WELCOME TO THE BOARD:

An Orientation for Volunteer Leaders in Community Living Affiliated Organizations

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"Wecome to the Board" is an introduction to selected topics of interest to volunteer leaders in community living affiliated organizations in Ontario. It is meant to be a platform for collaboration and dialogue about values and issues that shape community living organizations. The Provincial Executive Directors Coordinating Committee produced this resource document at the request of Community Living Ontario.

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Foreword

If you are reading this for the first time you've probably been recruited to serve as a member of the Board of Directors of a Community Living Affiliated organization. It is also probable that you or someone in your family is affected by an intellectual disability. Or perhaps, you have been recruited because you can supply a specialized competency that the Board needs, for example a Treasurer with an accounting designation.

Whatever brought you to this role, the chances are that you are not entirely clear on what you've signed on for. There is more to this job than meets the eye. This *Orientation for Volunteer Leaders* may be helpful for you to get your bearing.

Community Living grew out of a social movement in the 1950's and 60's that was driven by parents of children with intellectual disabilities. At the start it was about getting access to public education for children with intellectual disabilities. As the children of the founding generation matured into adulthood, many local organizations moved on to activities intended to offer supports to adults with intellectual disabilities. Many, but not all local Community Living organizations built up service agencies that receive government funding to provide developmental services.

What is most important to keep in mind in your role as a volunteer leader is that the purpose of all this is to make life better for people with intellectual disabilities. That means, among other things, changing how government treats citizens with intellectual disabilities. Throughout our history, changes in public policy were brought about through non-partisan political activities of the organization. Services are only one means to the sought-after end of a good life in the community, and only one of many ways to contribute toward that outcome. There are many things that contribute to a good life in the community and most of them are already in communities throughout Canada, but access is not automatic.

I hope you enjoy your volunteer role in the governance of a Community Living Affiliated organization. In this role you will have opportunities to make a positive difference in your community and in the lives of individuals and families. Community Living was founded by volunteers, built by volunteers, and continues to evolve in communities throughout Canada because of what committed volunteers do. Rest assured; you are in good company.

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Introduction

As a Director of a Community Living organization, you need to know a lot about how your community works. What makes for a good life in this community? Which other community organizations can your organization partner with to advance our purpose? Who are the actors who influence public opinion? Who's got your back, and who do you need to keep an eye on? Many of these concerns are particular to your specific community, and they are part of the work of building up a community's capacity to support a good life in the community. All this is happening within a bigger context with a history, a present, and a future. The subject of this Orientation for Volunteer Leaders is mainly that bigger context.

Community Living began with parents banding together to bring about change in public policy so their kids, who at that time were legally banned, would be allowed in school. Leadership was charismatic in nature and determined to challenge and shake up the status quo in their efforts to bring change.

Over time Community Living organizations developed community programs, initially special schools and later day programs, group homes, and other services. As organizations grew more complex and programs more professionalized, structures of management and governance evolved.

By the 1970s, Inclusion Canada (then Canadian Association for Community Living) had a plan. The aim was to develop comprehensive community-based service systems to replace large, remote institutions. Many factors, including a few insightful allies within government, contributed to building community programs and phasing-down institutions. In 2009 the last of Ontario's provincial institutions closed. Community programs now dominate developmental services. What had begun as a disruptive parents' movement demanding change had become the establishment - the new status quo.

The ten topics I have selected for this Orientation affect all member organizations in the Community Living confederation. They have evolved over many years and are ongoing. With each of these topics I speak to why it is significant, what past this has come from, where we are now, and ideas and indicators of what could be coming next. How member organizations deal with these topics today will affect the future just as surely as the closure of institutions changed today's expectations for people and families.

What would it take to ensure that every citizen living with an intellectual disability can have a good life in the community? The answer to that question has always had two parts. One part is the community must change so that barriers are taken down and people are included in the life of the community. The second part is that people who need specific disability supports to navigate the community have the supports they need when and where they need them.

Community Living is a work in progress. We've come a long way, but the challenges ahead of us are in proportion to what has come before. As a leader in a Community Living organization, you have an opportunity to contribute to the future of your community and the lives of families and individuals.

Executive Summary

This orientation resource is addressed to new and experienced leaders in Community Living Affiliated organizations in Ontario. It speaks to topics that are relevant to local community living organizations and shared interests at community and provincial levels. The Provincial Executive Directors Coordinating Committee produced this document at the request of Community Living Ontario. It addresses the following topics:

1. Board Mandate, Role, and Responsibilities
2. Policy Governance Model
3. Values and Beliefs
4. The Confederation and Its Powerbase
5. Self-Advocacy and the People First Movement
6. The Dual Role of Community Living Affiliated Organizations
7. Resources and Capabilities for Building Inclusive Communities
8. Partnership with the Ministry of Children, Community and Social Services
9. Toward a More Person-Directed Approach: The Evolution of our Service Models and Approaches
10. Human Rights and a Rights-based Approach

Overview of Topics Discussed in this *Orientation for Volunteer Leaders*

1. Board Mandate, Role, and Responsibilities
The Board of Directors acts as trustee-owners to carry out the mission of the Community Living Affiliated organization. Vision, values, and the empowerment of Board, staff and the constituency are emphasized. In this spirit the Board of Directors:

1. Determines its philosophy, its accountability, and specifics of its own job including maintaining the vitality of its constituency.
2. Focuses chiefly on Ends, meaning long-range planning, defining which human needs are to be met, for whom and at what cost.
3. Establishes the boundaries of acceptability within which staff methods and activities can responsibly be left to staff, meaning limiting policies that apply to the Means staff may not use.
4. Makes clear the way it delegates authority to staff as well as how it evaluates staff performance as it advances the Ends and applies executive limitations policies.

Governance models that served well in the decades when Community Living was a parents' movement challenging and disrupting the status quo are increasingly outmoded. An evolution of our understanding of constituents, stakeholders, and members is unfolding in the 2020's. In part it has been prompted by legislation, but mainly it reflects changing times and the maturing community role of Community Living organizations. CLO Affiliates are trying new ideas, sharing experiences, and working toward new norms of board governance.

2. Policy Governance Model
It is the Board's job to provide effective, ethical governance on behalf of the constituents, stakeholders and the wider community for the organization's long-term success, stability, and trustworthiness. It works to ensure that the organization focuses on its Vision, Values, and Priorities for citizens with intellectual disabilities. The Board has additional responsibilities pertaining to public trust that it should make clear to its employees, funding bodies, and the wider community.

The primary tools the Board employs for this role are (a) making policy, (b) monitoring the organization's adherence to policy, (c) evaluating the results, (d) consequent refining of policy, and (e) employing an Executive Director or Chief Executive Officer to manage the organization's implementation of policy.

The Board is responsible to ensure that the organization functions effectively, efficiently, and ethically through clear governance mechanisms. In other words, the Board's job is to govern, and the Executive Director's job is to build and manage an organization to implement the Board's policy agenda. Despite some unavoidable overlap, these two roles should be kept as clear and distinct from one another as possible.

3. Values and Beliefs

Leadership integrity is paramount. Clear, sound values and beliefs are essential to effective leadership. As Community Living organizations reach out in support of families and individuals who are underserved or not served at all, or who need assistance to represent their interests and rights, it will be necessary to approach our work from a strong, clear, and shared value base that applies to everyone without discrimination.

At its heart, our Community Living confederation is made up of people who strongly believe that community living is for everyone, that full school inclusion is important and can be attained, that all people can express preferences and give direction to their life in large and small ways, that all people should be valued and respected, that all people have contributions and gifts to offer their community, that valued social roles can be acquired regardless of ability, and that human rights and justice should be equally available to all citizens. We are not half-hearted adherents to our values and beliefs, no matter how difficult this may sometimes feel in challenging moments.

4. The Confederation and Its Powerbase

Families who are concerned about the wellbeing and future of a family member are motivated to contribute to relevant efforts — Community Living organizations were created by the parents' movement as its toolkit for that job. The movement for Community Living was, and still is mainly driven by families who have a family member with an intellectual disability. By doing their part in a Community Living organization, families have hoped to improve life circumstances for all Canadians with intellectual disabilities, but the main driver for most families is to secure a future for someone very close to home.

As a leader in a Community Living organization, you need to reach out to the whole of the concerned community, not only those who are most in need. Meaningful change in public policy is brought about by people who hunger for change on behalf of someone dear to them. In the long run, we will not be able to help those most in need if we are seen as indifferent to those families whose needs may be modest, or perceived to be out in the future, but who have talents, insights, and energy we need to advance the common cause today.

5. Self-Advocacy and the People First Movement

People who live with an intellectual disability speaking out for themselves can be a very potent form of advocacy. That potency can be enhanced when it is well supported. The self-advocacy movement has strong ties to Community Living. Local organizations that actively involve self-advocates in their governance structure are more likely to stay on track. Two types of support should be distinct from one another: (1) support to autonomous groups like People First, and (2) involving self-advocates in local organization governance. It is very difficult for self-advocates to be able to maintain an independent

voice if their organization or local group is too closely identified with a local Community Living Affiliate or other agency. In general, People First groups guard their independence and maintain some distance from our organization. The key to involving self-advocates in governance is to ensure that self-advocates have access to skilled support to optimize their participation on their own terms.

6. The Dual Role of Community Living Affiliated Organizations

Community Living Affiliated organizations in Ontario carry a dual mandate to enact two deeply rooted and complementary roles:

  (a) Our basic, original community development role as an organizer of concerned people in our communities to advance the interests of people with intellectual disabilities — especially those without adequate support, and

  (b) The Transfer Payment Agency role defined by contractual relationships with the Ministry of Children, Community and Social Services and often other ministries and other levels of government.

The skillful management and balancing of these roles are elemental to the organization's value to people and communities. There is a cleavage between our core role with families and communities and the acquired role of operating government funded and regulated services. Community Living organizations have always engaged with families and their community to make things better for families, especially for those who are without much support. A contractual relationship with government may alter our work plan, but it does not define a local Community Living Affiliate's vision, values, and priorities for advancing the interests of people with intellectual disabilities.

7. Resources and Capabilities for Building Inclusive Communities

Local Community Living organizations are constituted for accountability to our communities through lawful governance structures and parliamentary traditions. When the public views us as an extension of government, that constrains our capacity for our role in community development. Such downgrading of Community Living organizations hinders our ability to recruit board members and volunteers, raise discretionary funds, and invest in vital community development work.

Activities in support of families, family networks, and self-advocates should not be sacrificed by diverting scarce resources from volunteer, non-government sources to cover shortfalls in government funding. Our first loyalty must be to people and families in our communities. The organization should stubbornly resist pressure to starve its first role to feed the second one. We need to invest more in better, more direct ways to support families and grow communities, and we should avoid using volunteer dollars to fill gaps caused by government cutbacks.

We need to ensure that Community Living Affiliate Board members understand that the operating environment is changing in fundamental ways. Government is changing the funding model and we need to think differently. As transfer payment agencies, we urgently need to adapt our business model.

8. Partnership with the Ministry of Children, Community and Social Services

The partnership between local Community Living organization and the MCCSS regional office and its designated contact person requires your attention. The management of this partnership should be conscious and intentional. This relationship, at its best, has the potential to interpret our intentions up the bureaucracy, and strengthen and support our interests and efforts creatively. At its worst it has the potential to aggravate, restrict, reduce organizational efforts, and even remove service contracts. Wise leaders attend to and nurture this relationship.

9. Toward a More Person-Directed Approach: The Evolution of our Service Models and Approaches
There are four distinctly different approaches in Ontario to the provision of services and support for people who have an intellectual disability: (a) institutions, (b) community programs, (c) person-centred planning, and (d) person-directed support. They have evolved over time, and each has influenced what followed. At each stage, service approaches evolved to compensate for the failures and limitations of what existed at the time and in response to external influences. One major influence is the Canadian Charter of Rights and Freedoms which includes "mental and physical disability" as prohibited grounds for discrimination and articulates people's rights that were previously insulted, denied, and overridden.

The institutional approach in Ontario officially lasted for about 135 years (1874-2009). The community programs approach, established in the 1960's, was in part a response to the institutional model that became and remains the predominant model still today. The person-centred approach, often called person-centred planning, grew slowly beginning in the 1980's as a reaction to the limitations of the community programs model. It is significantly influencing how the ways we support people are evolving and how community living organizations are creatively redeploying program resources. Implementation of the person-centred approach has yet to be fully realized and its implications yet to be fully appreciated. As individualized funding supplants program funding, person-directed models are increasingly driving the evolution of supports. The dynamic is different when the service user comes to the planning table in control of the money, especially when assuming a rights-based posture. Over the coming years, this shift is likely to disrupt and extensively transform the way agencies do business.

10. Human Rights and a Rights-based Approach
The concept of *people having rights* is having a major effect on how organizations advance the interests of people who have an intellectual disability. For most of the history of the community living movement advocates used a "needs-based approach" to promoting and advancing goals. This approach is now undergoing a reformation, and a "rights-based approach" increasingly characterizes our efforts.

Human rights are international norms of a high order that outline how people should be treated by their governments and institutions. In Canada a pivotal event in the rights movement was the inclusion of "mental or physical disability" as prohibited grounds for discrimination in the 1982 Canadian Charter of Rights and Freedoms. The Charter entrenched the rights of Canadians with disabilities in our Constitution for the first time. The attainment of that goal inspired confidence and gave tremendous momentum to Community Living's advocacy efforts.

There is now an increasing focus on the rights of persons with disabilities, and law makers are conscious of it. The emphasis on rights was enhanced significantly when the UN General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD) in 2006. Canada ratified the Convention in 2010. The UN CRPD has profound significance for our work.

Reality, of course, is more complicated, but the CRPD sets a course and underpins the principles and values of the community living movement in a clear way. It lifts our aspirations. It gives credence to our emerging person-centred and person-directed orientation.

WELCOME TO THE BOARD

Board Mandate, Role, and Responsibilities

Community Living Affiliate organizations[1] are community-based, voluntary, non-profit organizations supporting citizens with intellectual disabilities. The organization works to build the capacity of its community so that people with intellectual disabilities enjoy equal rights, respect, and belonging. One expression of our *Goal is that people who have an intellectual disability live in a state of dignity, share in all elements of living in the community, and have opportunities to participate effectively*.

This is a much broader societal role than receiving and spending public funds to deliver a government licensed social program. Community Living organizations can be likened to a vital organ of a healthy community. It is integral to the community and cannot function outside its proper context.

The Board of Directors acts as trustee-owners to advance the purpose of the Community Living organization. It emphasizes vision, values, and the empowerment of board, staff, and the constituency of families and individuals with intellectual disabilities. It is dedicated to fulfilling its mandate within the legal framework provided by its Articles of Incorporation and By-Laws. In this spirit the Board of Directors does the following:

➢ Board process: Determine its philosophy, its accountability, and specifics of its own job.
➢ Organizational purpose: Focus chiefly on Ends, meaning long-range planning, defining which human needs are to be met, for whom, and at what cost.
➢ Executive Limitations: Establish the boundaries of acceptability within which staff methods and activities can responsibly be left to staff, that is limiting policies that apply to the Means staff are not permitted to use.
➢ Board-Executive Relationship: Make clear the way it delegates authority to staff as well as how it evaluates staff performance on provisions of the Ends and Executive Limitations policies.

The fulfillment of this community responsibility requires commitment to outcomes consistent with the UN Convention on the Rights of Persons with Disabilities (2006, ratified by Canada in 2010):

• That children are nurtured within a family environment, and consequently enjoy the benefits of family life.
• That children go to their neighborhood schools where they grow and develop together with their age peers.
• That throughout their lives, people have access to and participate in leisure and cultural activities.

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[1] The term "Community Living Affiliate" organization is used throughout this document to mean an organization that is formally affiliated with Community Living Ontario. Not all CLO affiliate organizations are named "Community Living", a term that cannot be copyrighted. For that matter, not all organizations with the term "Community Living" in their names are affiliates of Community Living Ontario. Neither is the commonly used term "Association" universally used by CLO affiliates, and when used may be used in different ways. These artifacts of our history are not easily remedied by changes in terminology; previous attempts to resolve the problem in that way have further contributed to it over time. What binds the organization together is not words, but a shared commitment to a set of values and goals and a shared vision for a future where people with intellectual disabilities can take their rightful place in society.

- That as they grow, young people can aspire to and gain worthwhile career options and appropriate recognition of accomplishment (real work for economically commensurate pay).
- Persons with disabilities can choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.
- Persons with disabilities have access to a range of in-home, residential, and other community support services, including personal assistance necessary to support living and being included in the community, and to prevent isolation and segregation from the community.
- Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.
- That, as a senior citizen, a person can retire with their age peers to enjoy a lifestyle and activities of their choice.

Bringing about these outcomes is usually accomplished, not by the organization acting alone, but through partnerships with families, community groups, and allied organizations that enable and empower people.

To fulfill this mandate, Community Living Affiliate organizations actively engage in non-partisan political activities to influence public policy. Normally this role involves working in partnership with individuals with intellectual disabilities, families, staff, volunteers, and other concerned persons and allied organizations. This work is advanced by providing leadership in advocacy, skill development, and community education.

The above responsibility takes continuing work to ensure that public authorities enact and enforce laws and allocate resources to support citizens to achieve these outcomes. This type of non-partisan political action has characterized the work of Community Living organizations from our origins in the 1950's, and it continues to be essential to success (see discussion of the Powerbase elsewhere in this document).

Evolving governance structures: Constituents[2], Members, and Stakeholders

Distinguishing among members, constituents, and stakeholders has become more complex in recent years. Community Living began as a broadly based social movement. Traditionally, the constituency of families and individuals with intellectual disabilities made up the bulk of the membership and could reasonably be assumed to represent that population. However, as formal membership has declined since the 1980s, that assumption is open to question.

In response to this changing pattern, some local organizations have redefined membership for purposes of the Ontario Non-Profit Corporations Act to equate "membership" with the board of directors itself (closed membership) while putting in place alternative mechanisms to ensure that the Board maintains first loyalty to its constituency of families and individuals with intellectual disabilities. For example, Community Living Kingston and District adopted a policy in 2017 that includes the following statement, "*Community Living Kingston and District will, without exception, operate in the most transparent and inclusive manner possible and will continually engage with and welcome the participation of community members and agency stakeholders as an important part of that objective".* In this governance model, the constituents no longer have a direct vote but instead have assured channels of influence in the

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[2] In this context the term "Constituency" must be interpreted through such mechanisms as the organization has put in place to ensure Board accountability to the families and individuals with intellectual disabilities and other key stakeholders, recognizing that governance structures are evolving with societal change and changing legislation.

governance structure. The term "stakeholder" refers to a wider cohort than families and individuals and includes allied community bodies, partner organizations, employees, and municipal and provincial government entities that share common interests with Community Living.

Community Living Kingston and District (CLKD) provides a living example of a common pattern. For example, in 1992 CLKD (I was ED at the time) had a formal membership of about 150 people made up mostly of aging parents. By the early 2000's constituents were still actively engaged but many regarded formal membership as unimportant. By 2010 the organization had three times as many regular volunteers (~130) as formal, 'card-carrying' members (~40). By 2017, the number of formal registered members had dwindled to the Board itself.

There was a conversation about what could be done, and the decision was made to accept reality and adapt. The organization switched to a closed membership model. The Board adopted a policy statement (noted above) committing to openness and transparency with respect to all stakeholders. It then set about strengthening existing mechanisms for engagement with the constituency of which there were a trove of examples including the following:

- The Family Support Division hosts a monthly drop-in. It is advertised and promoted, and it has been well attended. Families connect with one-another and with information and support to do things like apply for Passport funding.
- On the CLKD website, there is information that is regularly updated and available to all stakeholders. During the pandemic, it has carried a lot of information regarding COVID-19. Ordinarily it is used to share information of general interest.
- There are formal ties to Queen's University and St. Lawrence College.
- CLKD provides instrumental support to a local Parents' Network including meeting space and communications.
- The Education Committee is actively working with local school boards on promoting accessibility and inclusive education.

To be clear, stakeholder involvement did not go down when CLKD switched to a closed membership. The reality is that the organization has a vibrant constituency that is engaged, but the old model of formal membership with its structural subordination to the parents' movement lost its relevance to most people. There were multiple ties to the community in terms of communications, partnerships, and strategic planning. These ties are around interests, activities, and projects.

The role of Community Living organizations in the community 50 years ago was to challenge and disrupt the status quo. Over time it focused on the cause of ending the injustice of large institutions housing people with intellectual disabilities. That lasted until 2009 when the last ones closed. After that time, the role of the organization has been to serve the needs of its constituency and the wider public interest of the community. The switch is the logical outcome of a long-continued series of actions and events that have successfully changed the wider community – not that Kingston has arrived at the ideal, but they're clearly in a different place that calls for a constructive leadership role, and not so much a disruptive one.

In the old days, the board was elected by a constituency of parents involved in a social movement to do their will. Today, CLKD is a community institution with a $24M budget, 300 employees and over 200 active volunteers. It is part of an extensive network of organizations linked by formal partnerships and shared interest. Parents who are involved are unlikely to see themselves as responsible to jump into the

driver's seat and take the wheel. Back then, being on the Board was a highly valued leadership role in the parents' movement, but now it a community leadership role in a completely different environment.

Other Community Living Affiliates are experimenting with other models. Along with the shift in the structure of membership, some organizations have created a tripartite structure in which organized family networks, self-advocacy groups, and professional advisory bodies are each assured a voice at the board table. This model of organizational governance is relatively new and is still evolving. The establishment of norms within the confederation is likely to take several more years of experience with these new and evolving patterns.

Implications for Community Living Affiliate Boards of Directors
Governance norms are shifting as traditional forms of membership are being superseded by more complex structures and mechanisms attuned to Community Living's constituency of families and individuals as well as other key stakeholders and organizational partners. This shift reflects a general trend that has become more pronounced since the proclamation of the Ontario Non-Profit Corporations Act (2010) that regulates and limits the types of membership.

As a newcomer to a Community Living Board of Directors, you may find your organization at the beginning, middle, or maybe near the end of this evolutionary process in governance. Wherever you find yourself, be aware that we're all going through something similar in the 2020's. This confederation has a long history of working our way through one major change after another. We share our growing pains and our learning, and if history is a reliable guide, at some point new norms will be established and generally accepted. These times can be stressful, but a group of committed, well-meaning people can find it invigorating and very satisfying shared work.

Policy Governance Model

It is the Board's job to provide effective, ethical governance on behalf of its constituency and wider community of stakeholders to secure the organization's long-term success, stability, and trustworthiness. The Board represents the community to the organization, and the organization to the community. It ensures that the organization focuses on its first loyalty to citizens with intellectual disabilities. That can be expressed differently by each Affiliate; most expressions resemble Community Living Ontario's long-term Mission, Vision[3], Values, Priorities statements.

The Board is responsible to ensure that the organization is managed effectively, efficiently, and ethically through clear governance mechanisms. These include, but are not limited to:
- an adopted governance framework[4] defined by written governance policies, and regular review of the performance of the organization and of the Executive Director[5]; and
- separating the duties of the Board and Executive Director to ensure that organizational strategies, plans, decisions, and actions are delegated to where they will best advance the interests and performance of the organization over the long term while managing inherent risks.

In other words, the Board's job is to govern, and the Executive Director's job is to build and manage an organization to implement the Board's policy agenda. Despite some unavoidable overlap, these two roles should be kept as clear and distinct from one another as possible.

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[3] **CLO Mission Statement**
> Community Living Ontario advocates with people who have an intellectual disability, their families and member organizations, to create inclusive communities across Ontario.

Community Living Ontario's Vision (2022):
> We envision an Ontario where everyone belongs, is valued, and has the freedom to live the life they choose.

Community Living Ontario's Values (2022)
- Diversity, Equity, Inclusion –We believe in diverse communities where everyone is fully represented and belongs.
- Respect-We welcome and encourage input from those with lived experiences, their families, and member organizations in the work we do.
- Integrity –We always strive to do the right thing.
- Leadership -We lead by example and are seen as leaders in social inclusion.
- Innovation –We embrace new ideas and ways of doing our work by investing in learning and continuous improvement.

Community Living Ontario's Strategic Priorities (2022)
> Priority 1: Lead the way in advocating with people, families, and member organizations to change policy and remove barriers to inclusion.
> Priority 2: Strengthen our members' efforts to realize the shared vision of inclusive communities across Ontario.
> Priority 3: Be a Diversity, Equity, and Inclusion Leader in the Community Living movement.
> Priority 4: Connect, support, and empower families.

[4] The Board of Directors should have written policies to guide the collective and individual behaviour of Board Members that address such topics as conduct of meetings, finance and audit, investments, directors' code of ethics, conflicts of interest, executive succession, and so on. These topics are not directly addressed in this Orientation for Volunteer Leaders; there are numerous reliable sources and generally established practices that Boards can draw upon to assist it in crafting such policies.

[5] Throughout this document I have used the title "Executive Director" although "Chief Executive Officer" is increasingly used by CLO affiliates. I understand these terms to be interchangeable. The Executive Director title is consistent with its use in the organizational names "Provincial Executive Directors Group" (PEDG) and "Provincial Executive Directors Coordinating Committee" (PEDCC).

The Board has additional responsibilities pertaining to public trust that it should make clear to its employees, funding bodies, and the wider community. The primary tools the Board uses to carry out this role are (a) the making of policy, (b) monitoring adherence to policy, (c) evaluating results, and (d) consequent refining of policy.

Community Living Affiliate organizations typically have three levels of articulated policy:

1. Corporate Policy (Articles of Incorporation, By-Laws, Resolutions)
   The *Constituency* has the ultimate power to govern because the organization cannot be sustained without the confidence of its constituency and key stakeholders. Public trust is prerequisite to the exercise of powers to enact and amend the By-laws, elect a Board of Directors, require public reporting by the Board, and ensure there are regular, independent financial audits. This obeisance to public trust is made operable through various mechanisms that are continuing to evolve in the 2020's.

2. Policy made by the Board of Directors (Board Policy)
   The Board governs primarily by making policy, overseeing the organization's activities related to its policy, and by employing an Executive Director to implement its policy. The Board has the power and the duty to hold the Executive Director accountable, and a defined mechanism for that purpose is to articulate policy and require adherence to it.

3. Policy made by the Executive Director (Executive Policy)
   The Executive Director is charged with responsibility to advance the Vision, Values, and Priorities of the organization and may employ any lawful means to do so that are not explicitly prohibited by the Board. Executive policy is made by the Executive Director to give direction and set limits on organizational activities and practice. Subjects of executive policy include finance, human resources, and general practices employed by staff. Executive policy standardizes those functions that need to be stable, reliable, and ongoing.

Implications for Community Living Affiliate Boards of Directors
It is beneficial for volunteer leaders to recognize the value of their own local and provincial level connections (related local, regional, and provincial organizations). Community Living Boards, not only the ED, need to reach out and connect through multiple channels.

The Board should expect and make explicit that the Executive Director should engage with the broader community and relevant local entities, and the ED should participate in provincial level activities. Boards should be clear when recruiting or in succession planning that the job is building inclusive communities; it is not confined to managing the agency and its employees.

An ED who is involved in the broader context can expand the board's awareness of the environment where the organization is operating. That matters because the board needs insight into how its work relates to potential allies (or adversaries). Also, Community Living organizations need to influence the thinking of other relevant actors. The ED's connection and engagement at regional and provincial levels can facilitate the board's influence in the wider community.

Values and Beliefs

Today it would be difficult to find a Community Living Affiliate organization's stated Vision, Values, and Priorities that did not include some reference and commitment to people's dignity, respect, inclusion, autonomy (self-determination, choice), equality, justice, and human rights. Statements of beliefs and values adopted at all levels of our confederation act like the rudder that steers a ship. Formal statements of our values and beliefs are worth investing the time and effort it takes to peel back their layers of meaning and see their sometimes-subtle implications for our work. We sharpen our focus when we cultivate our appreciation of these values.

Clarity about values and beliefs is foundational for leadership effectiveness. We in Community Living take our values seriously. They are not just for *some* people. Over the years this has been debated in many ways. For example, institutions, it was once argued, would always be needed for *some*; or school inclusion, it was said, would be possible for *some*; or we may be able to honour the choice and preferences of just *some* people; or only *some* people may be able to acquire valued roles in the community. The implication in these examples is that our values are tentative and situational.

Community Living has continually championed the application of our values and beliefs to all people. We recognize this as elemental to the social movement that created our organization. We understand that the limitations faced by people we support are built into systems and society, and they are not inherent in the people themselves. For example, we know that all children can be fully included in schools and be with their same age peers if support services and teaching assistants are available and if curricula are adaptable. The way society is structured, with deep-seated attitudes and biases, puts up real barriers for people we are mainly concerned about.

At its heart, our confederation is people who believe that community living is for everyone, that full school inclusion is important and can be attained, that all people can express preferences and give direction to their life in large and small ways, that all people should be honoured and respected, that all people have contributions and gifts to offer their community, that valued social roles can be acquired regardless of ability, and that human rights and justice should be equally available to all citizens, no matter what. We are not half-hearted about our values and beliefs no matter how difficult this may sometimes feel in challenging circumstances.

The debate, growing pains, and ultimate commitment to a clear set of beliefs and values distinguish Community Living from service agencies in general. Values provide grounding for leadership, and they guide us through disagreements and tensions that we work through with our partners and allies.

Increasing respect for people who have an intellectual disability has not come about by luck. For a good introduction, Michael Kendrick (www.kendrickconsulting.org) explores the variables, including leadership, that have contributed in his article *"Historical contributors towards increasing respect for the voice of people with disabilities in western societies"* in the International Journal of Disability, Community & Rehabilitation (http://www.ijdcr.ca/VOL09_01/articles/kendrick.shtml). This article is valuable for volunteer leaders because it gives historical and international context to issues that daily confront the people we support.

Tools and processes that support the alignment of beliefs and values in our everyday actions are essential to the ongoing improvement of our work. In recent years many Community Living organizations have adopted various accreditation programs (CARF, CQL, and FOCUS) to accurately measure their progress and the alignment with their values, beliefs, and best practices. The expectations set out in these accreditation and analysis tools have helped these organizations stay in touch in a practical, applied way with their core values. They also provide a common frame of reference for communicating among ourselves. Measuring what we do and how we do it really is a necessary support to our values in human service practice.

The relationship between values, rights, standards, and accreditation requires conscious attention to their effects and implications for the people we support. Without this attention and analysis, we may be at risk of adopting practices that comply with Ministry regulations but do not align with human rights or other held values. For example, the adoption of Ministry approved physical restraint practices for the management of disturbing behaviour may comply with regulations, but they can run counter to our commitment to human rights and dignity. Consequently, we may at times find ourselves advocating for different practices, or against the Ministry's officially approved practices.

As Affiliate organizations reach out in support of families and individuals who are underserved, or not served at all, or who need assistance to represent their interests and rights, we must approach our work from a strong, clear, and well understood value base that applies to everyone without discrimination.

Implications for Community Living Affiliate Boards of Directors
Leadership integrity is paramount. Values and beliefs have profound implications for the direct support staff of a local organization. Consequently, a high priority is teaching and inspiring commitment to sound values. To ensure we stay on course, leaders such as boards of directors need regular opportunities to grow in knowledge and understanding of Community Living's values and beliefs. This activity is becoming more important as agencies are pressed by the Ministry to comply with their regulatory agenda in a time of fiscal constraint and increasingly centralized management of the service system.

When we are asked by funders to do more and more with less and less, we need to think clearly about what we truly value, not just the price of a unit of service. In practice, trade-offs are unavoidable. Understanding the difference between a trade-off and a sellout is a basic life-skill for leaders. Not being sufficiently alert to the risk can result in betraying our values, perhaps unconsciously.

A trade-off is not letting the perfect be the enemy of the good, while still aspiring to perfection. A trade-off implies a well reasoned decision that considers what is possible to achieve today in the face of external barriers. In a trade-off we resolve to stick with the goals implied by our values and beliefs in the longer term, even when accepting that something short of perfection is the best we can do for now.

It is essential that we strategically prioritize the right values in times of government austerity. As the conflict among the interests of various stakeholders intensify due to fiscal constraint, local organizations will be faced with serious, hard decisions that will have real consequences for the people we support, for their families, and for workers. These decisions need to be transparent, clear-headed, and informed by our shared values in ways that are seen and understood by all concerned.

The Confederation of Community Living Associations and Its Powerbase

The Confederation

Local Community Living Affiliates are connected to an extensive set of affiliations provincially, nationally, and internationally. Community Living Ontario and its affiliated organizations are part of Inclusion Canada (formerly the Canadian Association for Community Living). Inclusion Canada[6] is a national federation of 13 provincial-territorial member organizations. As part of an international network, Inclusion Canada is a member of Inclusion International.

Provincial and local organizations across the country, while linked together, are not all the same. In Ontario, the confederation currently has about 120 autonomous local affiliates that are defined partly by their service role and partly their commitment to promoting and protecting the rights of people who have an intellectual disability. Community Living Ontario (CLO) is the provincial body that engages in and coordinates our advocacy at the provincial level. CLO also engages in community development projects throughout the province in collaboration with local members.

What binds us all together is our shared history, our commitment to a meaningful and progressive Vision, Values, and Priorities, and our collaborative efforts to advance our common purpose.

The history and evolution of the Community Living Ontario confederation

It began shortly after the Second World War when Virginia Glover, a grandmother of a child who had an intellectual disability, wrote a letter to the editor of the Toronto Daily Star (September 29, 1948) soliciting *help and support for the education of children with disabilities in their community rather than just for those living in institutions*. Because of this published, unsigned letter another parent, Wesley Stitt, brought together more than 70 parents to a community meeting in Toronto to advance the aims of "a special type of education" for their children. The Parents' Council for Retarded Children was formed in November 1948, and later incorporated in 1951. It was the beginning of what is now Community Living Toronto.

Prior to that, an experiment was carried out in Kirkland Lake in 1947 to open a class for children who were not permitted to attend school because of the Special Classes Act (1911). The leader was Don Frisby, an auxiliary schoolteacher. The effect of the Act was to prohibit children with an IQ below 50 from attending publicly funded school classes. This first experimental class was funded by service clubs, families, and local community groups. It was the first such education program in the province, and it drew the attention of provincial education authorities.

By 1953 seven parent-based groups in the province, including Kirkland Lake and Toronto, had organized to advocate for public education for their children. These seven parent groups gathered in February 1953 in Hamilton to form our provincial organization. By 1958, when our national organization was founded, over 50 local parents' associations had formed in Ontario. Within 20 years of Virginia Glover's letter, 115 local associations had been Chartered by our provincial confederation. Those organizations share a common history today. In recent years other organizations that may not share this history are affiliating with Community Living Ontario based on a shared vision, values, and goals.

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[6] For further information about Inclusion Canada, see their website: https://inclusioncanada.ca/

The school issue was at the heart of the movement in the early years, and it is noteworthy how those families generously shared their energy, time, and resources towards their shared purpose. A culture of sharing the work is remembered as a defining characteristic of the parents' movement. The founding generation, having grown up during the Great Depression and World War II, shared a belief that institutions and public policy can be made over by people working together. They are our precursors, and they organized to accomplish things that all knew they could not do, or at least not do as well by acting alone. By working together, they changed Ontario for their children and thousands more.

> **A definite improvement in the conditions faced by families and people with intellectual disabilities is possible and is urgently needed in Ontario. Strong collective leadership and robust action are required to make that happen. To bring about such an improvement will take a shared belief that the situation must change, a shared vision of what that change would look like, and able and willing leaders who will carry the effort forward until that goal is achieved.**

How the confederation works

Leadership is a critical component of Community Living, locally, provincially, and nationally. We are most effective when volunteer and family leaders, self-advocacy leaders, and staff leaders work together in close collaboration.

In this confederation strong leadership has been responsible for innovation, change agentry (showing the way forward), advocacy, and conscious risk taking to secure better lives for families and people with disabilities. Leadership is a key and dynamic characteristic of the confederation, and it takes consistent, strategic investments to keep it strong.

Our history, rooted in families working together, is reflected in the way Community Living Ontario is governed today. For instance, each local affiliate is permitted a minimum of three votes at the annual meetings of the provincial body. Local affiliates are permitted an additional two votes if they bring delegates including a self-identified self-advocate and a youth representative. Individual delegates are permitted at the AGM to bring forth Resolutions. Individuals who are active members of their local affiliate organization continue to be integral to this confederation.

Like a family, however, the members and local organizations do not always agree. The disagreements, while at times impassioned and divisive, have allowed for meaningful exploration and debate of our beliefs, values, and our core purpose. We debate and discuss and agree and disagree within this confederation. It is a characteristic of our organizational culture, and we are stronger and more purposeful because of it. We do not shy away from difficult discussions.

Today while a central focus of most local affiliate organizations is running services, Community Living Ontario advocates and promotes the full participation, inclusion and citizenship of people who have an intellectual disability. CLO acts through its policy work, community development projects, public awareness initiatives, education and advocacy, and leadership development.

The Powerbase

Families who are concerned about the wellbeing and future of a family member can be highly motivated to make change happen – Community Living organizations were created by the parents' movement as its toolkit for that job. The movement for Community Living always was, and mainly still is driven by families who have a member with an intellectual disability. At the start, they joined forces with other families who were up against the same unfair situation. By doing their part in the organization, families

have hoped to improve life circumstances for all Canadians with intellectual disabilities, but the main driver for most families is to secure a future for someone very close to home.

Change in public policy is brought about by people who hunger for change for the sake of someone dear to them. Families with a member who has an intellectual disability are the real "powerbase" of this confederation. Their voices are politically credible in a way that paid employees or contractors cannot be. It has always been this way. However, due to a set of factors, this base may be losing its potency. That has worrisome implications, and we need to do something about it.

A source of hope, on the other hand, is growth in self-advocacy. Increasing presence and participation of self-advocates in Community Living Affiliate organizations is growing the powerbase. Our alliance with self-advocates comes from our deep-seated belief that people should have a voice in their own affairs. Through their membership in Community Living organizations and their participation on advisory councils, committees and on boards of directors, self-advocates have become full-fledged partners in our work and a growing part of the powerbase.

The dilemma we face with our Powerbase
When we look back to see who did the heavy lifting over the years, we see intact families of modest but comfortable means – father, mother, and children and sometimes extended family members. In the early days, parents who were able to share care giving responsibilities made it possible for one parent to attend meetings, work on projects, talk to community leaders, and do those time-consuming things that activists must do to succeed.

To be strong and effective today, a Community Living organization needs the same types of inputs as it did in the past. That is, it must be able to engage the resources, time and talents of ordinary families that are intact and strong. Successful leaders know that this contribution is not entirely altruistic. For families to volunteer actively and sustain that effort over time, they need to see a connection between what they're putting into it and improvements in the lives of their family member and others.

Some of our members are quick to point out that during the drive to empty Ontario's last large institutions, people had a sense of being part of something bigger. Membership numbers, while slowly declining as the founding generation aged out, stayed somewhat stable until the final closures of Huronia, Rideau, and Southwestern Regional Centres. After that, the decline was steeper. That people are still being inappropriately placed in Long-Term Care doesn't generate as much excitement. People are still drawn to the organization's ideology, but that is not marketable in the way it was when big, dramatic changes were in motion.

Participation in Community Living organizations as formal 'card-carrying' members has been declining since the 1980's and rapidly since 2009. To some extent, this decrease in that form of participation parallels the movement's success in returning people to the community from institutions. Community Living relentlessly advocated for bringing people out of institutions from 1974 on. In response, institutionalized persons were given high priority for government funding. Also given priority were transition-aged youth with complex needs coming out of the child welfare system. Meanwhile families were put on waitlists during a time of fiscal restraint. In other words, persons who were already seen by government as its dependents were filling up the community programs that volunteer organizations were building <u>while their own kids were asked to wait</u>.

Those priority groups are still prioritized for a large share of the scarce resources allocated to the Ministry for developmental services. While we strongly affirm the importance of supporting the above noted priority groups, being forever on a register or waiting list for services provides little incentive for families to gift their time and treasure to our confederation. Families on waiting lists typically find themselves stressed and lacking time and energy to give. If, on top of that, our organization does not appear to be doing much for one's family member, then diminishing interest and engagement is a likely result.

Implications for Community Living Affiliate Boards of Directors
You as a leader need to counteract the erosion of the powerbase. If you want to have families engaged with and supportive of Community Living's work, then the organization must do things and involve them in ways that families see as relevant to their main concerns. If leaders cannot manage to deliver on that, don't be surprised to see families drift away to other community organizations that they see as more responsive to their priorities.

As a leader in a Community Living Affiliate organization, you need to reach out to the concerned community and those who are doing well along with those who are struggling and most in need. In the long run, we will not be able to help those most in need if we are seen as indifferent to those families whose needs may be modest, or thought to be out in the future, and who have energy and talent to offer toward our common cause today.

We must invest in our powerbase if we expect to be an active confederation that builds up our communities and accomplishes something more significant than run-of-the-mill social programs. This should include meaningful activities and outreach that engage families and self-advocates, whether they are currently counted on our service roles or even on waiting lists. Growing future leadership for your local and our provincial organization is needed and pressing, and that growth will take a well-thought-out strategy for recruitment, training, and engagement of volunteers as well as staff.

Citizens who share a passionate concern, when acting in concert, can re-shape public policy and priorities. That is, in fact, how we got this far. We need to actively remember the lessons of our history. Collaborative work, commitment, and a shared vision were the ingredients that made the Community Living movement successful. Opportunities and actions that foster that spirit are crucial for local leaders of Affiliate organizations today, as always.

Self-Advocacy and the People First Movement

People who have an intellectual disability speaking up for themselves is one of the most powerful ways of promoting and protecting people's rights. It is often called "self-advocacy", a term attributed to the founding group of People First. The self-advocacy movement has strong ties to Community Living. It is an elemental model that Community Living Affiliate organizations can endorse and proactively support.

A prominent example of self-advocacy is People First of Ontario (www.peoplefirstontario.com), a provincial organization with local chapters dedicated to promoting people's voice, rights, and interests. People First has its roots in the mid to late 1970's when people who had experienced institutionalization began to come together and share their experiences. It is now a national organization, People First of Canada. (www.peoplefirstofcanada.ca/).

Being treated with respect and being listened to are foundational aspirations of self-advocates. It is about speaking out with one's own voice and helping others to do so, organizing groups of people with similar life experiences, identifying actions that can be taken to promote people's rights and interests, and educating community members about what is important to self-advocates.

Self-advocacy has contributed to significant change in many ways. It has influenced court decisions and government policy. It has challenged the stereotypes and prejudices of community members. Self-advocates have had a voice at the United Nations and in our country's parliaments. Self-advocacy has had an impact on our service models and our approaches with assisting people daily. It has helped to make us change to more person-directed approaches. Self-advocacy has bolstered people to speak up for their rights and dreams with their families, agencies, communities, and governments. Self-advocacy, at its best, enables people who have been hurt to imagine a positive future. It has supported people to find their voice, stand up and take more control of their lives.

The relationship with Community Living began with the 1979 annual general meeting of Inclusion Canada (previously the "Canadian Association for Community Living") where, for the first time, self-advocates from around Canada were invited to gather and share their stories. This event is generally acknowledged as the start of People First in Canada (see Bruce Kappel's article noted below[7]).

Critical to the success of self-advocacy in general and People First in particular is the support received from allies, advisors, and financial supporters. Founding members of the self-advocacy movement comment on aspects of this relationship in an article entitled *Challenges in Self-advocacy*[8]. This article is an informative read for any Community Living organization interested in advancing self-advocacy. The article notes how skilled support and advice for self-advocacy can enable, facilitate, and strengthen people's voices and People First groups. The article also notes the kinds of interactions that can hurt People First groups and reduce self-advocates and their work to mere tokens of agency interest. This is very important to think about because people with good intentions can (unintentionally) cause harm due to blind spots, insensitivity, or unconscious bias.

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[7] Kappel, Bruce "A History of People First in Canada" in *New Voices: Self-advocacy by People with Disabilities* Edited by Gunnar Dybwad and Hank Bersani, Brookline Books 1996

[8] Hutton et al, Rights, Respect and Tokenism; Challenges in Self-advocacy, Journal on Developmental Disabilities, Vol. 16 No 1, pgs 109-113 (https://oadd.org/wp-content/uploads/2010/01/41006_JoDD_16-1_109-113_Hutton_et_al_v6f.pdf)

In addition to support for People First and self-advocacy generally, many local Affiliate organizations have formally involved self-advocates in the governance structure of their organizations. Sometimes this has been done directly through the local nominations process or through appointments as per by-law requirements, or through the development of committees or councils of self-advocates who then are provided with opportunities to represent their interests at meetings of the Community Living organization. In the latter case these groups should not be confused with People First chapters. They are different groups with different purposes.

Involving self-advocates in the governance of local organizations makes a difference that reflects the spirit and the intent of the UN Convention on the Rights of Persons with Disabilities (CRPD) that was ratified by Canada in 2010. The phrase *"Nothing About Me, Without Me"* was a defining statement during the CRPD discussions concerning the involvement of people with disabilities in the issues that affect them. Many local Community Living organizations have structured this intention into their governance process.

Community Living Ontario has developed mechanisms to ensure the voice of self-advocates is always strongly represented in its governance process. *The Council of Community Living Ontario* consists of 12 self-advocates from across the province that come together to make a difference in the lives of people who have an intellectual disability by making sure their voices are heard. The Council members are elected at Community Living Ontario's annual conference and consist of at least one representative from each of the following geographical areas: Northeast, Northwest, Southeast, Southwest, and Central. They work together with Community Living Ontario's Board of Directors to find solutions and share information, opinions, knowledge, and experience on important issues such as poverty, safe and affordable housing, human rights, and barriers to quality health care.

Implications for Community Living Affiliate Boards of Directors
Two types of support should be distinct from one another: support to autonomous groups such as People First and involving self-advocates in local organization governance. In general, People First groups guard their independence and maintain some distance from local Community Living Affiliates and other agencies. It is very difficult for self-advocates to be able to maintain an independent voice if their local group is too closely tied or is a formal part of a local Community Living organization, especially if support staff are acting as their advisers.

The type of meaningful assistance that Community Living Affiliates have given to People First groups include such things as space for meetings, photocopying and telephone use, sponsorship of people to attend conferences and meetings, co-sponsorship of events (fundraisers, community events), encouragement and facilitation of the formation of autonomous groups, and providing contacts for them to consider recruiting as potential advisors or other allies.

Local Affiliate organizations should consider the involvement of self-advocates in decision making roles in the governance structure. The key to doing this well is to build it so that self-advocates have the necessary and skillful support to facilitate meaningful participation on their own terms.

The Dual Role of Community Living Affiliate Organizations

Community Living Affiliate organizations in Ontario carry a dual mandate and enact two deeply rooted, complementary roles:

1. Our basic, original community development role as an organizer of concerned people in our communities to advance the interests of people with intellectual disabilities — especially those without adequate support, and

2. The Transfer Payment Agency role defined by contractual relationships with the Ministry of Children, Community and Social Services and often other ministries and other levels (municipal, federal) of government.

Mutually supportive, complimentary roles

The skillful management of these roles is elemental to the organization's ability to be of value to people and communities. Advocacy and support are two sides of a coin. It takes both advocacy and disability supports to make the positive difference we envision in the community and in individual lives.

Our long-term goal is to bring about a definite improvement in the life circumstances of Ontarians with intellectual disabilities and their families. Community Living Ontario's Vision, Values, and Priorities drive engagement with communities where families are facing challenges.

Community Living Affiliated organizations have traditionally engaged with families and their community to make things better for families, especially for those who are struggling without much support. Life transitions, for example from child to adult, often bring a crisis because support systems (children's services, education, health, social services, justice) are fragmented and uncoordinated.

Hardship is compounded when rules about service access stand in the way of families linking up and working together to leverage generic and other community resources. In healthy communities, people help each other and do not depend on government for everything. Normal communities have many relevant resources, but access to them is not automatic.

Two sides of a wedge

If we let ourselves be narrowly confined to the role of a delivery agent for a government social program, we will fail in the broader purpose. We could find ourselves cut us off from our roots. That would do serious harm to our ability to engage the community, recruit members and volunteers, and raise discretionary funds. We would forfeit the role we aspire to–to be a vital organ of a healthy community.

Community Living organizations have diverse responsibilities and must manage the competing obligations we have toward people and families versus funders and regulators. There is a crucial distinction between our core role with families and communities and the transfer payment agency role of operating government funded services.

The two roles are usually complementary, but they can become antagonistic. Over the history of Community Living Ontario, these two roles have been at the heart of debates about the gap between our vision—what could be—and reality—what now exists and must be dealt with. As far back as the 1970's Community Living Ontario struggled with the tension between providing services with government funding versus advocating for change. *The Position Paper on the Future Role of OAMR* (David McCoy and Associates, 1976) analyzed this debate. The membership was divided on the question

of whether one organization could enact both roles. It was said that it is hard to advocate for change [in public policy] with our hands held out to government for money.

In an ever-changing society, the Community Living Affiliate's role has shifted away from being the place in the community where people gathered for mutual support, learning and to organize advocacy. Now people get together in one place less often. Some worry that we may lose our advocacy role and become nothing more than a government franchise operation. Something like that happened to home health care providers in the nineties. Others lament the difficulty in attracting new members to carry on this vital work.

Balancing act

Maintaining the balance between these two roles has proven to be a very difficult job. As the demands of being in the service business grew over the decades, and local organizations necessarily became preoccupied with the challenges of funding relationships, quality assurance, compliance checks, labour-management tensions, and other pressures including more and more regulatory requirements.

A Community Living Affiliate that drifts along, allowing itself to be defined by contracts with the Ministry, has lost its way. Local Community Living organizations are not creatures of government. Drifting away from the rights-based social movement weakens our powerbase. Skillful balancing of these complementary roles is the only way to sustain the organization's vital relationship with people and families. A service contract with government may affect our work plan, but it is not our core purpose. It does not define our vision, values, purpose, or who we are.

Implications for Community Living Affiliate Boards of Directors

Community Living's reason to exist as an organization is to improve the quality of life for people with intellectual disabilities through any and all appropriate means. Those means include but are in no sense limited to receiving and spending public funds to run government licensed programs.

Local organizations grow by feeding the rights-based social movement. That is by enabling families to organize around common interests, by reaching out to underserved constituencies and organizing a political response, by enabling self-advocacy and family support groups to form (without having to control them), by developing activities to enhance the community's ability to accommodate and welcome people (community development projects), and by developing non-traditional supports to people and families of types not funded by the Ministry.

A balance point between our contractual obligations to government and building up the capacity of communities to include people must be found and maintained. A broader strategy than service is required to promote and protect the rights and interests of people who have a disability and their families.

In the wider view, formal, regulated developmental services are only one relatively small piece of a healthy, inclusive community where people with disabilities and families can thrive. Keeping that in perspective is critical if we are to seize opportunities to achieve definite and clearly visible improvements in the situation faced by Ontarians with intellectual disabilities and their families.

Resources and Capabilities for Building Inclusive Communities

We need to better define what it takes for people to commit to stand together and to stand up for one another in the face of competing interests. There is a need today to restore the balance between the business of developmental services and our member organizations' close identification with families. Partnerships with families beyond the boundaries of the service system is crucial.

The competing demands of our dual mandate can challenge Community Living Boards. For example, an issue affecting families is the government's rules for applying for services. The way that process works interferes with our traditional role in organizing families to leverage community resources. What people typically need is access to ordinary and specialized resources that may need to be augmented or supplemented with disability supports. That dynamic is short-circuited when families are directed to go through the Developmental Services Ontario (DSO) office as a first step. This reverses the sequence and works like a wedge between families and the supportive, inclusive community we're working to build.

Community Living Affiliated organizations have traditionally partnered with families and community leaders to make life better for families. Many families continue to face hardship. Resources are always scarce, and the need is great. We have a practical role forming alliances with families who are <u>not</u> getting supports as well as those who are.

Community Living Affiliated organizations are constituted for accountability to our communities through lawful governance structures and parliamentary traditions. Being misleadingly identified as an extension of government constrains our capacity for our role in community development. It redefines the organization as a franchise operation that delivers programs for MCCSS (and nothing more). This is a pattern of miscommunication that negatively impacts how potential board members and volunteers see the organization. That in turn impacts the ability to raise discretionary funds and engage the community.

A system apart from the community will not achieve the goal of a good life in the community.
The provincial government looks at the developmental services system as a free-standing government program apart from its community context. They are committed to manage this system better and more efficiently, but their efforts to do so are often decontextualized and discordant.

Families and people who deal with the system want it to support people, as and when needed, to live good lives in the community. When the system acts as something apart for the community, it frustrates the central goal of having the support one needs to enjoy a good life in the community.

One of the four strategic goals identified in the Provincial Executive Directors' Work Plan is "*To ensure that public resources will be applied to meeting individual, and community needs in a fair and equitable way, subject to transparent public oversight, in an environment where innovation and improvement are encouraged and supported*". Meeting this goal will take prudent management of the resources available to families, communities, public services, and Community Living Affiliate organizations.

Despite the discordant effects of setting up the system to be apart from the community, there are opportunities and challenges worth pursuing in this situation.

1. <u>We can establish and maintain fiscal transparency linking expenditures to person-outcomes</u>
   Accountability for public funds implies that spending is consistently linked to outcomes for persons served. This works both ways: (a) measure the benefits for people that result from prudent spending, and (b) measure the impact on people consequent on under-funding or cutbacks in funding. Outcome measures that relate dollars to person-outcomes can show the connection between spending and results. This information should be applied in the budgeting process.

2. <u>We can encourage innovation and excellence through quality improvement</u>
   Individual funding and person-directed planning tend to drive innovation because people seek out or invent what works best for them, rather than just accepting what is on offer. Initiatives such as the Housing Task Force[9] illustrate possibilities, but so far, they have had little global impact on the system. Community Living Affiliates are typically open to innovations that emphasize reducing the level of control imposed on people's lives by the conditions for access.

3. <u>We can ensure that individual supports purchased with public funds meet quality standards</u>
   There may be opportunities to work collaboratively with the Ministry to improve access to quality supports. It could serve the interests of government to ensure that families with Passport funds can apply those resources to supports that meet clear standards to ensure safety, inclusion, and adherence to labour laws. We can work together to get results that better satisfy the Ministry's objectives and the needs and goals of families and individuals.

4. <u>We can find opportunities to improve administrative effectiveness and efficiency</u>
   Community Living Affiliate organizations are usually open to proposals for office consolidation, partnership, or amalgamation where such changes would not run counter to our shared values. We are accustomed to working together to develop collaborative arrangements among Community Living organizations. Ideas for combining or sharing administrative, human resources, and/or clinical expertise and services should be considered and evaluated carefully when an opportunity to make a change arises.

The threat to families, individuals, and Community Living organizations if we fail.
Families use their Passport funds to buy a safe place for their family member while the caregiver(s) goes to work each day. Passport allocations are often insufficient to pay for quality support, so compromises are made. In response to that economic reality, entrepreneurs set up low-cost congregate care. The result is that public funds are financing low quality service models like ones the Ministry has condemned and dismantled in other times and situations.

The Ministry's increasing reliance on outsourcing to private operators, such as for-profit group homes without effective quality control, compounds the problem over time. Long waitlists and inadequate direct funding have the unwanted consequence of forcing people to rely on child welfare, health services, long-term care, police services, correctional services, and opportunistic entrepreneurs to patch the holes in the safety net.

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[9] https://www.planningnetwork.ca/en-ca/Resources/27718/final-report-project-outcomes-supporting-resources

A generalized erosion of quality follows from the Ministry's practice of placing excessive emphasis on risk avoidance and cost containment. Risk mitigation can also stifle choice because living a good life in the community inherently comes with risk. That leads to systematic impoverishment of formal services over time because some cost factors cannot be contained due to inflation and legal obligations such as Pay Equity.

None of these outcomes are consistent with the policy direction articulated by MCCSS or by Community Living. To avoid these undesirable outcomes will take a collaborative approach on the part of government and service provider organizations.

Implications for Community Living Affiliate Boards of Directors: Make New Rules

- **Keep funds that belong to the community segregated from MCCSS transfer payment funds.**
  Why: Our first loyalty must be to people and families in our communities. The organization should stubbornly resist pressure to starve its first role to feed the second one. It is necessary to protect those scarce resources that are available for building stronger communities. The Affiliate organization's community responsibilities, such as opportunities related to the PEDCC's Strategic Goals on "Families and Communities", and "Child-Friendly Communities", should not be sacrificed by diversion of scarce resources to cover shortfalls in government funding. Some weakening of community capacity for inclusion in recent times points to a necessity of keeping community dollars separate from transfer payment dollars. If government funding is insufficient, that does not justify taking funds from volunteer and non-government sources that are needed for other family and community priorities.
  (Note that government counts on agencies and families to raise funds to bridge gaps caused by inadequate program funding.)

- **Raise discretionary funds that are not tied to Ministry licensed programs so we can invest in building the community's capacity to include people with disabilities.**
  Why: Responsibility toward families, family networks, and self-advocates should not be sacrificed by diverting scarce volunteer (non-government) resources to cover shortfalls in government funding. There are better, more direct ways to support families and grow communities than by raising volunteer dollars to fill gaps caused by government cutbacks.
  (Note that the Ministry is moving money from program funding to direct-to-the-family funding, thereby casting agencies in the role of vendors. In addition, the Ministry shows resistance to funding core agency operational and administrative functions.)

- **Recognize and adapt to the changing business environment. We need to ensure that local Board members understand that the operating environment is changing in fundamental ways.**
  Why: As transfer payment agencies, we must adapt our business model to survive the changes government is making to the funding model. We need to think differently about customer service, fixed costs, and labour relations among other things.
  (Note: MCCSS is pushing the system in a different, market-based direction.)

Partnership with the Ministry of Children's, Community and Social Services

The partnership between a local Community Living organization and the MCCSS regional office and its designated contact, typically a Program Supervisor, requires your Board's attention. The development of this partnership should be conscious and intentional. This relationship at its best has the potential to strengthen, interpret up the bureaucracy, and support community interests and efforts creatively. At its worst it can aggravate, restrict, reduce organizational efforts, and even withdraw service contracts. Wise leaders attend to and nurture this relationship.

The relationship with the Program Supervisor may have many practical forms of expression. Some local Affiliates invite the Program Supervisor to attend general and annual meetings of the organization. They may come as a special guest at sponsored events, for example an employer recognition breakfast that celebrates the hiring of people with disabilities. The Program Supervisor may be invited or may request an invitation to address the Affiliate's Board of Directors from time to time. These occasions are opportunities for a two-way dialogue to promote understanding about Community Living's values, plans, concerns, and operational issues while at the same time hearing from the Ministry about its interests.

The relationship is also evident at local service system planning tables. These meetings typically include the Program Supervisor and the executive directors of MCCSS developmental service agencies (a larger cohort than Community Living Affiliated organizations) and can include other community partners in health, child welfare, social services, police service, and municipal governments. These are not "planning" meetings in the strict sense of the word. However, they offer opportunities to exchange information and views about policy and operational issues, to organize some service responses, and to speak frankly about concerns such as growing waiting lists or the effects of regulations.

Keeping the Program Supervisor informed and engaged with our issues is about more than compliance with regulations, such as reporting serious occurrences. It should be an eyes-wide-open strategy to cultivate a strategic partnership.

Maintaining the "no surprises" rule is a prudent consideration. Boards wisely practice open dialogue with the Program Supervisor as a strategic partner to keep them informed of issues or actions that may affect the Ministry. We should avoid blindsiding the Program Supervisor with advocacy aimed at elected officials, and it is best to have him or her in a position to explain our intentions to those higher in the bureaucracy. This could include alerting them ahead of time about advocacy activities in support of our constituency's interests. It could also include keeping the Program Supervisor informed as to the outcomes of political activities (correspondence, meetings, actions, etc.) with local MPPs or senior government officials.

However, despite our best intentions, this relationship can sometimes become strained. That can happen because of actively honouring our dual role, promoting, and protecting people's rights and interests, while at the same time implementing MCCSS service contracts. This can occur when the Ministry's priorities compete with service users' rights and interests. For example, a request to quickly fill a vacancy in a residence with a high priority person on the government waiting list, as opposed to respecting a promise to current residents that they will have a say in who moves into their home.

Boards must skilfully manage these competing interests in the context of a government partner who may view the local organization as the Ministry's service tool and not value our community activities. They may not always respect our commitment to the values and principles that define us as *more than an extension of government* if, in fact, the Ministry sees us as exactly that. Civil servants who come to the Developmental Services Branch from other Ministries or other branches of MCCSS may not have considered that Transfer Payment Agencies could be anything other than a tool of government.

The relationship with MCCSS is unique in another significant way. Community Living Affiliated organizations grew from community roots with a mission to change public policy and priorities. At its essence, a Community Living organization is not like a school board, a child welfare authority, or a public health agency. These entities are public authorities that exist for a specific public purpose.

Local Community Living organizations began as a grassroots advocacy movement before government responded to our cause and have evolved as autonomous, non-profit, community organizations. We have a duty and a mandate handed to us by our community constituency of people and families to always represent their rights and interests — and *sometimes* to provide services and supports.

Over time, however, the provision and growth of MCCSS funded service contracts have created conditions that are bending our relationship toward the government. Some argue that it has brought us much closer to the hierarchical relationship that government has with other service providers such as child welfare, school boards, public health, or Community Care Access Centres. CCACs, you may note, do not advocate for elderly citizens or people with physical disabilities; their role is to fund services and monitor compliance with contracts as per Ministry of Health directives. Local Community Living Affiliates do not revolve around mandated services like those above, but around voluntary supports (not entitlements) for people with intellectual disabilities and their families.

The Social Inclusion Act[10] details the conditions and protocols whereby the MCCSS could assert control over a local agency's operations. This is new and largely untested ground in our partnership. It has been argued that the autonomy we once had is being incrementally taken away.

It is quite unclear how the "take-over" provisions of the Social Inclusion Act would play out in such a scenario. Community Living Ontario contends that its advocacy efforts have resulted in the wording of the intrusive regulation concerning "take-over" being changed and consequently confined to only MCCSS funded services. However, assets are entangled. For example, residential and other programs often operate in or on properties that were acquired with volunteer fundraised dollars. In fact, many local Community Living organizations receive funding from multiple sources including municipalities, various federal and provincial ministries, donors, and fundraising organizations such as the United Way.

The context for this shift in the relationship is (a) the growth of our service contracts over the years and (b) the increased emphasis on systems management and the related compliance requirements from the Ministry. It is also a reflection of the fact that we no longer have government operated institutions as the service provider of last resort. Consequently, community agencies are required to fulfill government commitments to people formerly in their care. Community agencies are now the service providers of last resort, and although there is no statutory entitlement to developmental services, no government

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[10] The Services and Supports to Promote the Social Inclusion of Persons Act (2008), often referred to in short form as the "Social Inclusion Act".

wishes to be seen to be abandoning dependent, vulnerable citizens. We (community agencies) are now government's primary if not its only means of meeting certain of its fiduciary responsibilities.

Community Living leaders are concerned about the effect of the management provisions of this Act on our mandate to vigorously promote and protect our constituency's interests. In the eyes of the funder (MCCSS) we operate *under government license* and how we may perceive our duty to our constituency is often of little or no interest to them. The effect of this trend toward being seen to be an extension of government must be carefully monitored so we do not lose sight of our original, core purpose and duty to influence public policy in the interests of our constituency. We need to be able to continue our advocacy efforts both locally as community associations and provincially as a confederation of Community Living Affiliated organizations.

Implications for Community Living Affiliate Boards of Directors
Skilfully balancing our dual role without over-stressing our partnership with MCCSS promises to be a challenging role for the leaders of local organizations into the future. This is not new — it always has been so — but probably more intensely so in the future.

Leaders at the local level should pay attention to government's increasing emphasis on management of the developmental services system and the risk of it undermining our allegiance to our core values and purposes. We must ensure that the decisions we make in the future do not degrade the relationship we have with people, families, and communities. We must guard against drifting into seeing them as our "clients" rather than our constituents to whom we owe our first loyalty.

This issue is important to every local Community Living organization and is one of the reasons why we have needed a strong provincial confederation from 1953 until today — and tomorrow. We need to be effective partners with government, and if we remain strong and committed to our values, we can avoid being reduced to the status of servants to a branch of a ministry of a provincial government. This has not been easy, and it appears to be getting harder. The future will undoubtedly continue to test this partnership, but it is too important to us – and to them – to let it slip away.

Toward a More Person-Directed Approach:
The Evolution of our Service Models and Approaches

Ontario has four distinctly different approaches to the provision of services and support for people who have an intellectual disability: (1) institutions, (2) community programs, (3) person-centred planning and services, and (4) person-directed planning and individualized support. They have evolved over time, and each has influenced what followed. These service approaches have evolved because at each stage serious limitations were recognized in the previous model and because of significant external influences such as the Canadian Charter of Rights and Freedoms (1982). The Charter included "mental and physical disability" as prohibited grounds for discrimination and articulated people's rights that were previously denied and overridden.

A brief overview:

1. The institutional approach in Ontario officially lasted for about 135 years (1874-2009) and continues to influence the thinking of some members of the public. People with intellectual disabilities being inappropriately placed in long-term care facilities is evidence of its persistence.

2. The community programs approach, established in the 1960's with the enacting of the *Vocational Rehabilitation Services Act* and the *Homes for Retarded Persons Act*, was in part, a response to the institutional approach and became the predominant model. Traditional program-based services were developed to deliver supports to people on a needs-based approach as in "what do you need; here's what we can offer".

3. The person-centred approach, a needs-based approach often referred to as person-centred planning, grew slowly in the 1980's as a reaction to the limitations of the community programs model and is now commonly cited in both community living and government literature. It is significantly influencing how the community programs model is evolving and how community living managers and workers are creatively redeploying their program resources. The potential of the person-centred approach has yet to be fully realized and the implications yet to be fully appreciated. It is a profoundly different service approach than we had seen in the past.

4. As individualized funding models supplant program funding, person-directed approaches are increasingly driving the evolution of the field. The dynamic is different when the service user comes to the planning table in control of the money, especially when assuming a rights-based posture. Many progressive agencies are now moving to a more responsive service delivery model based on choice and tailored to people's goals where self-determination, flexibility and creativity are highly regarded. Over the coming years, this shift is likely to disrupt and extensively transform the way agencies do business.

Institutional Approach
There are three big implications of the institutional approach: (1) people are congregated together and excluded from the mainstream of community life, (2) societal attitudes and beliefs about people who have an intellectual disability are negatively affected in many ways because of the images and messages associated with institutions, and (3) important and valued life experiences of people themselves are

severely diminished, (i.e. respect, dignity, autonomy, competence development, belonging, and being in caring, loving relationships). Many people have lived lives of hurt, anger, abuse and despair in institutions and had their basic human rights insulted, denied, and overridden.

Within the institutional approach have been several different models that reflect beliefs and values as they changed over time. The *custodial model* of the late 19th century lasted well into the mid 20th century and provided for the very basic necessities of life. Some would argue that this is a *too kind* interpretation of the model. The *medical model* which saw people's lives defined by medical authorities and surrounded by people with medical-type professional identities (doctors, nurses, etc.) was predominant from the early 20th century (some models overlap). This model reinforced the still held perception that people are sick or afflicted and require medical care. This idea is so deeply entrenched in society that citizens with intellectual disabilities are still being inappropriately placed in long-term care facilities. People were often referred to and known by a diagnosis rather than a name. It officially lasted until the transfer of responsibility for funding, services, and people from the Ministry of Health to the Ministry of Community and Social Services in 1974 under the Developmental Services Act. This transfer was also symbolic in that the issues and concerns of people and families were no longer defined as a health issue but a matter of community capacity.

Attempts were made to improve institutional life in the 1960's and 70's, partly because of advocacy from the parents' movement and the rise of community services. The *developmental and rehabilitative models* were introduced. These models focused almost exclusively on the deficits and deficiencies of people and how to address these identified problems. This gave rise to all manner of plans and programs usually beginning with the word "individual" *{Individual Program Plan (IPP), Individual Treatment Plan (ITP), Individual Development Plan (IDP), Individual Service Plan (ISP), Individual Education Plan (IEP)}.* The deficit-based assumptions, however, did not address people's real need for being listened to, being respected, being involved, having control and choice, and having meaning and purpose. And it did not address societal prejudice, misunderstanding or the need for people to claim and exercise their basic human, legal and civil rights. It was limited to the service responses that the service provider could offer and did not include contributions from the individual, or their friends, allies, and families. Most importantly, the assessment and diagnostic tools associated with individual plans did not uncover people's hopes, wishes, preferences, passions, gifts — nor their fears, frustrations, anxieties, or nightmares. It did not help understand who a person really is as a human being. It focused on their "problems" and their disability and not on their personhood, rights, and opportunities for personal fulfillment. It would not be until the rise of a more person-centred approach in the 1980's that these personal questions would begin to influence service design and the system.

Community Programs Approach
The community programs approach really grew out of the institutional approach, even as a reaction to it. Initially it differed mainly by scale and by locating programs in neighbourhoods and communities.

The community programs approach has been somewhat successful in that it built the architecture of the current service system and captured hundreds of millions of dollars in new funding. It was successful also because it provided a progressive continuum of program support that could respond to people at different stages of their life. It evolved to provide real opportunities for people to live and participate in their communities. It helped bring people out of institutions. It developed and enabled employment, places to live and a context for real friendships and intimate relationships to grow. It provided comfort

and care for thousands of people. It is the approach where we learned how to improve our ideas and our work. It continued to evolve over the decades, but that evolution ran into barriers.

The community programs approach does have some serious limitations. After a time, they became painfully obvious. If managers aren't sensitive and careful, day programs, residential programs, work programs, recreational programs, can circumscribe and define life for people. We discovered that it was possible for people to live in community programs and still be socially isolated.

The community programs approach is funded through monies allocated for beds and spaces. From 1974 on, Community Living managers typically submitted proposals to their MCCSS Regional Office for, say, eight more beds or sixteen more spaces. And into the bed or the space went people who were treated as interchangeable units. As a person moved on or away (or died) the bed or the space was simply filled by the next person. While consideration was given to "best fit" there usually wasn't much discussion with other people in the home about whom they might want to live with. Vacancies were usually filled by the next in line, not chosen by a person from a range of options.

Within the community programs approach, choice was typically accommodated by offering another program. For example, when it became clear that some more independent people do not need the support of a group home, we created a different program–the supported independent living program (SIL). Similarly, when we recognized that group work activity, often called vocational programs, did not serve the interests of some people, we built a supported employment program, or a retirement day program was rolled out. When we recognized that people needed more physical activity, we started a recreation program.

We learned to see people as beneficiaries having needs that we could fill with programs.

Often the programs we offered had similar problems as institutions had, but in a more local context. Our programs often led to people being separated from other citizens or even excluded from typical community activities. By doing so we (unintentionally) reinforced stereotypic perceptions that *"they belong with their own kind, over there".* We (unintentionally) diminished our communities' capacity to accommodate differences and be more welcoming and interdependent. And we (unintentionally) created a 'service life' for people as opposed to a community life.

As a result of the limitations that were widely recognized by the end of the 1980's, community living managers began to unbundle program resources so we could use them in more and more person-centred ways, sometimes bending and warping the terms of funding contracts. Sometimes we sought approval after the person-centred change or innovation had been introduced. While it is not easy to adapt community programs, this response demonstrates the level of commitment to our values and the type of calculated risk taking that has characterized community living leaders since its inception.

Person-Centred Planning and Services
One definition: *Person centred planning refers to a family of approaches to organizing and guiding community change and to creatively seeking principled resolution to the real and enduring conflicts in collaboration with people who have an intellectual disability who want to consider a change in their lives that requires organized support or adaptation of available services or policies*[11].

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[11] John O'Brien and Connie Lyle O'Brien, Responsive Systems Associates

Person-centred planning aims to change the common life experiences of people who have a disability. It aims to change the community's pattern of living with people who have a disability. It aims to redesign service practices, policies and how service systems work. And it aims to engage personal commitment from friends and allies to make change happen, and success depends on maintaining a shared vision among these stakeholders. Just imagine …

- Imagine a time when everyone, families, allies, service workers, service managers and government officials, sees a single person as the unique focus in the planning, development and delivery of whatever support or service they want and need.
- Imagine the thinking, planning and implementation of a more desirable future for a person as including those who really know and care about that focus person, and imagine seeing these allies as integral to the effort.
- Imagine a "plan" that begins with really and truly listening to what a person has to say about their life, with all the time and support to do so.
- Imagine a "plan" that begins with discovering how a person wants to live or spend their time, what gifts and talents they may have to offer others, what bores the person to tears and what interests or even excites them to no end, what it's like for a person when they are at their best.
- Imagine a "plan" that enables all people in the neighbourhood and community to get to know each other and see each other for real valued citizens and sees each person's potential.
- And imagine a "plan" that welcomes communities and neighbourhoods as assets with opportunity and capacity.
- Now imagine translating this very personal plan into a clear definition of what it would take to actualize the life that is envisioned including costs for disability related supports that are tailored to the person just as a pair of glasses or a prosthetic arm is customized.
- Imagine that the funds for disability related supports are portable, flexible, and responsive to changes in circumstance. The support goes with you wherever you go.

Person-centred planning envisioned such an approach when it was introduced in the early 1980's. It was responding to the limitations of the community programs model. Its influence has grown significantly even though the implementation of key elements is still more often the exception than the rule.

Person-centred planning was adopted as government social policy in the United Kingdom through the 'Valuing People' White Paper in 2001. In 2011 the first international conference on transforming the community programs model to a more person-centered approach was held in San Francisco.

A practical challenge for community living proponents of person-centred planning has been how to personalize the community program model and discover how best to assist people to live in their community (and not in "programs"). This challenge has drawn on the creativity and commitment of people served, families, service managers, direct support workers and sometimes Ministry officials.

A current example of this approach can be seen in the 2020-21 virtual Community of Practice (CoP) on the topic of Re-Imagining Day Supports. In the aftermath of having programs shut down or shifted to virtual during the COVID-19 pandemic, Community Living Affiliated organizations had a unique opportunity to return from the situation of people being isolated and dependent on virtual supports to re-engaging with their community in new ways. The CoP has provided an opportunity for interested agency leaders to share ideas and network with likeminded colleagues throughout Ontario.

There are many examples of similar thinking and processes being applied to personalizing living arrangements. When personalizing the community programs model it is often best to consider moving forward individually but with several people at the same time who are all sharing a bundle of resources that can be unbundled, such as a group home.

Personalizing the community programs model is a good way to develop the organizational capacity to respond to individual differences and to grow, adapt and engage the social capital and flexible service resources that make person-centred planning work effectively.

Person-centred planning is everywhere in one form or another even though it still depends on shared good will and voluntary coordination. The intentions, words and even actions of leaders in the field are littered with references to it. Go to any conference, read any government document, or speak to any advocate or service manager these days and you are likely to see or hear something that relates to person-centred approaches.

Read the proud stories that local Community Living organizations boast in their newsletters, or on their websites. It usually has to do with a person and how they have been welcomed, included, supported, mentored, and befriended. It is usually about an accomplishment or relationship. It is often about personal autonomy. If you dig deeper behind the story, typically, you will find lots of invisible hands and hearts and minds enabling this personal story.

Leaders in the Community Living movement strongly believe that we should be person-centred and that we should focus our energies on solving the problems associated with this approach. Bringing a more person-centred approach to our work in a time of protracted funding constraint will take boldness and commitment to our work at all levels—policy, practice, systems, and service reformation.

Securing person-centred plans by means of direct funding and person-directed support
There are many proponents, including Community Living Ontario, who advocate taking the person-centred approach a step further and ensuring that supports are "person-directed". The thinking around this change is that person-centred approaches can, and sometimes do get hijacked. Lazy managers can let them degrade to the level of the IPPs of the 1970s and tamp down the person's active participation. On the other hand, a person-directed process cannot happen without the person's active engagement. With the shift to direct individual funding, we have a paradigm shift that empowers the individual in an unprecedented way. It is a shift in thinking from needs-based to rights-based. Over the coming years, this shift is likely to disrupt and transform the way agencies do business.

Implications for Community Living Affiliated Boards of Directors
Up until recently, agency staff have entered the person-centred planning process in control of both the delivery of disability supports and the program funding, resources that the agency could unbundle. In the developing scenario where the service user comes to the table with direct individualized funding, the agency is cast into the role of a vendor. Correspondingly, service users increasingly see this is the way things should be. That shift at the planning table can be expected to change the dynamic incrementally as more and more service users gain control of their funding.

Individualization and person-directed funding tend to drive innovation because people seek out what works best for them. People typically choose to minimize the amount of intrusion into their personal lives, and that usually translates as taking only the support that the person really needs. Will that

translate into efficiencies? Our new leaders will need to be agile as the new paradigm shifts the ground under our feet.

Today one of the big challenges for local Community Living organizations is how to avert having old-style program responses dressed up and relabelled as 'person-centred'. The leadership of tomorrow is saddled with the responsibility of continuing the evolution of our work from the community programs model towards a more person-centred/person-directed approach. It will take work with all the partners at all levels.

Adapting our business model to changing market conditions is a matter of survival. Agencies increasingly depend on paying customers who are often not getting enough funding to cover the cost. At the same time, transfer payment agencies are regulated by a government that demands measures it won't fund directly. This puts agencies in the precarious situation where operating costs exceed what customers can afford. A major challenge in the 2020's will be evolving the business model of agencies to support the lives people choose for themselves without crashing the agency off a fiscal cliff.

There needs to be adequate funding that is portable, flexible, and responsive. Advocacy efforts to achieve this goal will be necessary. For such advocacy to have sufficient impact, history would suggest that local organizations acting alone are not likely to get very far. All stakeholders need to speak with "one voice", or experience shows that we're likely to be played against one another. Coordinated efforts in collaboration with allied organizations of families, self-advocates, and other partners including Community Living Ontario and the Provincial Network on Developmental Services, will all be needed to succeed.

Human Rights and the Rights-Based Approach

Human rights are international norms of a high order that outline how people should be treated by their governments and institutions. For more information on human rights, the following UN link *"What are Human Rights"* is helpful: http://www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx

In Canada a pivotal event was the inclusion of "disability" in the 1982 Canadian Charter of Rights and Freedoms, which for the first time entrenched the rights of Canadians with disabilities in our Constitution. When the Charter was being drafted the Canadian Association for Community Living (now Inclusion Canada) vigorously advocated for the inclusion of "mental and physical disability" as prohibited grounds for discrimination. For the first time, Canadians with disabilities could claim equal protection and equal benefit of the law without discrimination under Section 15. This milestone achievement inspired confidence and gave tremendous momentum to our advocacy efforts.

For example, Ontario Court of Appeal Justice Louise Arbour invoked the Charter in the case of *Emily Eaton vs the Brant County Board of Education* (1996). Arbour, in her landmark ruling in favour of the integration of a child in a local school in Ontario, ruled contrary to the rulings and administrative decisions of lower courts, the Ontario Ministry of Education and the local School Board.

Canadians are increasingly focusing on the rights of persons with disabilities, and Canadian law makers know it. Our emphasis on rights was boosted when the UN General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD) [12] in 2006. Canada ratified the Convention in 2010.

The concept of *the rights of people* has had a significant effect on the approach used by organizations in advancing the interests of people who have an intellectual disability. For most of the history of the community living movement advocates relied on a "needs-based approach". This approach is now undergoing a reformation, and a "rights-based approach" is beginning to characterize our efforts to communicate and advance our constituency's goals.

Rights-Based Approach vs Needs-Based Approach

A good description of the difference between the rights-based and the needs-based approach is found at the following link: http://www.unfpa.org/rights/approaches.htm
...... (agencies) pursuing a "basic needs" approach identify basic requirements of beneficiaries and either support initiatives to improve service or advocate for their fulfilment.
...... a rights-based approach works to fulfil the rights of people, rather than the needs of beneficiaries. A need not fulfilled leads to dissatisfaction. In contrast a right that is not respected leads to a violation, and its redress or reparation can be legally and legitimately claimed.

A human rights-based approach to programming differs from the basic needs-based approach in that it recognizes the existence of rights. It also reinforces the capacity of duty bearers (usually government) to respect, promote, and guarantee these rights.

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[12] United Nations Convention on the Rights of Persons with Disabilities (CRPD)
https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

A rights-based approach develops the capacity of duty bearers to meet their obligations and encourages rights holders to claim their rights.

In a rights-based approach every human being is recognized both as a person and as a rights holder. In a rights-based approach mechanisms are developed to ensure that entitlements are attained and safeguarded.

Implications for Community Living Affiliate Boards of Directors
The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) has profound significance for our work. Consider the following clause from the preamble:
(n) recognizing the importance for persons with disabilities of their individual autonomy and independence, including their freedom to make their own choices

And consider the implications of Article 19:
Living independently and being included in the community.

State parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation, including by ensuring that:
  (a) *Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement,*
  (b) *Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from the community,*
  (c) *Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

These CRPD references entitle persons with disabilities to claim rights heretofore only offered as possibilities by willing agencies and governments. While the reality is not as simple as the previous statement, the CRPD sets a course and underpins the principles and values of the community living movement in a clear way. It lifts our aspirations. It gives credence to our emerging person-centred and person-directed orientation.

One of the key implications of the UN CRPD and the rights-based approach to our work is the need for conscious and skillful support of people's capacity to understand, express and lay claim to their rights.

As a legal concept, this is commonly called "supported decision-making". It is not a simple or easy task, and it is complicated because service agencies may find themselves the target of rights holders' claims. In addition, we need to pay careful attention to the service system practices we support so that the rights and the capacity of people are enhanced and safeguarded. Support for independent personal planning would be an example of a useful service in this regard.

Considering the UN CRPD and Canada's ratification, it is perhaps no coincidence that the MCCSS regulations (QAM) in support of the Social Inclusion Act (2008) require all service agencies to develop

policies and procedures that promote social inclusion, individual choice, dignity of the person, independence, rights, and individualized approaches.

Local organizations' services will need to consider how to integrate the concept of rights into the everyday work of direct support staff. This will take both policy direction and personal support that enhances people's capacity to understand, express and lay claim to basic rights within our services and our communities.

Afterword

It has been my pleasant task to put together this resource for volunteer leaders. I took on this task at the request of the Provincial Executive Directors Coordinating Committee (PEDCC) with the intention of supplying a resource that would be accessible and relevant to new members of Boards of Community Living Affiliate organizations in the Province of Ontario.

Some parts of this document are revisions of selected sections of "Orientation for New Leaders" (PEDCC, 2021) intended for use in orienting new Executive Directors and other senior staff of Community Living Affiliate organizations. "Orientation for New Leaders" is a resource that is based on the excellent work of my friend and colleague, Doug Cartan, in 2012. I modified Doug's foundational work by bringing in updated information reflecting changes between 2012 and 2021.

This document also contains material that was drawn from the work of the "Inspired by our Grassroots Steering Committee" of the PEDCC. I have also drawn on policy statements of members. The sections "Board Mandate, Role, and Responsibilities" and "Policy Governance Model" reflect ideas from various sources, especially the work of John Carver and Miriam Mayhew Carver, as it has been interpreted in application by local Boards of Directors.

I have presented many of the ideas in this document as if all member organizations of Community Living Ontario operate in the same way. If my language suggests some type of orthodoxy, consider it a product of my imagination. Really, there is a lot of variability in how we do things. However, member organizations are constantly sharing information and learning from one another, and that tends toward establishing norms within the confederation.

Here are a few parting observations related to the appearance of orthodoxy or lack thereof:

Board Mandate, Role, and Responsibilities, and Policy Governance Model: The model separating governance from management presented here has become the norm since the 1990s, but before then it was common for committees of boards to exercise some executive functions. Before the 1980s smaller organizations could not afford to employ an executive director, and volunteer leaders directly managed programs. The evolution of the governance model has been uneven, and some, especially smaller organizations continue to mix governance and management functions, sometimes in idiosyncratic ways. In the last decade, significant change in governance structures is evolving in response to the shift from being a disrupter of the old status quo to being part of the new establishment. New norms are being worked through collaboratively with some outcomes still in the balance.

Values and Beliefs: Local member organizations define their own mission, vision, and values. Formal statements of these are revised by successive boards, so that in any given organization there will be a trail of re-imagining and rethinking. In my view, this is a regular, healthy part of organizational renewal. Others may opine that recurring collective introspection is a poor use of time. This debate is a perennial feature of Community Living organizations. You are welcome to your own opinion.

The Confederation and Its Powerbase: In any Affiliate the level of political activity waxes and wanes. Mostly people attend to day-to-day matters unless or until confronted by a threat. When things are going well, local organizations tend to delegate provincial government relations to Community Living Ontario and national level issues to Inclusion Canada. From time-to-time issues emerge that excite or

disturb people at the grassroots level. In those times, people may look to their provincial confederation for leadership to mobilize against a perceived threat. Over the decades, governments of every political stripe have done things that disrupted the work of Community Living to the point where constituents rose in significant numbers to challenge the government. I see no chance of this pattern changing soon.

The Self-Advocacy Movement: Most member organizations in our confederation actively support self-advocates. There is variability among us in the depth and intensity of that support.

The Dual Role: The interpretation of the dual role I have outlined is rooted in the study of the role of the provincial association conducted by David McCoy and Associates in 1976. This issue was debated at great length then in the (former) 14 Regional Councils of the confederation and in more than one provincial AGM. The debate has continued ever since in varying forms. It has become a part of the culture of Community Living, a feature that is not generally shared by other provincial umbrella organizations that form the Provincial Network on Developmental Services.

Resources and Capabilities, and Partnership with the Ministry: The interpretation I have provided was first articulated by the PEDCC's Subcommittee Reviewing Critical Emerging Issues in a report titled "Inspired by our Grassroots" in 2013. That subcommittee was made up of nine senior executive directors, most of whom have since retired. The central ideas were further refined in the PEDCC document titled "Inspiring Opportunities, Sustained Conversations" in 2017. Applications of it can be seen in the Work Plan adopted by the PEDCC in 2019. While people's experiences vary widely over time and across regions, some common themes are recognizable. I view this interpretation as a set of insights contributed by numerous colleagues over the past decade. The PEDCC and its various subcommittees have distilled that wisdom and given it expression. If local experiences differ, it is still prudent when planning or strategizing to take note of this wider context.

Toward a More Person-Directed Approach: The picture of the evolution of society's response to people with intellectual disabilities in Ontario is far from unique. The same general pattern can be seen in many other jurisdictions of Canada and the United States over roughly the same timeframe. It resonates with me because it fits comfortably with my 50+ years of work experience in the field. The pattern of evolution in how North American society treats people with intellectual disabilities is culture wide.

Human Rights and a Rights-based Approach: As noted throughout this section, this is an international pattern championed by the United Nations. It is gaining traction in Ontario, but resistance to a rights-based approach is holding us back. Ontario is still institutionalizing people with intellectual disabilities in Long-Term Care, forcing people into unnecessary guardianship arrangements, and denying their rights and autonomy in various ways. A lot of work remains, but the overall trend is in the direction described.

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