

institution watch

PEOPLE
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PERSONNES
D'ABORD
DU CANADA



50 years

Canadian
Association for
Community Living

Diversity includes.

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Monitoring the progress toward a vision of full community living for all persons with intellectual disabilities.

This is a newsletter written and produced by PFC-CACL Joint Task Force on the Right to Live in Community. For more information, contact Don Gallant at (416) 661-9611 or Shelley Rattai at (866) 854-8915.

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"An institution is any place in which people who have been labeled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day to day decisions. An institution is not defined merely by its size."

MESSAGE FROM THE TASK FORCE

Laurie Larson and Shane Haddad, Co-chairs



Over the past 30 years we have witnessed large institutions that warehoused people with intellectual disabilities close across this country. The remaining few facilities – in Alberta, Saskatchewan, Manitoba and Nova Scotia – have either announced closure and/or have stopped admitting people and are now actively assisting people to return to community.

If the goal of deinstitutionalization was the closure of large buildings, we could celebrate and congratulate many provinces and territories across Canada on a job well done. However, if the goal of deinstitutionalization is to assist people with intellectual disabilities become valued, contributing and participating members of their communities – then it is safe to say we have not been truly successful.

Have our efforts over the past decades really changed the way in which we and our communities view people with intellectual disabilities? Are our communities and associated services really more inclusive and supportive? Have we finally closed institutions or merely substituted large institutions for smaller, less visible ones within communities? Is the institutional culture any less prevalent today than it was 30 years ago?

Despite successful facility closures, the rhetoric of supportive policy, the expansion of community based supports and services, and indeed despite the promise of rights as guaranteed by the *UN Convention on the Rights of Persons with Disabilities*, the majority of people with intellectual disabilities are still prevented from exercising true choice and control over their lives. For many people this lack of choice and control is as much a feature of their lives today as it was when they lived in a large institution.

Many of the supports and services created in the past to facilitate deinstitutionalization, are now the very structures that stand in the way of their full inclusion. People continue to be placed rather than given a choice. Governments continue to fund place-based options rather than investing in people. Control of resources remains vested with service providers rather than with the people needing support and/or their families. Far too many community services continue to segregate and congregate people based on the label of disability and thus contribute, albeit perhaps unintentionally, to their further isolation and marginalization. Regulations, policies and practices continue to serve to protect rather than empower. Governments, bureaucrats, service providers, and even advocates use the words 'inclusive communities' and yet as we look around this country, we see we are very far from reaching that goal.

In this edition of *Institution Watch* we have asked individuals from across the country to provide their perspective on this issue. To provide commentary as to why we have successfully closed large institutions but have not yet enabled people with intellectual disabilities to exercise true choice and control in and over their lives, and to offer suggestions as to how this situation can be changed. ■

The 21st Century Challenge: Building Sustainable and Inclusive Communities

David Towell



David Towell is the Director of the London-based Centre for Inclusive Futures. He is one among many leaders of the deinstitutionalization process in the U.K. driven by the philosophy of An Ordinary Life.

I am very happy to accept the Joint Task Force's invitation to contribute to this special edition of *Institution Watch* from across the Atlantic.

Institutional segregation is not the only challenge that faces people with intellectual disabilities but for well over a century large institutions have been the most visible and concrete representation of their exclusion and the deprivation of human rights other citizens take for granted. The Joint Task Force has done a great job in keeping this historic injustice high on the agenda in Canada and *Institution Watch* is a valuable source of accessible news and wise guidance on what needs to be done.

Most important, people everywhere will celebrate the news that this nightmare is nearly over in Canada!

My own interest in DI = deinstitutionalisation (horrible word!) started young. My birth was the occasion for my profoundly disabled sister, Patricia, to be admitted to institutional care – a separation from family and community which lasted 51 years. It wasn't until 1997 that she moved with a few friends to 'an ordinary house on an ordinary street' and thus in some senses at least 'came home'. Both as a brother but also as a social scientist interested in policy change, we could say that much of my adult life has been concerned with how we could bring about this small revolution, not just for her but for tens of thousands of other people who shared similar experiences.

In England, some 50,000 people with intellectual disabilities moved out of large institutions, mostly in the 1980s and 1990s, but with a 'long tail' so that the final closures (or so we thought), mostly of recently-built 'campuses', only occurred in the last couple of years. But here is my first warning to Canadian friends. Watch your back! Not only did many of the alternatives, especially in our early enthusiasm for

group homes, reproduce institutional practices; we also left a back door open for the private sector to create new institutions, typically claiming to offer some specialised service ('assessment and treatment') while actually warehousing people for profit. As so often in the past, it took another scandal (the BBC's undercover investigation of Winterbourne View) to generate the political support for a fresh wave of deinstitutionalisation, now focused on about 1500 people mostly said to have 'challenging behaviour'.

Beyond this, the Joint Task Force *message* which leads this edition is an excellent summary of where we are in the U.K. and the big questions this statement asks are important for all of us. They are not easy to answer, not least because our agenda now has to be about 'community' not just about 'services'.

Let's start from DI itself. I volunteered for CACL in 1991 and met, among many great leaders, Jo Dickey and Paulette Berthiaume. Jo and family colleagues in BC had invented 'individual funding' several years earlier; Paulette and colleagues had recently organised a mass 'escape' of people with intellectual disabilities from an abusive Montreal nursing home. Great stuff! But that was more than a quarter of a century ago. Why has it taken us so long to finish the job they started?

Clearly any large service system is dynamically conservative: various parties have an interest in retaining the status quo. But in this case the injustice was visible, the money and the people were there and technically the DI process we have mostly followed is not so difficult. Essentially we have taken a service system which focused on congregate care and dispersed it – with some of the consequences identified in the *message*. Clearly there are some powerful forces at work in our societies which make generating the necessary political will for this transformation problematic. These forces haven't gone away. Indeed in 'austerity' Britain at least, there is rising inequality, increasing division and a depressing trend for poor and disabled people to be scapegoated for what is clearly a crisis of global capitalism.

Of course we have learnt a lot in 30 years about ways of improving on our early DI efforts which address points in the *message*. We have tried to strengthen self-determination ('I can say what matters to me and how I want to live') by redefining legal capacity, encouraging different kinds of advocacy and welcoming the leadership of people with intellectual disabilities themselves. We are addressing personalisation ('I get the assistance I need to live as I want') through rediscovering individualised funding ('self-directed support'), elaborations of person-centred planning, new versions of supported living and quality checking which listens directly to people's experiences. And we are trying to advance inclusion ('I'm included in my family and community and benefit from the services other people use') by changing public awareness, passing equalities legislation, mainstreaming public services, investing in community connecting and discovering that 'buddies' can be good. All these are important and hopefully other contributions to this special edition will elaborate on them.

But this won't be enough to deliver on the CRPD vision of equal citizenship. I think we can learn most about what else is required through the example of inclusive education, where parts of Canada have provided international leadership.

Inclusion in education can't be just about action addressed to particular sub-groups in the population (e.g. disabled people) even though it is essential to identify what kind of adjustments individuals with specific impairments will require to participate fully. Rather we are talking about changes in culture, policy and practice in schools and the wider education *system* which make everyone not only welcome alongside their peers but also able to participate fully in educational processes personally tailored to their needs, across distinctions of gender, ethnicity, income, disability etc. To coin a phrase, *Diversity Includes!*

The CRPD applies this reasoning to all areas of life: health, housing, employment, transport, leisure, participation in public life, etc. The daunting but obvious conclusion is that the aspirations for equal citizenship of people with intellectual disabilities requires the same kind of radical system change in each community and at the level of the whole society.

But our 21st Century challenge is even more daunting. Inclusion in what? The psychiatrist, R.D. Laing made a distinction between being 'out of formation' (not included) and being 'off course' (going in the wrong direction). Currently our societies, especially in the economically richer countries, are way off course in failing to face up to the critical 21st Century challenge of living in harmony with our planet so as to achieve a sustainable future.

In this Century, we need to advance sustainability *and* inclusion. A better future for all of us will require deep change in the relationship between the environment, economy and society. At heart, we need to move away from individualism and materialism towards an alternative set of values grounded in family, friendship and community in which we redefine prosperity as residing in the quality of our lives, the health and happiness of our families, and the capacity of our communities to 'live well' together.

Daunting it may be but this challenge also presents a new opportunity. Clearly it is in the interests of people with intellectual disabilities and other marginalised groups to be part of the broader movement required to achieve this transformation: this is about all our futures. Equally our communities need to respect diversity and welcome everyone's contribution if these broader strategies are to succeed. Radical action is more likely where it is possible to forge alliances among different interests and establish convergence on shared priorities.

Put differently, my proposition is that, while many kinds of incremental action are highly desirable to address the deficiencies identified in the *message*, we now need to define our over-arching purpose as being to ensure that social justice and inclusion are central to the action we need in all our communities to secure a sustainable future. Hopefully it will soon be time to re-title this magazine as *Community Watch*. ■

It's Time to Rethink Training

Susannah Joyce and Rick Tutt



Susannah Joyce, Director of Realizations Training & Resources in London, Ontario, has offered workshops and consultation on person centered support in Canada, the US and the UK for 25 years. She is the author of Guidebooks on personal planning, friendships, Circles, supporting people labeled with challenging behaviour, and most recently, on using training/learning opportunities effectively. Susannah has served on Boards and Committees locally and provincially and is a long time member of several Circles of Support.



Rick Tutt, Director of Rick Tutt and Associates in Ottawa, Ontario, has worked and volunteered for over 45 years in the community living movement and currently consults on a wide range of issues related to people labeled as having an intellectual disability. He volunteers extensively with People First of Ontario and Canada and also sits on the PFC-CACL Joint Task Force on the Right to Live in Community. Rick is committed to community living for all as defined by people who live with an intellectual disability.

A recent report was released in Nova Scotia on reforming supports and services for people with an intellectual disability. It is called, "Choice, Equality and Good Lives in Inclusive Communities: A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program" and we encourage people to read it. The report is a testament to how community and government can work together with a solid value base on behalf of citizens with disabilities.

However, it struck us that the success of many of the Report's initiatives, indeed many initiatives that people with disabilities are struggling to achieve all across the country will rely on a major re-thinking of training opportunities provided to people who use services and supports and their families, and to organizations and employees who deliver those supports.

Unfortunately in the world of human services, training is one of the first areas reduced in times of economic stress. It should, however, be one of the most fiercely preserved elements. The greatest resource of any human service organization is its employees and the work they carry out. Training opportunities not only need to be maintained and enhanced, but also need to undergo some revolutionary changes. If we are to transform services and supports...then we must also transform attitudes and practices.

We would not trust a car mechanic or computer technician who was unaware of current technology. We look to doctors who possess the most up to date skills. So why do we continually train employees in methods or values that are outdated and not in the best interests of the people for whom we work?

The following hints can help us look at the types of training we should be developing and delivering. Effective training:

- Is based on the needs and wishes of people who have an intellectual disability. Ask them what they mean by "living in the community" and what needs to be learned to support them in community.
- Always considers the perspective of the person who has an intellectual disability.
- Focuses on the values that the community living movement holds dear: individualization; self-determination; inclusion; relationships; community participation and contribution; valued roles.
- Is delivered by people who hold these values to be important and self evident.
- Invites people to explore and deepen their values and how these are reflected in offering support.
- Exposes barriers to real community living and provide opportunities to replace those barriers with opportunities.
- Challenges us all to think differently...of new ways of assisting people.
- Is not "trainer oriented", but offers everyone present opportunities to participate and think of better ways to carry out their roles.
- Uses language that is always respectful and never includes acronyms such as PWD (person with a disability) or offensive language. Seek out plain language always and model it.
- Offers ways for learning to be ongoing through mentoring, books and taped resources, and opportunities for continued discussion.
- Provides ideas for information to be shared with others not attending a training event.

"Learning is when you suddenly understand something you've understood all your life, but in a new way."

– Doris Lessing

Training that is effective and inspiring exposes people to the most creative and positive thinking and the most current strategies to support people to live a meaningful life in their community. Training is an expensive and valued resource. We all have a responsibility to make sure that it is as beneficial as possible...and reflects the values of our movement. ■

Community For All - Making the Dream Real

Steven M. Eidelman



Steven M. Eidelman is the H. Rodney Sharp Professor of Human Services Policy and Leadership and the Faculty Director of the National Leadership Consortium on Developmental Disabilities at the University of Delaware. He has been involved in efforts surrounding deinstitutionalization for his entire professional career.

Institutions are places that long ago served their purpose. Originally, they were not totally ill intended, but we know that the results for those who were placed there were often very poor. And they were “placed”. They did not get to choose where they would live. Or with whom they would live. At best those who lived in institutions had their basic needs met while being congregated and segregated and at the worst were warehoused, exploited, neglected, degraded and abused.

Sometimes people were placed in institutions because families had no other options and sometimes institutionalization was thought to be best for them and their families based on professional or conventional advice, lack of resources, fear or revulsion. Over the past 4 decades we have learned a great deal from our experiences, perhaps most importantly we have learned to ask better questions such as how people with intellectual disability want to live, and how to support them and their families. We have gone from assessment and placement of people to “how can we make meaningful, included lives possible?” We know now that large institutions are not the answer.

In the beginning of the deinstitutionalization movement the issue was real estate, getting people out of big buildings and into small places that looked just like where people without disabilities lived. Well, one of the things we have learned since the beginning of the deinstitutionalization movement is that it is about a lot more than real estate: size, space and location. Even small group homes can be much like institutions; when others decide where you will live and with whom you will live, what you should be doing during the day, what time you need to awake and go to bed. The goal now is about being a valued and participating member of your community, about being interdependent with people who are not paid to take care of you. The results of our early efforts that focused primarily on real estate inadvertently created new systems of support that were a lot like the institutions they replaced, only smaller. The care was routinized and there were a lot of rules that in hindsight had few purposes other than to try to control people and reinforce who was in power and who was not. Few efforts were made to listen to what people wanted and needed. People were physically closer to people in the rest of society, but largely remained psychologically and socially segregated. Many of those early efforts of deinstitutionalization are still with us. Now, we need to shift our efforts into creating systems of services that support people in being included in ways that are so much more than just a postal code.

Early group homes often provided (and research showed this to be true) a vast improvement in the quality of life for people who moved from institutions and provided relief for families who were growing tired and wanted other options for their children. But being better is not good enough. While these changes were not insignificant, they lacked an affirmative philosophy of person centeredness, self-determination, inclusion and full participation in the life and fabric of the community. Though it was certainly not the intention, in all too many instances it has been the result; group homes and day programs became the new institutions.

Over the past few decades we have entered into a new phase of the deinstitutionalization movement where we are now faced with the challenges of remodeling or transformation of existing community

services to better support people in living lives of their choosing. This is known as Second Order Deinstitutionalization. It is difficult and important work; maybe more difficult than deinstitutionalization itself. People often ask “can people with intellectual disability be valued community members?” “Can they really form meaningful relationship with people not paid to take care of them?” We have sufficient collective experience in the developed world that they can and do. In a word, yes. People are contributing, in ways that make the entire community stronger, not just for people with disability, but for all people. Strength is found in these reciprocal relationships.

Many of the community programs developed in the past as alternatives to institutions are now the very programs which must change. Many people in leadership roles in these programs are the very people who have helped to create them and remain intimately invested in their success. In some instances this is a barrier to positive change. However we have also seen examples of programs that have met the challenge and have transformed in order to better support people in living lives of their choosing, lives of participation, inclusion and valued roles in their communities. This has involved including people with intellectual disability in both organizational decision making as well as having people self-direct and choose their own supports and services. We see programs that support people living how they want, and with whom they want. We see programs supporting people to volunteer in their communities, gain paid jobs in the main economy of their communities and create small businesses. These changes are nothing short of revolutionary.

The fulfillment of this mission involves the elimination of institutional care. We know from research and from news headlines that institutions with their impersonal and routinized care are incompatible with people living lives in which they have real choice, control and dignity. And, no matter how much money we spend, the problems persist. Spending time and money on something that is a proven failure is just plain bad public policy.

Are there risks for people with disabilities living in towns, cities and villages? Of course there are, but there are even greater risks for people who live in large, isolated environments, without eyes and ears to hear and see the nature of their daily experiences. We have learned how to reduce risk in the community. The system is far from perfected, but so many people are now enjoying freedoms and opportunities that there is no turning back.

I have a professional colleague for whom her church is very important. She has a son, now an adult, who has Down syndrome. He also happens to dress like someone out of a men’s fashion magazine. Always a proper shirt and tie, a sports jacket and khaki pants. One Sunday, he was about 21 years of age at the time; he was at the entrance to the church handing out church bulletins. My colleague saw a young couple hugging him and crying. As she did not recognize this couple, she went to inquire. The couple told her that they had recently given birth to a daughter with Down syndrome and they had come to pray about what awaited their daughter in the community, about whether she would have a place in the world? And then this nattily attired young man greeted them at the entrance to the sanctuary and handed them a bulletin. Seemingly a simple act. But it was not so simple. This young man showed how he was helping to strengthen and support his community. He was playing a valued role that had nothing to do with whatever his limitations and label were and everything to do with being someone giving something to his church and his community.

Stories like this one repeat themselves every day, in every place where people with intellectual and other disabilities live and work.

Collectively, we can make it possible everywhere. ■

Community Living: How Far Have We Come? How Much Farther Do We Have to Go?

Diane Richler



Diane Richler is the Joseph P. Kennedy, Jr. International Fellow and also Inclusion International's Ambassador to the United Nations. She has previously served as President of Inclusion International, Director of the Roeher Institute and Executive Vice President of CACL.

I first started working with families of people who had an intellectual disability over 40 years ago – probably before many people reading this were born. At that time, in the early 1970's, almost all the money being spent to support people who had an intellectual disability was being spent in institutions. Families had few choices. Schools wouldn't accept students if they had an intellectual disability. There were no employment programs. Families had to provide all the support on their own. Often if one parent became ill, or if a new baby was born into the family, the family wasn't able to cope, and sending the child who had a disability to the institution was the only choice.

But families knew that institutions weren't the right place for their sons and daughters to live. Parents said "no" to institutions and began to create services in the community -- schools, sheltered workshops and group homes. As people who had been labelled started to have more experiences living in the community they became self-advocates and began to talk about the kind of lives they wanted to lead. Their vision of the future had no place for institutions. They said "no" to institutions but they also said "no" to other services that forced people to live, work and play together simply because they had been given the same label. They fought against labels for people. They fought against labels for organizations that wanted to support them. And they were the first to suggest that the national organization which worked to promote their rights should be called the association for "community living". It took a while for the new name to be understood by the public at large, but it has made the goals of the organization much easier to explain and understand – that is, the goal is not to change people, but rather to change society so that everyone can participate.

When Inclusion International conducted a global study last year to find out what people who have been labelled as having an intellectual disability and their families thought it meant to live and be included in the community, people around the world said the same thing. People want to decide how to live their lives, who to spend time with and what to do. They don't want to live in institutions, but they also don't want to be forced into other services that take away their liberty to make their own decisions, both big and small. Steve Eidelman, a university professor from the United States called what we need now "second-order deinstitutionalization". That is, we need to focus not only on changing the physical places where people live, but we also need to ensure that people are supported to make their own decision and can fully participate in all aspects of their community. And for that to happen, communities need to change.

When CACL first started to talk about closing institutions many people thought that could never happen. But gradually we have seen institutions close from coast to coast. The challenge now is not to transfer the kind of control that institutions have over the people living there but to find ways both to support individuals and families, and to make our communities welcoming. That is not an easy task, but hopefully 40 years from now, services that control people instead of supporting them will be a distant memory. ■

Where Do Dreams Come From?

Debbie Dandy



Debby worked as a Case Manager and Program Manager for Family Services and Labour for 34 years in the Westman Region of Manitoba. During her time with Family Services she was actively involved in the closure of Pelican Lake Centre and a lead with the transition team supporting people to leave Manitoba Developmental Centre. She is currently working for a private agency as a staff training and development coordinator and is the President of Community Living Brandon.

I was privileged to be part of the Family Services team which supported the transition of 69 individuals from a small institution, the Pelican Lake Center, in 1999 when it was closed. This center closed for many reasons, but it would be inaccurate to say that the Government of the day was motivated by the principles of inclusion. I was involved again in supporting transition when the Manitoba Government initiated a downsizing of the Manitoba Developmental Center about ten years later, following a Human Rights complaint.

The transition of individuals to the community always begins with a plan for their life in their new home. Asking individuals who have never lived in a normal environment what their hopes and dreams for the future are is like asking me what the best exotic holiday location is! Without any experience, I am unable to make any choice except one that includes those things I already know. The plans which were developed with individuals, most of whom had no family involvement or at least no family who knew them well, were the sparsest planning reports I have ever been involved with. And the community experiences we provided to assist in decision-making about how life might be lived upon leaving the center, were out of context and foreign. The choices we could be sure of were that people enjoyed going for coffee, listening to music, crafts, spectator sports, bowling, etc. These were the choices which they had opportunity to experience at their institutional homes.

We know that the most important need of individuals supported in the community is for relationships. The idea of friendships, of people present in one's life because they want to be, not because they are paid to be, is one that institutions may understand but find impossible to implement. The policies and structure of institutional life makes developing friendships for people outside of institutional walls a challenge. When people say that they enjoy going for coffee, it is the experience of drinking a cup of coffee in a busy social setting away from their usual living area that they are referring to, not having a social time with a friend. Their activities are organized by staff and attended by other residents not of their choosing. The dream of developing real friendships and participation in a natural social community is not a choice that people understand when they leave an institution, but one that we put forward for them as they begin a new lifestyle in a new home.

Down the road from the Pelican Lake Center, a previous resident lives in a small farmhouse. He had lived in a group setting, but it was difficult. He was disruptive to others, and they were actually afraid of his activity level. He had trouble controlling his actions, and things tended to get broken. One of the staff in the home lived on a nearby farm, her kids grown, and she and her husband decided that they would become his caregivers. Today, this man is a part of the rural community - he accompanies the husband when he hauls grain, knows all the farmers who gather in the local common places to talk farming, travels to Brandon with livestock, and enjoys getting out on the farm equipment. When he goes to the restaurant

in town he is known and greeted by name, and interacts with the people he meets there. At house meetings sheep were likely to poke their heads in the window to see what he was up to. He has led those sheep in the fair parades in town, alongside other community members riding horses and bikes, and driving old tractors. And last year, his support providers used all their Air Miles to travel, amazingly, by plane, to Edmonton, so he could visit a brother that he has not seen since he was a child. It is clear to all that these are more than caregivers, they have become his family, and that he is part of the community that surrounds him.

On the Labor Day weekend I was out to the community near where the institution was. A woman I know had searched for a house suitable for sharing with a person who needed support. It is a great country house, in the middle of nowhere! Together, they had invited friends out for a huge barbecue and party. There were people who had lived for 25 years at Pelican Lake; some support staff; they had invited friends from work – her work, and his work at the workshop in Brandon; other friends from the local community; and a couple of farmers strolled in when a sprinkle of rain shut down their combines. There were some kids getting everyone wet as they splashed in a big pool set up. A slip’n’slide was set up down the hill. I visited with one of the guys from the workshop. He is confined to a wheelchair, and needed his communication board to communicate. He invited me to his wedding. I have known the bride for years, and it should be exciting. When the food was ready, Lorna coached her co-host as he yelled: “It’s time to eat”. Then he said grace.

I do staff training now, and talk about how the most important thing that staff has to understand: that every single day they need to be assisting people to be in active relationship, participating in their community. Those individuals who left the protected setting of the institution 14 years ago could not have said that one of their dreams for the future was to have friends, go to picnics, and have some laughs. They could not tell us many hopes or dreams for their future - you must have experiences from which to make choices and dream dreams. Institutionalization has denied so many people experiences from which they can make choices and dream dreams - that is the injustice of living in the institution. What a loss for them to be denied the experiences from which dreams for the future are made. The future most have found is good, and there are some natural friendships present, but they shouldn’t have to wait so long to find out what the possibilities are, and what community feels like. ■

Where To From Here?

Carol Ann Brennan



Carol Ann Brennan is currently the Executive Director of Regional Residential Services Society where she has spent most of the past thirty years planning and developing community based residential supports with individuals with intellectual disabilities and their families in Nova Scotia.

In three decades of work supporting individuals with intellectual disabilities and their families in Nova Scotia I have borne witness to and celebrated enumerable accomplishments and successes in forging toward social inclusion. During this time Nova Scotia closed many large institutions and developed a broad system of community based supports. Much good emerged out of deinstitutionalization efforts in Nova Scotia that began in the mid 1970’s and continued into the mid 1990’s. Individuals have become gainfully employed, are living in a home of their own and are supported by family and friends. Unfortunately, such examples are more the exception than

the rule. The past fifteen years has seen little by way of advancement in support of these directions despite ballooning waitlists, family crises, and the entrenchment of inherent rights for the social and economic inclusion of persons with disabilities internationally.

Nova Scotia had not merely stalled in its efforts to advance deinstitutionalization, decisions were made and actions taken that contradicted previous efforts toward inclusion. Enhancements to remaining institutions were funded and outdated large scale group homes were replaced with new congregate care living arrangements leading to feelings of frustration, anger and disillusionment. Nova Scotians' with intellectual disabilities and their families' dreams and goals "to live good lives of their choosing" have been stifled by bureaucratic systems with prescriptive service models, overarching legislation and policies that have served to undermine the personal control and self-determination of the very people it was designed to support. Not only is it evident that the capacity of existing services is markedly inadequate, the services that exist do not align with what individuals and their families are seeking.

After decades of supporting individuals with disabilities in our communities I am struck by the challenges individuals face on a daily basis; to be heard, respected and be afforded opportunities guaranteed to their fellow citizens to exercise their inherent rights. The early days of my career were rooted in the People First movement in Nova Scotia. I am baffled that, these thirty years later, those of us without disabilities who have developed systems, informed policies and legislation and strengthened our bureaucracies in the name of "good service" struggle to appreciate the negative impact of our efforts. If we unwrap the complex web we call supports and honestly examine who it serves it would become clear that the individuals for whom all this was designed have become lost in the maze. The power inherent in our organizational hierarchies has become that which, both intentionally and unintentionally, jeopardizes society's ability to guarantee the rights of people with disabilities to choose, to achieve social and economic inclusion and be afforded their rightful place alongside their fellow citizens.

Each of us must acknowledge the part we have played in creating barriers to inclusion. Considerable self-reflection is required to reach an enhanced understanding of how the roles we play into the future will support the evolution toward an inclusive society. If people with disabilities are to be truly valued and respected we will need to step away from our positions of power, making space for people to make their own choices and live their own lives. I am buoyed by the new directions outlined in Nova Scotia's roadmap for transformation of services for persons with disabilities. It is broad in its scope toward seeing a future that guarantees social and economic inclusion for all Nova Scotians. It is my sincere hope that with this transformation initiative we will witness intentional and bold actions toward guaranteeing 'greater self-direction, choice and control by people with disabilities and their families'. Nova Scotians will need to navigate this new roadmap by following the lead of our fellow citizens with disabilities.

As an individual in receipt of supports often has reminded, "if you want to know what we want, you have to ask us and then *really* listen to our answer". ■

Former Woodlands resident tells his story

Richard McDonald, a former resident of BC's Woodlands institution has just recently written a book, which tells his story of living in the institution. Written and printed with the support of Heather Bax from the New Westminister Writer's Guild and Meaghan Feduck, a graduate student with the UBC School of Social Work, Richard's book, *My Story*, is now available for purchase. Contact posAbilities at 604-299-4001 to learn how you can obtain a copy.

Time For a New Story!

John Lord



*John Lord is a researcher, author, and facilitator from Kitchener-Waterloo, Ontario. He is the author of several books on alternative community living, including *Return to the Community: The Process of Closing an Institution*, *Pathways to Inclusion: Building a New Story with People and Communities*, *Friends and Inclusion: Five Approaches to Building Relationships*, and *Facilitating an Everyday Life*.*

In 1983, the British Columbia government announced they were closing Tranquille, a huge facility in Kamloops. Over the next three years, I researched the closure process and initial outcomes for people leaving the institution. Although our research clearly showed that people were far better off living in the community, years after the closure we found that most people had few relationships and many continued to be isolated from community life.

In many ways, what happened in British Columbia in the 1980's and elsewhere during the last 30 years, shows the limits of deinstitutionalization when it is not accompanied by a paradigm shift in the way we provide support to people. As a result, many people with disabilities living in the community continue to be poor, have few friends, and are often segregated from community life. Albert Einstein put it best when he said, "The significant problems we face cannot be solved at the same level of thinking we were at when we created them".

Governments and most service providers did not change their thinking very much during deinstitutionalization. In fact, the myths that kept people from changing their thinking during deinstitutionalization *are the same myths that are making it so hard to change the community institutionalization that now exists across the country.* These myths include:

Myth #1: People with complex disabilities require institutional care (or segregated support).

Reality: *Citizens with complex disabilities have been able to live full, rich lives in the community (in every province)*

Myth #2: A continuum of services is still the best way to provide support to people with disabilities.

Reality: *A continuum approach always leaves some people with disabilities segregated and less equal.*

Breaking these myths requires a New Story. In research for two recent books I have co-authored, we have learned that a new narrative is in fact emerging across the country. In every province, we can find innovative approaches, often reflecting this idea of a New Story, where people's dreams are heard and genuine relationships are being developed. In every province, we find fearless families, who have figured out how to support their vulnerable family member to be part of a neighbourhood, employed in meaningful work, or included in a faith community.

The problem is that the elements of a New Story are typically local, small in scale, and somewhat fragile. Large scale change has eluded this movement, so that even in the most progressive communities, we witness old story approaches (segregated day programs, large group homes, isolation, loneliness, etc.) side by side with the New Story (individualized funding, independent facilitation, dedicated people building relationships and support networks, strong family networks, etc.).

Some would say this is the way social change always happens. A small group of social innovators show us a New Story with their ideas and their practice. The innovators inspire us to be committed to self-determination and community, because they know that these values are the foundation of significant change. The assumption is that early adopters then move toward the New Story and over time, a ground swell of support for the new ideas will take hold.

Yet, this scenario has been played before. The innovators do find some early adopters of their ideas, but little else changes for the better. Governments are moving at such a slow and incremental pace that the lessons and research of the social innovators are seldom being embraced. Sadly, the lack of impetus toward a New Story means that service providers who resist paradigm change have time to organize against the change. Even some families are now seeking old story solutions, since the promise of a New Story does not have strong policy and funding support. To make matters worse, governments have typically refused to re-allocate resources from the old story to New Story infrastructures.

I hope that closing all institutions in Canada can be an impetus for more concerted action. We need strong national and provincial voices speaking for a New Story. While it is difficult to be optimistic in the light of the current reality, we can be inspired by Gandhi, who reminded us to remain hopeful and work with others to “be the change we require in the world”. ■

The Roots of Possible Antidotes to Today’s Harmful Institutional Culture in the Community

Michael J. Kendrick PhD



Michael J. Kendrick PhD is an independent international consultant in human services and community work as it relates to aging, disability and mental health. His interests, involvements and writings have included leadership, service quality, the creation of safeguards for vulnerable persons, social integration, change, innovation, values, advocacy, the role of individual persons and small groups in creating advances, evaluation, alternatives to bureaucracy, personalized approaches to supporting people, and reform in the human service field amongst others.

Critiques of institutionalization have tended to be focused on the settings themselves rather than the underlying and typically unconscious mentality that creates custodial preoccupations, neglect, abusive treatment and eventual dehumanization. We can see this more clearly now as we witness the same phenomena manifest anew in “mini-institutions” and even in our personalized “institutions for one” deep within communities. Buildings are more tangible than beliefs, attitudes and ideologies, yet it is the latter that we must focus on.

There were in the past, what many at the time would have called “good” institutions, much as there were better and worse people working in institutional settings. This variability in the character of institutionalization would not have been evident if the simplistic idea that environments *entirely* predict and define attitudes was questioned. Similarly, in the present, not all personalized support arrangements in the community have a mini-institutional ethos to them, thereby indicating that deep set attitudinal factors favoring non-institutional developmental mentalities and conduct are also present, variable in nature and potentially able to be strengthened.

Nonetheless, we have repeatedly acted as if unconscious devaluing attitudes and values are not greatly problematic in terms of how vulnerable people will likely get treated. Much of this naiveté about the role of values in guiding conduct is due to a failure to grasp that human beings are capable of both virtues and evils and for the former to prevail the better side of our nature needs constant reinforcement. It is a given that personal character and integrity based on positive values will always be at risk of being compromised by the conditions of life. Unless these values and the resolve to live them are strengthened repeatedly in people, then we can expect a largely unrecognized yielding to the easiest, least demanding and custodial conduct in those people who are involved with both present and future services. This is as true for those indirectly involved in legitimating services as it is for those involved in “hands on” roles, as institutional culture has always been both explicitly and tacitly defended at the highest levels of society largely through inaction and denial.

If we are to change the present critique from solely a lament about emerging institutional conduct in an ostensibly person centered era, it would force us to have to name and pursue a more explicit sense of what are fundamentally desirable attitudes and conduct and to more consciously and thoroughly take on the challenges they embody.

Remembering that much of the definition of the mentality and desirable conduct that guided earlier anti-institutional thinking was explicitly laid out in social role valorization theory (formerly normalization theory), and that of similarly explicit values oriented guidance, we can see that the comparative decline in this emphasis has left a whole new generation of people vulnerable by having to rely solely on largely inexplicit ideological constructs for guidance. These are defined so vaguely that they are not much more than reassuring slogans rather than the more explicit and challenging demands upon our conduct that was exemplified by systematic theories such as social role valorization. These include slogans such as “community inclusion”, “membership”, “citizenship”, “person centeredness”, “social networks”, “self directed” and other nebulously formulated pseudo values into which we can project whatever we please, since they demand nothing specific from us, yet they are summoned routinely to provide legitimation and obfuscation for all manner of present expressions of institutional conduct within everyday life in the community. In contrast, former constructs that were much more explicit and critical of us such as dehumanization, deprivation of rights and abusiveness recognized the reality of persistent social devaluation and the harm it causes. These also prescribed remedies that relied heavily on values, consciousness and taking personal responsibility to view and treat people in valuing ways i.e. supporting valued social roles.

“Institutions are a state of mind rather than a place”

Peter Millier

There are obviously potentially legitimate uses for any of these terms, but our next generation of conceptual and values leaders will need to be much more forthcoming in spelling out considerably more clearly what terms like these are meant to mean in terms of positive conduct and what are conceivably perverse distortions of their meaning. We cannot defend and uphold the life potential and worth of people at great risk of social devaluation and mistreatment by embracing categories of thought that lack moral meaning and obligation. On the contrary, we must see the renaissance of institutional conduct and the eventual wasting of people’s lives and potential as being fundamentally a moral and values failing that must be answered with exceedingly clear ideas of what proper conduct and service design ought to be. Should we have that kind of clarity, it will be considerably easier to both tackle the coming manifestations of unacceptable treatment of people by emphasizing the qualities and conduct that is possible by asking something of ourselves and society itself. ■

Everyone Wants to Belong

Connie Lauren-Bowie



Connie Laurin-Bowie is Executive Director of Inclusion International which is recognized by the UN as the global organization of people with intellectual disabilities and their families. Inclusion International has over 200 national member organizations in 115 countries. Connie led Inclusion International's representations at the UN Ad Hoc Committee meetings that led to the new UN Convention.

EVERYONE WANTS TO BELONG. We value being a part of families, neighbourhoods, a group of peers at school, a group of colleagues at work, clubs and sports teams, and having friends and neighbours who care and look out for us. Unfortunately, people with an intellectual disability are often left out –

hidden, excluded or kept separated from the rest of their communities. While many countries have taken steps to close large residential institutions few have achieved real inclusion in the community.

That's why Inclusion International fought for the **right to be included in the community**, to be recognised as a basic human right for people with disabilities in the UN Convention on the Rights of People With Disabilities (CRPD).

Article 19 of the (CRPD) articulates the right to *Live Independently and be Included in the Community*. It obliges governments and societies to:

- Enable people to make choices about how and where they live;
- Provide support so that people who have a disability can live in the community; and
- Ensure that mainstream services and systems are available and accessible to people with disabilities on an equal basis with others.

In our recent Global Campaign on Article 19, people with intellectual disabilities and their families from around the world reported that despite some good examples and practices, there is no country in the world where the goals of living and being included in the community have been fully achieved. In the absence of services and natural supports in the community and the failure of communities to build inclusive systems, the vast majority of people with intellectual disabilities around the world depend on their families for lifelong support and care.

Despite the promise of the Convention and Article 19 the reality for the vast majority of people with intellectual disabilities is that they are almost always denied the right to make decisions about where and with whom they want to live. They have little or no access to services and supports (other than those provided by their families) and they are excluded from participating and contributing in their communities because community supports are not welcoming or accommodating and /or because they lack the supports necessary to use these services (e.g., accessible transportation, personal supports, financial capacity).

While many issues emerged from the collection of experiences and knowledge of people with intellectual disabilities and their families that were shared in our Global Campaign, the central messages from self-advocates and families were:

Choice – People with intellectual disabilities require and have the right to choice and control about where they live and with whom; they have the right to support in their decision making and they have the right to choose from the same range of options that others in their community have.

Support – To live and be included in the community individuals need disability related services and supports on a day to day basis. Some of those services are currently state sponsored but in the vast majority of cases they come from families. Families need support from governments and communities to play their role in promoting the inclusion of their family member into the community.

Inclusion – Unless communities are organized to be inclusive of people with disabilities through education, employment, social, cultural and political processes, investments in services alone will not enable the realization of the right to live and be included in the community.

To achieve real inclusion in our communities, governments, service providers and community advocates will have to move away from a focus on segregated and specialized services towards strategies that engage community partners in taking responsibility for inclusion. Instead of employment centres for people with disabilities, we need employers and employment agencies to include people with disabilities; instead of housing for people with disabilities, we need housing in the community to be accessible and affordable to people with disabilities and instead of providing one size fits all services, we need to create services that respond to and are accountable for meeting the needs of individuals. ■

From a Voice to a Movement

Shane Haddad



Shane Haddad has been an active member and volunteer with the People First movement for over 30 years. Currently serving as the President of People First of Canada, Shane is a founding member of People First of Saskatchewan and a long-time advocate for the inclusion of people with intellectual disabilities in all aspects of life.

People First of Canada believes that people should exercise their right to voice and choice in choosing where they live and with whom they live. We believe that all people can live within their community, with appropriate supports. We believe that no person, regardless of disability, should live in any kind of situation where they are kept apart from the community.

While People First of Canada focuses on areas such as employment, inclusive education, legal capacity, and raising awareness on issues faced by Canadians labelled with an intellectual disability, the essential core of our movement is the right to live in the community. People First of Canada originally started in a British Columbia institution – by people who lived in there and wanted to get out. They didn't just want that for themselves. They wanted a country where institutions were not part of the lives of Canadians with intellectual disabilities.

We have used every tool available and even created a few of our own that would work towards bringing people home to community. The progress made to close institutions has been happening locally, provincially and territorially, nationally, and internationally. People First members in Canada and worldwide have been part of this progress for a long time.

Right now, we are closer to realizing our goals than we have ever been before. It seems like we are on the edge of the end and circling the reality of an institution-free Canada. When we get there, we will celebrate in our victory. We will dance and sing. We will mourn those who did not survive the institutions. We will remember those who dedicated their lives to this cause but are not here to see it realized. We will remember the people who mentored us, who lit our fire or kept it bright, the ones who showed us the why, and taught us the way.

Then we will once again gather our resources, come together and make our next plan. Because if you believe that closing large, red brick buildings warehousing thousands of people across this country means that people now have control over their lives and their day-to-day decisions, then you are sadly mistaken. Closing institutions is only the first step. It's a good first step, but by no means is it the last. We need to remind ourselves that we are no closer to being an institution free Canada than we were 30 years ago. The buildings are just harder to find now.

Free our People! ■

No One Ever Said That it Would Be Easy

Zana Marie Lutfiyya, PhD



Zana Marie Lutfiyya, PhD, is a professor and Associate Dean responsible for research and graduate programs at the Faculty of Education at the University of Manitoba. Her ongoing research interests remain the factors that help or hinder the full participation of individuals with intellectual disabilities in the community. She has been involved with the community living movement since 1972.

Forty years ago, when the impetus to close the large institutions for people with intellectual disabilities began to be felt, we assumed that it was the right thing to do. Children should live with their families, attend school and other activities, and make a contribution to their community as adults. This was the normal, expected and typical thing for everyone else, and so it should be for those with intellectual disabilities. While no one said that this transition would be easy, most of us probably thought that it was at least possible. And we dedicated ourselves to this work. As parents, and family members, we wanted a good life for our daughters and sons, all of them, whether or not they lived with a disability. As individuals who worked or volunteered in 'the field', we could see the difference a community orientation had for the people we served and for us as well. Those with intellectual disabilities also told us their aspirations for their own lives. It was easier to hear some people than others, but we slowly learned how to pay better attention.

So what happened? Today in Manitoba, some things have changed. In 2000, the province of Manitoba closed one institution, the Pelican Lake Training Centre, where 69 individuals were housed. Virtually all children with intellectual disabilities do live with their families and attend school. Most of these children receive their education in typical classrooms and school divisions and educators largely accept this responsibility. The Amendment to the Public Schools Act (2005) provides a clear mandate to fall back on, should this prove necessary.

As these children grow up, the struggles for a fully integrated life in the community are more obvious. Some adults continue to live with their families, or on their own, or in agency-operated group homes, apartments or so called 'foster families.' Most attend a variety of day programs, some of which are work imaged, if not real work. Fewer receive assistance to find, and keep, jobs where individuals receive a fair wage and related benefits, and are able to work alongside their nondisabled peers. Adults may spend more of their time with other service recipients and less time with family and nondisabled individuals. Despite legislation that is supposed to guarantee a measure of self-determination, few adults with intellectual disabilities are able to effectively pursue or enjoy the same opportunities of nondisabled peers. Even when considered legally competent, adults with intellectual disabilities may be refused sole control of their bank account and possessions. They may be required to have someone else give consent for just about everything. These practices are meant to indemnify another person or agency, rather than serve as a measure of appropriate support. These individuals rarely have a real say in the services they receive. This means that they may not be able to (help) decide where they live, or whom they live and associate with.

How exactly did we arrive at this place? Laws, regulations, policies, mission and values statements all suggest one thing, yet our practice suggests another. When we pay attention to what people with intellectual disabilities are actually getting and what their lives are truly like as opposed to what others say they are getting, we may find fewer advances than we had hoped for forty years ago. The province of Manitoba still operates (directly or via a not for profit community board funded by the government) two institutions in this province, namely the Manitoba Developmental Centre and the St. Amant Centre, housing approximately 450 men, women and children. It should be noted that St. Amant also operates several community placed group homes as well, and the organization plans to support residents who want to live in the community to do so. However, politicians have been clear that there is no intention to close either of these facilities. This makes Manitoba the only province committed to the institutional model that operates alongside community services. As the institutional model has not been validated as a positive one for residents by research (see, for example Jim Conroy's work at www.outcomeanalysis.com) or legal precedent (see Article 19 of the *UN Convention of the Rights of Persons with Disabilities*), the various governments of Manitoba have presumably had other rationales for this ongoing commitment. It is known that some families, as well as organizations that represent staff of these facilities have remained the most vocal supporters of the institutional approach.

While vigilance and action are still needed to confront those who remain committed to institutions for people with intellectual disabilities, we need to be equally attentive to the situation of those who do live in the community as well. Unnecessary and possibly illegal constraints remain in place for many. Most individuals with intellectual disabilities will need supports (whether these are paid or unpaid, agency mediated or not) to live good lives. The need for support should not needlessly subject them to superfluous oversight and supervision. We need to have enough respect and appreciation for the essential humanness of individuals with intellectual disabilities to commit ourselves to ending the suffering they experience at our hands. No one ever said that it would be easy. But it will be worth it, and it is still the right thing to do. ■

Deinstitutionalization – What Does Justice Demand?

Michael Bach



Michael Bach is the Executive Vice-President of the Canadian Association for Community Living (CACL), and Managing Director of the Institute for Research and Development on Inclusion and Society (IRIS). For the past twenty-five years Michael has undertaken research and development on law, policies and programs in Canada and internationally on ways to advance the full inclusion and human rights of persons with disabilities. He holds a Ph.D. in Sociology and Equity Studies from the Ontario Institute for Studies in Education, of the University of Toronto.

What does justice demand? An age-old question applied over the decades in Canada to unequal access to health care, to addressing long-term and entrenched poverty, to confronting what many have seen as cultural genocide of First Nations and Aboriginal peoples by residential schools and other means. The thing about answering ‘what does justice demand?’ in any particular situation is that it’s never a completely straightforward answer. People and governments struggle over what it requires in a particular context. Sometimes a government policy decision or a court ruling give a temporary answer, but if it doesn’t fully satisfy those who experience injustice, the case isn’t permanently closed. Political philosophers, policy makers and activists give answers to the question that tend to fall into two camps. Justice requires redistribution of resources, or it requires new ways of recognizing certain people and groups. For those who say it requires both, there tends to be a tilt in favouring either one or the other – redistribution or recognition – as a kind of formula that justice requires at any particular moment.

So what does justice demand when it comes to confronting the confinement of people with intellectual disabilities to institutions? There is no question that it requires distribution – a re-allocation of resources from facilities to providing individualized supports to people in ways that finally give them greater choice and control in their lives; and opportunity to live in homes of their own choosing, to make friends, find a job, get connected to their communities and re-build their lives. Many of us have been working for years with governments and other stakeholders – raising our voices and demands, undertaking research, launching court cases, convening round-tables, engaging law and policy makers, delivering community supports and building community leadership – to get resources re-distributed, re-allocated.

We know the job is still not done. We still have large facilities to close, and after them large group homes and living arrangements. We have made progress, many people who were institutionalized have rebuilt lives and are living in the community in ways that we couldn’t have imagined a few decades ago. But we also see many who have left the confinement of a large facility to live a life confined in the community. And many more lying in unmarked graves on the grounds of facilities. Dis-respected and abused even in death, no mark to remember them by. Is re-allocation of resources sufficient to do them justice?

So what is to be done? I wonder if in the balance of our efforts we have won more ‘redistribution’ of resources than ‘reconstruction’ of the social and legal recognition of people with intellectual disabilities. Undoubtedly an advance in the political rhetoric of inclusion has been used to justify closures. And we will continue to leverage that rhetoric for more redistribution to ensure people access goods and services in the community of their own choosing.

However, in doing so has society – governments, communities, the courts, schools, employers, unions, political parties – yet come face-to-face with the centuries of misrecognition of people with intellectual disabilities, and what that has cost? Is it enough that the last door, of the last ward, of the last institution close? Is it enough that we tear the buildings down? Is it enough that people have moved to the community and are now living much better lives, or at least more people are, and for those that aren't yet at least we know the policies of redistribution that can help make that happen? I don't think so. There is a kernel of justice in the apologies we heard from the Government of B.C. to the residents of Woodlands, and in the anticipated apology from the Government of Ontario in the announcement of a settlement in response to the class-action suit by former residents of the Huronia facility. As residents in both cases said, apologies aren't enough. But are the cash settlements – the redistribution of resources – enough either?

My belief is that the institutionalized patterns of social and legal *mis*recognition of people with intellectual disabilities run so deep that we need some ways of restructuring widespread perception in the face of such historic and systemic abuse of power. The steps by both the governments of B.C. and now Ontario are very encouraging. But as with the first steps of recognizing the history of residential schools in this country, or the internment of Japanese Canadians in the Second World War, we are far from confronting the injustice against people with intellectual disabilities in Canada. Truths have yet to be told, clearly heard and understood. Reconciliation is far from accomplished. Is a truth and reconciliation commission part of the answer? A Royal Commission? What does justice demand? Let's not accept today's settlements as the answer too quickly. They are a momentous and hard fought step on the way. To those who made them happen our deepest gratitude for your courage and tenacity.

But justice is not yet done. Lest we forget. ■

Settlement Reached in Huronia Abuse Lawsuit

Survivors of the Huronia Regional Centre (HRC) to finally receive the justice they have been demanding from the Ontario government for years.

Located in Orillia, Ontario, the Huronia Regional Centre, was a provincially operated residential institution for persons with developmental disabilities. First opened in 1876, it was finally closed in 2009.

In April 2009, representative plaintiffs, former residents Marie Stark and Patricia Seth, commenced a class action on behalf of the nearly 4,000 people who had lived in the institution between 1945 and 2009. Specifically, the class action alleged that the Province's failure to care for and protect former residents resulted in loss or injury, including psychological trauma, pain and suffering, loss of enjoyment of life, and exacerbation of (existing) disabilities.

After almost 5 years of litigation, the production of over 65,000 documents, numerous motions, pre-trials and failed mediations, the common issues trial was scheduled to finally begin. As proceedings were set to begin however an historic



Marie Stark (left) and Patricia Seth, former Orillia residents who took Ontario government to court.
Credit: Stephanie Lake/CP images

settlement was finally reached early on September 17th, between lawyers for the Huronia Regional Centre (HRC) survivors and the Province of Ontario.

Preliminary details of the settlement, still subject to court approval, are:

- An apology to all former residents of Huronia from the Province of Ontario;
- \$35,000,000 Settlement Fund;
- The Province will pay for the cost of notice to the class and administration of the claims process;
- Compensation awards not subject to tax or government clawbacks;
- The application process does not require former residents to testify;
- The documents produced in this case will be accessible for scholarly research; and
- Commemorative Initiatives including:
 - A commemorative plaque on the grounds of Huronia;
 - Opportunity to access the grounds of Huronia;
 - Proper maintenance of the cemetery at Huronia and registry of those interred; and
 - Opportunity for scholars to attend and archive artifacts from Huronia.

Upon hearing of the settlement, Huronia survivor and one of the lead plaintiffs, Patricia Seth said: "I'm so relieved. Now everyone will know I wasn't lying about how they treated me in that place. I'm glad they're going to apologize."

Laurie Larson, President of the Canadian Association for Community Living (CACL) says "a financial settlement, regardless of amount, can never erase the horrific trauma experienced by former residents, nor can we allow it to cause us to forget the terrible history of institutions in this country - HRC being no exception. This settlement does however send a powerful message to all governments in this country that simply closing an institution is not enough, that closure does not erase the years of abuse experienced by former residents, and that an apology is both necessary and long overdue. While elated with the outcome, I am also deeply saddened by the ordeal that Marie and Patricia, on behalf of so many others, had to undergo to finally get that apology."

"Is this settlement enough? No. Is this settlement and formal apology long overdue? Yes." says Shane Haddad, President of People First of Canada (PFC). "Our members, many of whom are institutional survivors, have been for years telling stories of the personal abuses experienced while living in institutions. This settlement is important because it finally recognizes the truth of our stories and that government no longer is trying to hide the fact that horrible things did in fact happen in the institution. For that we are grateful, and hope that it gives former residents peace and the ability to move on with their lives."

This Task Force congratulates and commends Marie and Patricia for their bravery and courage in pursuing this lawsuit, and for helping to bring some degree of closure to this issue, for the many thousands of people who were forced to live in Huronia. The Task Force also acknowledges the tireless efforts of Jim and Marilyn Dolmage who stood beside and alongside Marie and Patricia throughout this process.

It is also noted that two further class action lawsuits (certified In 2011) launched by former residents of Rideau Regional Centre and Southwestern Regional Centre, two other Ontario institutions that closed in 2009, are still outstanding. ■

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