



Ministry of Children and Family Development

Discussion Paper on Community Living Services

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Discussion Paper on Community Living Services

Introduction

This Discussion Paper represents our evolving thinking on why change to community living services is necessary. It also contemplates our response to the challenges inherent in any change of this very large service delivery system. The paper considers key principles to guide the ministry through these changes — these key principles are discussed in the context of three major policy and service objectives:

- Strengthen individuals, families and communities.
- Reform service delivery.
- Deliver on our obligations to Government.

We welcome your comments.

Background: An Overview of Community Living Services

Community Living Services for adults provides a range of services and supports for adults with developmental disabilities to enable them to participate as fully and independently as possible in their communities. The eligibility criteria for service are in keeping with the internationally accepted criteria for developmental disability:

- Onset prior to age 18;
- Measured significant limitations in 2 or more adaptive skill areas; and
- Measured intellectual functioning of approximately 70 or below.

From the early 1950s, most individuals with developmental disabilities were moved from their home communities and placed in large institutions in British Columbia. These were Woodlands in New Westminster, Tranquille in Kamloops and Glendale in Victoria. Although this general trend was to continue until the early 1980s, by then parents and advocacy groups had already developed alternatives to institutional placements and activities under the aegis of community boards. Government, communities and families used this infrastructure to build on when the move to deinstitutionalization began.

In 1981, the Government of British Columbia committed to the closure of institutions and began the long and challenging task of dismantling one system while simultaneously developing and enhancing another. By 1996, the transition process was complete and the working partnership between government and the community living sector was fully established. The combination of funding and shared priorities at this juncture provided opportunities for creativity and growth, within a context of stability and strong financial support. Much of this is attributable to the environment of the day – the deinstitutionalization process had few financial constraints and the priorities of families, the service sector and the government were congruent.

Over the last five years the relationship and the service delivery system we have jointly developed has been challenged due to factors such as rapid growth in the sector, reduced availability of funds, the Munroe settlement and corresponding labour accords, changing economic priorities,

and the evolving expectations of families and communities with respect to the design of and access to services.

Using demographic and prevalence data, 1% of the population can be considered to be developmentally disabled. However, community living services are voluntary and, historically, only 30% of the potential 1% of the general population have required them: the remaining 70% live independently or with minimal support. The individuals the ministry does serve are the most vulnerable and require continuing care through residential placement or ongoing support to remain in their own or their families' homes. Others may have such complex physical or mental health issues that a specialized resource with intensive support is needed. Residential services range from costly facilities for mentally disordered offenders to semi-independent living to respite and relief services which enable families and family care homes to maintain individuals at a considerably lesser cost.

Additionally, many Community Living Services clients participate in some form of day program activity focused on creating environments which allow them to contribute to their communities. Some of our service partners have been incredibly creative in this area. Involvement on an individual basis can be as passive as company on a community outing, as demanding as supported work or as intensive as a full day centre based program; for the majority there will be a requirement for lifelong continuing care and support. The goal is to provide adults with developmental disabilities with opportunities which will promote and support their independence and capacity to contribute to their families and communities while still meeting their particular needs.

Services for Adults with Special Needs

Ministry of Children and Family Development Community Living Services for Adults encompass a wide range of services designed to assist people with developmental disabilities to live as fully and independently as possible in the community. Services include Residential Programs, Professional Support, and Training and Support programs. The Ministry now supports over 8,000 adults living in the community with an annual budget of nearly \$500 million. The bulk of these expenditures are dedicated to more than 5,000 individuals in residential care at an approximate budgeted cost of \$365M year.

It should be noted that most CLS clients do not receive their benefits directly as payments are directed instead to community-based suppliers of these services.

Since 1981, client numbers have nearly doubled and the growth in expenditures (adjusted for CPI) is slightly less. The number of clients needing services continues to grow, while existing budgets are fully committed and budget increases have been targeted primarily to increased compensation costs as a result of provincial collective bargaining (e.g., Munroe Agreement and accords). For the last two fiscal years this has resulted in new services for adults being authorized only where the health and safety of clients are at risk and in the case of children already in care turning 19 years old.

Residential Programs

Adults with developmental disabilities are provided with places to live that promote their independence while still meeting their needs. Where possible, placements are arranged in the person's home community. More specifically, residential program options include the following:

- *Community residential program* — Community residences vary in size from small family homes to larger residential facilities. All residences provide care and support for adults with developmental disabilities.
- *Semi-independent living program* — programs are designed to assist adults with developmental disabilities to live either alone or in small groups in homes or apartments. People live

as independently as possible with the help of in-home support staff as required. Services are tailored to the needs of the individual.

- *Respite/relief program* — provides emergency or short-term care for adults living in community residences. Respite care provides for temporary care out of the home, while relief services provide for alternative in-home care. The purpose of these services is to allow service providers and families periodic relief from their responsibilities.
- *Intensive adult care program* — offers short-term community-based care for adults with challenging behaviours or unique needs that cannot be served by existing respite or temporary care facilities and specialized facilities such as Willow Clinic remaining in use providing tertiary, institutional care.

Professional Support Services

Professional Support Services, either through individuals or agencies, provide assessment, support, consultation, and planning to individuals or those who support them, to ensure continued success of community placement.

Professional Support Services also assist service providers, field staff and families of adults with developmental disabilities to plan, implement, monitor and evaluate programs and services related to community living and fund training for caregivers.

Training and Support Programs (Day Programs)

Training and support programs include the following:

- *Self-help skills* — provide training in personal care, social integration and job readiness. Clients may receive one-on-one or group assistance and are encouraged to progress towards more demanding or challenging activities as they are able.
- *Home support programs* — assists adults with developmental disabilities to maintain independent or semi-independent living arrangements through direct homemaking or household management or training in these skill sets.
- *Supported work program* - assists adults with developmental disabilities to find and maintain work experience placements and employment. Provides a combination of work experience, training and support for adults with developmental disabilities.

For the fiscal year ending March 31, 2001, more than 8,000 adults (including almost all those in residential services) with developmental disabilities received services in residential programs. Projected expenditures for these services in the current fiscal year exceed \$130 million.

Services for Children and Youth with Special Needs

This ministry provides a range of programs and supports for children and youth with special needs and their families to live and participate fully in the community. Programs are based on a family-centred approach that supports parents with as much choice as possible and generally fall into one of two categories: developmental and support.

Developmental Services

- *Infant development* — provides home-based services to infants up to age three who are at risk of developmental delay or who have a developmental delay, and their families.
- *Supported child care* — finances the extra supports children with special needs require to participate in pre-school and childcare settings.

- *Early Intervention* — provides a network of services for early intervention and support to children and youth with special needs and their families, including physiotherapy, occupational therapy, speech and language therapy and family support.
- *Behavioural Support for Children with Autism* — provides special consultation on issues such as child-specific training, demonstrations of behavioural techniques, and development of behaviour management plans for children with autism and their families.
- *Summer Program for the Deaf/Blind* — provides individualized plans to ensure deaf/blind students maintain skills gained through the school year.
- *School-Aged Therapy Services* — provides school-based occupational therapy and physical therapy services to school-aged children with special needs.
- *Early Childhood Autism Initiative* – provides intensive therapy support for children from birth to school age through three regional programs just launched in 2001 with support to be expanded through the balance of this fiscal year.

Support Services for Families

- The *At Home Program* supports families caring for children with severe disabilities at home. Eligible families can receive respite and/or medical benefits.
- *Respite Services* offer families an interval of rest and relief from daily care of children with special needs. Services may include recruitment, training and/or monitoring of respite caregivers, matching families and caregivers, and the provision of respite services.
- *Associate Family Services* provide a trained family to work in partnership with birth parents to provide care in the trained-family home.
- *Nursing Support Services* provide qualified nursing services to support at-home care. This program combines the resources of the In School Support Program, the Nursing Respite Program, the assessment component of the At Home program, and nursing support for children with special health care needs in child care settings.
- *Children and Youth Care Workers* help improve families' child management and/or parenting skills by assisting children to develop identified social, life and other skills.
- *Homemaker/Home Support Workers* provide care and supervision for children, in the family home, while parents are temporarily absent.
- *Parent Support for Families* provides a range of community-based services including parent support groups, parent skills training, counselling life skills and organized activities.
- The *Professional Support for Children with Special Needs Program* enhances and supports community integration opportunities for children with special needs and their families.

A New Era for Community Living Services

Why Change is Needed

As a government, both before and after the creation of the Ministry for Children and Families, we have been in a struggle with our communities to retain, or regain, the rights of management and to motivate our employees towards a standard of excellence that even we have had difficulty defining. Part of this difficulty is that we really have two distinct mandates and two major business components: child protection and related services, and community living and related services. The goals and objectives are significantly different and so are the cultures that

are necessary to effectively accomplish those goals and objectives. In child protection matters, the ministry has a statutory obligation to intervene. In contrast, to fulfil our mandate in the provision of community living services we need to promote independence and autonomy. Although there are overlapping issues (for example, including special needs children in community living services), they are distinct and will inevitably have distinctly different solutions.

If we want to provide exemplary service in both areas we cannot proceed, as we have in the past, with incremental changes and program compromises designed to accommodate these distinct mandates. Instead, we need to effectively separate them at all levels and then consider changes to improve services.

Perhaps even more important, is our need to break out of the system of social services we have developed that is predicated on the basic tenet that professional intervention is the initial and primary response. We are collapsing under the weight of our experience. It is simply too expensive to be responding to every community need through professional intervention. No matter how much money we have, it will never be enough.

Aside from affordability, our approach has often been characterized as disenfranchising and disempowering those who best know what services and supports are required to assist persons with developmental disabilities to independence — their families, their care givers and their communities. We have imposed ourselves in ways that have too often proven to be both unhealthy and unsustainable.

We have to change our approach. We need to recognize that it is the community that has been the incubator of innovation — with a healthy history of partnerships and entrepreneurship, they have helped us blaze new trails. The new government has recognized the value in this approach. Through the core review process that is now underway across government, policy and service issues are being examined through a lens focused on community involvement and governance, ownership and accountability, local decision-making, transparent processes, reduced bureaucracy and deregulation.

We are aware of a strong community-based initiative now underway, involving both service providers and families, to define governance and service delivery structures that meet the needs of the community living sector. We welcome their participation in considering the design issues around devolution of service responsibility and authority.

We will encourage this work and build upon it.

Our Response

To meet the needs of individuals and families, our messages to all audiences must reflect our willingness to change. We need to:

- Embrace the interest within government to devolve service responsibility and authority closer to communities.
- Stimulate interest outside government in what devolution of services means in terms of governance, decision-making processes and accountability.
- Be excited by the scale of what is possible, not be afraid of it . . . we cannot change a culture that says every problem can only be solved by professional intervention through tinkering with the system – a change in governance is necessary.
- Encourage the current dialogue amongst service providers and families within the community living sector.

- Support ideas that are taking hold in the civic sector around contribution in relation to individual sense of personal worth, around contribution in relation to family and individual responsibility, and around citizenship as a policy framework.
- Define a position on non-profit services and private, for-profit services and be able to articulate that position to government, families and our communities.
- Move to a policy and service delivery framework that recognizes the importance of personal relationships in relation to individual safety, security, and quality of life, particularly the empowering themes of self-determination and individualized funding.
- Create an environment that encourages partnerships between individuals, families and caregivers, communities, governments, service providers and the business sector as a vital component of strategies of meeting the needs of people with disabilities.

Our Principles Going Forward

We must be open to completely new ideas on how to better serve those in need. We have to be prepared to get out of the way when individuals, families and even communities create the means of solving their own problems. In fact, we need to encourage this. We have to surrender some of the territory many of us have spent our careers protecting for this ministry. Above all, we need to listen.

Our driving principle is to honour and respect the dignity and equal worth of persons with developmental disabilities. We will uphold their rights and support their equitable participation in everyday life.

To achieve this, we will:

Strengthen individuals, families and communities

Our policy objectives have to respond to this family and community interest by reflecting new principles to govern our own decision-making processes. We must be prepared to approach challenges with creative policy and service decisions. In terms of individuals, families and communities, our prime objective must be to remove obstacles that prevent them from solving their own problems and, when we need to provide support, our first response must be flexible enough to enable individuals and families to solve their own problems.

Within this environment of reinforcing the family and supporting the individual, we have to:

- Reinforce our focus on the individual by reflecting that focus in policies, governance and funding. This implies moving from funding programs to funding individuals; it also implies providing supports that are individualized, flexible and portable.
- Help the community build a governance structure and service delivery system that encourages the contributions of other sectors of society including families, individuals, and corporations.
- Ensure decisions are measured by a policy and regulatory framework that promotes the contribution and full citizenship of individuals with disabilities.
- Ensure that community living services reflect government's commitment to all people with development disabilities, recognizing that we must continue to consider the full continuum of support from childhood through to old age.
- Accept that people with a disability and their families have the knowledge and skills they require to protect their rights, welfare and safety from vulnerability.

Reform service delivery

We need to change what services we deliver and how they are delivered. To make meaningful changes, we need to ensure that:

- People with a disability and their families have choice regarding the services they receive.
- Key stakeholders are involved in government planning and decision-making and have a lead role in suggesting ways that the system could be more responsive and supportive.
- Services are more responsive to the needs of people with a disability and their families throughout their lives.
- People with a disability, their families and service providers have a key role in the development and implementation of service standards and outcomes measurements.
- Advocacy mechanisms and safeguards are in place to promote, protect and defend the rights, welfare and citizenship of people with a disability and their families.
- Change will increase and improve collaboration between community service providers, families, individuals and ministry staff.

Deliver on our Obligations to Government.

As an organization that expends a significant portion of government tax revenue, we have responsibilities and obligations. In this environment of change, we must ensure that we are able to:

- Provide a solution that allows government to maintain fundamental control over the money, remain accountable for it, and ensure sound fiscal management and good value for the taxpayer.
- Facilitate open and accountable decision-making.
- Ensure that our executive and staff work together as a team
- Implement and report upon service standards and outcome measures that are developed in concert with our service delivery partners.
- Materially remove impediments that limit our capability to improve service delivery.

Next Steps

Time is short. We need to pull together as a team to deliver on the commitments our government is making. We have set directions and principles to guide us. We must meet the challenge of defining the role of the Ministry of Children and Family Development — something our predecessors have struggled with for decades.

Encouraging the Community Response

At the very highest levels, the ministry has been vocal and visible inviting the community to present solutions to the issues that challenge us — waitlists, funding, governance, labour relations and accountability. Leaders in the family movement and among our service provider partners have taken up the invitation to respond to us on these issues. We will continue to encourage this process. We will be open and willing to share our thinking and do everything possible to ensure the success of this process.

It may be that this leads us to an accord with the community to work with them to develop funding and community service solutions that meet our joint needs. This can be scary — opening up and sharing our strategic thinking is not something with which we're particularly familiar — it is a challenge but it is also an opportunity and we need to embrace this opportunity, not turn away from it. Joint ownership of whatever solutions evolve from this process is the most critical requirement for success. It is clear the system can no longer be fragmented into 'camps' — the new era must be marked by partnerships and mutual trust.

Core Services Review Process

We are mid-way through our core services review. We must ensure that our response to this review process, despite the tight timelines, is consistent with the direction we want to head as a ministry. We simply cannot be caught saying one thing during the core services review process and something different as our planning evolves.

Piloting Electronic Service Delivery

The ministry must change how we deliver services. Our administrative services, systems and processes are widely seen to be amongst the most ineffective and inefficient. We must immediately begin partnering with community agencies and private sector partners in developing new business processes that take advantage of technology and systems improvements that the public sector has been slow to adopt.

Electronic Service Delivery is a key enabler to change. Without the means to share information, we will not be able to fulfill our vision for change in a timely or cost effective manner.

New Approaches to Information Management Technology

Much of the ministry's recent investment in information management reflects approaches that will change significantly as we explore new models of governance and service delivery. Even more likely is change to a degree that would make much of our recent work obsolete.

We are moving away from very traditional, top-down case management to a system that will require individual information be shared on a real-time basis so as to facilitate collaboration with our service partners and even go so far as to accommodate parents as case managers. We have to adjust our thinking from case management of information in a world of paper files to the electronic case file.

We are moving away from the contract management demands of our present direct contracting relationship to one that could very well demand accountability in a more direct fashion at all levels. We have to move from a process that tracks contract payments to financial oversight in a world of electronic service delivery.

For these reasons, a month ago, the ministry was reorganized to separate the maintenance of internal systems from the planning, consultation and collaboration that must take place to shift our thinking on information management requirements.

We need to link both our work on the electronic case file and contract management with new ways of managing and evaluating outcomes and alternative models for accreditation, particularly for smaller agencies. Information is not only fundamental to our success in these areas but is another key enabler of change.

Closing Comments

Much of our legacy is in the health care system. Community living services for children and adults were an extension of the services developed to help people who were sick. They were founded in

the premise that to require their service you need to have something wrong with you. As much as our ministry would like to believe otherwise, we have created systems that force us to approach things much the same way. In fact, particularly in recent times when funding has been insufficient to meet needs, we have constructed gatekeeper rules and regulations — roles for ourselves that make people tell how many things they have wrong with them in order to access those services.

We have to change the way we think. We have to move to a philosophy, a culture, rooted in personal capacity, valuing people for their contribution; to an asset-based, closer-to-community approach. This means changing our thinking so we are providing support that will enable individuals to contribute to their community, based on their assets rather than providing services based on their deficiencies.

This way of thinking about community services has been described as “putting everything we do within a framework of citizenship.” It means deconstructing our traditional view of citizens we serve based on their deficiencies and reconstructing our view of the citizen based on capacity.

This is a time of greater fiscal accountability, of restraint and even of cutbacks. It is when we have made this shift in our thinking, and truly believe in it, that honouring the principles and positions outlined in this paper will give us the courage to simply get out of the way. To see our responsibilities in terms of removing obstacles so individuals and families can solve their own problems rather than, as we have done so often in the past, try to insert professional help to fix something that we perceive is wrong. When we do need to provide support, it should support that helps families solve their own problems. It's not like this is completely new territory — there are times when we really get it right — the At Home Program being probably the best example.

But it would be wrong to underestimate the journey ahead of us. The challenge of living the principles and ideas outlined in this paper is huge. The key to beginning this journey is a serious dialogue with the community on governance. A change in governance will invite in other players at the community level that government simply cannot ignore regardless of how hard we try.

The creative tension that characterizes this dialogue with advocates for community living services has worked for us in the past. We were the first jurisdiction anywhere to close adult institutions, we have no children with special needs left in institutions, and we have the best barrier-free legislation and some of the most resourceful employment initiatives in the world. We can be justifiably proud of what has been accomplished in our province. But, in many respects, we have been stalled for the past five years. Maybe it's just that people were taking time to catch their breath and get the wind back in their sails — it is natural that we've stumbled around a bit trying to determine what the post-institutional agenda should look like.

This paper talks about that new agenda — issuing a challenge to once again inspire those around us to innovative and imaginative solutions. Individually, each of us, and collectively, all of us, has to be ready to take up this challenge.