

# Back to the Future

## Some Considerations for the Leadership of Community Living St Marys & Area

John O'Brien

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This is an informal record of my reflections on what I heard in a series of interviews and meetings on 1-5 October. It is intended for Board and staff leadership and for members of the Quality Committee. A number of you participated in my presentation on Thursday evening and the board-quality committee meeting on Friday morning. I'm counting on your recollections of those meetings to supplement what's written here and I have attached copies of the slides from my talk and the posters from our group discussion of the positive core of Community Living as an innovating organization as appendices. In the few situations where I had ideas related to support for specific people I have shared them with senior managers. I make a few specific suggestions here, but mostly raise questions that I think are worth consideration over the next year or two.

### **Focus on Innovation**

The Signature you have selected highlights innovation, community engagement and commitment to people. I've arranged these notes as a series of possibilities for innovation that arise from maintaining a commitment to people in a service system that is experiencing very significant change driven by MCSS Transformation. There are three big obstacles to innovation. One is fear of speaking or taking action, another is a lack of knowledge of what may be possible, the third is getting stuck in a story that hides positive possibilities. In what follows, I'll speculate a bit on ways that Community Living could be even less affected by these impediments to innovation.

Innovation happens when people choose to take on a question for which no easy answer yet exists. I'll introduce each possibility for innovation with the phrase, *How might we....* If I wonder whether settled assumptions are hiding good chances for innovation, I'll introduce my speculation with *Challenge?*

It's easy for an outsider who only knows a small part of your story to make suggestions, so the list of invitations to innovation here is a long one. I intend it only as a set of possibilities for Community Living's leadership to consider. It's up to you to decide which of these invitations are worth your time.

From what I can hear, Community Living is in a strong position to meet whatever challenges you choose to face. All of the people and family members I heard from are satisfied with the supports Community Living provides, though some family members might manage the organization differently if they were in charge. Finances are reported to be sound. The leadership –Board, senior managers and external Quality Committee members– are capable, experienced and deeply committed to the people and families Community Living Supports, to Community Living's Mission, and to St Marys as a community. There are good and enduring relationships between many staff and the people they support and their families. As a community St Marys has many assets and Community Living has a long history of active partnerships that have benefited the whole community.

## **Limitations**

I am grateful to those who spent time telling me some of their perceptions of Community Living and some of their ideas about its future. My schedule gave me the chance to listen to many people but interviews were short, usually a bit less than a half an hour. I think it was a good choice to trade numbers for time, but some interviews might have usefully been longer and, when more than one person was present, time to explore was limited. While people were friendly and open, it's very likely that people's level of trust in me and the process varied, so I don't assume that each person told me all of his or her thoughts within the time we had.

Some of the questions I recommend to the leadership concern the possible effects of changes in the system that funds services to the people Community Living supports or wants to support in the future. I have no more knowledge of the Ministry's Transformation plans than any of you do, but I do have some experience of what look to me like broadly similar changes aimed at controlling costs in other systems and the effects of these changes on small, innovative, individualized service providers. Please remember how speculative the questions I raise are. They are the darker side of "What if something like this happened?" questions, not predictions of what will or must happen in Ontario or St Marys. The changes I imagine may never happen at all and even if they do they are unlikely to happen exactly as I imagine them. But perhaps the DSO and Funding Entity (when it is implemented) and related changes will function enough like efforts to manage costs in other jurisdictions to make some attention to my questions worth while.

## **Givens<sup>1</sup>**

I take these as realities that Community Living would need to deal with, even if the MCSS Transformation initiative did not exist. The Transformation program will influence Community Living's capacity to deal with these givens.

## **Generations**

A substantial number of the people Community Living currently supports are growing older. This means...<sup>2</sup>

- More people are likely to need support to deal with the health care system, from negotiating treatment for cancer or heart disease to making use of health financed in-home care or hospice services. This increases their vulnerability to the perceptions and values of health care providers, whether positive or negative. It also faces them and those who support them with difficult decisions about questions that many people, disabled or not, might prefer to

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<sup>1</sup> These are the "givens" I take from what I heard through the filters on my ears. They need to be challenged and refined.

<sup>2</sup> In this section I am drawing on both what I heard in St Marys and what I have learned with other agencies that support people individually,

avoid. Helping people through these experiences may take time that is not reflected in a person's usual support schedules, especially when family members or other allies are not available.

- More people will experience the loss of family members and friends. People will be grieving loss and need support. As well, some people in St Marys who have lived with their parents will lose hours of parent support and some may lose their role as providers of assistance and companionship to their parents. Family responsibility for the person's housing, assistance and support with decision making may pass to sisters and brothers, sometimes in a thoughtful way and sometimes perhaps not. Some people in these circumstances may be part of families who have chosen not to ask for (much) help and may be vulnerable to the way the MCSS system will handle them. Without knowledgeable accompaniment from Community Living they could end up "placed in an available bed" somewhere in the Region. This change will have particular impact on people who do not have a diverse and committed circle of support to hold their stories and assist them.
- More people are vulnerable to losing meaningful roles, especially if meeting their need for practical physical assistance takes over and deprives people of attention to maintaining or modifying existing roles, or generating new valued roles that match the person's changed capacities.
- More people will acquire additional disabilities and require more hours of paid assistance. Sometimes this need will grow gradually, as often happens with dementia, but sometimes it will come suddenly with a stroke or a broken hip. This will have particular impact on people who have required only a little paid support until their needs for support significantly increase.
- More people will die.
- Many staff have important and sometimes longstanding relationships with the people they support. People's illnesses, increasing needs for assistance, losses and deaths will have emotional as well as a practical effects on involved staff. Supporting people well through illness, loss and dying can be deeply meaningful. Feeling as if Community Living has let someone down as their needs change and grow would wound staff as well as the person and family involved.
- While preferences are shifting and reducing the legitimacy of long term nursing home residency among elders in the community, nursing homes remain a key part of the service system's answer for people with additional needs for support. Unless a person with significant needs for assistance that can be attributed to a medical condition has strong allies, they are at great risk of placement into this more local form of institutionalization regardless of their age.

### ***How might we...***

#### ***Build the capacity, in local partnership, to offer people the option of a good death at home.***

This could involve...

...encouraging and supporting parents and family members to think ahead, recognize positive possibilities for greater disability in old age and for a person's last days and what it takes to realize them

...strengthening (or forming) people's circles of support and discussing vulnerabilities, choices and points of influence around dealing with serious illness, or need for substantially more assistance or end of life concerns

...challenging our acceptance of people's or families' choice not to bring a circle together for a person: this can't involve trying to coerce people into a circle but we might discover more innovative and effective forms of invitation if we realized that the presence of a diverse group of committed others can be a matter of maintaining or losing ones' place in community

...allying even more strongly with local people and organizations working to offer better options to all elders (Community Living has much to offer in knowledge of how to organize and deliver individualized supports that keep people in their own homes)

...joining sister individualized support organizations to support people, family members and staff to learn more about positive options for dealing with people's increased vulnerabilities.

As I understand it, one of the ways that Community Living manages changing needs for support is through fiscal sharing, a local source of flexibility that allows funds underspent in some individual budgets to cover assistance not currently paid for in other's budgets. This allows timely, individualized response when there are short term needs or delays in amending people's individual budgets with MCSS.

### ***How might we...***

#### ***Assure that Community Living is best positioned to meet needs for increased support*** among people who have been supported on relatively low budgets for a long time.

This could involve...

...doing a series of fiscal *what if* scenarios to discover the potential level of demand for additional supports that would overcome current fiscal sharing arrangements

(What if \_x\_ people who currently need relatively less costly assistance needed significantly more expensive assistance in the same year?)

...exploring options for increasing flexibility by making more exact use of current Community Living resources: increased use of available community assets, including supports available to disabled elders and people with other disabilities who want to live in their own homes; family support arrangements; and ways to increase the funds available at the point of need (e.g. by encouraging estate planning for families and RDSP's for younger people)

...developing an approach to learning and planning with people, their families and their circles that anticipates the possibility of increased needs for support and supports a positive approach; this approach, which might draw among other things on the practices of PLAN Toronto,<sup>3</sup> would engage the family concern that has animated associations since their founding, "what will happen to my child when I am gone" in a somewhat different frame: "given that his or her needs for assistance may increase in the future, what can we do now to provide the best possible future options for my child?"

...developing ways to give more people and families a deeper understanding of how their assistance is financed that includes clear recognition of the interdependencies among people served: over time, the sufficiency of any individual budget depends in part on the capacity to receive from and give to others -- "my money" is also "our money" and there is a shared responsibility to make best use of what we have<sup>4</sup>

Young people are graduating from special education and at some point many of them and their families will look to Community Living for support.

- Most young people will have grown up with their families and experienced some benefit from early education and special education. These young people's needs and preferences for support are likely to be different in important ways from the generations that have shaped Community Living's current offerings.
- At least some of the issues that have animated older generation's enthusiasm for People First may seem less relevant to younger people and other issues may be of greater interest.

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<sup>3</sup> [www.plantoronto.ca](http://www.plantoronto.ca)

<sup>4</sup> A family that believes that the government and Community Living should accept complete responsibility for a person with a disability will be challenged by a request to see themselves as responsible and contributing not only to the well being of their own family member but to the whole association of people and families. Those who see an individual budget solely as "my money" will also be challenged.

- Those who attend school in the Public Board will have experienced segregation for much if not all of their school experience. Their expectations, and their families' expectations, may not include their participation in open employment and other contributing community roles. Their social networks may be smaller and less diverse. They may be accustomed to activities that gather them with other disabled people.
- A number of families of younger people are active in Perth Parents, which Community Living assists. This is a critical resource to develop.

### ***How might we...***

***Substantially increase the chances for young people with disabilities to play contributing roles in our community*** both before and after graduation from school.

This could involve...

... group and individual learning and planning opportunities for young people and their families and allies outside the school-controlled individual planning space aimed at...

- \* forming strong circles of support and making their own independent plans to inform both action independent of paid services and participation in school and adult system sponsored plans
- \* recovery from segregation through integrated leisure and civic activities, integrated summer and part-time jobs, etc.
- \* organizing to get the most possible from school system resources in the years between 16-21: appropriate technology to support communication, mobility, learning; expert consultation from professionals committed to positive approaches and inclusion to get the best possible understanding of complex impairments; the option of inclusive post-secondary experiences, especially between 18-21; a paid, integrated job, especially between 18-21 (this has been accomplished in a number of places that still segregate young people in the classroom)
- \* organizing to get the best possible supports for the family through Children's Service until age 18 and getting the best possible results from the transition to MCSS funding and Passport

...developing new offers of support such as a sort of on-demand back up to deal with issues as they arise for a person –from interpreting letters concerning benefits

to mediating landlord troubles to encountering the police– rather than scheduling weekly hours of support

...negotiating an initial understanding with those younger people and families who choose Community Living that makes clear Community Living's focus on contributing community roles, shared responsibility and as much continuing family investment as possible

### ***Geography***

One of Community Living's greatest assets is its identification with and participation in the community life of St Marys and the number of people it supports who play valued social roles in St Marys.

As time has gone by Community Living has come to serve a growing number of people who live in places beyond St Marys and what is usually understood by "and Area". This has happened one person at a time, for several good reasons. Most other service providers in Ontario have not chosen to move very far down the path to individualizing supports and replacing congregate services. This means that some families who live nearby approach St Marys for a level of individualization that no provider closer to them offers. Some people may have good reasons for moving away from St Marys. They may want to be closer to family members who have moved or want to experience life elsewhere. Shifting the support to a more local service provider may be difficult because current MCSS practices around funding might jeopardize continuity of the person's funding or because a local provider doesn't provide the individualized support the person needs.

This geographic expansion of the "and Area" in Community Living's name merits careful consideration by the board. The focus of this thinking is not on individual circumstances but on the implications of what is happening to Community Living as a whole as the number of people supported at a distance grows. There are good reasons to support each individual instance reaching more widely, even to Toronto: a person who wants to participate more in the life of family more than two hours away wants something that it makes sense for Community Living to support. MCSS practices that have made it difficult to the point of impossibility for the person to take their money with them justify maintaining administrative responsibility for the funds even if distance and less than full commitment to the person by the local provider who works as Community Living's agent make it harder to maintain the level of engagement typical of Community Living.

### ***Challenge ?***

***Consider the effects, over time, of greater geographic dispersal of the people Community Living holds responsibility for serving.***



- ? What must be safeguarded with particular attention and care to assure that the support a person receives at a distance results in a quality of life comparable to that of the people Community Living supports in St Marys?
- ? How do we assure, as much as possible, that people hired at a distance have as much or more opportunity to internalize the values that distinguish Community Living? (It may be that those who work at a distance need even deeper roots in what Community Living values because they work without the supports that those in St Marys have.)
- ? When (if) a person's needs for support increase substantially, or family capacity to contribute to assuring the quality of support decreases, or a team's cohesion or effectiveness decreases does that person have fewer options than a person who lives in or near St Marys? Under what conditions is it feasible to deal effectively with these eventualities?
- ? Are all additional financial costs associated with serving people at a distance accounted and are those costs fully covered by people's budgets?
- ? Is there a point at which the number of people served outside the Area might diminish Community Living's identity with and investment in St Marys as a community? If so, how will we know when we are approaching that point?
- ? Given the growing number of people living in Stratford, does it make sense to support local families to organize a Stratford provider of individualized supports, or an organization to back-up self-managed services?

### ***Person-Level Innovation***

Local residents have pride in St Marys as a place where there are many opportunities to participate in community life and create new ways to make life even better. Community Living has initiated and supported partnerships that have increased the stock of affordable housing, improved transportation, increased accessibility, and promoted intentional welcoming to name four. People Community Living Supports have taken up valued roles in community life.

Currently, some people and their supporters show the ways that people with disabilities and their teams can make a positive difference in community life. Some people remain more on the sidelines of community life, though they may enjoy good relationships with staff and family. It would be easy to think that the difference between these people is completely explained by individual characteristics. Some people are outgoing and have few impairments to participation; others prefer a much smaller social world and face many barriers. There is some truth here but this easy explanation ignores the fact that shy people also can contribute and people who face many challenges also have gifts to bring. It also discounts the contribution

that staff intention and skill makes in inventing the person-level innovations necessary to identify and encourage a person's gifts and capacities in a contributing community role.

### ***How might we...***

#### ***Engage even more people associated with Community Living to be active community builders.***

This could involve...

...supporting all staff to build on the Core Gift work they have done by finding ways to bring these gifts not only to the people Community Living supports but also to the larger community. This support could range from assisting staff who want or need help to identify possibilities for community involvement, to focusing some more scheduled support time to pursue community improvement work in the company of a person they support who shares an interest with them, and possibly to attracting additional funds that would allow more staff to devote some paid time to community building on behalf of Community Living.

...extending the Core Gifts work to more of the people and families that Community Living supports and making sure that attention is paid to how a person's gift can make a positive difference in their local community

...testing SSR: *Supporting Social Roles*<sup>5</sup> with a few people who currently play contributing roles in community life to gather some of what people have learned about the path to active participation

...assuring that Community Living staff are up to date with the most effective ways to assist people into employment, including current developments in customized employment for people with substantial impairments (including older people) and an up to date understanding of the ways that earnings affect benefits

...building on the Welcome initiative to create partnerships that would open even more pathways to civic engagement and devise community supports to encourage more people to follow those pathways

### ***Challenge ?***

***Consider the possibility that the current understanding of person-direction or personal or family choice might make some Community Living staff sleepy about possibilities for more people to assume more valued social roles, including employment.***

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<sup>5</sup> <http://www.inclusion.com/ssr.pdf>

? The practice of planning with people who ask for it or people at important points of transition respects the value that many people place on stability and a measure of privacy in their lives and avoids wasting time. Is it possible to imagine ways, based on personal knowledge, of inviting a very small number of people who have not recently thought about their lives to gather some people to do so, even if their first response to the invitation is negative?

? Many staff have strong, longstanding relationships with the people they support. The satisfying routines that have grown with these relationships might make it harder for people to notice opportunities to stretch themselves into more active community participation. How can these good relationships be the foundation for stronger connections to community?

? Many people experienced exclusion, rejection and low expectations earlier in their lives and some people have responded to that by inhabiting a small space in the world. Are there respectful ways, based on personal knowledge of particular people, to encourage and support people to find new ways to cope with these wounds and try new ways to be involved?

? Many people and families simply don't know what could be possible. Are there ways to increase people's awareness of and interest in new ways of supporting people in new roles?

### ***How might we...***

#### ***Align even more staff energy with active participation in contributing community roles***

This might involve...

...continuing effort to find more ways to increase economic security for staff. One issue arises when staff's desire for full time work exceeds need or available funds. This desire could be simply economic, but for at least some staff it also involves a belief that Community Living offers better opportunities to do meaningful work than other employers do. In any event, staff's sense of security is affected by two additional factors. The value Community Living places on family choice of staff leaves some staff feeling vulnerable to please a person's family even if their demands seem excessive, wrong or unfair. The control that Community Living supervisors have of allocation of hours leaves some staff feeling vulnerable to meeting supervisor's needs. The path to progress isn't at all clear to me but it may be worth investing some concentrated time (a day or a half day) in a facilitated discussion that includes a cross section of people from throughout Community Living to reconsider the economics of direct support and the ways hours are

allocated. This reconsideration would aim to build a sense of the health of the whole by honoring the value of family or person choice of staff, the value of insuring that the time people need from staff is covered, and also honoring the value of economic security for staff. It would be a search for an incrementally better way to respond to staff's legitimate interest in more certainty about their income and more opportunities for full time work. This search might fail to find a next better step. It certainly won't satisfy everyone. But it might be worth the trouble.

...a few staff talked about actively playing a contributing role in community life as if that meant "getting the person out in the community" and talked about that as something imposed on an unwilling person and their staff by "the powers that be". It is important for the leadership not to be reactive to this perception but instead to look for a deeper understanding of this way of experiencing Community Living's mission as a step toward supporting staff to greater knowledge and commitment.

People have more confidence and energy for community engagement when they have a sense of security and wellbeing. People with disabilities are vulnerable and it is critical to encourage anyone who believes that a situation is neglectful or abusive or that a person's well-being is compromised to speak up. In organizations like Community Living, where relationships are generally good and support is individualized and effective, there may be room for good people who care about a person to disagree about whether a situation rises to this level. But it is crucial to safeguard people and in situations where there is any uncertainty and disagreement about a person's wellbeing, it is prudent to involve outside judgement. This is especially true when the disagreement about the compromise of a person's well being is between a direct support staff who has a concern and managers who have good reasons for not being concerned to the same degree.

### ***How might we...***

***Provide the safeguard of a trustworthy third-party view of any situation in which anyone sees abuse or neglect or a significant compromise of a person's well being***

Person-level innovation is more likely to flourish when teams are cohesive. Because people have different ideas, different ways of thinking and assign different weight to values, conflict is a critical source of energy for change. The voices of those who see a possibility and want to go for it and the voices of caution and stability need each other. Energy for developing and enacting contributing community roles leaks away when significant conflicts remain unresolved and divide a person's team. Teams may fracture along family/staff lines or form factions that polarize staff or divide staff and managers. This potential threat to Community Living's mission seems to be built in to any honest effort to provide individualized supports. This makes it

worthwhile to consider making an extra effort to develop even better approaches to conflict resolution.

***How might we...***

***Expand our repertoire of ways to turn conflicts into shared understanding and constructive action, especially when the disagreement concerns people's capacity to grow and develop or participate in a contributing community role.***

As institutional placements decline across the province, Community Living is likely to meet a few people who pose significant challenges to their competence and to the coherence of their efforts. Sticking to Community Living's values and making these values real in a person's everyday life demands exceptionally high levels of personal commitment, team cohesion, willingness to stretch and learn, and ability to join with the person to create a path into an active community life, often against long odds. The integration of consciousness, heart and hands in support of people's development is central to effective support for anyone. For people with complex needs it can be a matter of life and death and it certainly makes the difference between true support for a real life in community and the reproduction of an institutional experience on an individual scale.

Expert advice has a powerful effect. When it aligns with Community Living's mission and supports personal commitment and team cohesion it can strengthen the foundation of understanding of a person's impairments and vulnerabilities and provide guidance about the forms of accommodation and assistance that will best support the person's development. When it runs counter to the values that animate Community Living, it can contribute to a team splitting into factions and leave some support workers feeling like their hearts and minds are irrelevant and their hands are all that matters. They feel harnessed to carrying out a plan that they do not agree with or indeed believe to be wrong.

This creates a strong challenge to the skills necessary to turn conflict into creative action. There are risks in ignoring expert advice once received, even when it undermines the strength that comes when team members feel a shared commitment to common values and think and learn together with the person what works to promote development. Discernment of what the person can teach us is essential. Is this person showing us the limits of something we have valued and must give up to offer what he or she needs or is he or she calling on us to risk sticking to what we value and discover new ways to offer support that embody those values even more deeply?

***How might we...***

***Acknowledge situations where team members consciousness and hearts are disconnected from their hands and learn a way to greater coherence***

## Government<sup>6</sup>

Innovation means working creatively with constraints. For much of its history, Community Living was able to function with considerable autonomy. Ontario's whole community system was largely built in collaboration with local, family rooted associations. As long as Community Living stayed on budget, kept the confidence of a well constituted board, and stayed within the limits of programmatic rules there were relatively few strings on local innovation. Good management and good results for people built strong relationships with Regional MCSS management. Changing individual needs could be negotiated on a person-by-person basis. Community Living grew strong by doing what its board and staff leadership believed was the right thing for people they knew that made sense locally.<sup>7</sup>

For at least the past five years, more constraints have appeared as MCSS continues on a long path to what it calls System Transformation. This process is not complete and there is uncertainty about timetables and the final design of the system. But enough is clear now to identify a number of what one board member aptly named "restrictions on our taken-for-granted". Maintaining Community Living's signature gift of innovation by committed citizens of St Marys will require new levels of organization and creativity to meet the challenges of a new service policy and funding environment.

### ***MCSS Transformation: What could be***

MCSS Transformation is Ontario's response to changing conditions in much of the developed world. How different jurisdictions deal with these conditions varies, but that they must face them, sooner or later, does not.

- Political perceptions of the effects of fundamental changes in the global economy strengthen an economic frame for public issues. We are more likely to hear talk of "value for taxpayers money" than "support to citizens building more just and inclusive communities". Cost control and market regulation are dominant policy ideas across much of the political spectrum. The common idea that there are "economies of scale" to be had creates pressure to reduce the number of service providers and encourage larger scale operations.
- The numbers of people who require publicly funded, long term support will increase considerably as more and more elders live long enough to acquire disabilities and more people with disabilities live longer lives. These same demographic facts substantially increase demand for acute health services and public expenditure for income support in retirement or to cover the additional costs of disability. These demands on public expenditure are

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<sup>6</sup> Please remember the limitations under which this section was written (see p. 3)

<sup>7</sup> This greatly oversimplifies a complex history to draw a contrast that highlights what I hope are valid points about the system's changing locus of control and mechanisms of coordination.

increasingly seen as in competition with other public goods such as education and economic development.

- The MCSS system is overcommitted. More people are eligible for publicly funded supports than currently receive them. Some people receive more services than others with apparently comparable needs. The allocation system historically tends to favor those who came to community services from a public institution in a time when the priority on deinstitutionalization made allocations more generous and those whose families have not maintained them at home. It may also favor families more skilled in advocacy. Equity, understood as having good and universally applied reasons for differences in allocations, is an important value in MCSS Transformation.
- Public policy is increasingly likely to embody the principle of individual choice of services, but for a variety of different reasons ranging from recognition of a claim to the right to self-determination to a belief that competition in an economic market for services will hold down costs.
- In Ontario, family advocacy and self-advocacy has prevailed in setting the terms of service quality. One stop access, individual budgets, person-directed planning, and individualized services delivered by a capable workforce have been absorbed into the service bureaucracy, promulgated as policies and detailed regulations, and embodied in practices (such as application of the Supports Intensity Scale to determine eligibility and eventually allocation of individual budgets) and given rise to new decision making entities (such as the DSO and the anticipated Funding Entity).
- While only a minority of Ontario service providers have developed the level of capacity for individualized supports that Community Living has, nearly all have adopted the vocabulary of the MCSS Transformation. Many if not most large organizations proceed from the assumption that congregate day services and group living arrangements are necessary to give people and families cost effective choices and that it is possible to practice person-directed planning and deliver individualized supports in these settings. In the political process, the interests of large organizations have a good chance of outweighing the interests of the few small, highly individualized providers of support that do not have substantial real estate.

Emerging and probable changes from MCSS Transformation include these:

- Decisions about eligibility, entry into funded services, and amounts of money allocated will be made at a greater distance from St Marys, based on objective scores from assessment instruments

- People will be reassessed regularly and allocations reduced when people demonstrate less need on the assessment instruments
- People and their families will spend time waiting when services or more services are required; providers will “declare vacancies” which will free up funds or, perhaps spaces in day programs or group homes, that the DSO will allocate based on its priorities
- The assumption that unpaid support will be widely available will be reflected in the allocation process
- Service providers will have more rules and conditions to comply with and more reporting requirements
- People and families’ expectations and experience of services will be shaped by MCSS and DSO definitions of service coordination, person-directed planning, service outcomes and other matters that are at the core of Community Living’s approach to support
- Definitions of offerings like person-directed planning, brokerage, and community connecting may treat these offerings as distinct services with attached rates and expenditure limits
- The belief in “economies of scale” will create a continuing pressure from MCSS for “shared back office functions” (accounting, human resources, purchasing, etc) if not for the amalgamation of agencies
- Agency level cost-shifting strategies could result in greater acceptance of nursing home placement for people of all ages with needs that can be defined as health related

Imaginable changes, based on what has already happened in other systems that have implemented cost management structures like the proposed Funding Entity, include these:

- Setting tight boundaries around individual allocations that discourage or forbid sharing funds among participants –unspent funds go back to the entity that allocates funds for reassignment
- Tightly controlling administrative costs, usually in the name of spending every available dollar on direct support
- Tying every reimbursement to a documented, auditable face-to-face contact for a purpose specified in an approved individual plan
- Restricting services to a menu of “cost-effective, evidence-based” services

The posters from our discussion of the positive core that makes innovation possible for Community Living have important messages: relationship and standing with one another is central; Community Living is imaged as a natural growing presence in the community, like a tree or a flower or a questioning heart; awareness, creativity, choice, courage and risk are prominent themes and have been for more than 20 years. As the service system moves more



mechanistic and distant management systems into the lives of people and their families, these messages are important. They alert us to new challenges that people and families face and potential threats to Community Living's current capacities. These are the challenges of growing a tree when the system wants to pay for a machine. They also remind of us the assets Community Living can draw on in continuing to be innovative no matter how the system changes.

### ***How might we...***

***Anticipate some of the unintended negative effects that system changes could have on Community Living and consider options for minimizing them.***

The point is not to try and predict and prepare for any eventuality. The pace and specifics of the MCSS Transformation is too uncertain for that. The idea is to spend some time before situation develops getting as clear as possible on what principles at stake are and what some possible responses might be. This thinking might be shared among some of Community Living's sister agencies around the province whose capacity for individualized support could also be compromised by the MCSS Transformation. This could involve allocating some time to considering what might be done now to reduce the possible negative effects of likely changes, for example...

...how can Community Living support young people and their families to make the best of Passport and whatever time lags there may be

...MCSS desire (which might become a demand) that providers, especially small ones, share back office functions seems to assume that accounting and human resources are somehow generic functions, whereas for Community Living they are integral to providing support; are there any forms of sharing that would make sense and if so which agencies would be good partners?

...what alternatives are available if there are restrictions on our practice of fiscal sharing?

...what are the pros and cons of diversifying services and funding sources to include Children's Services or other services?

...what supports could Community Living provide to people and families who come out of the SIS assessment and allocation process with significantly lower allocations or long waiting times?

...what are the implications of these changes for Community Living's commitment to the people it is supporting into old age?

There is reason to think that people and families could face a longer wait for MCSS funded services, especially services that support a person to move into their own home in non-emergency situations.

***How might we...***

***Play a constructive role in mobilizing people and their families to deal with the changing system.***

This could involve inviting, supporting and encouraging...

...more people and families to embrace and act on the realization that most of them face a future in which continuing active relationships among family and other allies is essential to assuring as good a life as possible

...the people and families who will most feel the effects of the Transformed MCSS system to assume leadership roles in Community Living's committees and Board. If the spirit is to stay alive this must be a process of personal development not just a formal changing of the guard.

...people and families to try to influence the MCSS Transformation (though much of the opportunity for this has past and left many those who poured their energy into trying to influence it are frustrated at the results)

...forming circles and groups of circles for both mutual practical support and local action

...exploring other routes to contributing community roles by making the best of other community and family assets and whatever public funds may be available

...embedding the values of individualized support for contributing community roles and the practices of person-centered planning outside the adult service system among people and families and perhaps in other community associations in St Marys.

Like most other ACL's in Ontario, Community Living has held a distinctive position because of its identity as an association governed by and dedicated to people with disabilities and their families. This position could be changing, with ACL's increasingly being seen and treated by MCSS as simply one of a network of providers coordinated by DSO-Funding Entity. This would mean less flexible funding, not only for fiscal sharing across people, but also for a variety of community engagement activities.

### ***How might we...***

***Lay an even stronger foundation for doing the work of an Association for Community Living that depends less on MCSS funds allocated to direct services to adults.***

This might involve...

...beginning supports with younger people and families with the expectation that the person and family is entering an active partnership with Community Living; that the partnership is based on a shared interest in supporting the person to be a contributing member of St Marys community; and that family members will continue to be a contributing part of the person's life

...building substantially on the ways that Community Living could support self-management without taking over responsibility for a person's support

...considering alternative sources of funding for community building activities

...exploring the possibility that meeting the changing demands of the MCSS system might require a different, even a separate, organizational body than the organizational form necessary to engage in community development and supporting people and families to get the best from the Transformed MCSS system.





**Our Vision:** A community where everyone belongs.

**Our Mission:** To nurture the ability and willingness in our community to welcome and support all people as valued and **contributing** citizens.



#### **Our Signature**

We have a long history of being **innovative, engaged** in community and **committed** to people



#### **Our Signature**

We have a long history of being **innovative, engaged** in community and committed to people



## Generations



## Geography



Government

Ministry Transformation

DSO

SIS

Passport

IB



The Funding  
Entity

Innovation

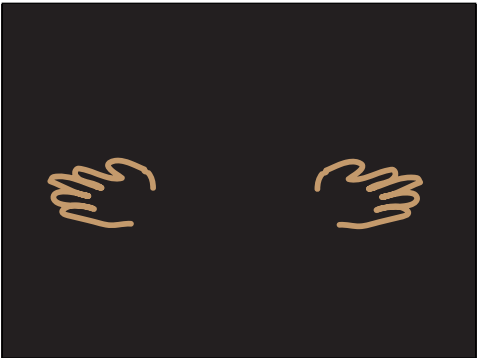
How might we...



How might we...



Increase economic security for staff people



How might we...

Acknowledge situations where people's  
consciousness & hearts are disconnected  
from their hands & discover more coherence



IrFearon

How might we...

Encourage the voices of those who are silent



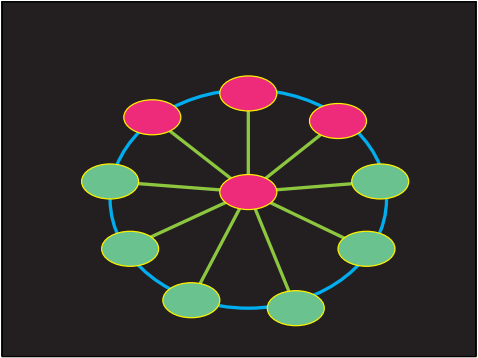
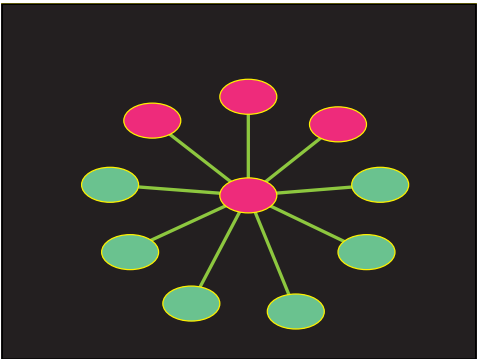
How might we...

Provide the safeguard of an outside, 3d party  
view when anyone sees a person as abused  
or neglected

How might we...

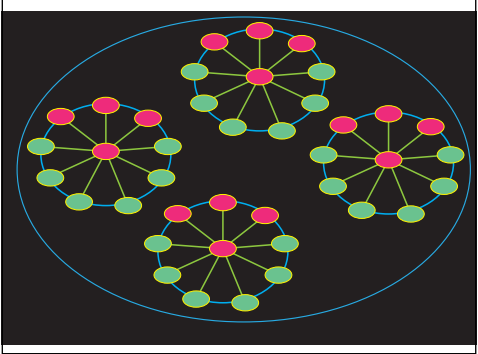
Engage more families & people we support in  
understanding & actively managing their funds





How might we...

Recognize the value of different ideas & ways of thinking & find ways to turn conflicts into shared understanding & action, especially when the disagreement concerns people's capacity to grow and develop or participate in a valued community role.



How might we...

Encourage more people & families to experience the benefits of organized mutual support

## Generations

### Elders

building capacity to offer people the option of a good death at home  
responding to increasing needs for assistance

supporting one another to grieve losses & cope well with illnesses

finding meaning

contributing to how St Marys community supports elders who become disabled & their families



## Generations

Invest in leadership development: people & families

Learn by doing, reflecting, exploring values in conversation



## Generations

Define options for preserving \$ viability if...

...demand for support grows among older people

...cost controls reduce individual budgets, Admin



## Generations

### Young people & families

support for inclusion: individual & community level  
recovery from segregated schooling  
new forms for self-advocacy (?)  
partnership & support vs entitlement & delegation  
organizing & learning to get the most from 16-21:  
technology, jobs, understanding the system  
organizing young people & families to make good use  
of waiting time & Passport Funding and build the  
association

## Geography

Significantly increase the  
number & impact of  
community builders

More staff have chosen  
project time to express  
their gifts while expanding  
opportunity

Individual engagement as  
well as Association  
Contributions



## Geography

Individualized  
support remains  
uncommon

System \$ weirdness

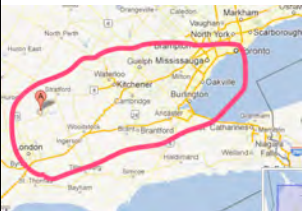
Commitment to  
people's choices

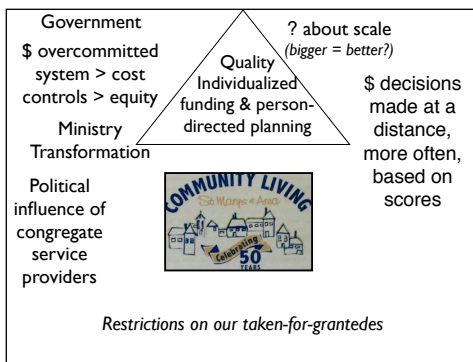
Growing +  
reputation



## Geography

Sense of place?  
Costs covered?  
Connections to  
local resources?  
Multiple  
relationships;  
story holders?  
Access to values  
development  
among assistants?  
Family  
contribution?  
Other allies?





How might we...

Mobilize people and families to influence policy

How might we...

Increase our flexibility & decrease response time, because system may impose delays, then demand response.

How might we...

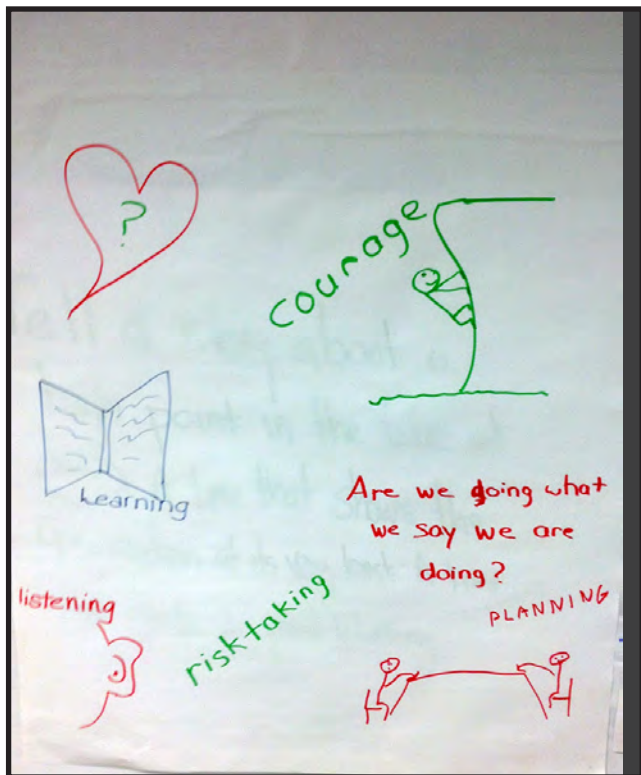
Lay a foundation for doing the work of the association that depends less on Ministry funds dedicated to adult services

## Appendix B

People connected to Community Living created these posters in answer to an invitation to create images that express the sources of the innovation that the organization claims as a key part of its Signature Gift.







How might we...

Move more and more relationships with  
people & families from “you take care of it”  
to “we are allies”

“My money” is also “our money”

