The Evolution of Community Supports:
Sorting Out What Really Works!

Keynote presentation by:

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I am honoured to be here at this 50th Anniversary conference. When I told my daughter Karen that I was speaking at the conference and that Community Living was 50 years old, she said “that’s old.” I reminded her that I was a lot older than 50, she said, “that’s really old.”

Like most 50 – 60 year olds, the Association has had quite a journey, not always predictable and never dull. When I think of the 50 years of the community living movement what stands out for me more then anything is the incredible commitment and energy of families and the number of family pioneers who were never satisfied with what we had. Family pioneers who constantly remind us that, no matter what progress we had made, there is always a better way! And now we have many people with disabilities who are the new pioneers!

The evolution of community supports! Sorting out what really works in terms of community supports is a little bit like sorting out what works in a family. You have to look at individual needs, but you also have to look at the needs of the whole family unit, and the capacity of the family and the community. I think we also need to look at the theories, practice, and research that have been part of the community living landscape for the last fifty years.

In some ways I bring a unique perspective; as a family member I am very much part of the movement, while as a researcher, I am more an observer. In looking back at what has worked over the years, I have identified some threads that are vital to understand. I think these threads can be woven together to create some possibilities for the future.

The year is 1973, thirty years ago. I am about to visit my first institution and I am nervous. I had read Irving Goffman's book, *Asylums*, and I wonder if facilities for people with developmental disabilities will be as controlling as Goffman describes for psychiatric institutions. As I go through the hallways of the institution, I meet an older man by the name of Harold. As we talked, Harold began pointing out the window, and says to me "mountain, home, me go". I could feel tears welling up in my eyes and I replied, "so you would like to leave here." "Yes, but it is OK, don't be sad" he said, as he noted me wiping away a tear. Later I realized that what this story told me very early on in my career was that **people accept where they are at, but they also have hopes and dreams of where they want to be**.

As I began a research career, I knew I had to study institutions and their alternatives. After my first experience with Harold, I visited an institution every year for the next fifteen years. What I gathered from institutions in Canada were **stories that break your heart**. In one major study, we learned from parents that in the 1950's and 1960's there were no community supports – in such an environment, many families became worn down by the lack of support, and the stigma and isolation associated with disability. Often families institutionalized their loved one with the support and encouragement of professionals. This was a shameful period in the history of disability policy. And yet, the most poignant insights about this period come from people with disabilities themselves.

Roberts Williams, a man who spent years in an institution has written;

Look deep
Deep into the hearts of my people;
Witness their horror
Witness their pain
Your spoken words alone
Will never soothe.
Do not try to explain it away
They will never believe you…

That we still have **over 1000 people in three institutions in Ontario in 2003 is appalling, and shows how we are still trapped in the world of custodial care**. It is difficult to move to full human rights and liberation for all as long as some of our brothers and sisters are incarcerated.

How money is spent by government is often an indication of priorities and social values. In 1973, most funds for formal disability supports went to institutional supports (almost 90%), smaller amounts went to community agencies, and none went to individualized supports or directly to families.

Yet as institutions closed between 1972 and 1995, we learned something profoundly important about that era that can have implications for community supports today. **We learned that people with disabilities are amazingly resilient**. This resiliency is reflected in several ways – many people survived 20, 30, 40, and even 50 years in an institution. Once in the community, many people have thrived – we now know it is important to make plans for people leaving institutions, but we know we shouldn’t stay wedded to the plans, because people will change faster than you think, once they are out….what we are seeing is resilience in action!!

The year is 1981, and my family is about to adopt a child with Down syndrome. We visit a foster home, where a three and a half year old is sitting in a crib. She spends hour after hour, day after day in that crib, but her tilted head and radiant smile captures our hearts and Karen becomes part of our family forever. **We learn very quickly that being a parent of a child with a disability is a lot about figuring out what community supports will work.** Sometimes it is not too difficult; three days after adopting Karen I take her to our co-op day care centre and drop her off, despite the fact that she doesn’t walk and isn’t toilet trained. The co-op day care accepts her willingly for three reasons, I have two other kids there and they liked our money, I knew most of the other parents and I had their support, and thirdly, I was president of the non-profit day care! So, our family learned early on that **relationships are central to building responsive community supports**. Community supports that are created without an understanding of relationships lack any connection with people and community. And yet, in the early 1980’s we were also learning that finding the right community supports was difficult. This was the era where the call from the community living movement was for more integration - - but beyond relationships and some decent recreation and leisure programs, few strategies had evolved to assist families in how to facilitate integration.

The year is 1990. I am involved in a research study on community living. By now, some provinces have decided to close all institutions and British Columbia does this by 1995. As part of this study on community living, I visit a home with a manicured lawn that is beautifully decorated … I meet four men who live in this house and call it their home. They are not unhappy, yet I sense a sadness that I do not quite understand. As I get to know these men over the next few hours and days, I begin to understand another story that breaks my heart. This beautiful home is three blocks from the library but these men have never been there. On a Tuesday evening, all the men go to the same bowling alley – they have fun, but they never connect with others who are bowling beside them. I find the house rules – now I know that all households need guidelines to function as a community – but this is not a community. There are rules about when families can visit the group home and there are also rules about bedtime. These are not guidelines of a community, but rules of a program or an agency. The reality is that these men are disconnected from community life, both inside and outside their home. As I discover this, I begin to understand their sadness. They have almost no genuine relationships, and they are alienated from self and from others.

I ponder the visit to this home and I reflect on my research and the research of others which shows that most people with developmental disabilities are stuck in similar services. By 1990, many of us have begun to realize a profound reality, that **people's lives are too often defined by community agencies and their services and programs**. What does this mean?

Usually agency driven services mean that;

- staff make the major decisions;
- planning tends to be more about managing the details of daily lives rather than fulfilling true dreams;
- and people have to fit into programs.

An executive director of a community living organization that I have been working with recently said to me, “we think of everything in terms of programs. I know this has to change, but it is hard when we have been dong it for so long.”

In 1990, I found these insights perplexing, because community-based services had promised so much. In the 1970’s and 1980’s, community based services were the mantra of the community living movement. Most people believed that if we could just get the services co-ordinated and the programs based on good principles, life would improve for people!! And life had improved for some people by 1990, especially those who were recipients of good quality programs and services, as well as those people who have left institutions. Yet, far too many people had very limiting lives in community. **Compliance was usually expected and thus there was little in the way of intentional connecting with community**. Many research studies in the early 1990’s showed that citizens with disabilities have fewer friends, limited relationships, high unemployment, and far fewer avenues to participate in the community than other citizens. I noticed something else in the early 1990’s that persists today; families had been taught (too well) that being on a waiting list is not only acceptable but is expected. The idea of building capacity of the person or the community was not yet in our vocabulary.

Many community living organizations began to discover by the early 1990's that they needed to address the compliance of people they supported. While tackling this issue has been very difficult, it has led to the insight that you **must move away from fitting people into programs if you are going to break away from compliance and clienthood.** Many organizations began to do just that. This shift from programs to people is a vital thread in finding community supports that work. We also learned in the 1990's that **values matter greatly in terms of developing appropriate supports for people.** Those organizations that have based their community supports on values of person-centredness, empowerment and participation, inclusion and citizenship, community and hospitality have begun to make a difference in people's lives. John Ralston Saul, a leading Canadian thinker on our era, has stressed that the absence of values is a serious issue for our times. It is significant to know that addressing compliance through participation asserts some important values, especially the values related to citizenship.

The emergence of intentional values in our movement coincided with the shift in many fields toward an understanding of holistic or ecological approaches. Ecology is an environmental concept, yet applies to how we all live our lives. Ursula Franklin, a renowned scientist at the University of Toronto, points out, for example, that diversity in human systems is vital – just like a forest, human service systems need to recognize and honour diversity. Trying to fit everyone into programs or into narrow guidelines does not honour diversity. **Diversity demands individualization** and even though we have talked about individualization for two decades, it was not until recently that we started to truly understand what it really meant.

By the mid-1990's, there was discontent in the family movement because community based services had so many flaws. I personally saw this dilemma and discontent as a healthy thing, because it created an important awareness that was first highlighted by Albert Einstein in the 1940's. Einstein had said, "**You cannot solve the problems we face today with the same level of thinking that you used when you created them**." The architects of community based service system learned from institutional models that families wanted safety and security. Too many community based services addressed safety and security, but failed to see that people were resilient or that they wanted self-determination and meaningful relationships in community life. Understanding Einstein's point also helps us understand why the first group homes in the community had many features of institutions. Yet, now as we move to the next stage in the evolution of community supports, we know that Einstein is correct and we have to change the way we think. Starting with bricks and mortar will not enhance quality of life. In Ontario, unfortunately, we are still learning this lesson very slowly.

The year is 1993. I have the honour of being the project director of the provincial evaluation of the Special Services at Home Program. Most of you will know that SSAH is an individualized program that enables families to access funding to hire their workers and determine both how and when they want these workers to be employed. What did we learn from SSAH? Primarily, we learned what families have been telling us for years, that

when families have control over the resources for disability supports that they need in their lives, they are not only more satisfied, but good outcomes are more likely to happen.

There is an important kernel of wisdom here; people need to be engaged in their own lives, to have a say, to express their voice and their dreams. By the mid-1990s, I began to realize that SSAH might be a template for what could be a better way to organize community supports that would build on the principles of self-determination and community. After all, we were learning from SSAH and from five provincial government pilot projects set up in 1993 to deliver innovative disability supports, that **individualized supports not only make sense, but in fact are also cost effective.** And yet, we were also learning that SSAH had limits – families often use it to survive, not thrive, and it lacks the supports and infrastructure families often need to plan a good life, or to build strong links with the community.

By the late 1990's a huge amount of research was being published on determinates of health. This research answers the question, what makes people healthy? The results of this research confirm what family leaders had been saying for some time – that people who have relationships and strong personal networks in their lives are healthier than those who are lonely and isolated. So another critical piece or thread gets added to what community supports work for people. Not only do supports need to be individualized, but **other people who know the person need to be involved**. Social networks have a huge impact on health and well being. As the 20th Century came to a close, **many projects across the country were beginning to**

explore three inter-related concepts – the power of values, including the self-determination and community, the importance of individualized support, and the usefulness of personal networks and relationships.

By this time, we were beginning to see a shift in how governments were allocating funds for disability supports. In general, money for institutions had decreased dramatically in the previous two decades, while money for community agencies had increased significantly. By the mid-1990's, direct funding to individuals and families was still a very small amount of total disability budgets, and in most provinces only amounted to 2-3 percent. Typical of social change, the "idea" of change was far ahead of its implementation.

The year is 2000. Having left a very busy research position in 1996, I now have time to do some volunteer work and to reflect and write about community supports that work. I also spend a lot of time caring for aging parents. I am reminded again and again that supporting another person is an honour and a way to open the heart. I realize that I have learned much about community support, from my daughter, from my friends with disabilities, from my parents in their last years, and from innovative projects I have studied. I would say, as we have learned how to individualize supports, **seven things stand out about personal support, and I want to frame these in terms of the person facilitating or doing the support:**

- the importance of being present and mindful
- the importance of respect and patience
- the importance of deep listening and reflection
- the importance of honouring strengths, self-determination, and choices

- the importance of engaging other people who really know the person
- the importance of using community as a first resort
- importance of being creative (not just about 1:1) in designing supports

As Judith Snow has said, support is a relationship and can be like a dance. What has changed since the 1970's and 1980s is that we now know that **paid support workers should no longer be leading the dance.** To be mindful is to learn to follow what the person and the family wants. To listen deeply is to build on people's dreams and start with what people want a good life to look like. To be creative means to create individualized supports with the person and their network.

Who has these attributes? Many current support workers do not. The good news is that most people can, with training and support, develop these attributes. The other good news is that many fellow citizens have them naturally. In my daughter's case, the director of the choir she sings in has them, and the mother of her best friend has them in spades. We need to look for these qualities in people and provide opportunities in community for them to be nurtured.

We were also learning by the year 2000 that **building a good life in community requires planning**. Sometimes this is called person-centred planning. Richard Rustan, President of People First of Ontario calls it person-directed planning. Person-directed planning more accurately reflects to new story we were trying to create by the year 2000. We were recognizing that we need to be intentional about planning and building capacity – whether helping someone expand their relationships, or assisting someone to connect with more places in the community, supporting families to become comfortable with asking others, or helping someone develop a plan.

In the year 2000, I had an opportunity to study several innovative projects that are creating full lives for people in community and I discovered that the best planning is well facilitated, either by a family member or an outside facilitator. A facilitator is someone who provides information, helps with personal planning, and assists people to build networks. In this study, we also learned that there is power when this planning is independent from service provision. It is not enough for agencies to provide this facilitation, but we need to work toward independent planning functions. Families need to know that facilitators will listen deeply and honour their choices, not steer them into their agency's programs.

By the year 2000, nine provincial organizations were calling on the Ontario government to provide 25 % of new government monies in developmental services to go directly to families and individuals, rather than to agencies. This widespread call for change to direct funding is quite astonishing – nine provincial groups, including Community Living Ontario saying to the government, we want a paradigm shift, and we think that families deserve more options, and families should have more control over the funds they use for individualized supports. Such an individualized funding approach, if realized, would dramatically impact the current service system.

The year is 2010. Imagine that all elements of community support that we know enhance quality of life are available for people. In the year 2010 these include…

- → The values of diversity and person-centredness, empowerment and participation, hospitality and community, and rights and social justice guide government policy and community living initiatives.

- → Good independent planning and effective facilitation are available for families and individuals who want it – facilitators are well trained in listening and being able to help the family think creatively regarding how to develop individualized supports that connect their loved one to the wider community. Not all families choose a planner/facilitator but those that do get to choose the facilitator they want.

- → Most families by 2010 understand the value of inviting others into their lives and the life of their child – personal support networks begin to flourish.

- → Individualized funding is available, which means that individuals and families can develop a plan, submit it for approval, and then develop the individualized supports they require, which include both unpaid and paid supports.

- → In 2010, service organizations and the service system are now more responsive because power has shifted more to self-advocates and families – people can stay in agency services or they can take their resources and individualize them. Portability of funds and supports make this possible.

→ Provincial policy and funding reflects the shift of power to individuals and families. Provincial funding strategies recognize the need to fund innovation, including independent family groups and mutual aid projects in the community for families or self-advocates.

→ By 2010, the community living movement embraces and understands community and civic society. More and more, community is the first resort for people's support. Civic society is more broadly engaged because people have been reaching out to their neighbours, to their local community groups, to city hall…natural supports in community are beginning to really work.

→ By 2010, all large institutions have closed in Ontario and the last people who came home experienced all the "Best Practices" of community support, including individualized planning and funding, and support network building. People are experiencing self-determination and citizenship.

→ By 2010, government funding for community supports have shifted dramatically when compared with earlier eras. No money goes to large institutions and 40% of new money and 20 % of money overall goes directly to families and individuals.

How will we get to 2010?

The paradigm shift toward individualized support and community inclusion that is occurring in all areas of disability is well underway, yet it only exists in pockets throughout the province. The challenge is how to build on the pockets of excellence that exist and move toward change in community supports that are truly transformative.

Let me be bold and suggest several things I believe we need to do:

1. We can begin by looking around to see what others are doing. We may be surprised to learn that several other provinces are doing it much better than Ontario and this should be an incentive, since Ontario hates to not be leading the other provinces! British Columbia, for example, is about to pass legislation that will mandate 17 planning centres throughout B.C. and provide individualized funding for those who want it. Great Britain since 1996 has national legislation that mandates direct funding for people with disabilities and families. And just last year Britain extended this legislation to include vulnerable elderly people, which is dramatically changing long term care in England. The reality is that there is sufficient research to show that individualized planning, support, and funding can work effectively.

2. We need to build partnerships and alliances with groups that understand what we have learned. This can happen both locally and provincially. Some important partners include People First of Ontario, the Individualized Funding Coalition for Ontario, Family Alliance for Ontario,

and the Special Services at Home Coalition. All of these groups are committed to the new values and paradigms we have explored today. In the future, partnerships with non-disability organizations will also be critical to building a “community first” agenda.

4. We also know that short-term change is one key to transformative, longer term change. What we do today matters in terms of what we build for tomorrow. So the small projects that many of you are involved in - perhaps a Foundations project, or the reform taking place within SSAH, or families that have demanded and received individualized funding, or agencies that are developing a cadre of facilitators and a separate planning division, or family support groups that are nurturing personal networks – these are all important initiatives that are helping us learn what works, and they create a foundation for the larger, transformative change we need.

5. We also know that short term change is about personal change. No long term change will happen without personal change and strong character development of families and staff. The shift we are talking about is not just about changing “them”– it is about each of us being willing to change in our hearts and minds, to truly see persons with disabilities as full citizens, with gifts and strengths, and with the capacity to build meaningful relationships. During the last two years, the Individualized Funding Coalition for Ontario has sponsored training events and workshops that have enabled families to look within themselves and at their communities as they develop an understanding of individualized planning, support, and funding. These capacity building experiences are vital in helping us get to a new story in 2010.

6. We have a wealth of stories and experiences that point to possibilities of how we might be in the future. This growing number of experiences can enable us build a new story that inspires. Surely, we have had enough stories that break our hearts. It is time for stories that inspire and show a change in heart and a change in structures. Stories of course, are not enough, but they are often an important the starting point for change.

7. Ontario Government policy must catch up to the stories and visions of individuals and families, and to the wisdom of the community living movement. Frankly, during the last eight years, government policy has begun to lag further and further behind what we know needs to happen to build effective community supports. As the new Liberal government begins to address the issues of disability supports, it is vital that they bridge this gap between what we know and what government is doing. They will also need to involve families and self-advocates in this journey. There is incredible family leadership in this province that could be utilized in very creative ways to assist with transformative change. And this may mean that agencies will need to step aside and support family leadership to once again be at the head of the table.

Finally, I would suggest that our job as a community living movement is to do what the movement has always done best --- be clear on our vision, study and know how to implement the details of the vision, build capacity of families to embrace the vision, and raise hell with those in power who also need to embrace the vision and the alternative policies.

Ann Mortifee, a wonderful Vancouver singer who has performed at People First events, sings a song called, “It is within every one of us to wise.” We can find ways in Ontario to create a better life for citizens with disabilities and their families. Let us use our individual and collective wisdom to make it happen!!