Canadian Home Care Association

High Impact Practices

www.cdnhomecare.ca

The Family Care Home Model

Facilitating community living for people with acquired brain injury

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About High Impact Practices

The Canadian Home Care Association (CHCA), as a national voice, promotes excellence in home care through leadership, awareness and knowledge to shape strategic directions. The Association is committed to facilitating continuous learning and development throughout the home care sector to support and promote innovative and effective practices across Canada.

During the CHCA's annual Home Care Summit, health care leaders from across Canada and abroad share new and emerging approaches to home care and engage in dialogue about their experiences so that leading practices from across the country and, around the world, can be examined and adopted. Every year there are initiatives that stand out – those that clearly will impact the health care system. The potential of these practices is such that home care stakeholders want to hear more and are eager to explore the applicability within their respective jurisdictions. Building on the momentum of the Home Care Summits and recognizing the potential "ripple effect" of expanding the dissemination beyond the Summit participants, the CHCA has undertaken to document and publicize a selection of these innovative practices from across the country as High Impact Practices.

EACH OF THE HIGH IMPACT PRACTICES:

- **Promotes** home care that provides evidence-informed service delivery directed toward the achievement of health outcomes in the settings that best support the individual, and family
- **Enhances** the effectiveness of home care
- **Raises the awareness** of the ways that home care contributes to an effective health care system
- **Mitigates** rising health care costs and accentuates existing resources and expertise
- **Enables sharing** and transferring of knowledge, expertise and experience through networking and peer-to-peer learning.

Thank-you to our High Impact Practices Partner…

Comcare Health Services has been a Gold Sustaining Patron of the CHCA for over 15 years. As a national home health care provider, Comcare is a leading innovator for community health care solutions to those in need throughout Canada. Clinical excellence and commitment to improved client care at Comcare is supported by a dedicated contingent of highly skilled professionals having exceptional practice standards. Comcare is proud to contribute to the advancement of leading practice in home care in Canada by supporting CHCA's High Impact Practices. **www.comcarehealthnetwork.ca**

The Family Care Home Model

SUMMARY

Presented by staff from the Vancouver Island Health Authority (VIHA) in British Columbia, this innovative practice fosters client respect and independence enabling those with Acquired Brain Injury (ABI) to reintegrate into the community.[1]

The **Family Care Home Model** is a key component of the community's capacity to care for and support individuals with ABI. A Family Care Home is a single family residence that provides supportive accommodation and an individualized care approach for up to two clients (the maximum allowed in a non-licensed facility). Family Care Homes support clients with ABI to successfully reintegrate into the community by providing a family environment, and/or close adult supervision. The Model is based on a premise of maximizing each client's independence. Different approaches include designing the Family Care Home as an independent suite with regular monitoring and support by the caregiver; or in situations where, for example, the risk of self-harm is greater, the level of cognition or the requirement for assistance with activities of daily living is such that the need for supervision and support is higher, clients may be fully integrated into the family setting.

The support and attention provided by a caring and committed caregiver in a Family Care Home results in improvements in a client's abilities and overall health status beyond that which can be achieved in any other health care setting. As a consequence, clients are coached to attain a higher level of independence and have their other health care needs addressed proactively. While not formally quantified, the impacts are impressive – reduction in acute care admissions, prevention of other secondary health issues, and most importantly a significantly enhanced quality of life for the client.

VIHA Brain Injury Program

Although services vary amongst the Health Authorities, the mandate of the Brain Injury Programs in BC is to provide access to appropriate needs-based services and supports within the community and specialized services as close to home as possible.

The health and social system costs; challenges to existing organization infrastructure and personnel (ABI survivors do not fit into a standard sector); but most importantly, the quality of life for ABI survivors and their families, are the key drivers behind the VIHA's Brain Injury Program.

1989 – Program established within the Ministry of Health with a staff of one
1991 – Two more staff were added allowing for coverage of the Island and the Interior
1997 – Program functioned as a tertiary care service through one Health Authority
2002 – Program was decentralized to each Health Authority
2002 – VIHA Brain Injury Program established - a division of Home and Community Care

For more information on the VIHA Brain Injury Program:
www.viha.ca/hcc/services/brain_injury

Special thanks to *Ceri Davies for her guided tour and patience in answering all our questions. Also thanks to the families and ABI clients who opened their homes so we could visit and capture a moment of their life in this program.*

Project Background

Acquired Brain Injury is defined as "damage to the brain which occurs after birth and is not related to a congenital disorder or a degenerative disease. These impairments may be either temporary or permanent and cause partial or total functional disability or psychological maladjustment."[2] The damage may be caused traumatically or through a medical problem or disease process which causes damage to the brain.

With the advances in health care and our expanded understanding of ABI (as it applies to younger individuals who experience a stroke, for example), the incidence of survival from severe ABI is increasing. On Vancouver Island (population 750,000) an estimated 100 new clients per year (individuals over 19 years of age who are not eligible for other sources of Long Term Care funding) will be referred to the Brain Injury Program. While most individuals who are identified as needing residential services will choose the Family Care Home option and will be prepared for this Model, there are some for whom the Model is not appropriate. Some clients with extremely high care needs will need other service options offered by the Brain Injury Program; others may decline the 24 hour supervision and opt for the 'tenant support program' (one of the service delivery models offered by Brain Injury Program). Currently, the complexity of care needs and limited resources (human and financial) contribute to a waiting list of about 150 clients (Nov 2005). The effects of a waitlist on this client population are often detrimental as they may remain in acute care settings or long term care institutions, receive limited home care services or go without care, living on the streets which may often result in their involvement with the judicial system and/or developing addiction issues - an additional complication to their recovery and reintegration into the community.

Management of clients with ABI is challenging and complex for the injured person, the family and the health care team. No two individuals with acquired brain injury are alike.[3] Individual differences are compounded by the severity of the injury and location of the damage to the brain, secondary medical complications, and how the individual adjusts to motor, cognitive, and emotional effects. The symptoms of Acquired Brain Injury are varied and often subtle necessitating skilled client caregivers who understand the behavioural symptoms which can often frustrate and confuse care providers. Compounding the symptoms is a high prevalence for mental illness amongst those with ABI. Clients usually require long term care incurring significant costs to health and social systems. Furthermore, after a brain injury the risk of a second injury is three times greater.[4]

Brain Injury Program Guiding Principles (based on early WIT Principles[6]

1. No two brain injuries are alike.
2. Environments are easier to change than people
3. A person with a brain injury is more likely to acquire a skill in the environment in which its needed
4. Interventions must be individualized
5. Individual Program Plans (IPPs) must include a community evaluation to screen for barriers
6. Natural supports last longer than paid supports
7. The Service System presents many of the barriers to community integration
8. Respect for the individual is paramount
9. Needs of individuals with disabilities last a lifetime

Implementation

The Family Care Home Model has been integral to the Brain Injury Program in B.C. since its inception in 1989. The VIHA Brain Injury Program staff (total of seven serving the Island) has focused on the development of the Family Care Home Model in order to integrate ABI clients into the community. Presently, 120 clients receive long term supportive funding for severe ABI. Of these, 50 require residential options – the Family Care Home being one of several housing options provided. There are currently 37 clients living in 32 Family Care Homes.

A Family Care Home is a single family residence that provides supportive accommodation and an individualized care approach for up to two clients (the maximum allowed in a non-licensed facility). Established in both rural and urban settings, the Family Care Home may have a separate suite where the client can be more independent and prepare some meals; or the home may provide a full family integrated setting where the client has his/her own room and eats all meals with the family. The level of engagement with the family activities depends on the client's needs and preferences.

Once placed in the Family Care Home setting, clients are expected to access the health system as all other citizens. The Brain Injury staff do not provide emergency response and do not replace the existing system.

The Brain Injury staff focus on developing individual programs for clients with ABI in order to maximize their rehabilitation potential so that they can live as independently as possible post injury. Brain Injury staff advocate on behalf of the client and their families to health authorities and other partners. They participate in the planning, delivery and evaluation of services and supports; and provide community leadership, share information to assist in community development and provide technical support and training to persons with brain injury, their families and service providers. The staff are also responsible to monitor trends, provide information and identify priorities within the community.[5]

* * *

> "It's been a long time coming (over a year!!!) but I'm finally out of the hospital and in the community!... They're a large family (who all get along quite well) it's quite neat to be a part of..."
>
> *Client, Vancouver Island*

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Program standardization is difficult as the nature of ABI is such that a particular approach rarely works for more than one client. Hence the Program's guiding principles (see insert) provide direction to staff.

Client / Family Responsibilities

Clients and their families are expected to participate in the planning for home care and respite services and evaluation of services and supports that they require. With support, clients/families are encouraged to present their needs and desires in accessing services and supports for themselves and to articulate the support needs of their family members. As much as possible, clients are expected to acknowledge and accept the existence of brain injury and its consequent deficits. They must actively engage in recovery and demonstrate a willingness to adopt the necessary life-style changes or other required adjustments necessary to achieve rehabilitation.[7]

Finding the Caregiver

Identifying caregivers is an intensive and challenging process. Although conventional recruiting approaches are used, typically caregivers are identified through word of mouth and referral.

* * *

> "The FCH provider seems to feel that my son has made good progress in the last few months and I do credit the routine that the FCH has put in place for most of the improvement. I guess some of it will be just the brain recovering naturally, but I really think the FCH has done a marvelous job."
>
> *Family Member, Vancouver Island*

* * *

Caregivers typically are:

- People who have made a lifestyle choice to include people with disabilities in their lives.
- A family where the adults may have a human service background and want a lifestyle that enables them to work from home.
- Individuals or couples where one or both would like to incorporate work into their home life.

Staff find that caregivers can be taught the skills to support ABI clients; but there is a lot of intuition in the selection of the caregiver. Fundamentally they must be dedicated, have the right personality, and the right energy to do the job. This is a 24 hour 7 day a week responsibility.

It takes approximately three to six months to develop a Family Care Home for a client as the search for the right caregiver and family setting is client specific and initiated once the client needs are understood. Once the match is confirmed, the details of fees, method of payment, length of contract and any additional supports such as respite or day programs are discussed and finalized. A contract is established and the living arrangement begins.

Brain Injury Program staff provide caregivers with ongoing coaching, support and guidance to manage their client(s). They monitor the client's progress through home visits and quarterly reports submitted by the caregiver.

Evaluation

While there has been no formal independent evaluation of VIHA's Brain Injury Program and more specifically the Family Care Home Model, the results speak for themselves. Providers have noted that as a result of the Program, there are:

- Significant system cost savings – care in the Family Care Home Model typically ranges between 65 to 100 dollars per day. There are some more complex situations that cost as much as 200 dollars per day afforded through cost sharing across programs, but nonetheless the model still compares favourably to institutional per diem costs.

- Decreased hospital admissions – most remarkable was the client who was reported to have had 87 trips to the emergency room in one year and when placed in a care home had none.
- Decreased social issues – clients are not on the street or in the jails.
- Improved related health care – when cared for in the family care home model attention is paid to dental, vision and other general health care needs. (Facilities are often just not resourced to proactively manage these type of health concerns.) Further, through supervision, management of medical conditions, such as diabetes is better achieved.
- Clients are stabilized in the community for the long term – the longest placement has been 15 years for VIHA (life of program). In many situations, when a Family Care Home provider re-locates, so does the client, who is often involved in the decision making.

• • • •

> "Thank you once again for all you've done for me, especially this new 'awakening of life,' – a second chance..."
>
> *Client, South Vancouver Island*

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Key Success Factors

The Family Care Home Model is a dynamic program that is built on a premise of flexibility and solutions orientation. The Program's success is, to a large part, a consequence of the following key success factors.

- The Program's guiding principles - which address the absolute commitment of the staff to client-centred and client-driven care. Staff seek to understand the client's needs and work with them to identify the model of service that they would like. They then work to find at least two options that they believe will be acceptable. Clients visit the home, interview the families and have full authority to make their selection. If the client decides that the home is not acceptable (even on move-in day, which occurred on one occasion) the staff accept the decision and work to develop a new home setting.
- The generosity of the caregivers - who modify their houses and bring these individuals into their homes is indeed remarkable and not offset by the modest compensation they receive for room and board. Families who choose to do this work make a conscious decision to work from home and to be a stable, consistent influence for the client. As the symptoms suggest, clients often need cueing, coaching, structure, and guidance to manage their lives safely and more successfully. Caregivers may need to help the client with hygiene issues, eating habits and understanding appropriate boundaries in the community. The normative environment forces clients to understand and respond to the natural consequences of their behaviour in the community. (The contrast to the institutional environment is striking. Often in the institution, by virtue of being contained and isolated; and by the numbers of individuals with ABI congregated in one setting, unacceptable behaviours accelerate and become difficult to redirect. Furthermore, shift changes and the structured staff/patient relationship result, to a certain extent, in behaviours that are not acceptable in the community.)
- Staff who have a wide range of knowledge and come from an allied health background. These professionals are experts in accessing community resources and working with a broad range of stakeholders including the client, their families, care providers, the health care team, law enforcement personnel and the judicial system. They provide case management, caregiver recruitment, support, education and retention and supportive counseling for clients and their families on the program and to a limited extent for those waiting. Accessing funding and negotiating the various bureaucracies to cobble together a package of funding resources to support the client in the community is one of the most time consuming tasks for the staff.
- Balancing the client's family expectations to the client's decisions regarding the management of his/her life which can be challenging. There is a natural instinct amongst the family members to want to protect the client with ABI. However, the program principles embody client self-management and independence. This requires supporting client decisions which may be inconsistent with the level of protection that the family wants to ensure.
- The will amongst the stakeholders to provide long-term solutions for ABI clients and accordingly employ flexibility within the system to reallocate funds. Home Support funding is transferred to this care model and in some cases funding from sources external to VIHA (i.e. disability pensions, or auto insurance policies) are accessed.

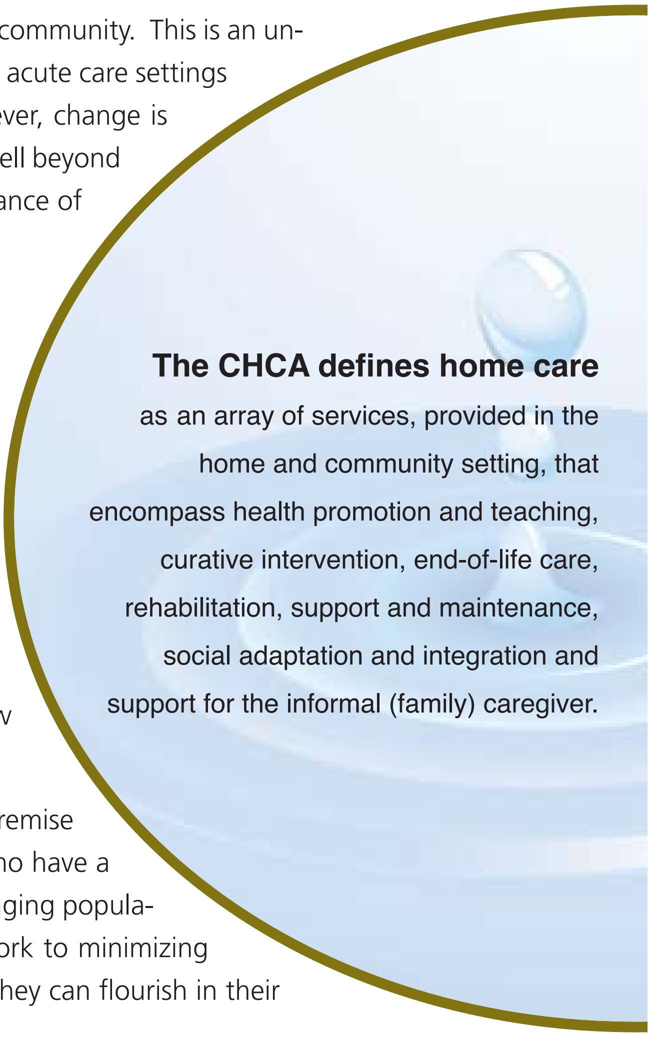
Outcomes

VIHA's Brain Injury Program is an important component of the Region's Home and Community Care program. The Family Care Home Model has demonstrated considerable savings for the health system (as compared to some other models) and VIHA has been creative in their use of home care dollars for this population. While exceptions are made to the rules governing funding allowances, the system is still such that if the client's need exceeds the 120 hour per month home care ceiling, s/he may not be supported in the community. This is an unfortunate outcome as many young ABI clients end up in long term or acute care settings that are costly and inappropriate to their mental well-being. However, change is happening and the successful reintegration of clients who function well beyond what was anticipated after their acute episode speaks to the importance of this Program within the Continuing Health Services sector.

CONCLUSION

The Family Care Home Model, as described, works for the people of Vancouver Island. Its impact to the health care system and to the clients themselves is immediately obvious and exciting. However, the model is not easy. While there are standards and guidelines governing operational processes (such as interviewing of clients, potential caregivers, overnight procedures, fees, supports, etc.), no two Family Care Homes are ever going to look the same. Each client requires a new and unique approach and staff must rely on the Brain Injury Program principles to guide their work. They must create new solutions for each client and each situation.

Fundamental to the success of the Family Care Home Model is the premise that within a caring society, there are people who are willing and who have a special talent for caring for clients with ABI – one of the more challenging populations that the health system serves. Health care leaders need to work to minimizing barriers to home and community based care for clients with ABI so they can flourish in their unique and individualized settings.



The CHCA defines home care as an array of services, provided in the home and community setting, that encompass health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration and support for the informal (family) caregiver.

For more information on the CHCA's High Impact Practices or other initiatives, contact **www.cdnhomecare.ca**

End Notes:

[1] Judith Armstrong, Regional Program Coordinator for the Brain Injury Program; Emily Macdonald, Manager of Acute Intervention, VIHA British Columbia
[2] World Health Organization, Geneva 1996
[3] "Whatever It Takes" (WIT) Model, Willer and Corrigan. http://www.ohiovalley.org/abuse/pdf/wit.pdf
[4] Fact sheet http://www.biam.ca/about.htm
[5] Guidelines for Planning Brain Injury Services and Supports in BC 2002, Ministry of Health Services and Ministry of Health Planning, http://www.health.gov.bc.ca/mhd/pdf/guidelines_brain_injury_2002.pdf , p 15
[6] "Whatever It Takes" (WIT) Model, Willer and Corrigan. http://www.ohiovalley.org/abuse/pdf/wit.pdf
[7] Guidelines for Planning Brain Injury Services and Supports in BC 2002, Ministry of Health Services and Ministry of Health Planning, http://www.health.gov.bc.ca/mhd/pdf/guidelines_brain_injury_2002.pdf , p 15

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