safely and appropriately supported at home or in home-like settings^{32,33}.

The data in Table 1 show key needs of wait-listed individuals in ESC as a whole, and in Windsor-Essex specifically. Table 1 also includes data from previous *BoC Projects* across Ontario measuring the range of variation observed in key characteristics of wait-listed individuals; these ranges are presented to provide general comparisons only, not to establish benchmarks.

³² Kuluski, K., Williams, A.P., Berta, W., & Laporte, A. (2012). Waiting for Long-term Care: The Role of Home and Community Based Care Capacity in Shaping Risk of Placement in Urban and Rural Regions. *Healthcare Policy* 8(1): 92–105. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3430157/>

³³ Kuluski, K., Williams, A.P., Berta, W., & Laporte, A. (2012). Homecare or Long-term Care? Setting the Balance of Care in Urban and Rural Northwestern Ontario, Canada. *Health & Social Care in the Community* 20(4):438-48. <http://www.ncbi.nlm.nih.gov/pubmed/22582906>

Table 1: Comparison of the ESC and Windsor-Essex LTC Wait-list to Ontario Range

Cognition	ESC	Windsor-Essex	Ontario Range
Intact	19%	19%	29-48%
Not Intact	81%	81%	19-48%
Difficulty with ADLs			
None	16%	15%	16-62%
Some	33%	33%	17-33%
Great	51%	52%	19-35%
Difficulty with IADLs			
None	1%	1%	1-3%
Some	9%	9%	9-41%
Great	90%	90%	57-77%
Live-in Caregiver?			
Yes	40%	42%	35-55%
No	60%	58%	44-65%
Total (N)	1,320	909	

The data in Table 1 show that:

- More than eight in ten (81%) individuals waiting for LTC in ESC experienced cognitive challenges: they had short-term memory problems, consistently made decisions which were poor or unsafe, and required cues/or supervision on a continuous basis; the same proportion (also 81%) in Windsor-Essex also experienced such challenges. Note that these proportions far exceed the range (19-48%) observed by our team elsewhere in the province, suggesting a greater concentration of individuals with cognitive challenges, at least on CCAC client lists
- About half (51%) of LTC wait-listed individuals in ESC and the same number (51%) in Windsor-Essex experienced high levels of difficulty performing ADL tasks such as eating, personal hygiene, toilet use and locomotion in the home; less than a fifth (15%-16%) were able to manage such tasks on their own. Compared to other regions of Ontario, where between 19-35% of LTC wait-listed individuals dependent on others to perform ADLs, wait-listed individuals in ESC appear to have higher levels of ADL needs
- A large majority (90%) of wait-listed individuals in ESC and Windsor-Essex experienced high levels of difficulty performing IADL tasks such as meal preparation, housekeeping, telephone use, and medication management; they required others to perform these tasks for them. While the Ontario range shows that IADL challenges are common in LTC wait-listed populations across Ontario, such challenges are particularly prevalent in ESC

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- About four in ten (40-42%) individuals waiting for LTC had an informal caregiver (often an adult child) living with them in the home; however, the majority (58-60%) did not, although they may receive help from informal caregivers living elsewhere. Compared to data from other parts of Ontario, the likelihood of having a caregiver in the home thus appears to be comparatively low in ESC and Windsor-Essex, an issue of considerable importance, since informal caregivers provide the bulk of IADL support for older persons, as well as 24/7 monitoring for persons with cognitive challenges.

Overall, therefore, substantial proportions of wait-listed individuals in ESC and Windsor-Essex have relatively high levels of assessed need. Of particular interest, large numbers experience cognitive problems, have great difficulty with instrumental activities of daily living, and do not have a caregiver living with them, putting them at risk of illness and loss of independence.

Such needs appear to be more marked in ESC than we have observed in other parts of the province, noting that our provincial estimates stretch back over a period of 6-8 years; differences could be due to population aging. As well, higher needs on wait-lists could reflect system changes which have led CCAC and other community-based providers to “triage-upward,” so that individuals are not referred to LTC until they reach higher levels of need.

3.2.4 Erie St. Clair and Windsor-Essex RAI-HC Data by BoC Sub-groups and Vignettes

As discussed earlier, we used four measures of needs (cognition, ADL performance, IADL performance, and presence of a caregiver) to stratify individuals on ESC and Windsor-Essex home care referral lists and LTC wait-lists into 36 relatively homogeneous sub-groups; we then calculated numbers of individuals falling into each sub-group. (A full listing of these 36 sub-groups, with distributions of home care referral and LTC wait-list clients, for ESC and for Windsor-Essex, is found in Appendix 2).

For the Windsor-Essex Expert Panel we selected 8 of these sub-groups for in-depth consideration by panellists; data for these 8 sub-groups is presented in Table 2 below. These sub-groups were selected because they are relatively heavily populated and capture key dimensions of need (e.g., cognitively intact vs. not intact; presence/absence of a live-in caregiver; different levels of ADL and IADL performance).

Table 2: Distribution of the 8 Selected Sub-groups for the Windsor-Essex Expert Panel

BoC Sub-group	Cognition	ADL Difficulty	IADL Difficulty	Live-In Caregiver	ESC Home Care Referral	ESC LTC Wait-list	Windsor-Essex Home Care Referral	Windsor-Essex LTC Wait-list
Copper	Intact	Low	Medium	Yes	14.2%	.6%	13.9%	.6%
Davis	Intact	Low	Medium	No	23.9%	2.0%	22.7%	2.4%
Quinn	Intact	High	High	Yes	2.7%	2.9%	2.4%	2.6%
Rogers	Intact	High	High	No	1.1%	5.8%	1.2%	5.3%
C. Cameron	Not Intact	Medium	High	Yes	7.0%	11.7%	8.0%	12.5%
D. Daniels	Not Intact	Medium	High	No	5.0%	16.0%	5.7%	15.4%
I. Innis	Not Intact	High	High	Yes	5.9%	19.2%	6.9%	20.5%
J. Johns	Not Intact	High	High	No	2.2%	21.5%	2.4%	22.1%
Total Percent					62.0%	79.7%	63.2%	81.4%

The data in Table 2 show that these 8 selected BoC sub-groups capture a large majority of individuals on CCAC home care referral and long-term care wait lists in ESC as a whole, and in Windsor-Essex specifically.

The also show that home care referral clients tend to be concentrated at the low end of the needs ladder: for ESC and Windsor-Essex, “Copper” and “Davis” (at relatively low levels of need) account for more than a third of all clients; by comparison, “I. Innis” and “J. Johns” (at relatively high levels of need) account for over 40% of individuals on LTC wait-lists.

Nevertheless, the data in Charts 3 and 4 suggest that there is still considerable overlap in home care referral and LTC wait-list clients:

- In ESC, home care referral clients in the “C. Cameron” sub-group (characterized by cognitive challenges, moderate to high ADL and IADL difficulty, with a live-in caregiver) actually outnumber LTC wait-listed individuals in this same category; the same is true for “D. Daniels” (cognitive challenges, moderate to high ADL and IADL difficulty, with no live-in caregiver); and for “I. Innis” (cognitive challenges, high ADL and IADL difficulty, with a live-in caregiver)
- A similar pattern emerges in Windsor-Essex, where, with the exception of J. Johns (cognitive challenges, high ADL and IADL difficulty, with no live-in caregiver), home care referral clients again outnumber wait-listed clients in higher needs sub-groups.

Chart 3: ESC Home Care Referral List & LTC Wait-list by 8 Selected BoC Sub-groups

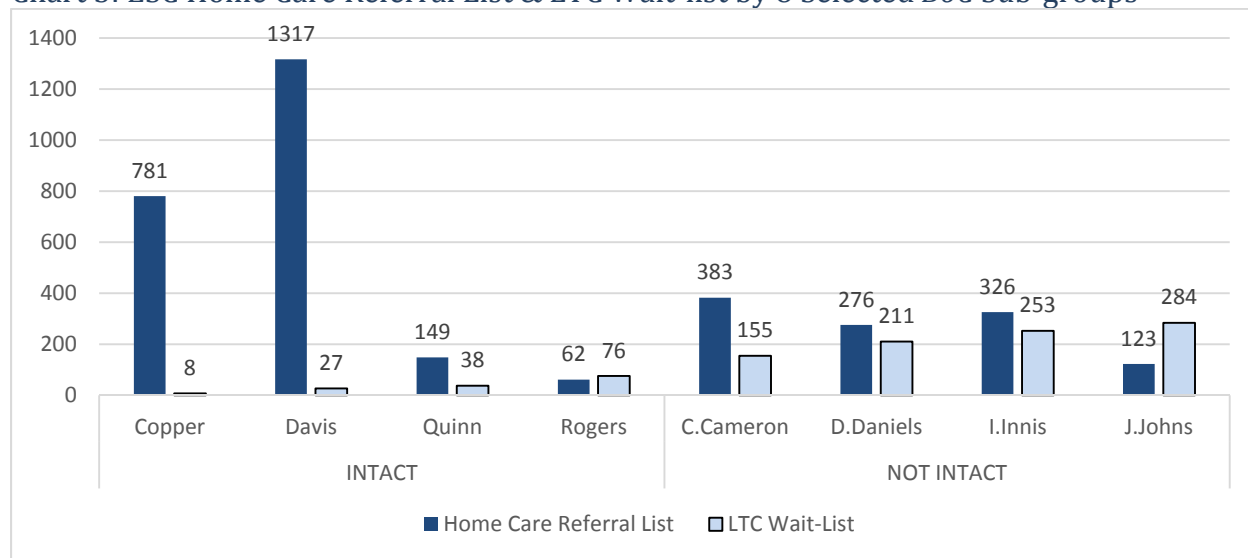
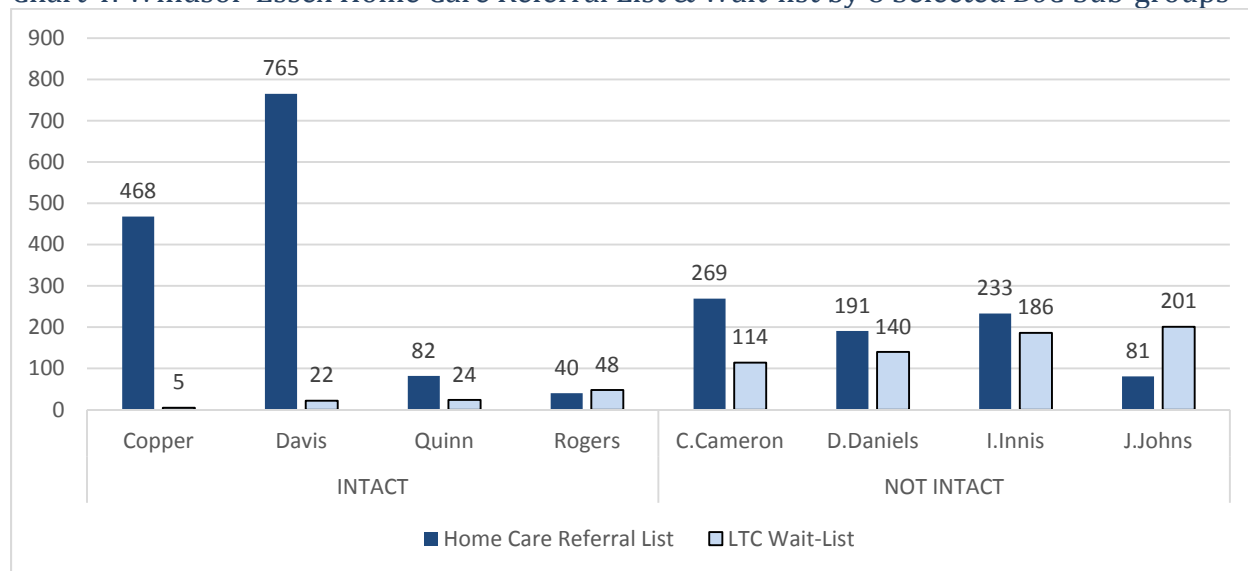


Chart 4: Windsor-Essex Home Care Referral List & Wait-list by 8 Selected BoC Sub-groups



3.2.5 Comparison of MAPLe Scores

The MAPLe scores in Charts 5 and 6 confirm these patterns -- MAPLe (Method of Assigning Priority Levels) is a screening algorithm contained in the RAI-HC, and widely used by CCACs across Ontario to determine eligibility for admission to LTC – higher MAPLe scores measure higher levels of need, and a greater likelihood of referral to LTC. In the two Charts, MAPLe scores have been classified into 5 discrete levels: low, mild, moderate, high, very high. These data show that:

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- Individuals on LTC wait-lists tend to have higher MAPLe scores (most are classified as moderate, high or very high) compared to those on home care referral lists (who are more likely to have low, mild and moderate scores)
- Nevertheless, substantial numbers of those on home care referral lists also have high and very high MAPLe scores, again suggesting considerable overlap in needs with LTC wait-listed individuals.

Chart 5: ESC MAPLe Level for Home Care Referral and LTC Wait-list

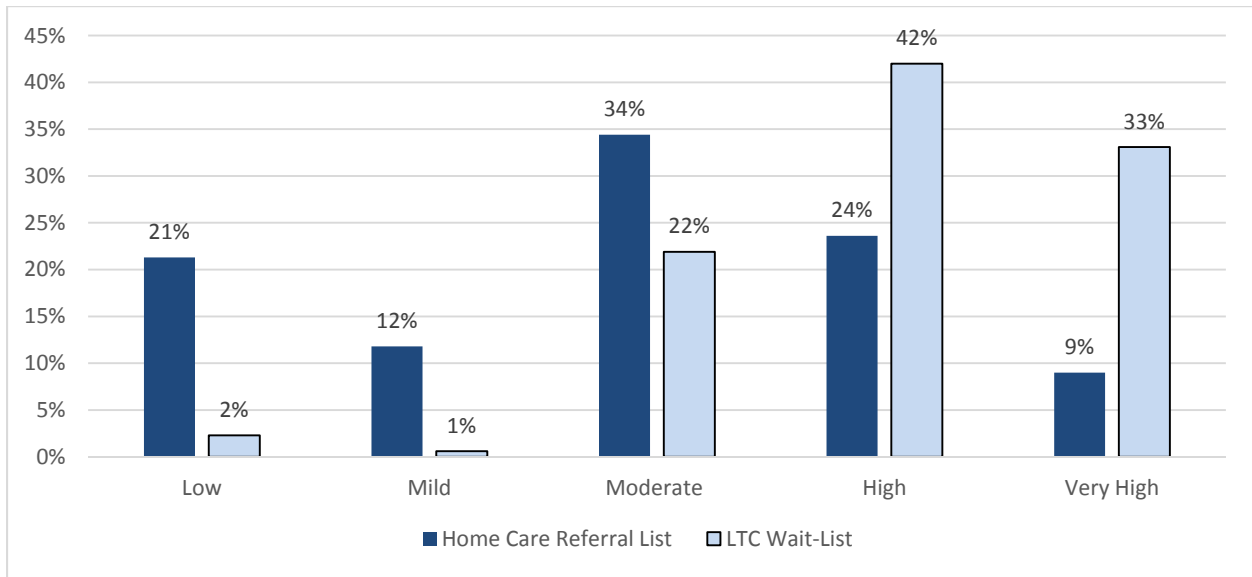
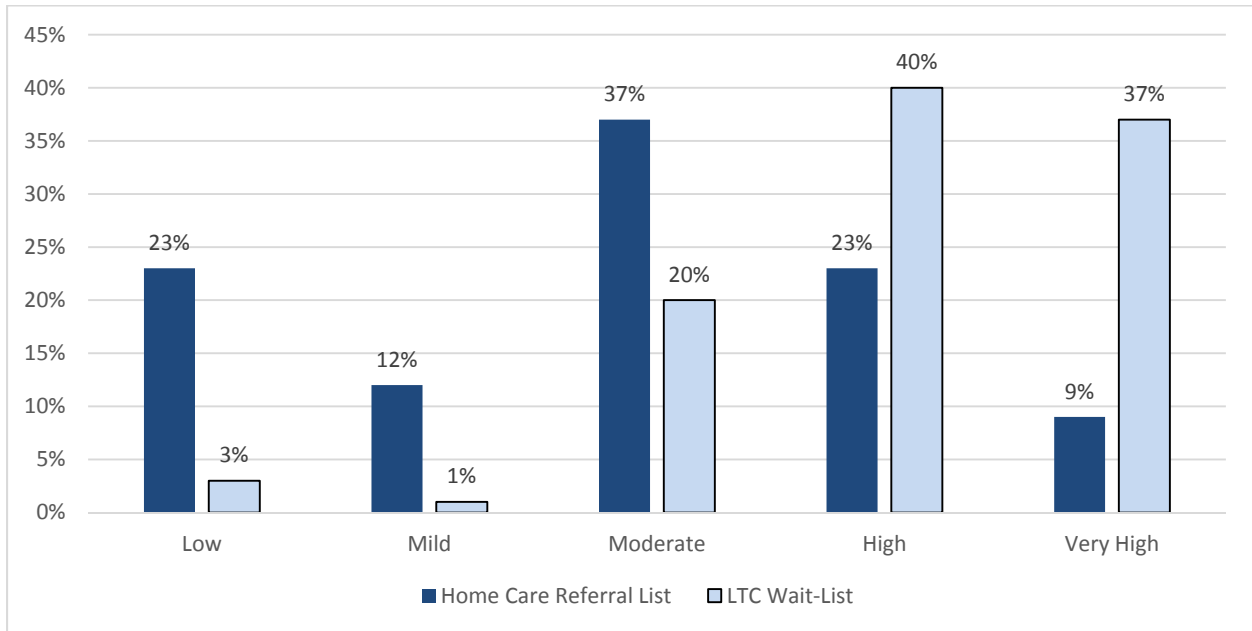


Chart 6: Windsor-Essex MAPLe Level for Home Care Referral and LTC Wait-list



3.3 Expert Panel

We conducted a full day Expert Panel in Windsor with 14 individuals representing provider organizations from across the care continuum including home care, community supports, community mental health, supportive housing/attendant care, primary care, residential LTC, and acute care.

After briefly introducing the *BoC* approach, and outlining the purpose of the Expert Panel, we asked panellists to consider the first of 8 selected *BoC* case vignettes; this vignette, named “Copper” includes individuals at relatively low levels of assessed need. As the vignette (given below) details, typical “Coppers” in ESC have few cognitive issues; they are completely independent with respect to activities of daily living (ADLs) such as eating, toilet use and personal hygiene; however, they experience great difficulty with some instrumental activities of daily living (IADLs) such transportation and meal preparation; but they have a live-in caregiver who provides emotional support and help with IADLs (usually an adult child).

The RAI-HC data show that there nearly 800 Coppers on the ESC CCAC home care referral list (N=781), but only a few on the LTC wait-list (N=8). Appendix 3 provides all 8 vignettes constructed for the Expert Panel.

Vignette: Copper (Home Care Referral List N =781, 14.2%; Wait-list N=8, 0.6%)

Copper is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Copper has no difficulty using the phone, some difficulty managing medications and great difficulty with meal preparation, housekeeping and transportation. Copper has a live-in caregiver. This live-in caregiver provides advice/emotional support and assistance with IADLs.

- 1) Cognition- Borderline Intact (short-term memory recall is good for most people in this group; some are showing signs of short term memory problems, makes consistent/reasonable/safe decisions and can express ideas without difficulty)
- 2) 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).
- 3) IADL- No difficulty using the phone, some difficulty managing medications (needs some help, is very slow/fatigues), great difficulty with meal preparation, housekeeping and transportation (little or no involvement in the activity is possible).
- 4) Caregiver (in home?)- Yes, adult-child provides advice/emotional support and assistance with IADLs.

3.3.1 Service-by-Service Approaches

We then asked Panellists to consider what mix and volume of community-based services and supports would be required to maintain an individual with Copper’s characteristics and needs safely and appropriately in the family home; Panellists were not to consider costs.

Rather than constructing a “community care package” from scratch, which in previous *BoC Projects* has required hours of intense discussion among Panellists (recall that time for the Windsor panel was limited), we offered a pre-loaded community care package based on those created by Expert Panels in other LHINs and then asked Windsor panellists to make any revisions needed to reflect local circumstances in the Windsor area. Refer to Appendix 3 for sample care packages for each of the 8 vignettes selected for the Expert Panel.

Table 3: Sample Care Package for Copper

Service	Frequency
Meals on Wheels	3 times per week
Congregate Dining	Once per month
Transportation	1 two-way trip per week
Home Maintenance	Once per month
Caregiver Support Group	One hour every other week
Home Help/Homemaking	2 hours every other week
In-Home Support PSW (CCAC)	2 hours per week
Occupational Therapist (CCAC)	Assessment once a week (total 2 visits)
<i>Care Monitoring once every six months</i>	

Our suggestion to revise this sample package was strongly contested by a number of panel members who argued that service-by-service approaches are inherently ineffective for persons with complex needs; even when all required services are available (which is often not the case particularly outside of the urban core), they may not be easily accessible, and they are always difficult to manage in combination. Even for someone like Copper, at a comparatively low level of assessed need, an appropriate community care package would require multiple providers, each with their own assessment protocol, client records, eligibility requirements, services levels, and co-payments. In addition to driving up system costs, since individual providers would have to be transported to the client’s home, and each provider would have to administer their services separately, client resistance and caregiver burden were also likely to increase as needs grew and providers multiplied, thus also increasing the likelihood of “default” to hospital or residential LTC.

Some Panellists argued that service-by-service community care packages could and already were effectively managed in ESC through forms of “system navigation;” however, the weight of opinion was to move directly to consideration of integrating mechanisms and models.

3.3.2 Integrating Approaches

Expert Panellists identified a number of different approaches to integrating care which they felt could quickly be adapted to the Windsor area; many of these parallel those identified by the HayGroup and found in the international literature. Examples given included:

- **Technology-enabled virtual rounds.** Virtual rounds, using web-based technologies, smart phones, or teleconferencing, could build on existing hospital-based rounds to encompass all community-based providers, including primary care, involved in the ongoing care of individual clients. Such rounds would facilitate multi-disciplinary, cross-organization team approaches without requiring all providers to travel to the same location. They could be held in the client’s home to facilitate holistic assessment of a range of factors impacting on health and wellbeing including living conditions, rehabilitation needs and caregiver capacity. In addition to improving the care of clients and caregivers, such rounds would advance system integration by forging stronger working relationships among providers.

Panellists proposed that virtual rounds could initially be targeted at individuals who are:

- Hard-to-serve
 - Frequent flyers (e.g., frequent hospital users)
 - At risk of institutionalisation.
- **Enhanced care navigation.** Panellists noted that individuals requiring multiple services and providers within and across sectors (e.g., hospital acute care, primary care, home and community care) could face formidable challenges accessing the care they required. While it was noted that care coordination does take place for clients in certain settings (e.g., supportive housing) and for clients of particular providers (e.g., CCAC), the effective scope of such coordination is typically limited to the “basket of services” under the direct auspices of a setting or provider. Beyond that, needed connections may be made through referral, or clients and caregivers may be left to navigate on their own.

Expert Panellists envisioned that an enhanced care navigation model would be:

- Led by a single organization, or that clients with different needs (e.g., mental health, rehabilitation) would be attached to different lead organizations to ensure follow-up and prevent individuals from “slipping through the cracks”
 - Use a multidisciplinary team approach
 - Include primary care, mental health and other community-based providers.
- **Multi-service in-home care provider(s).** Another suggestion from the Expert Panel was around organising multi-disciplinary teams to provide in-home support to clients. Multi-service in-home care providers would reduce the number of different providers visiting the homes of high-needs individuals. This could lead to efficiencies for care providers as

well as reduce the stress associated with multiple visitors coming into the homes of clients and multiple hours of the day. Panellists suggested two possible ideas:

- Teams of providers could travel together (nurse, personal support worker, housekeeping in one visit)

OR

- Individual care providers could provide multiple services (same individual providing meal support, bathing, housekeeping, med checks etc.)

- **ACT Team model.** The Expert Panellists identified the Assertive Community Treatment (ACT) Team as a potential model for other community-based services for hard-to-serve seniors in ESC. The ACT Team model currently focuses on community-based psychiatric care and is already in place in Windsor-Essex; it could be adapted to serve other high needs populations as well (e.g., persons with dementia).

3.3.3 Important Considerations for Integration

The Expert Panel also identified a number of areas that they felt should be highlighted in any conversation about integration of community based services. These areas include a system-wide culture shift, barriers to integration, as well as system gaps which they viewed as priorities for action.

The Expert Panel stressed that in order for any integration efforts to be successful, there is a need for a system wide culture shift that encompasses 4 key tenets:

- The person at the centre of all decisions
- Restorative care – decline is not inevitable
- Preventative care – less reactive, more proactive
- What does the person need? What can I do? (Instead of what can't I do...), need to stop focussing on exclusion criteria.

In addition to a culture shift, there are barriers to integration which may prevent action:

- Organizational silos (including inflexible mandates)
- Information sharing (including privacy/consent legislation and technology)
- Red tape (including eligibility criteria, union barriers).

Finally, Expert Panelists identified priority areas for immediate attention:

- Transportation
- Medication management
- Hospital to community transitions
- Coordination/navigation of community-based services
- Mental health and dementia services.

3.4 Expert Panel Follow-Up Interviews

We conducted semi-structured follow-up interviews with 11 Panellists from 7 different provider organizations. These interviews gave Panellists a further opportunity to provide ideas and insights.

3.4.1 Common Themes

A number of common themes emerged:

- **The transformation from the current “provider-centred” care system to a “person-centred” care system needs to be accelerated.** There was common understanding that the current system is provider centric, that it focuses too much on what providers can do, and too little on what people need. As a result, clients may have to rely on care which doesn’t fit their needs simply because it is available; thus unnecessary or avoidable hospital visits become the inappropriate substitute for a lack of needed community-based care, including primary care and mental health services. Providers have to find ways to “take off their institutional hats” to accelerate change. Improved data sharing between providers and across sectors is essential.
- **Communication and collaboration can be strengthened.** The majority of those interviewed felt that the Expert Panel had been very helpful in surfacing diverse perspectives from across the care continuum; some said individuals and organizations would benefit from having more frequent opportunities to hear what others do, raise issues, and share best practices. Such opportunities could lead to closer working relationships, better information sharing, smoother transitions, and higher quality care for clients. Collaboration could be strengthened by engaging in shared projects: Health Links can help to stimulate new conversations, and in the process, build ‘community capacity.’ Enhanced communication would also help to eliminate overlap and redundancy in programs and services.
- **The importance of supporting IADL needs has to be recognized; IADLs keep people in their homes.** Interviewees emphasized a common theme: prevention and maintenance are essential, and assessments have to consider the wider range of emotional, social and mental aspects which contribute to an individual’s health and well-being; rehabilitation needs should be emphasized. The Ontario Common Assessment of Need – the mental health version of the RAI-HC – which works toward shared ‘goal setting’ -- can assist in developing a more holistic understanding of needs and approaches to meeting them.
- **Housing-based care models offer advantages.** Combinations of housing and community supports (such as supportive housing and assisted living) can facilitate more effective provision of needed services “where people live” by reducing transportation needs of clients and staff, and allowing better coordination and case management. Housing in and of itself is vitally important, since lack of appropriate housing can lead individuals to be admitted to LTC even if they could potentially be supported in the community. The fact that an individual lives in housing with 24 hour coverage can shift thinking away from the automatic assumption that once someone enters acute care they automatically require long-term care. In addition to supporting residents, housing models can build “critical mass” for crucial community based services and supports including primary care, which could then “radiate” out into the community to serve

others through “hub-and-spoke” models. LTC homes also have potential in this regard; their facilities and programming could be accessed by those in the community, for example, by locating adult day-programs on site, also smoothing transitions to LTC when it is needed.

- **Residential LTC should be seen as only one option within a broader continuum.** Some panellists felt that too much of the conversation around care for older persons revolves around LTC, not because it is always the most appropriate option, but because it is an easy option. Too often there is an assumption that once an older person is hospitalized, institutionalization is inevitable. Transitions to LTC, when needed, can be improved, and community-based alternatives can become an essential element of all discharge and care planning.

Panellists also noted that:

- There is a gap in service from the point at which an individual is assessed as LTC eligible and when they actually enter LTC. Spouses and family members are expected to fill this gap, resulting in caregiver stress and unnecessary hospitalization
- Community-based services stop at the door of LTC disrupting relationships with familiar providers and reinforcing care silos
- The needs of clients entering LTC are increasing; for example, many now require assistance during meal time. Family members are now frequently called upon to continue to provide significant levels of support even after transition to LTC, without being offered caregiver supports or respite
- The frequency of inspections needs to be increased to improve the quality of residential LTC.

3.4.2 Additional Data on Client Needs in Alternate Care Settings

As noted, we asked Expert Panellists to provide data which could be used to compare clients served by their organizations to CCAC home care clients, including those on LTC wait-lists. The aim was to estimate, with more precision, the extent of any “overlap” in the needs of clients served in different care settings. One provider was able to do this: Assisted Living in Southwestern Ontario (ALSO). While unable to provide individual-level assessment data on clients, the Alzheimer Society of Windsor-Essex County did provide a detailed description of its adult day program.

Assisted Living in Southwestern Ontario (ALSO). ALSO estimated the numbers of its 380 current clients falling into each of the 8 *BoC* sub-groups selected for the Expert Panel. ALSO provides housing and a range of supportive services, on a 24/7 basis, to older adults and persons with disabilities who need physical, social or emotional supports to remain independent in their own homes for as long as possible. Services include home and personal care, life skills, family supports, access to health professionals, transportation, recreation, education, and employment services.

Chart 7: Comparison of Windsor Essex CCAC clients with ALSO clients

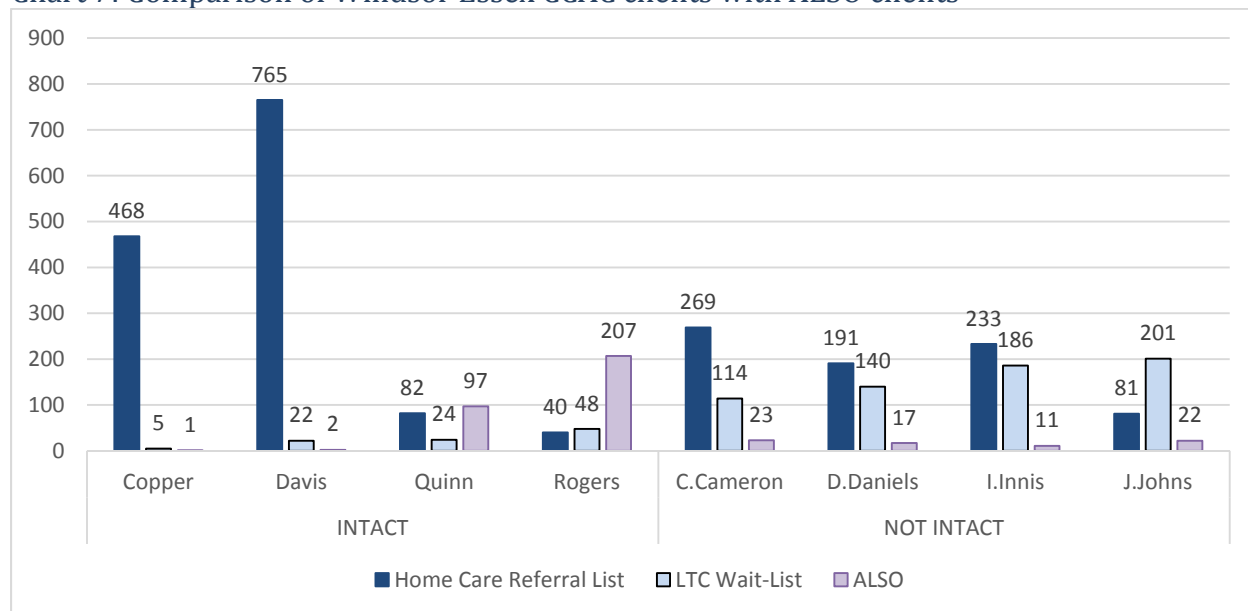


Chart 7 compares the distribution of ALSO clients with CCAC home care referral and LTC wait-list clients. The numbers show that the majority of ALSO clients fall into the low to mid-range of the *BoC* vignettes; most (about 80%) of ALSO’s 380 clients are represented in “Quinn” and “Davis” which encompass persons who experience challenges to ADLs and IADLs, but are cognitively intact. Nevertheless, close to a fifth (about 18%) fall into higher needs categories (e.g., C. Cameron, D. Daniels and I. Innis) including persons who are not cognitively intact; in fact, about 5% fall into J. Johns, the highest needs sub-group. This suggests that supportive housing/attendant care offers potential to substitute for residential LTC even for persons at high levels of assessed need.

The Alzheimer Society of Windsor-Essex County. The Alzheimer Society provided background information on 4 Adult Day Programs (ADPs) in the Windsor area.

The Windsor ADP, which operates 6 days a week, offers a range of health and wellness services to older persons with comorbidities including hypertension, cardiovascular disease, cardiopulmonary obstructive disorder and diabetes. Services include: recreation/activation, meals, exercise and falls prevention (cardiovascular conditioning and strength training, muscle endurance, balance and power, stretching and relaxation), nursing services (weight, oral care, blood pressure, oxygen levels, etc.), foot and nail care, health education, assistance with medication updates, follow-ups with specific health concerns (e.g., diabetes management), and bathing.

ADPs are also offered by South Essex Community Council in Leamington and Hôtel-Dieu Grace Healthcare– Tayfour Campus in Windsor; these day programs serve individuals with mild cognitive impairment. Assisted Living Southwestern Ontario (ALSO) in Windsor hosts a day program for those adults and seniors with physical disabilities.

3.5 Key Informant Interviews

Our qualitative interviews with key informants elaborated by-now familiar themes.

When asked where the ESC health care system should be in five years, they offered a forward-looking vision emphasizing:

- **Integration:** Bring together all of the players in the system, such as governance and funding organizations (e.g., MOHLTC, LHINs, CCACs), hospitals, and community service providers, to ensure that the system functions effectively and efficiently
- **Unity:** Share roles and responsibilities and work together to provide the best care
- **Client-centred care:** Shift to a client-centred care system focusing on what people need, and away from the current provider-centred system which focuses on what providers can offer. Quality and outcomes for people (person-centred) should replace ALC and ED visits (provider-centred) as the measures of system performance
- **Prevention:** Move focus from acute and post-acute care to prevention and health promotion to reduce risk factors for chronic conditions and decrease the number of preventable deaths, diseases and disabilities
- **Support at home:** Provide more supports at home to improve care for people and ease pressure on acute care.

Key informants identified barriers to achieving this vision. Among them:

- **Lack of communication:** Limited opportunities to have a conversation with other stakeholders, share best practices and experiences
- **Rigid funding requirements and regulations:** Inflexible rules which constrict the ability to collaborate with others both horizontally (e.g., between community providers) and vertically (e.g., between community and hospital providers)
- **Short-term funding:** One-time and time-limited funding which create uncertainty and work against providers taking a chance to implement needed changes (e.g., integrating with other organizations) that will take years to roll out.

Key informants noted measures to overcome these barriers:

- **Clear vision and leadership from the top.** The MOHLTC and LHIN should articulate a clear vision focusing on person-centred care, with more emphasis on prevention to avoid the 1-5% of high health care cost users
- **A mandate to innovate from the ground up.** Within this vision, community-based organizations should be given greater freedom to innovate, and to build strong connections within and across sectors. For example, organizations can co-lead initiatives which foster opportunities of collaboration and learning.

Key informants also provided examples of successful initiatives which they felt could be scaled-up and spread across the region to move their vision forward:

- **Street Health.** This program aims to identify who the top users of emergency services in Windsor are, and why they use these services. In doing this, it builds stronger

relationships with the hospital to facilitate access to crucial health care data, while finding ways to protect privacy (e.g., passwords, audit trails)

- **Partnership Advisory Committee at the Community Health Centre.** This working group includes the hospital emergency department, community support agencies and CCAC, with the goal of facilitating better communication and collaboration through the care journey
- **Joint working – Supportive Housing (Windsor-Essex Housing) and Assisted Living Southwestern Ontario.** This is a great example of complementing each other's expertise and service as Windsor-Essex Housing funded subsidies for rent and modified housing units, while Assisted Living Southwestern Ontario facilitated the transition of seniors considered ALC into a rent-geared-to-income housing option, and provided supports to dedicated units in the building where they resided. Both the housing and health needs of seniors were met
- **Joint working – mental health and addictions (LHIN project) and the school board.** In Essex, mental health workers were sent into the schools and were able to communicate with community agencies, youth, parents and the school board, all of whom are important stakeholders. This is seen to have worked extremely well and stimulated collaboration across all agencies
- **Addiction services for people with disabilities.** The first barrier-free facility for addictions in Ontario was built but did not include services for people with disabilities; a community agency now provides specialized services to this underserved population
- **Student practicum placements.** A project has been developed to bring students into social housing as their practicum. This has allowed residents to access needed supports and it has promoted youth engagement
- **Consumer Council.** One community agency created a Consumer Council to receive feedback on booklets or information brochures for the general public; in addition to improving the quality of resources, it gets consumers more involved in decisions about their health and the health of their communities.

Key informants went further to identify “quick wins,” initiatives which they felt could be implemented rapidly without a lot of new resources, which would help to accelerate needed system change:

- **Menu of services.** Having a comprehensive listing of providers and services in the region, including a “how to” section on access, would be valuable not only for clients but for other providers and system navigators
- **Mental health in supportive housing environments.** A mental health team, comprised of nurse practitioners, could be located in places where seniors or other needs populations congregate (such as seniors' buildings). These would build critical mass to proactively address mental health issues, make connections to needed community services, and avoid crisis leading to hospitalization or institutional care

- **“Hard-to-serve” table.** Regular meetings where providers could brainstorm around how to serve “frequent flyers” or other special needs groups, could facilitate conversation, collaboration and joint working across providers and sectors
- **Assertive Community Treatment (ACT) teams.** ACT Teams offer intensive support for services individuals with mental health challenges who find it difficult to engage with other mental health services; mobile teams (possibly facilitated by EMS) could be used to reach other vulnerable populations such as seniors living alone.

3.6 Think Tank

The Think Tank, held in late March, provided an opportunity for system leaders to review the project findings, and think about what would be needed to scale-up, spread, and sustain community-based capacity.

We used a live Twitter feed to facilitate discussion. Three main themes emerged which reinforce those heard earlier:

- **Collaborate and share.** Think Tank participants reinforced the need to start conversations and build collaboration across organizations and sectors. Examples include: integration of supportive housing with geriatric assessment and adult day programs in the hospital; the movement of dialysis patients outside the hospital to home in partnership with CCAC and LTC; and virtual community care teams. Finding ways to gather and share information is a crucial step (i.e., a single assessment, client record, and plan of care). Particularly for older persons with multiple, ongoing needs, integrating informal caregivers into care planning and delivery is crucial; without informal caregivers, community-based care is often simply not feasible
- **Build flexible hub models which match local needs and resources.** Community hubs can be established to provide a single point of access for clients and critical mass for providers. It was observed that any community organization or site could become a hub; in addition to supportive housing, community health centers and adult day programs, hubs (or their satellites) could be established “where people go” such as in a shopping mall or public library. Hubs might begin by focusing on a specific needs group (e.g., high needs older persons) and then “radiate” services out to the broader community
- **Manage uncertainties.** While there was much talk of new opportunities and innovation, and the benefits of collaboration, there was also a sense that a climate of constrained resources, competition for available resources, and possible threats to organizations that do not immediately address system problems such as ALC, worked against needed change. Current regulations and funding mechanisms at the system level create uncertainties which inhibit sharing resources and risk taking. In particular, LHINs may not receive their budgets from the Ministry until the second quarter of the fiscal year, restricting their capacity to make financial commitments to community organizations; in turn, these organizations are wary of starting initiatives which might not be supported.

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It was noted that some community organizations have offered to lead integration and build capacity; however, without financial commitments and political will, they are reluctant to move forward. For its part, the LHIN may be reluctant to make commitments to risk-takers, particularly if they are uncertain about support they will receive from the Ministry, and if support for one organization or sector may be seen to disadvantage others. Ways need to be found to support organizations willing to take a risk and move forward.

4.0 Summary

ALC is a persistent concern and top priority driving change in the ESC LHIN, as it is across Ontario. No longer is ALC seen simply as a hospital problem; it is more accurately understood as a sentinel indicator of health system performance. Solutions to ALC problems depend on the ability to mobilize and connect with resources beyond the hospital walls.

In ESC, construction of a new state-of-the-art hospital, and the consultants' recommendation that ALC rates should be cut by half, provide further impetus for change. If the new hospital is to avoid taking on a costly ALC legacy, community-based capacity needs to be in place not only to discharge patients faster, but to avoid unnecessary use of hospital resources before-the-fact.

The question is, what to do? The findings of the *Windsor-Essex Balance of Care (BoC) Project* add valuable insight; they suggest that there are a range of promising opportunities to advance community capacity and system integration. As Walker, Sinha and others have observed, greater integration across a continuum is needed to provide appropriate, cost-effective care to growing numbers of persons with multiple chronic health and social needs, and avoid costly default to hospitals and LTC. We note that while many such persons are older adults, there are also growing numbers of children with complex medical conditions who will require multiple health and social supports throughout their lifetimes, and many persons with disabilities who are also aging.

Some of the opportunities for Windsor-Essex involve ramping up the volume of key community-based services and programs; *BoC Project* participants pointed to transportation and medication management, and to mental health and dementia care as top priorities. Given that mental health and dementia appear to be among the top factors impacting ALC rates in Windsor hospitals, this emphasis seems well placed.

Other opportunities have to do with scaling-up and spreading integrating mechanisms such as virtual rounds, electronic medical records, inter-disciplinary teams, and intensive care management/system navigation. A strong message from *BoC Project* participants, especially those on the Expert Panel, is that while particular services and programs need to be enhanced, the big challenge is finding ways to encourage joint working across providers and sectors to better serve people with multiple needs in the community and prevent default to hospital and residential LTC.

Still other opportunities anticipate the emergence of more complex organizations with greater scope to access and manage an array of community-based services including primary care, chronic care, mental health, community supports, and housing. These could be located in different sites including supportive housing/attendant care, adult day programs and community health centres. By building critical mass, and using available resources more effectively, they would offer potential, through "hub and spoke" models, to radiate services out into the community via "satellites" in shopping malls, libraries and other places where people congregate, as well as in buildings and neighborhoods where people live. Reach and impact

could be further enhanced through mobile teams, possibly modelled on current ACT teams, and possibly including Community Paramedicine³⁴, tasked not only to respond to urgent situations, but proactively to reach out and support people at risk of illness, and loss of independence.

The major point, emphasized by *BoC Project* participants, and reflected in recent reports and the international literature, is that solutions to health system problems may include, but go beyond changing the site of clinical care; they go to thinking more about health, what keeps people well and independent in the community and what's needed to support them, and their informal caregivers in the family home or in home-like environments following an acute care episode.

In this connection, the importance of Instrumental Activities of Daily Living (IADLs) emerged as a recurrent theme. Though not health care per se, *BoC Project* participants emphasized that everyday supports like transportation, and the consequent ability to get out to do chores and engage socially, can mean the difference between older persons continuing to live independently in the community, or “defaulting” to hospital emergency departments, and becoming ALC. For growing numbers of older persons with dementia, small things like medication checks, and cues for dressing and eating can have an enormous impact. The ESC RAI-HC data confirm that IADLs play a major role in referral to LTC in Windsor-Essex.

IADLs also draw attention to the pivotal role of informal caregivers who provide the bulk of IADL support on a daily basis, and to the consequences if informal caregivers withdraw or are not there to begin with. Across ESC and in Windsor-Essex, only four in ten persons on LTC wait-lists had caregivers living with them. This number should be considered against the 90% of wait-listed persons completely dependent on others to perform IADL tasks such as meal preparation, housekeeping, telephone use, and medication management. While informal caregivers can live outside the home, they are less likely to be able to provide continuous monitoring; this appears as a crucial consideration for the 81% of wait-listed persons who experienced cognitive challenges requiring them to be supervised on a continuous basis. Given constrained home care resources, the likelihood of formal providers being able to offer 24/7 monitoring in the home is virtually nil.

This speaks to the importance of recognizing and supporting informal caregivers, particularly those of high needs individuals who would be at imminent risk of hospital and institutional care if informal caregivers were not present; without informal caregivers, community care packages for people who cannot manage everyday tasks on their own are rarely safe or cost-effective.

Finally, as the literature suggests, even when seen as a good idea, shifts toward more integrated, person-centred care systems, particularly during periods of economic constraint and

³⁴ Sinha, S. (2013). Living Longer, Living Well. Highlights and Key Recommendations. Pg. 12. Accessed on-line at http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/docs/seniors_strategy.pdf

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competition for scarce resources, will face challenges. Nevertheless, as experience in the EU shows, and as *ESC BoC Project* participants emphasized, such challenges can be mitigated by clear policy directions at provincial and regional levels which support collaboration between providers, and incent “ground-up” innovations which lever local capacity and resources including informal caregivers and social support networks. *BoC* participants emphasized that they were willing to take risks and embrace positive change; however, they wanted to be assured that risk-taking and change would be supported at the policy level.

5.0 Recommendations

Based on these findings, we offer a number of inter-linked recommendations for Windsor-Essex.

5.1 Accelerate the Conversation

Consistent with recent policy reports in Ontario, and a growing weight of international evidence, all participants emphasized that “more of the same” would not be sufficient to address current challenges; a more fundamental “culture shift” was needed to embrace key principles including:

- Putting the person at the center
- Providing restorative and preventative care
- Considering mental as well as physical health
- Engaging informal caregivers and social networks.

To make this shift, on-going conversation is essential. In addition to building trust, conversation around what people need helps typically altruistic providers understand what others do, what gaps need to be filled, and how they can contribute to solutions. They also raise awareness of innovative approaches and models that can be scaled-up and spread to meet local needs.

There was strong enthusiasm for ongoing efforts (e.g., community capacity planning, health links) which bring stakeholders to the table to find collaborative solutions to pressing problems. Participants suggested, and we recommend:

- Hosting an annual ‘health fair’ that engages the public and providers (including hospital discharge planners and informal caregivers) to raise awareness of available community resources
- Creating joint working groups across providers and sectors focused on the care of high needs and “hard-to-serve” populations
- Holding open planning forums to encourage broad community engagement and innovative solutions that leverage local resources including cultural organizations and faith groups.

5.2 Make Targeted Investments in Community Infrastructure

As noted, *BoC Project* participants strongly advocated for fundamental system change over the long term; they also argued for more immediate enhancements to community-based services and programs essential to everyday living.

BoC Project participants suggested, and we recommend, targeted investments in:

- Transportation
- Medication management
- Enhanced coordination/system navigation.

Participants also suggested, and we recommend, enhanced program capacity in two areas impacting directly on population health and ALC rates in Windsor-Essex:

- Mental health
- Alzheimer’s disease and other dementias.

5.3 Encourage Joint Working Between Providers and Across Sectors

Participants identified a number of mechanisms which by themselves, or in combination, can facilitate greater collaboration, integration, and joint working.

Some, like standardized electronic medical records, seem difficult to achieve, at least in the short run, for technical and political reasons. Nevertheless, others can be put in place quickly to strengthen linkages across providers and sectors, and with informal caregivers.

Participants suggested, and we recommend:

- Establishment of technology-enabled inter-disciplinary and inter-organizational teams around the care of high risk and hard-to-care for populations. For example, in different parts of Ontario including the North, specialized rehabilitation teams are already using web-based technologies (sometimes OTN) to conduct virtual assessments and direct care in the high risk person’s own home
- Technology-enabled virtual rounds, including hospital and community providers, to build common care pathways for persons with complex chronic needs who are “at risk” of becoming “stuck” in the health care system
- Integrated care plans which follow the individual through their care journey. For example, such plans, including “hard” clinical outcomes (e.g., reduced hospital re-admissions, fewer hospital days), as well as “softer” personal goals (e.g., improved quality of life, greater confidence in adapting to changing life circumstances) are already being used by the Children’s Treatment Network of Simcoe York in the care of children with complex medical needs.

5.4 Scale-up and Spread Community-Based Integrating Models

Given the goal of reducing ALC numbers in Windsor-Essex by 50%, and the fact that ALC beds are often occupied by older persons with multiple chronic health and social needs including mental health problems and dementia, models which “bundle” integrating mechanisms to provide appropriate, cost-effective care on a 24/7 basis, seem like the way to go.

BoC Project participants pointed to the strengths of “hub and spoke” models which lever existing community resources, build critical mass in strategic locations for geographically-defined populations, establish an organizational focus and infrastructure for multi-provider collaborations, and radiate services out into the broader community through satellites and other forms of outreach.

BoC Project participants noted that “hub and spoke” models could be located in different settings; we recommend the following:

- **Community Health Centre (CHC).** CHCs already have interdisciplinary primary health teams, integrated client records, and experience serving hard-to-serve populations across Ontario; they have strong relationships with other health and social care

providers, and they are already taking on clinical programs (such as diabetes management) as these shift from acute care settings. Directly addressing persistent concerns in ESC, recent provincial data show that CHC clients are less likely than clients of other primary health organizations to use hospital emergency departments³⁵. The Minister's recent announcement of new provincial investments in community health infrastructure – including CHCs – make CHC's a timely option for scaling-up as integrating hubs³⁶.

- **Supportive housing/attendant care.** Previous *BoC Projects* in regions such as the North West and North East, have demonstrated that combinations of housing and community supports can be a cost-effective alternative to residential LTC^{37,38}. Data provided by an attendant care/supportive housing provider in ESC (ALSO), suggests that it currently serves many persons at high levels of need, albeit balanced against larger numbers of individuals who have low to moderate needs so that resources can be pooled. Major advantages of such arrangements are the ability to provide 24/7 monitoring, proactive “early warning” of emerging health issues, smoother transitions following an acute care episode, flexible use of staff, and the ability to generate critical mass by hosting a range of preventive services, primary health teams, and medication checks and dementia care. A Toronto study³⁹ showed that because they could access on-site staff, supportive housing residents were less likely to call 911.
- **Elderly Persons Centres (EPC)/Adult Day Programs (ADP)/Enhanced Adult Day Programs (EADP)/Alzheimer Day Programs.** According to Sinha, EPCs offer considerable opportunity to build social networks and provide access to wellness and prevention and care services; he recommends the number and role of EPCs be strengthened across Ontario⁴⁰. While definitions vary, ADPs typically offer a more extended range of supports including transportation, meals, activation, and

³⁵ Institute for Clinical Evaluative Sciences (ICES). (2012). Comparison of primary care models in Ontario. Access on-line at <http://www.ices.on.ca/~media/Files/Atlases-Reports/2012/Comparison-of-primary-care-models-in-Ontario/Full%20report.ashx>

³⁶ Government of Ontario. (2014). Investing in Community Health Infrastructure: Ontario Ensuring Access to Health Care Services, Creating Jobs. News Release. Accessed on-line at <http://news.ontario.ca/mof/en/2014/04/investing-in-community-health-infrastructure.html>

³⁷ SHS Consulting and Balance of Care Research Group. (2009). Seniors' Residential/Housing Options – Capacity Assessment and Projections. Accessed on-line at <http://www.nelhin.on.ca/assets/0/16/42/1228/008fda48-974c-4865-9e47-972aacb0f84f.pdf>

³⁸ Williams, A.P., Watkins, J. & Kuluski, K. (2010). The North West Balance of Care Project II: Final Report. Accessed on-line at http://www.northwestlhinc.on.ca/uploadedFiles/Home_Page/Report_and_Publications/NW%20BoCII%20Report%20Final%20July%2019th%202010.pdf

³⁹ Lum, J., Williams, A.P., Sladek, J. & Ying, A. (2010). Balancing Care for Supportive Housing Final Report. Accessed on-line at http://www.ryerson.ca/crncc/knowledge/related_reports/pdf/Balancing%20Care%20for%20Supportive%20Housing%20Final%20Report.pdf

⁴⁰ Sinha, S. (2013). Living Longer, Living Well. Highlights and Key Recommendations. Pg. 9. Accessed on-line at http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/docs/seniors_strategy.pdf

connections to other needed community services; EADPs, such as those now operating in Central LHIN, partner with CCAC and other providers to offer an extended range of services including foot care and medication checks; Alzheimer Day Programs offer specialized care and respite to older persons and caregivers coping with the disease, including many who are LTC-eligible. All offer potential to establish “hubs” which concentrate a range of health and social supports at central locations; link with other providers; provide respite to informal caregivers; and build service capacity for the broader community. The Alzheimer Society of Windsor-Essex currently runs an ADP offering exercise and falls prevention, an extensive range of creative and therapeutic activities, meals, transportation, staff trained in working with people with dementia, and nursing services through a partnership with VON Canada; bathing facilities are also available. As noted, the South Essex Community Council in Leamington and Hôtel-Dieu Grace Healthcare – Tayfour Campus in Windsor host day programs for those with mild cognitive impairment; and Assisted Living Southwestern Ontario hosts a day program for adults and seniors with physical disabilities.

5.5 Support Informal Caregivers

Our final recommendation addresses the formal/informal care divide. In the hospital where the focus is on short-term episodic care, informal caregivers may play a supporting role; in home and community, they are the lead players. Their capacity and willingness to care heavily influence not only whether cared-for persons can continue to live at home, but whether they can return home after a hospital stay. Sinha recommends a range of actions including spreading the Alzheimer Society’s First Link program across the province; First Link builds partnerships of health professionals with specialized knowledge about ADOD to ensure that families receive needed support and information⁴¹.

We go further to recommend leveraging the success of two innovative caregiver support initiatives in Toronto Central LHIN; these projects provide flexible combinations of counselling, case management, in-kind services, and cash, to “at risk” caregivers of “high needs” children with complex medical needs, and older persons eligible for residential LTC, with the aim of sustaining caregivers, and avoiding or delaying institutional care^{42,43}. By building caregiver capacity and ability to forward-plan, these initiatives promise to maintain high needs persons in the community longer, and reduce the likelihood of unnecessary hospital or residential long-term care. Most importantly, these initiatives recognize the vital role played by informal

⁴¹ Sinha, S. (2013). Living Longer, Living Well. Highlights and Key Recommendations. Pg.16. Accessed on-line at http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/docs/seniors_strategy.pdf

⁴² Williams, A.P., Peckham, A., Rudoler, D., Tam, T., Watkins, J. (2013). Formative Evaluation of the Alzheimer Society of Toronto Counselling Program. Final Report. Accessed on-line at http://www.alzheimertoronto.org/documents/evaluations/ast_cp_evaluation_report_2013.pdf

⁴³ Williams, A.P., Spalding, K., Peckham, A., Rudoler, D., Tam, T., Watkins, J. (2013). Caregiver Framework for Children with Medical Complexity: Formative Evaluation, Final Report. Submitted to Hospital for Sick Children, Toronto, April 2013. Report.

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caregivers, the personal costs they often incur as a result, and the consequences for the health care system, if current caregivers withdraw or if future caregivers fail to step up.

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Appendix 1: RAI-HC (Resident Assessment Instrument – Home Care) Data

To ensure relevance and accuracy, the project will need to access a “ready-to-analyze” cut of the most current RAI-HC data available from the ESC CCAC. As noted earlier, our Team has previously worked with 10 other CCACs across the province, and can assist Decision Support personnel with secure data transfer.

This should include anonymized assessment data for all long stay and long-term care wait-listed clients including:

- Section AA through Section Q
- All CAPs
- All scales (e.g. MAPLe, Cognitive Performance Scale etc.)

Prior to transfer, all individual identifying information should be removed including:

SECTION AA: Name and Identification Information

1. Name of Client

a. Last/Family Name

b. First Name

c. Middle Name/Initial

2. Case Record No.

3a. Health Card No.

3b. Province/Territory Issuing Health Card No.

SECTION BB: Personal Items

2a. Birth Date

2b. Estimated Birth Date

If other items in this section have counts less than 6 they should be excluded.

SECTION G: Informal Support Services

Name of Primary and Secondary Helpers

a. Last/Family Name

b. First Name

c. Last/Family Name

d. First Name

To facilitate analysis, each record should include:

- A unique identifier (e.g. ID#)
- A “flag” indicating:
 - If they are on the LTC wait-list or in any other special program of possible interest (e.g. Enhanced Care)
 - Care setting (e.g. Hospital, Community, LTC home waiting for bed of choice)
 - Geographic location (especially within CKHA & SAC catchment area)

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Where possible, please include any additional information on utilization including:

- Emergency Department Notification (EDN) data (or equivalent)
- Resource Matching and Referral (RMR) data

Data Transfer

Data can be transferred either through a secure portal or via an encrypted device using excel.xlsx file format.

Appendix 2: Distribution of Home Care Referrals and LTC Wait-Listed Individuals in ESC and Windsor-Essex by BoC Sub-Groups

Vignette	Cognition	ADL Difficulty	IADL Difficulty	Live-in Caregiver	% of ESC LTC Wait-list	% of ESC Home Care Referral	% of Windsor LTC Wait-list	% of Windsor Home Care Referral
Appleton	Intact	Low	Low	Yes	0	1.7%	0	1.6%
Bruni	Intact	Low	Low	No	.4%	1.7%	.4%	1.6%
Copper*	Intact	Low	Medium	Yes	.6%	14.2%	.6%	13.9%
Davis*	Intact	Low	Medium	No	2.0%	23.9%	2.4%	22.7%
Eggerton	Intact	Low	High	Yes	.4%	3.5%	.3%	3.4%
Fanshaw	Intact	Low	High	No	.9%	3.9%	1.1%	3.9%
Grimsby	Intact	Medium	Low	Yes	0	0	0	0
Hamilton	Intact	Medium	Low	No	0	0	0	0
Islington	Intact	Medium	Medium	Yes	.3%	2.9%	.4%	3.2%
Jones	Intact	Medium	Medium	No	.8%	2.6%	.8%	2.8%
Kringle	Intact	Medium	High	Yes	1.5%	3.5%	1.5%	4.1%
Lambert	Intact	Medium	High	No	1.9%	2.2%	1.8%	2.1%
Moore	Intact	High	Low	Yes	0	0	0	0
Nickerson	Intact	High	Low	No	0	0	0	0
Opus	Intact	High	Medium	Yes	.5%	1%	.6%	1.1%
Pringle	Intact	High	Medium	No	.7%	0.7%	.8%	.7%

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Quinn*	Intact	High	High	Yes	2.9%	2.7%	2.6%	2.4%
Rogers*	Intact	High	High	No	5.8%	1.1%	5.3%	1.2%
Smith	Not Intact	Low	Low	Yes	0	0	0	0
Thompson	Not Intact	Low	Low	No	0	0.1%	0	.1%
Upperton	Not Intact	Low	Medium	Yes	.7%	1.9%	.4%	1.4%
Vega	Not Intact	Low	Medium	No	2.3%	3.6%	2.1%	3.2%
Wong	Not Intact	Low	High	Yes	2.3%	3.3%	1.9%	3.0%
Xavier	Not Intact	Low	High	No	6.5%	3.8%	5.6%	3.4%
Yeung	Not Intact	Medium	Low	Yes	0	0	0	0
Zeleny	Not Intact	Medium	Low	No	0	0	0	0
A. Armour	Not Intact	Medium	Medium	Yes	.4%	0.5%	.3%	.3%
B. Biloski	Not Intact	Medium	Medium	No	.5%	0.8%	.2%	.8%
C. Cameron*	Not Intact	Medium	High	Yes	11.7%	7%	12.5%	8.0%
D. Daniels*	Not Intact	Medium	High	No	16.0%	5%	15.4%	5.7%
E. Edwards	Not Intact	High	Low	Yes	.1%	0	.1%	0
F. Fish	Not Intact	High	Low	No	0	0	0	0
G. Gallo	Not Intact	High	Medium	Yes	0	0	0	0
H. Hogan	Not Intact	High	Medium	No	.3%	0.1%	.2%	.1%
I. Innis*	Not Intact	High	High	Yes	19.2%	5.9%	20.5%	6.9%

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J. Johns*	Not Intact	High	High	No	21.5%	2.2%	22.1%	2.4%
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* Highlighted sub-groups are those selected for the Windsor-Essex Expert Panel session.

Appendix 3: Erie St. Clair Expert Panel Simulation: Selected Vignettes with Sample Care Packages

Vignette: Copper

(Home Care Referral List N =781, 14.2%; Wait-list N=8, 0.6%)

Copper is cognitively intact and functionally independent in all ADLs with the exception of bathing (limited assistance is required). Copper has no difficulty using the phone, some difficulty managing medications and great difficulty with meal preparation, housekeeping and transportation. Copper has a live-in caregiver. This live-in caregiver provides advice/emotional support and assistance with IADLs.

- 1) Cognition- Borderline Intact (short-term memory recall is good for most people in this group; some are showing signs of short term memory problems, makes consistent/reasonable/safe decisions and can express ideas without difficulty)
- 2) 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).
- 3) IADL- No difficulty using the phone, some difficulty managing medications (needs some help, is very slow/fatigues), great difficulty with meal preparation, housekeeping and transportation (little or no involvement in the activity is possible).
- 4) Caregiver (in home?)- Yes, adult-child provides advice/emotional support and assistance with IADLs.

Sample Care Package: Copper

Service	Frequency
Meals on Wheels	3 times per week
Congregate Dining	Once per month
Transportation	1 two-way trip per week
Home Maintenance	Once per month
Caregiver Support Group	One hour every other week
Home Help/Homemaking	2 hours every other week
In-Home Support PSW (CCAC)	2 hours per week
Occupational Therapist (CCAC)	Assessment once a week (total 2 visits)
<i>Care Monitoring once every six months</i>	

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Vignette: Davis

(Home Care Referral List N= 1317, 23.9%; Wait-list clients N=27, 2.0%)

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

- 1) Cognition- Borderline Intact (although most have good short-term memory, a short term memory problem is displayed by some in this group; makes consistent/reasonable/safe decisions and can express ideas without difficulty)
- 2) 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).
- 3) IADL- No difficulty managing medications and using the phone, some difficulty with meal preparation (needs some help, is very slow/fatigues), and great difficulty with housekeeping and transportation (little or no involvement in the activity is possible).
- 4) Caregiver (in home?)- No. Has an adult/child caregiver living outside of the home who provides advice/emotional support and assistance with IADLs.

Sample Care Package: Davis

Service	Frequency
Personal Support Services	1 hour twice a week
Occupational Therapist (CCAC)	Assessment once a week (total 2 visits)
Transportation	8 two-way trips per month
Meals on wheels	3 times per week
Caregiver support referral	
Home Help/Homemaking	2 hours every other week
Security Checks/Reassurance	7 days/week
Adult Day Service (Frail Elderly)	1 day/week
Home maintenance	Once per month
<i>Care Monitoring once every six months</i>	

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Vignette: Quinn

(Home care referral List N =149, 2.7%; Wait-list N=38, 2.9%)

Quinn is cognitively intact and requires assistance with all ADLs (extensive assistance with eating and is totally dependent with locomotion in the home, using the toilet, personal hygiene activities and bathing (full activity is performed by another person). Quinn has great difficulty in all IADLs (meal preparation, housework, medication management, phone use and transportation). Quinn has a live-in caregiver. The caregiver is a spouse or adult child who provides advice/emotional support, assistance with IADLs.

- 1) Cognition- Borderline Intact (short-term memory recall is good, some difficulty making decisions in new situations only. Can express ideas without difficulty).
- 2) ADL- Extensive required when eating (client can perform 50% of activity on own and requires full help for part of this task); total dependence with personal hygiene activities, locomotion in the home, bathing and toileting (full performance of these tasks are done by someone else).
- 3) IADL- Great difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in the activity is possible).
- 4) Caregiver (in home?)- Yes. Caregiver is a spouse or adult/child who provides advice/emotional support and assistance with IADLs.

Sample Care Package: Quinn

Service	Frequency
Occupational therapist	1/ week for 5 weeks then reassess
Physiotherapist	1 initial assessment
CCAC Nursing – medications management	1 visit then reassess, ongoing supervision required
In-Home Support PSW (CCAC)	4/day for 1 hour each time
Home Help/Homemaking	1/week for 2 hours
Home Maintenance	1/month
Adult Day Service (Integrated)	2/week for 12 weeks
Adult Day Service (Frail Elderly)	1/week
Transportation	15 (two-ways) /month
Caregiver respite and support(Paid)	5 hours/week + 3/month for support group
LTC respite short stay (1.5 weeks)	1 every 6 months
Emergency response system	
<i>Care Monitoring check-in call once per month, visit once every three months</i>	

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Vignette: Rogers

(Home Care Referrals List N= 62, 1.1%; Wait-list N=76, 5.8%)

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

- 1) Cognition- Borderline Intact (for most memory recall is good, for some there are signs of short-term memory decline, some difficulty making decisions in new situations only but can express ideas without difficulty).
- 2) ADL- Limited assistance required when eating (client is still highly involved in this activity but requires some assistance/guided maneuvering); maximal assistance required with personal hygiene activities and locomotion in the home (client performs less than half of the tasks for these activities and may require a 2 person assist), totally dependent in toileting and bathing (entire task performed by others).
- 3) IADL- Some difficulty using the phone (needs some help, is very slow/fatigues), great difficulty with meal preparation, managing medications housekeeping and transportation (little or no involvement in the activity is possible).
- 4) Caregiver (in home?)- No. Caregiver is adult child who lives outside the home, provides advice/emotional support but does not provide assistance with IADLs.

Sample Care Package: Rogers

Service	Frequency
Occupational therapist	1/ week for 5 weeks then reassess
Physiotherapist	1 initial assessment
CCAC Nursing – medications management	1 visit then reassess, ongoing supervision required
In-Home Support PSW (CCAC)	4/day for 1 hour each time
Home Help/Homemaking	1/week for 2 hours
Home Maintenance	1/month
Adult Day Service (Integrated)	2/week for 12 weeks
Adult Day Service (Frail Elderly)	1/week
Transportation	3 (two-ways) per week
Emergency response system	
Pharmacy Blister Pack Set-Up	
<i>Care Monitoring check-in call weekly, visit once every month</i>	

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Vignette: C. Cameron

(Home Care Referral List N=383, 7%; Wait-list N=155, 11.7%)

C. Cameron is not cognitively intact. C. Cameron requires assistance with all ADLs (supervision with locomotion in the home, eating and toilet use; limited assistance with personal hygiene activities and extensive assistance with bathing. C. Cameron experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, transportation and phone use). C. Cameron has a live-in caregiver (a spouse or adult child who provides advice/emotional support, assistance with IADLs and ADLs.)

- 1) Cognition- Not Intact (short term memory problem, decisions consistently poor or unsafe, cues/supervision required at all times. Has difficulty finding words or finishing thoughts, prompting usually required)
- 2) ADL- Oversight, encouragement and cuing required with locomotion in the home, eating and toilet use; limited assistance needed with personal hygiene activities (client is highly involved in activity but requires some assistance/guided maneuvering) and extensive assistance required when bathing (full performance of part of these activities performed by others).
- 3) IADL- Great difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in the activity is possible).
- 4) Caregiver (in home?)- Yes. Spouse or adult child who provides advice/emotional support and assistance with both IADLs and ADLs.

Sample Care Package: C. Cameron

Service	Frequency
In-Home Support PSW (CCAC)	2 hours/day
Occupational Therapist (CCAC)	1 visit/week (total 4 visits)
Transportation	10 two-way trips per month
Meals on wheels	6/week
Caregiver Respite (Paid)	10 hours/week
Caregiver Support/Education Group	1/month
Home Help/Homemaking	2 hours every other week
Home Maintenance	1/month
Adult Day Service (Alzheimer's/Other Dementia)	2 days/week
CCAC Nursing – medications management	1 visit/week
Pharmacy Blister Pack Set-Up and Delivery	1/week
LTC short stay (1.5 weeks)	1 every 6 months
<i>Care Monitoring visit monthly</i>	

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Vignette: D. Daniels

(Home Care Referrals List N=276, 5%; Wait-list N=211, 16%)

D. Daniels is not cognitively intact. D. Daniels requires assistance with all ADLs (setup help required when eating; supervision required with locomotion in the home; limited assistance required with toileting and personal hygiene activities and extensive assistance required when bathing. D. Daniels experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). D. Daniels does not have a live-in caregiver. D. Daniels has an adult child caregiver who lives outside the home who provides advice/emotional support and support with IADLs.

- 1) Cognition- Not Intact (short term memory problem, decisions consistently poor or unsafe, cues/supervision required at all times. Has difficulty finding words or finishing thoughts but if given enough time, little or no prompting is required).
- 2) ADL- Set-up help required when eating; oversight, encouragement and cuing required with locomotion in the home; limited assistance required with toilet use and personal hygiene activities (client is still highly involved in activity but requires some assistance/guided maneuvering); extensive assistance with bathing (client perform only 50% of tasks on own, full performance required by others for part of tasks).
- 3) IADL- Great Difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or involvement in the activity is possible).
- 4) Caregiver (in home?)- No. Adult-child caregiver lives outside of the home and provides advice/emotional support and assistance with IADLs but not with ADLs.

Sample Care Package: D. Daniels

Service	Frequency
PSW – Bathing, housekeeping , Medication	24 hours supervision – except when in day program
Pharmacist – Dosage of meds (Pre-packaged)	Once a month
Transportation	6 rides (return) week
Day program (Cognitive)	6 (full days)/week
Caregiver support (in home, Support group or in home counseling, education, social work support)	5 hours a month
LTC short stay Respite (for caregiver, i.e., vacation)	2 weeks a year
Home maintenance	Two a month
Life Line	
Wandering Registry	One-time fee- update annually
Professional Services: \$150 in 13 week period per person. (Variable Services: PT, Lab services, Foot care, Speech pathologist, dietician)	

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Interpretation/translation 2% overall adding to the cost at the end of the project for cultural competence **For every case!	
Client Case management: Interdisciplinary Navigation and on-going support	6 hours a month
Psycho-Geriatric *referral	

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Vignette: I. Innis

(Home Care Referral List N=326, 5.9%; Wait-list N=253, 19.2%)

I. Innis is not cognitively intact. I. Innis requires assistance with all ADLs (maximal assistance required when eating and is totally dependent with locomotion in the home, toileting, personal hygiene 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 who is a spouse or adult child. This caregiver provides advice/emotional support and assistance with IADLs and ADLs.

- 1) Cognition- Not Intact (short term memory problem, never/rarely makes decisions, ability to make self understood is limited to making concrete requests).
- 2) ADL- Maximal assistance required when eating (client performs less than half of the tasks for these activities and may require a 2 person assist); totally dependent on others to complete all other ADLs (locomotion in the home, eating, toilet use, bathing and personal hygiene) - full performance of activities performed by others.
- 3) IADL-Great Difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation) - little or no involvement in activity is possible.
- 4) Caregiver (in home?)- Yes. Caregiver is a spouse or adult child who provides advice/emotional support and assistance with IADLs and ADLs.

Sample Care Package: I. Innis

Service	Frequency
In-Home Support PSW (CCAC)	4 hours/day
Occupational Therapist (CCAC	1 visit/week (total 2 visits)
Transportation	10 two-way trips per month
Meals on wheels	6 times per week
Caregiver Respite (Paid)	15 hours/week
Caregiver Support/Education Group	1 every two weeks
Home Help/Homemaking	4 hours every other week
Home Maintenance	1/month
Adult Day Service (Alzheimer's/Other Dementia)	2 days/week
CCAC Nursing – medications management	1 visit/week
Pharmacy Blister Pack Set-Up and Delivery	1/week
LTC short stay (1.5 weeks)	2/year
<i>Care Monitoring visit monthly</i>	

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Vignette: J. Johns

(Home Care Referral List N=123, 2.2%; Wait-list N=284, 21.5%)

“J. Johns is not cognitively intact. J. Johns requires assistance with all ADLs (extensive assistance when eating, and is totally dependent with locomotion inside the home, personal hygiene, toilet use and bathing). J. Johns has great difficulty in all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). J. Johns does not have a live-in caregiver.” J. Johns has an adult-child caregiver outside of the home who provides advice/emotional support and assistance with IADLs.

- 1) Cognition- Not Intact (short-term memory problem, never/rarely makes decisions, ability to make self understood is limited to making concrete requests).
- 2) ADL- Extensive assistance required when eating (client perform only 50% of tasks on own, full performance required by others for part of tasks). Totally dependent in locomotion in the home, toileting, personal hygiene and bathing (full performance of activities by others).
- 3) IADL- Great Difficulty with housekeeping, meal preparation, managing medications, phone use and transportation (little or no involvement in activity is possible).
- 4) Caregiver (in home?)- No (caregiver is an adult-child living outside the home and provides advice/emotional support and assistance with IADLs).

Sample Care Package: J. Johns

Service	Frequency
Home and Community Care not a viable option	