



RESIDENTIAL OPTIONS PROJECT

PHASE ONE REPORT

June 2007

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The Residential Options Project (ROP) was created as an integral part of CLBC's vision of helping individuals lead good lives in welcoming communities. The project was introduced to give individuals with developmental disabilities throughout the province an opportunity to make informed decisions about where they live and to facilitate access to the type of home they desire.

The project is critical to ensure that we are meeting the needs of those we support and that British Columbia continues to be recognized as an international leader in the field of community living. It was designed to identify those individuals who, along with their support networks, are interested in exploring an alternative living arrangement.

The following values are at the heart of this initiative:

- ✧ respecting the rights of all people
- ✧ supporting people to make their own decisions
- ✧ supporting people to achieve their dreams for the future
- ✧ working collaboratively with others
- ✧ inspiring creativity and innovation
- ✧ using public funds effectively

Between September 2006 and March 2007, we met with every person in a staffed residential resource. We also spoke with family members, service providers, and others who were important to the individuals at the heart of this initiative. This report summarizes the project's design and initial outcomes.

RATIONALE

Residential services within this province have been slowly transforming for many years. During the 1980s, people with developmental disabilities left institutions to find homes within community, starting a movement of inclusion and conscious community development. Agencies and families worked together to create homes that would ensure people were safe and comfortable.

After 20 years of developing and refining the staffed residential model, services are entering a new chapter in their evolution. While group homes will continue to suit certain people for years to come, this is not universal.

*The key to immortality is to first
live a life worth remembering.
(Bruce Lee)*

Individuals and families are expressing a desire for alternatives. They have told us that people with developmental disabilities need, want, and deserve to have homes in community. These homes should be of their choosing and should fit their unique needs and preferences. These homes should be as varied in definition as those within the broader community.

CLBC is committed to enabling people with disabilities and their families to develop individual support plans that identify how their disability-related needs and their goals and dreams for living in community will be met both through funded and community supports. This represents a profound shift in the field.

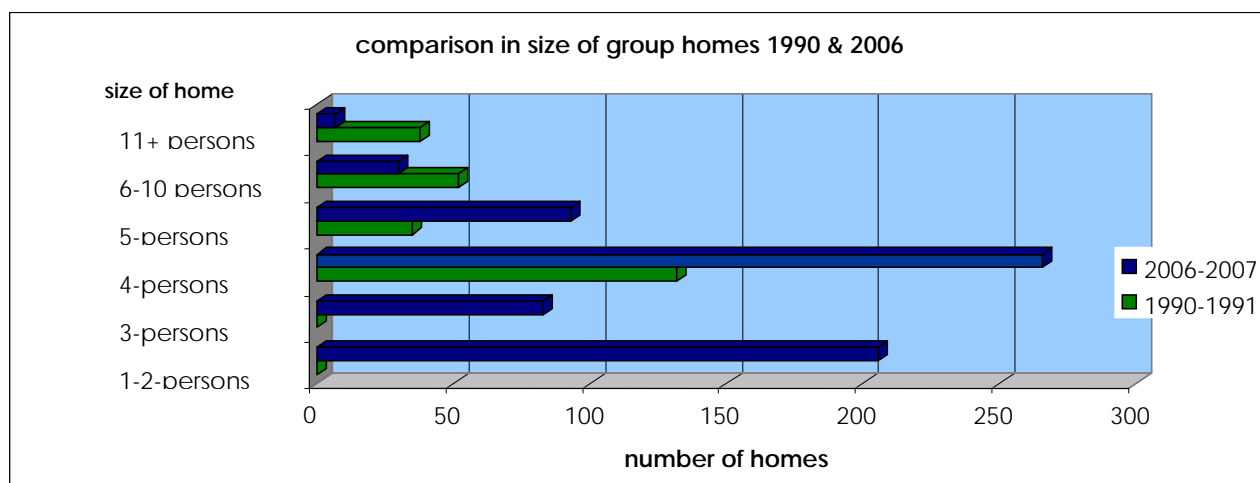
The Residential Options Project was an important bridge between the ways of the past and the ways of the future. It was a preliminary step to inform CLBC and its partners about the current and future residential needs of people living in staffed residential resources. The goals of the project were as follows:

- ✧ clearly identify those who are living according to their wishes and those who are interested in exploring other options
- ✧ assist in the development of cost effective alternative ways of providing residential support
- ✧ obtain comprehensive data for the purpose of future planning
- ✧ identify and assist in overcoming barriers to choice

Project staff were dispatched on a fact-finding mission to connect with each and every adult in a staffed residential resource to determine their preferred home setting. The project was designed to give people with developmental disabilities and their families or trusted advisors a chance to make informed decisions and to help people find homes that are best suited to their needs, wants, and dreams.

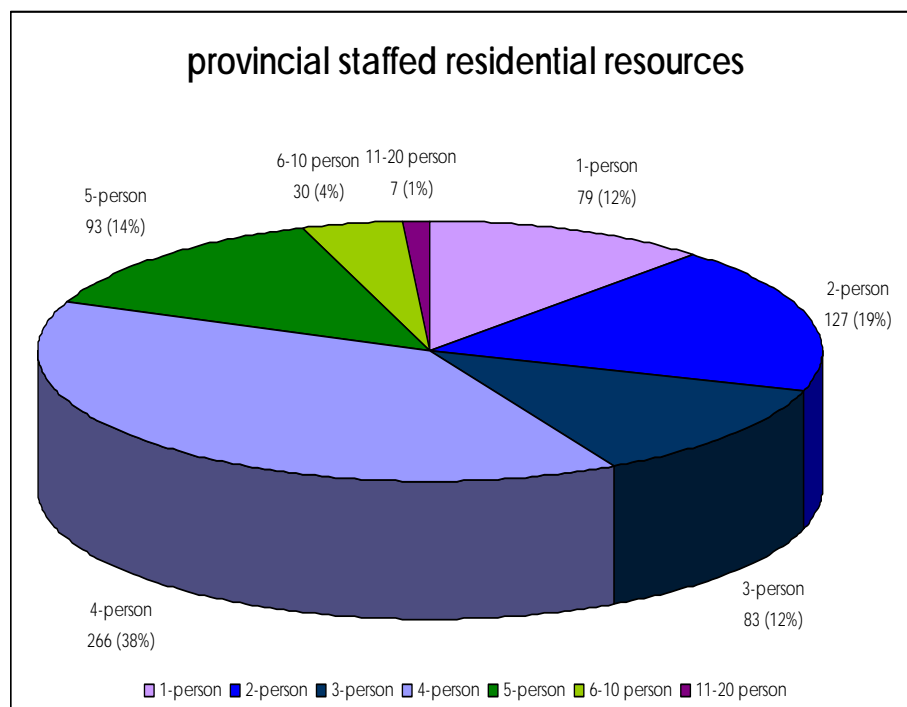
RESIDENTIAL SERVICES IN BRITISH COLUMBIA

While the closing of well-known institutions such as Woodlands and Tranquille in the early 1990s was a monumental endeavour, it was merely part of a larger international movement to create supports for individuals based on their unique wants and needs (person-centred supports). Over the past 15 years, British Columbia has seen a significant trend towards the development of smaller, more personalized resources.



In 1991, approximately 3,000 adults were receiving residential support. Seventy percent of this group (approximately 2,100 individuals) were supported in staffed residential facilities (group living with shifted staff support). The remainder lived in family care homes or received semi-independent living services. Facilities of the day tended to be quite large with the average supporting just over eight people. There were no staffed residential homes at all for less than four individuals.

The picture is quite different today. While more individuals live in staffed residential homes than ever before (30% increase since 1991), the growth in popularity of the staffed residential option has slowed over the past several years. In 2006, staffed homes



made up 48% of CLBC residential services. Of the 685 staffed homes that exist within the province today, 43% accommodate three persons or less, 52% accommodate four or five individuals, and only 5% have six or more individuals residing in the home.

Increasingly, people are requesting and receiving individualized supports that meet their own unique

needs and preferences. This is consistent with recent research that clearly demonstrates that “one size fits all” is no longer an acceptable standard. There is increasing evidence to suggest that group homes may be too large for many people and other models may be more beneficial. ¹ A comprehensive literature review demonstrates that people in small community homes (one to three people) fare better than their counterparts in large facilities. ²

Concurrently, service providers have developed varied and innovative living situations. The creation of microboards and individualized funding has allowed individuals and those who support them to focus on the needs and desires of one person. In doing so, they are able to design supports that work for that individual, rather than trying to balance the needs of a group. This explains the growing interest in home ownership, home sharing (living with a non-disabled individual), and cluster apartments (individuals who live individually in apartments and share support).

In 2007, 2,465 individuals with a developmental disability live with and receive support from a person or persons who are not disabled. This is the residential option that has

experienced the most growth and transformation over the past several years. Since 1991, the number of individuals using this type of support has increased by 387% and continues to show steady growth (13% since 2002). Formerly called proprietary care, adult foster care, or family care, this type of living arrangement was once seen as a replacement for the family home and support took on a “parental” nature. In looking for alternative ways to support individuals, families and agencies have developed person-centred supports that include meaningful, reciprocal, and interdependent relationships. The added safeguard of agency involvement has provided great comfort to many friends and families of those who may be vulnerable.

CURRENT PICTURE

Through conversations and visits with individuals, family members, trusted advisors, and agency personnel, Residential Options Project staff completed profiles on a total of 2,435 individuals living in staffed homes. The following trends were noted:

age of individuals

As with the general population of BC, the average age of individuals within group homes is increasing. During the 2006-07 fiscal year, 50% of individuals living in CLBC group homes were over 46 years of age, with the average age of 45 years.

	AGE GROUP					
% OF TOTAL	19-25	26-35	36-45	46-55	56-65	66+
individuals living in staffed residential homes	8.3%	18.8%	22.8%	28.4%	14.6%	7.2%

Given that the average age of mortality for individuals served by CLBC in 2006 was 51 years ³ and that younger individuals and their families are typically choosing smaller, more person-centred living situations, this suggests that the need for traditional group homes of 4-6 people will diminish over time.

support needs

The type and amount of support required by individuals living in staffed residential homes appears to have shifted. Prior to the closure of institutions, most individuals in group homes required a low level of physical / emotional support. In 2006, the majority of individuals needed assistance in multiple areas of their lives. Approximately 64% of individuals visited by ROP staff had complex support needs.

- ✦ 54.6% require intense support for day-to-day decisions
- ✦ 52.5% communicate in a way that is understood only by familiar people
- ✦ 22.3% need assistance walking
- ✦ 19.7% have hearing and / or visual difficulties
- ✦ 35.4% have major health concerns
- ✦ 34.3% have persistent mental health support needs

It is likely that those who currently prefer this living arrangement and those who are drawn towards it in the future will continue to fit this profile. However, it is also likely that these complex support needs will be better addressed in years to come than they have been for adults with developmental disabilities in the past. Improved connections to resources in the community and targeted community development will help ensure that communication, mobility, and various health concerns are less of a barrier to independent living than they have previously been. As families, friends, and agencies become more skilled in finding community supports to ensure the safety of people with quite complex needs, the need for traditional staffed residential facilities should gradually diminish.

assisted decision-making

The project highlighted the lack of family or trusted advisors for individuals as an important issue. The trend was particularly apparent in areas where there are large numbers of people who formerly lived in institutions. While there is awareness of the importance of relationships with those outside the group home, most agencies have struggled with assisting in their development.

There also appears to be a widespread misunderstanding amongst staff and families about legal status, guardianship, and representation agreements. 15% of individuals have a formal arrangement in place to assist with decision-making.

PROJECT OUTCOMES

Of the 2,435 individuals who participated in the review process, 170 (7%) were identified as interested in exploring other options. Another 160 (7%) people were identified for follow-up at a later date. These decisions were made in collaboration with the individual and those around them (i.e. family, trusted advisors, and agency personnel).

In 2006-2007, 89 (4%) individuals moved, many to another staffed resource. Twenty-eight individuals moved to homes that were not staffed resources.

items of interest

- ✦ While the existing home was seen as a good fit with the individual's current needs in just 47% of situations, only 10% were identified as likely candidates for exploration of alternatives. Project staff, families, and agency representatives tended to be quite conservative when asked to identify individuals who might benefit from a residential change. In some cases, the individual had recently moved to the home and was seen as needing some time to settle. In other situations, family commitment to the home or the individual's health- and / or age-related needs meant that an exploration of alternatives was probably not in the person's best interest at the present time. Historically, individuals and their families did not have the opportunity to choose their home or design something that supported their unique circumstances. Lack of experience in choices and fear of risk has created a barrier to looking at alternatives.

- ✧ Group homes are the only option available to individuals in many smaller communities. We anticipate greater movement in these communities once service providers have an opportunity to develop new models of residential service and once individuals and families become more aware of various options. The ROP team is assisting in the development of initiatives to support movement within certain regions.
- ✧ While most areas of the province have moved towards smaller staffed residential resources, the Interior region still contains several large settings (i.e. greater than 5 people). Most individuals who moved to these homes did so as a result of institutional downsizing. In visiting these homes, ROP staff found that most individuals are entirely content. They are living with people they have known for many years and are comfortable with the quantity and quality of support they receive. Most families are not interested in a change from the existing home.
- ✧ We met several individuals who are potential candidates for an alternative placement, but are not proceeding at this time. ROP staff will follow-up with these individuals at a later date. In some cases, the individual and family may require more information / time to make a decision or disagree on the best alternative and need support to reach a consensus. In other cases, the community may simply lack the resources at the present time to support an alternative placement.
- ✧ British Columbia continues to be seen as an international leader in the field of community living. The ROP team has been consulted by representatives from the governments of Alberta and Ontario who are undergoing significant downsizing of their own institutions.

INDIVIDUAL OUTCOMES

The individuals we met were pleased to be asked about their residential preferences. Some have been living happily in their existing homes for years and wish to remain while others are ready for a change. Many had interesting stories to tell about what brought them to that particular home and about where they see themselves living in the future.

It became clear that not everyone enjoys living among a group of other people. Sensitivity to noise, incompatibility of housemates, staff rotations, lack of personal space, and limited control were frequently cited as having a negative impact on quality of life. In addition, after moving from institutions to community settings, many individuals report that they have not experienced genuine inclusion. All too often, their only meaningful relationships are with staff members.

An unanticipated outcome of this project has been the rekindling of past relationships between individuals living in staffed resources and important persons with whom they had lost contact. In looking for trusted advisors to assist individuals in decision-making, interviewers made a determined effort in every region of the province. The following is perhaps the most dramatic of many examples:

A ROP interviewer visited the local Band Office to ask for volunteers to assist three individuals of aboriginal heritage who had no known family. In doing so, an elder told Colleen (interviewer) that her daughter, who had the same name, died decades ago while in care. Within days, it became apparent that the mother had been misinformed. During the Christmas week, members of the family received a truly remarkable gift. They were reunited.

It is important to note that individuals have always been supported by agencies and CLBC (or its various predecessors) to move to more ideal arrangements. However, planning for these moves has often been crisis-driven. Some agencies have provided exceptional support to assist individuals in having a more person-centred life. This project provided a consistent, province-wide vehicle to ensure that all individuals had an opportunity to voice their preferences and to minimize some of the barriers that tend to complicate the process. Planning for moves identified through the ROP is careful and comprehensive. It involves the active participation of individuals, their family members and trusted advisors, service providers, and regional CLBC staff.

As mentioned previously, 89 individuals in staffed residential facilities were supported to move during the 2006-07 year. In some cases, individuals moved to a different staffed residential home. This allowed people to choose a similar home that was more compatible with their needs and, in some cases, allowed them to reunite with family members living in a different community. In other cases, individuals chose to move to new types of homes. The homes to which people have moved include: moving home with a family member, home sharing arrangements, living with a roommate, cluster apartments, and independent living.

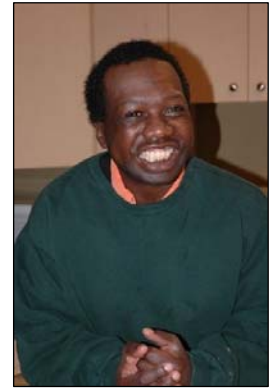
Throughout this process, we met many people who were excited to share their residential success stories. The following are just a few examples.



Candice is an independent, free-spirited young woman who has her own studio apartment at the edge of Vancouver's trendy Yaletown district. Spectrum Society for Community Living provides Candice with ten hours of staffing support each day. They help with personal care, homemaking, and transportation when Candice wants to leave her power chair at home. She is on her own overnight, but has the security of a "lifeline" she can call at anytime if she needs help.

During her adult life, Candice has had a variety of living arrangements including a group home with four other individuals and a condo that she shared with a roommate who provided around-the-clock support. When asked if she would consider a return to group living, she says that would feel like moving backwards. Candice is all about moving forward in her life and feels she is doing that with the support of her community.

Thai is a very engaging gentleman who lives in his own apartment in a fourplex in Victoria. Thai has a big warm smile and welcomes visitors to his home. He has lived in his own place for two years now and is proud to say, "This is my house!" Thai works for his sister around the property. He mows the lawn and keeps the grounds of the fourplex neat and tidy. He looks forward to payday.



Thai previously lived in a group home. It was difficult for Thai and those around him were extremely worried about the number of upsetting incidents that were occurring in the home. The residents in the home would touch Thai's books or move his things. Thai's sister, Me Kon, was very concerned about him. One day she noticed an ad in the paper for a duplex and wondered if it could be possible for Thai to have his own apartment. Me Kon and the agency that supported Thai began to look for the right place for Thai. Me Kon bought the fourplex and Thai and two other fellows moved in to their own apartments. The fourth suite is occupied by the overnight staff that provides support from 10 PM to 10 AM.

Life is much more settled for Thai now that he has a place to call his own.



Sarah is a lovely young woman who lives on Vancouver Island. Since turning 18, she has lived in many different places including her own trailer on her parents' property, two family care homes, and a group home. Sarah describes the group home as too restrictive for her needs. Due to licensing requirements and the needs of others in the home, her choices were very limited. She was not allowed to walk down to get the mail and did not have access to the kitchen area. The washrooms had to be locked at all times so Sarah had to ask staff when she wanted to use the washroom.

During October 2006, we met with Sarah and her family. They were excited about the possibility of developing a plan that would allow Sarah to have the independence she desired. Her parents set up a registered society, developed a proposal for funding, and began remodelling a duplex to create an apartment for Sarah. Things happened very quickly and Sarah moved into her apartment during December 2006.

Sarah is thriving within her new home and recently spent her first evening without overnight staff. She and her circle of support are dedicated to making this work. Sarah is on the way to making all of her dreams come true. When you ask her very large and wonderful family how they feel about this transition, they will tell you that "this is more than we had ever hoped!"

Penny grew up in Winfield, just north of Kelowna. When her mother moved into a care home, Penny tried out a few different arrangements. She lived on her own for a while and with a family friend, but eventually moved into a group home in Kelowna. She moved from the group home into a duplex that was set up to teach Penny the skills she needed to live independently. Penny was successful and moved to a subsidized apartment on her own.



Eventually, she felt unsafe and moved into the roommate companion program until her health needs increased. She briefly lived in a family home, but didn't enjoy it and moved to a group home for three years while her health improved.

When asked if she would like to move in with her best friend Susan, who lives with a family that Penny knows well, Penny agreed immediately. The pair now lives happily together. She and Susan eat supper with the family, but have their own space. Thanks to a trust set up by Penny's mom, she has been able to go on a cruise and has joined the local travel club on trips to Hawaii, Disneyland, and Mexico. She has also traveled to Scotland with her cousin Mac. Penny has a great life. She enjoys going to the library, painting classes and a painting group, and is a member of an advocacy group. When she needs support, Penny relies on her cousin Mac and her caregivers.

At the age of 54, Penny feels that she has been there and done that. She wouldn't have it any other way. In her words, "I am really happy now and don't want to move."

AGENCY OUTCOMES

The Residential Options Project involved a total of 235 service providers. These included non-profit agencies, private operators, and microboards that had been established for specific individuals.

highlighting innovation

Most agencies were quite receptive to the project and supported our team to meet with individuals, families, and other stakeholders.

Many took the opportunity to

highlight the strengths of the agency

and the many creative things they have already done to individually support people with a developmental disability. Despite initial apprehension from some agencies, a combination of experience and independence from the field allowed Residential Options Project staff to provide a solution-focused lens to the process. Most agency board of directors and senior staff responded positively to the invitation to

"We felt welcomed, encouraged, and inspired by the dedication of the service providers we met. Many families were so thankful that we asked the question about the happiness of their loved ones."

interviewer's comments

collaboratively design the process and provided leadership within the agencies and with families.

encouraging creativity

A goal of the project was to encourage creativity and innovation among service providers. To further this objective, CLBC established a *Service Provider Transformation Grant* to assist providers who expressed an interest in developing a broader array of residential alternatives.

Many agencies across the province have already developed residential alternatives that are both person-centred and cost-effective. In addition to creating more responsive services, this approach has allowed agencies to provide a broader range of supports to more individuals.

"Many agencies are well on their way to changing or moving those individuals who could be more independent out in the community. I found that most agencies were very responsive and welcoming. It was great to see some of the positive and innovative work being done."

interviewer's comments

Service Provider Transformation grants allowed agencies to propose an expansion of their existing range of options or the implementation of new residential services. Grant funding was established at \$5,000 to a maximum of \$50,000 and was determined based on the service provider's submission and the extent to which that submission met the criteria for the grant.

This provided an exciting opportunity for service providers to transform existing services. Eleven agencies were awarded funds to support a process of transformation. In some cases, the service provider will be implementing a multi-faceted transformation of their residential services. In others, the provider will be developing a particular resource that is needed within the community or required by a specific group of individuals.

RECOMMENDATIONS AND FUTURE DIRECTIONS

The Residential Options Project can be viewed as a catalyst for change. It has the capacity to promote transformation through advocacy for system change, education of families and agencies, and monitoring that change occurs in a thoughtful and person-centred way. As noted in this report, there were particular areas of concern that should be addressed:

1. Lack of friends, family, or trusted advisors was noted as a consistent issue, particularly in areas where there are large numbers of people who formerly lived in institutions. While there is awareness of need, many agencies are struggling to find ways to assist individuals to develop relationships.

Recommendation # 1: That CLBC work with the five agencies involved with its Building Personal Support Networks pilot project (2007) to provide leadership to the province.

Recommendation #2: That, as part of the contract management process, CLBC assist agencies to develop a plan of action to actively create circles of support for individuals.

2. There is widespread misunderstanding about legal status, guardianship, and representation agreements. Families, agencies, and CLBC staff were not always aware of the correct legal status of individuals.

Recommendation #3: That education materials regarding guardianship and representation agreements be provided to each agency and CLBC office.

Recommendation #4: That, as part of the contract management process, CLBC identify the current legal status of each individual served.

3. Thirty-seven group homes accommodate more than five residents each. Historical funding inequities throughout the province have resulted in an inability to change the configuration of many homes.

Recommendation #5: That CLBC establishes a moratorium on admissions to homes of greater than five individuals.

4. The referral of 170 individuals to explore options through the planning process will impact the manner in which services are developed.

Proactive approaches need to be explored and established so that CLBC actively supports agencies to transform its services.

Recommendation #6: That CLBC ROP and regional Quality Service staff actively work with agencies to set priorities regarding existing services and future transformation.

Recommendation #7: That CLBC facilitate the unbundling of globally funded resources on an as-needed basis for individuals and families to access individualized options.

Recommendation #8: That new resources reflect CLBC policy of providing person-centred and individualized support.

In the months ahead, agencies selected for transformation grants will work within their own communities to implement proposed changes and will come together to provide leadership for the entire province.

The following are the objectives for the next phase of the project:

- ✦ ensure co-ordination and timely responses for individuals for whom planning is underway
- ✦ provide individual and families with information about various home living options via local regional workshops highlighting experiences of families and individuals

- ✦ follow-up with those individuals flagged for future interest in alternatives
- ✦ assist agencies undergoing transformation and follow-up with others interested in the same process
- ✦ engage in community development work to transform supports and create new opportunities within the current funding envelope
- ✦ advise CLBC field staff on options and transformations as requested

ACKNOWLEDGEMENTS

We are particularly indebted to the hospitality of the residents and staff of each home for their welcoming attitudes and willingness to visit and share their experiences.

¹ Community Living Research Project (October 2006). *Residential Alternatives for Adults with Developmental Disabilities: Quality and Cost Outcomes*. This document is available in its entirety on the CLBC website (www.communitylivingbc.com).

² Community Living Research Project (October 2006). *Residential Alternatives for Adults with Developmental Disabilities: Quality and Cost Outcomes*. This document is available in its entirety on the CLBC website (www.communitylivingbc.com).

³ Dr. Brian Plain, MD. Medical Consultant, Health Services for Community Living. Personal correspondence (2007).