

# comingtogether

...to create change

Fall 2010

A National Family  
Leadership newsletter



## inside

What Heaven Looks Like	3
<i>Jim Flaherty</i>	
Life Imitating Work	4
<i>Tim Stainton</i>	
The Personal and Political – Coming Together	5
<i>Judy Wasylycia-Leis</i>	
Leadership – Grandma Style	6
<i>Mary Whitehead</i>	
A Life Without Labels	7
<i>Shane Haddad</i>	
First Down, and Goal to Go	8
<i>Andre Durie</i>	
A Life Changing Gift	9
<i>Ken Pike</i>	
Parent and Advocate: One and the Same	10
<i>Dr. Vianne Timmons</i>	
You're One of Us Now	11
<i>Dick Sobsey</i>	
Ten Objectives For the Next Ten Years	back page

## Families as Agents of Change

Leadership is defined not by the position we hold but rather by the action we take. The Community Living movement is in large measure a result of families taking action, individually and collectively. Families who refused to accept the status quo and the segregation and devaluing of their sons and daughters. Families stepping forward to provide leadership as and where needed. Leadership motivated and sustained by the presence of a family member with an intellectual disability.

Despite the leadership that families provide every day across this country, most families don't identify themselves as leaders. They see nothing 'unique' in what they are doing.

They are attempting to create the best life possible for those they love just as every other family does. 'What' they have to do, and sometimes endure, in order to do this though, can look a little different than for other families.

It can also be quite challenging for many families to create that life when so many are without the supports they need just to get through the day. Too many families still live in poverty. Too many parents are unable to hold a job due to care-giving responsibilities and the demands of inflexible systems. The very people who

need change the most are often the least able to create it. And yet – they try!!

Too often the contributions that are made by families go unacknowledged. Their stories are not told. New families are often unaware of the history and advances that have been driven by other families, families like themselves. It is important that we share the stories of family leaders to both inform and inspire.

In this edition of *Coming Together* you will read the stories of nine such family leaders who on behalf of their family members or on behalf of persons with intellectual disabilities (and often times both) have through their actions and efforts created real and positive change in this country. They come from all walks of life and from a variety of professions and occupations. What brings them together – what holds them together – is that they are family.

These stories are powerful not because they are unique but rather because they are so commonly shared. So reflective of the thousands of families in similar positions all across Canada who on a daily basis provide the needed leadership to this movement and who by this leadership ensure that we will continue to see progress toward full inclusion for our sons and daughters, our brothers and sisters, our grandchildren.



50 years

Canadian  
Association for  
Community Living

Diversity includes.

---

## Members of the National Action Committee on Family Leadership and Grassroots Engagement

Laurie Larson – Chair, CACL  
Julie Smith – PEI  
Kevin McTavish – SK  
Kim Akar – NS  
Dawn Gates – MB  
Leila Rahemtulla – BC  
Shauna Henry – NWT  
Tara Brinston – Secretariat, NBACL  
Anna MacQuarrie – Support, CACL

---

## The Council of the Federation

The Council of the Federation is the forum for bringing the broad Community Living Federation together to work collaboratively on advancing the full inclusion of people with intellectual disabilities and their families.

It is comprised of CACL and each of the 13 Provincial/Territorial Associations for Community Living. Through National Action Committees, members of the Council come together to share and exchange knowledge, to link existing efforts and to identify ways of working together to achieve our shared 10 point agenda.

---

## Photo Credits

Page 5 – photo courtesy of Tim Surbey

*If your actions inspire others to dream more, learn more, do more and become more, you are a leader.*

– John Quincy Adams

## On the Cover: The Soucy Family

On Sept. 27, 2010 Danny Soucy was elected to the New Brunswick legislature. Danny is a dad. He has spent most of his career working on behalf of persons with intellectual disabilities. He was the Executive Director of the Grand Falls ACL and most recently worked as the Program and Training Consultant with the New Brunswick Association for Community Living. Danny has volunteered on numerous provincial and national committees and was Co-chair of CACL's Family Leadership and Grassroots Engagement Advisory Committee. We congratulate Danny on his election win and know that he will take his experience and passion for those with intellectual disabilities with him on this next stage of his life.

## What is your story?

**We believe that it is important to highlight the contributions to change that families across this country are making. We would like to make a family story a regular feature of this newsletter.**

**So – what is your story?**

**If you would like to contribute a story for a future edition of this newsletter, or know of a family that is creating change and whose story should be told, contact:**

**Laurie Larson at: [ynot2@sasktel.net](mailto:ynot2@sasktel.net)**

**or**

**Anna MacQuarrie at: [amacquarrie@cacl.ca](mailto:amacquarrie@cacl.ca)**

# What Heaven Looks Like

## Jim Flaherty

John is the first born of our triplet sons. He is a handsome, charming 19-year-old with an intellectual disability. His two brothers are his pals and his supporters, but do not have his disability.

Being John's father has changed my perception of what really matters in life. The months during his second year of life when John was grievously ill and near death in the hospital were the most desperate time, but a time that I always recall when faced with some crisis or another – all comparisons fail when compared to the desperation of that time. John gave us context about what really matters.

Our family of my wife, Christine, and Galen and Quinn; all know that John almost didn't survive and that life in our family without John would be unimaginable and joyless. John shows us daily the simplicity and clarity of what matters in life: love, family, helping others, trying hard and having fun. John loves sports (both playing and watching). He tries to get me to go to games and tells family members that he "can get inside my head" to convince me to go with his persuasive words. He usually succeeds, but even when he doesn't, John doesn't complain or sulk but moves on with a plan for the next opportunity. His happy disposition teaches us to be happy too because of what really matters.

John looks on the bright side of life. When his brothers went off to university as he continued on at our local high school, he celebrated



**The Flaherty family.**

the fact that he would now control the TV remote. He sees clearly what we often miss in the cacophony of our lives. A few years ago, we were underwater in a submersible at the Great Barrier Reef in Queensland looking out the window at the sun's rays shimmering through the turquoise water on the colourful fish and plants, when John said simply and eloquently, "That's what heaven looks like". So now I know.

John has given us not only joy in life but also a strengthened desire to help others, especially persons with disabilities. His brothers volunteer coaching Special Olympics teams and community groups as well as, for example, taking vacation time to work with children with disabilities in Jamaica. Christine helped lead the creation of our local group homes for persons with disabilities. Today, as an Ontario Member of Provincial Parliament, she leads the Ontario committee studying mental health issues and providing useful recommendations. In my public life, John's disability has made me ever

mindful of the needs of persons with disabilities and the need for actions, not just words. Our government created the Registered Disability Savings Plan to help families support their children with disabilities in the future. We have made major access progress through federal funding. Canada was also one of the first countries to sign the United Nations Convention on the Rights of Persons with Disabilities in 2007, which we then ratified on March 11, 2010. And there is more.

John enriches our lives and those of others – and heaven looks pretty good too!

*The Honourable Jim Flaherty is a dad.*

*He is also Canada's current Minister of Finance. Throughout his career, Minister Flaherty has demonstrated a long standing commitment to advancing disability issues. Minister Flaherty championed the development and implementation of the Registered Disability Savings Plan.*



Diversity includes.

# Life Imitating Work

**Tim Stainton**

In the early eighties I was extremely fortunate to go to work with the families at the Community Living Society in Vancouver. These families, mostly Moms, had come together to liberate their sons and daughters from Woodlands Institution. It was an organization driven by a set of beliefs and values which demanded that their children had a right to be part of their communities and to determine the course of their own lives. In pursuing their dream they also happened to develop critical ideas which continue to shape our movement today: Individualized funding; brokerage; and the paramount importance of personal networks. At the time I was too young and naive to know I was privileged to be a small part of a critical social movement inspired and driven by families who believed things could be different. Since that time I have played many roles in community living from working at OACL to pursuing a career in research and teaching as a professor of social work, but whatever I have done, it has always been the wisdom and values of those parents who first taught me what community living means and how a small group of committed families can make an extraordinary difference that has guided me.

In 2000 I was working at the University of Wales when my son Gus was born. Gradually it became clear that Gus had an intellectual disability – suddenly, life was imitating work! My wife Si was also working in the field of intellectual disability so for both of us there was a certain irony in

Gus's disability. All of a sudden we were no longer hearing about the challenges of dealing with 'the system', but were getting an intensive course in it! We knew we were lucky having a greater knowledge of the system than many folks, but, like skydiving, you can understand what's involved, but that does not prepare you for jumping out of the plane! And through it all, our greatest help has been our connection with other families – sharing information, strategies, tears and trials.

One alternately amusing and annoying function of having Gus regularly occurs in the course of my work. When people ask what I do and I explain my work in disability, they often say – "oh! Well of course that's what you do having Gus and all". The 20 years of practice and academic work prior to Gus's arrival does not seem to register! What is so annoying about this is that the implication is that unless you have some 'personal connection' you would not choose to work in the field of disability rights, roughly akin to saying you need to be Black to care about racism. What people are saying is that the rights of people with disabilities is not a broad societal issue which all of us should be concerned with, but a concern of only those with a 'special interest'. The challenge we face in the fight for full inclusion of our sons and daughters could not be put more starkly.

I also get asked if having Gus has changed my views on disability and inclusion. I think it is a testament

to the families who first taught me that my fundamental beliefs or my views on how to achieve full citizenship have not changed significantly. I would say what has changed for me is the depth and passion of those beliefs. It is easy to talk about the challenge of achieving and maintaining an inclusive education, it is quite a different thing to get up and have to fight for it everyday. It is easy to recite the many joys Gus brings to our life and the lives of others, but harder to deal with the fears for his future or the heartache of seeing Gus watching others play baseball knowing he would love to be part of it but isn't. While my passion for change and dedication to the goal of a fully inclusive world has increased, I am less quick to judge families that maybe aren't there yet or are too consumed with the day to day struggles to join the broader struggle.

I have been blessed with a wonderful family and a partner who has a talent and tenacity for advocacy that I can only marvel at. Both of us take comfort and pride in knowing we are part of a much bigger movement of families who together will make a difference for Gus and all those who are labeled.

*Tim Stainton is a dad.*

*He is also a Professor, PhD Programme Chair and Director, Centre for Inclusion and Citizenship at the School of Social Work, University of British Columbia. Dr. Stainton is an internationally acclaimed expert in Individualized Funding.*



**The Stainton family.**

# The Personal and Political – Coming Together



Judy Wasylycia-Leis and her son Nick at an event in Winnipeg.

## Judy Wasylycia-Leis

It was August 1988. I was at an MLA function, five months pregnant with Joe, when our babysitter called to say Nick, our first born, then almost four years old, was having seizures. It was the beginning of a long journey of personal searching, emotional turbulence, endless medical visits and blood tests leading to the discovery of a brain disorder so rare only a dozen male cases have been identified in the world and meaning uncontrollable seizures, profound cognitive disability and complex developmental challenges.

Infinite challenges yes but exceptional rewards and life-defining moments! Most importantly my family and I have been on a journey of personal growth, intellectual enlightenment and new-found political purpose. My time in politics has been almost exactly concurrent with my time as a mother of a child with a disability. For the past 25 years, my husband and I have juggled the challenges of elected public office with the needs of a son living with a disability to the point where the personal and the political have become so interwoven, it is almost impossible to separate one from the other. And more than that it is the life of our son Nick, the joys and worries he brings, the people who have helped and supported us every step of the way, and the presence of the disability movement as a whole that have shaped the direction of our lives, guided my involvement in public life, and demanded ongoing political action.

Whether as an MLA, MP or as now as candidate for Mayor, one thing has remained constant and driven

me to stay in politics. That is the need to speak up for my son and all people living with a disability, to speak out against the speed by which society is ditching its responsibility for the at-risk and vulnerable, and to fight for the systemic changes needed to guarantee equality of condition for all and the right for everyone to be treated with dignity and respect as a matter of belonging to a civilized society. My journey started with a cringe whenever someone said “I’m sorry” after learning my son has a disability. It turned into speaking up about the blessings of Nick’s unique abilities and drawing on the inspirational words of others like Randy White who says about the r word, “you don’t suffer from an intellectual disability – it’s a way of being”. It ends with political action believing that it is the responsibility of government at all levels, of all political stripes to create the conditions of equality and use the tools of public policy developed in consultation with the disability movement to empower people with disabilities and their families to achieve self-fulfilment and lead satisfying, happy lives. Whether that means striving to ensure improvements to provincial human rights legislation and equity programs, working to require federal implementation of the UN Convention on the Rights of Persons with Disabilities, or now trying to design a city that meets the highest standards of

accessibility and livability, it has all been about turning emotions of fear, love, anger and hope into political action and positive change.

This personal transformation and journey to political action would not have happened without the pioneering work of organizations like the Association for Community Living, the Society for Manitobans with Disabilities and the Council of Canadians with Disabilities. It is thanks to those who came before to break down barriers to equality that my son and our family can enjoy community living and be supported in our choices. It is from those who have worked tirelessly for decades on behalf of people with disabilities that I have gained the insights, ideas and commitment to keep striving for political action and positive change. Together we find the courage to keep advancing an agenda of true equality and a vision, as described by Gloria Steinem many years ago, “of all people remarkable for the hopes and dreams and capabilities that exist in unique, unrepeatably combination in each one of us”.

*Judy Wasylycia-Leis is a mom.*

*She is currently a Mayoral Candidate in Winnipeg. She was also a long serving Member of Parliament and was instrumental in ensuring Canada’s ratification of the UN Convention on the Rights of Persons with Disabilities.*



Diversity includes.

# Leadership – Grandma Style



**Brian & Mary Whitehead with their grandson Joshua Smith.**

## Mary Whitehead

**O**ur family was always blessed with health, happiness and we viewed the world through rose coloured glasses. We greeted Joshua's birth with love and joy in our hearts. His arrival moved my husband and me up one rung on the family ladder. We took on the role of grandparents with vigor and enthusiasm. For the next year and a half we reveled in Joshua's every milestone. We rejoiced in emptying the toy store shelves at Christmas and birthdays. Our dreams for this baby boy were unlimited as we saw no boundaries to his abilities.

Then when he was about 18 months old, autism started to claim him and we watched helplessly as the chasm between us widened. Those milestones we celebrated were behind us now and he was headed in a direction for which we had no map. For a time we concentrated on finding the help we so desperately needed to nurture this sweet little baby. Our role as doting grandparents changed as we became part of his "team." That was 1996 and we quickly learned that services for children with autism in our province were nonexistent so we turned elsewhere. We hired consultants and received training necessary to implement and direct the intervention he needed. No more lavish trips to the toy store. Mortgages were taken out. Retirement plans and savings were depleted. Healing his spirit and helping him find his voice again was paramount and became our primary focus.

While his parents and grandfather worked to pay for this program, I became his primary early intervention therapist. I remember the first day Joshua and I were brave enough to start this journey together. I don't know who was more stressed but as soon as we started I knew we would be alright.

Joshua taught our family so much about patience, acceptance and diversity. We had glimpses into his world and learned some valuable life lessons along the way without compromising our dreams and expectations for him. We simply had to adjust our compass slightly. I will never take for granted the feel of his hand slipping into mine as we walked along the shore or the verbal request for a treat at the store. Joshua has shown us that the smallest things in life can be the most precious. He opened my senses to the wonders of a sunbeam warming my skin and how my heart fills with pride watching him make a peanut butter sandwich.

As we were able to come up for air, we realized there were five other families with preschoolers fighting the same battle. So we banded together. As the sense of isolation lessened, the determination to move forward strengthened. We knew this in-home therapy was working but we also knew Joshua and the others deserved more. Their communities needed to be ready to greet and accept them so we began our "outreach" programs. The effects rippled from our own doorstep to our neighbours and then to the rest of the street and village.

We lobbied government and by presenting the success stories of our children, we were able to help pave the road for the many coming behind us. The inroads made with daycares and schools were not without heartache and pain but anyone who has argued for the rights of their child knows that the struggle toward inclusion is worth every frustrating IEP meeting and long wait outside government offices.

I had gone from grandmother to therapist to community activist... who would have thought?

We view the world differently now. Although our dreams for Joshua are still relatively unlimited, the rose coloured glasses have been replaced with a softer lens. By and large people want to do the right thing; they just need help at times defining what that means. Joshua has taught us all to take chances, as evidenced when one shopkeeper recently offered him a summer job. Joshua politely declined stating, "I need to spend time riding my bike and playing on my iPod". We have attempted to foster an opportunity and community for Joshua where he can feel safe and unique and he has helped recalibrate our collective perspectives so that his response to that job offer could not have been more appropriate or impressive.

*Mary Whitehead is a grandmother. She homeschools her grandson Josh. Ms. Whitehead is a member of the PEI Autism Society, a member of the PEI ACL, and sits on the CACL Board of Directors. Mary is also a member of the PFC/CACL National Task Force on Deinstitutionalization.*

# A Life Without Labels

## Shane Haddad

“Label jars, not people” is something people hear me say a lot. I know just how damaging labels can be because I grew up with one. Having a label meant that people made judgments about me, placed limits on me – not based on my ability but based on what they thought that label said about me. Long ago I made the decision to become involved in both the People First and Community Living movements as I was determined to tell the truth about labels and to fight for the right of self-advocates to be heard and included. I want to make sure that just because someone has a label that it does not cost them their freedom and control over their life.

When I was a kid, I was not welcome in the local school. They did not believe I could learn with the rest of the kids so I was separated from my family and friends and sent to a segregated school in Alberta. This was not what I wanted but I had no say in the matter.

I learned over the years though, that with hard work, dedication and the support of people who believed in me, a good life was possible. I met Brenda, the woman of my dreams, and we wanted to marry. Once again, the label got in the way, but we stood up for ourselves and against other people’s advice got married. We have been happily married for 21 years now and have 3 amazing children, Tyler, Matthew and Whitney.



The Haddad family.

We are grateful for having people in our lives that believe in us and support us. Grateful for people who help us accomplish our dreams, not tell us what we cannot or should not do. More importantly, our success as individuals and as a married couple demonstrates the power of believing in ourselves, our abilities, our dreams, and not allowing a label to stand in our way.

Becoming a dad was scary. It is the most challenging (and rewarding) thing I will ever do. While I had become quite skilled and determined in fighting for the rights of people labeled with a disability over the years, having a family meant that my advocacy work took on even more importance. I want my children’s lives to be better than mine had been. I want them to be seen for who they are – not who others think they are based on a label. I want them to be fully included in school. Things are certainly better than when I was a kid, but it is still not easy. We still have to fight every step of the way, but I will stop at nothing to get them the best education I can.

There is still so much work left to do. As long as there are still

people with disabilities locked in institutions, in segregated classrooms and living without jobs or homes, our work is not done. As a dad, I want to do this work and make the changes necessary so the world is a safe and welcoming place for my kids. That is what every parent wants for their kids – to be included, to be valued, to be safe.

Brenda and I have chosen not to label our children but instead have focused on getting them the supports they need. We have raised our kids to believe in themselves and to stand up for their rights. I have no doubt that they too will all be very strong advocates for themselves and others and will one day join me to continue the important work that remains to be done.

*Shane Haddad is a dad.*

*He is also the Past-President of People First of Canada and an Executive Board Member of CACL. Shane also co-chairs the PFC/CACL National Task Force on Deinstitutionalization. Mr. Haddad is self-employed and owns a lawn care company in Regina.*

**Leaders don't create followers, they create more leaders.**  
—Tom Peters



Diversity includes.

# First Down, and Goal to Go



Andre Durie and his son Malcolm.

## Andre Durie

For someone looking in from the outside, it may seem like I have the perfect life. I have two beautiful children and I am living my childhood dream as a professional football player with the Toronto Argonauts.

But if they look a little closer, they will see that both my role as a parent and as a professional athlete have taken a lot of work, a lot of support and a great deal of love.

As a running back with the York Lions, I set several team and CIS records. But everything changed during the second game of the 2005 season. During a routine rushing play, I cut to the outside. When I pushed off, my left knee buckled. As I collapsed to the field, so did my hopes and dreams for the future.

I had paralysis below my left knee. Doctors told me that I had torn muscles and ligaments as well as severely damaged nerves in my knee. They also told me that I may never be able to walk normally again.

Then, nearly a year later, I felt a twinge in a toe on my left foot. That was all the motivation I needed to prove my doctor's wrong. I became determined not only to walk, but also to play football again.

It took a great deal of hard work as well as the love and support of my friends and family, but I progressed from a few simple steps, to running, to returning kicks for the Toronto Argonauts.

The lessons I learned during my rehabilitation prepared me for a second great challenge in my life.

When my oldest son Malcolm was two years old, he was diagnosed with autism. We were told that he would require full-time care and support in his daily life. Once again, my hopes and dreams for the future collapsed.

Then I realized that there were a lot of similarities between the adversity I faced with my career-threatening knee injury and the challenges I would have to face learning to parent a child with a disability.

Both situations have negative stigmas attached to them when they really shouldn't be looked at in that way. Both situations required me to rethink my future. But both situations presented me with new and exciting opportunities.

Shortly after Malcolm was diagnosed with Autism, we also discovered that he had the extraordinary skill of playing the piano. He loved music and still does to this day.

Now at age 9, Malcolm has grown fond of numbers, letters and is reading and writing. He has also learned to speak phonetically – a trait that children with severe autism sometimes lack. This is a huge step for him since he did not use words to communicate for years. He can now communicate with his younger brother Cian, who he greatly admires and looks up to.

When Malcolm and I are together, we do a lot of active things... such as going to the park, rolling down hills, playing on swings and slides or biking. When we are indoors we

enjoy reading which also helps Malcolm's spelling and listening skills.

Having a child with a disability has changed my life a lot. I believe it has made me a better parent by learning to understand my son and how he functions... instead of me just trying to integrate him into how our world functions. It has also made me a better person by showing me that, regardless of perceived limitations, anything is possible.

Malcolm is one of the happiest kids I have ever met and his happiness is so contagious and inspiring that he makes others happy being around him. I try to take his happiness and pass it along in my own life. Because of Malcolm and what he has taught me about life, I have become involved with Community Living Mississauga, and in my own small way try to contribute to changing how persons with disabilities are viewed by our society.

I believe that, regardless of the situation or the disability, life should be approached with enthusiasm. With love and support from others, we can always find the positives and opportunities in any situation.

*Andre Durie is a dad.*

*He is also running back, slotback and kick returner for the Toronto Argonauts of the CFL. Mr. Durie also works with the Argos Foundation's Youth Mentorship Program, the Children's Aid Society and Community Living Mississauga.*

# A Life Changing Gift



Ken and John Pike.

## Ken Pike

John Pike was a gentleman, friend to many, and a wonderful older brother. Two years ago, I lost my brother John when he passed away at the age of 60. John had Down syndrome and knew that he was somewhat different than most people. Growing up, I too was aware of my brother's differences but these were largely overshadowed by the person he was and by the circumstances of our family life. John and I were two of seven children, the rest being females. That meant that John and I had many opportunities for being together (having to share a bedroom for many years will do that!). Our parents ensured that John was just another member of the family – he did all of the family things the rest of us did. While he was included in many activities outside of the family (such as church), his life was significantly different from mine. John did not attend a regular school and he spent many years as an adult attending a sheltered workshop.

Growing up with a brother with an intellectual disability provided me with everyday experiences that (quite unconsciously) shaped my perspectives about people with disabilities and life in general. I learned to appreciate that having a label such as Down syndrome was only one aspect of my brother's life. John was a very social guy and his relationships with others within and outside the home were very important to him. Having John in my life also taught me that people have many things to offer their families and communities. John's great gifts were love and laughter. He cared deeply for his family and

friends and had the uncanny ability to remind us not to take anything too seriously. I also witnessed society's prejudices when John was teased, stared at and only provided opportunities that were designed for people "just like him". As a teenager and young adult I often wondered what John's potential could have been if he had been given better opportunities to read, learn and work. I learned that life for John and others who have a disability was not quite fair.

While I have been a formal advocate for people with an intellectual disability for over 20 years, I did not set out to make this my life's work. During my early days in law practice I was asked to handle a file from the local ACL that was supporting a group of families to challenge the education law that kept their children out of regular classrooms. These families shared a passion about the rights of their children to be fully included in school. Instinctively, I knew that their cause was right and just. Knowing that John had been denied the opportunity to learn in a regular environment, it was easy for me to understand why these families wanted something very different for their children.

It did not take long for me to become hooked into the ACL "movement". After two or three years in law practice I understood what role I wanted and needed to play. The values and perspectives I have gained in having John for my

brother have been my personal guideposts in my work (and life) for many years. For John, life was about belonging and being able to make a contribution to the people and world around you.

Following his death in 2008, I received a letter from a woman whom I had never met but who knew John from the church he attended. She (along with many other people) attended his funeral service. This woman had recently become a grandmother to a boy with Down syndrome. In her letter she wrote: "Being there and sharing in that celebration of John's life brought me so much peace and hope. I was shown the truth – John had (and so also my grandson can have) a happy and productive life.... He showed me that I don't need to worry – my grandson's life, like John's, does not need to be defined by Down syndrome and he too can find his way surrounded by love, friendship and support.... One day when the Lord calls me home I will hug John Pike and thank him for his life changing gift to me."

And so will I.

*Ken Pike is a brother.*

*He is also Director of Social Policy with the New Brunswick Association for Community Living. Mr. Pike has worked with the organization regionally and provincially for more than 15 years. In 2008, Ken was presented with the prestigious Human Rights Award by the New Brunswick Human Rights Commission.*



Diversity includes.

# Parent and Advocate: One and the Same

**Dr. Vianne Timmons**

When I look back on my life and career as a researcher and advocate in the area of inclusive education, it strikes me that if I am an agent of change, it's mainly because I am the parent of a child with a disability. My experience as a parent is what truly made me a strong believer in the value of inclusive education.

One of the most effective ways of learning is to learn by example – and sometimes the worst examples provide the best learning experiences. When I was 16 years old, I volunteered to teach swimming lessons to children with intellectual disabilities. That was my first real exposure to children with intellectual disabilities, but even then, I knew it did not make sense to segregate those wonderful children. This made a lasting impression on me, although it took many years before I took steps to try to change this sort of situation.

A real turning point came for me while I attended university. At that time, to help fund my education I worked in an institution for children with profound disabilities. I was appalled by how the children were treated there – institutionalized and separated from society. What had begun simply as a job to earn a paycheck became much more for me, and I vowed to make a difference in the lives of children with intellectual disabilities at every opportunity. I went on to complete a Master's degree in Special Education, and began working as a teacher, with one of my first assignments being to oversee the closure of a segregated school in British Columbia in the early 1980s.

I was passionate about this work and felt like I was really making a difference, but then something happened that took inclusion to a whole new level for me – I met my husband Stuart and his two young daughters. I fell in love with the entire package, and my role as a parental agent of change began, since Kelly, our youngest daughter at the time, has Fetal Alcohol Syndrome Disorder.

As I grew to know Kelly and understand her needs as well as her hopes and dreams, I became more of an advocate for inclusive education than I had ever been before. It used to be that I was teaching and advocating for other people's children, which was fulfilling in its own right. But all of a sudden, I was personally involved in the life of my daughter, and the lessons I learned teaching swimming when I was 16 came home to me again. I could not allow this wonderful child to be segregated from her peers – either in her education, or in all of the other facets of her life.

I have to admit that I wasn't the perfect advocate for Kelly's education, and I made many mistakes along the way. But in spite of this, Kelly persevered, graduating from high school and eventually from university – all the while benefiting from being in inclusive classrooms. Kelly has grown up to be a happy, healthy and successful young woman, and the education she received in inclusive classrooms is the primary reason for that.



**Vianne's daughter, Kelly Mason.**

Kelly's educational experience affected me in ways I could not have predicted. The more I learned about her and her disability, the more I wanted to learn so that I could perhaps help other families in their own journeys. Kelly inspired me as I worked on my Ph.D. in Education Psychology to continue a university research and teaching career focused on inclusive education. Having seen for myself the difference Kelly's education made to her life and her level of happiness, I have tried to create a body of research work that will allow others – parents, policy makers and politicians, for example – to see the benefits and embrace the challenges of inclusive education. That is certainly not what I expected would happen when I signed up to teach swimming lessons 35 years ago!

I think that everyone has the potential to be an agent of positive change in the area of inclusion – whether we are teachers, researchers, administrators, or policy makers, for example. But from my experience, the parents of children with disabilities are the most powerful agents of change, because their personal experiences and their unconditional love for their children give them an unmatched passion for inclusion that inspires their advocacy.

In short, being the parent of a child with a disability has been a turning point in my life, and has helped make me an advocate for my daughter and children like her

*Continued on back page*

# You're One of Us Now

## Dick Sobsey



Dick Sobsey

**A**s a teenager who got into more than his share of trouble, I ended up placed in a small residential school with others. I don't remember anyone ever using the word disability, but today they would have various labels like intellectual disability, behaviour disorder, etc. Shortly after I arrived, the one teacher at this small school, besides the couple who owned it, left suddenly. I was the oldest student and so I began to fill in until they could get someone else. The rest of the year went by and no new teacher arrived so I pretty much was promoted from special ed student to special ed teacher at the age of 16. I spent a lot of time teaching math and a little bit of some other subjects to an 8-year-old boy who had an intellectual disability. That was probably the first time that I really started to develop a perspective on disability.

Five years later, at 21, I went to work as an attendant in a large institution where more than 5,000 people with developmental disabilities spent their lives. It was truly a terrible place. Overcrowding, understaffing, neglect, abuse, and everything else that goes with institutional care led to short, unhappy lives. I knew that the people who lived there could be living better lives, but I couldn't understand why things were so bad or how to make them better. For years, I continued to work there and kept going back to school to get qualifications that would move me into jobs where I thought I could make things better. After 10 years I was a registered nurse and certified teacher. I had moved into

supervisory and administrative positions, but I had accomplished very little toward making the institution a better place. It had gotten a bit better in some ways. It was a lot less crowded; about half the residents had moved out. The physical facilities were better, and there were more programs. But these things would have happened with or without me, and the residents who remained still led empty lives. I finally had to admit to myself that there was little that I could do there, and left.

I went back to school, got a doctoral degree, and got a job at the University of Alberta training teachers to work with students with severe disabilities. In the process, I worked with a lot more individuals with disabilities and their families. I like to think that I was the kind of professional that families felt they could count on. I worked closely with the Alberta Association for Community Living and other community-based organizations. I supported their efforts to establish inclusive post-secondary education and to build inclusive communities. I was frequently called upon to advocate for families or to speak to community-based organizations.

Then something happened that changed everything. Our son, David, was born with severe and multiple disabilities in 1990.

I remember giving a talk at a Community Living conference some months later. After the talk, I got the usual thanks and friendly hug from the President of the organization, and she whispered something to me at the same time, "You're one of us, now." We both smiled and laughed a little. It was a joke, wasn't it? After all, hadn't I always been on the side of families? Wasn't I already one of them?

As time passed, I began to understand that there was more truth in her words than I first realized. Knowing about families is not the same as experiencing a family connection. Understanding something is not the same as feeling something in your heart.

Of course, I do not mean to imply that all my attitudes and beliefs about disabilities or about families and parenting changed. Many of them stayed the same. Many of my attitudes and beliefs simply grew stronger. Only a few changed significantly. Here is one example. As a professional, I used to be an advocate of training parents in therapeutic techniques such as physical therapy procedures or behaviour management techniques. As a parent, I became much more cautious about using parents like therapy assistants. Parents have distinct and essential roles as mothers and fathers that

*Continued on back page*



Diversity includes.

## Parent and Advocate: One and the Same

(Continued)

across the country and around the world. I could never have foreseen that becoming a parent and becoming an advocate would turn out to be the same thing, but they did – and I encourage all family members of those with disabilities to embrace the opportunity to be the strongest agent of change you can be, for your children and for ALL children.

*Vianne Timmons is a mom.*

*She is also President and Vice-Chancellor of the University of Regina and is President-Elect of the International Association of the Scientific Study on Intellectual Disability. Dr. Timmons has worked extensively in the area of inclusive education both in Canada and internationally. She was named one of the “100 Most Powerful Women in Canada” in 2008 & 2009.*

---

## You're One of Us Now

(Continued)

are not always compatible with taking on new roles as therapists or behaviour managers.

At the same time, my professional work and research continued to influence my perspective as a parent and an advocate. Too many times my work led me to places where I saw abuse and neglect in community-based services. Deinstitutionalization was essential to permitting better lives for people with disabilities, but it was not sufficient, in itself, to ensure better lives.

My work and my family life continue to bring me in contact with other families of children and adults with disabilities and with people with disabilities, themselves. Their commitment, courage, and resourcefulness have energized and inspired me. While I have taken my turn as an advocate for others at times, I have more often followed in the footsteps of others. Most importantly, our son and the challenges that arise for our family provide direction. I know my role as a father is more essential than any role that I can play in advocacy or leadership, because my role as father is the foundation upon which everything else is built. Recently, I decided to retire from my major professional responsibilities to allow me to focus more on my role as father, and I am very happy with that decision.

*Dick Sobsey is a dad.*

*He is also recently retired from the University of Alberta where he was Professor, Department of Educational Psychology and Associate Director of the JP Das Developmental Centre and Director of the John Dossetor Health Ethics Centre. Dr. Sobsey is also a member of the CAEL Values and Ethics Task Force.*

*“Coming together is a beginning.  
Keeping together is progress.  
Working together is success.”*

– Henry Ford

## Ten Objectives For the Next Ten Years

- Achieve equality rights and recognition.
- Close institutions and assure a home in the community.
- Secure child rights and needed supports.
- Ensure families have needed supports.
- Achieve inclusive education.
- Secure the right and access to disability supports.
- Establish safe and inclusive communities.
- Eradicate poverty for people with intellectual disabilities and their families.
- Achieve employment equality.
- Make a global impact on inclusion.

Our Ten-Year Agenda has ten objectives to guide how we'll realize our vision: communities, a country, and a world where diversity includes.

Join us in making this dream become true.  
Visit [www.cacl.ca](http://www.cacl.ca)



This project is funded in part by the Government of Canada's Social Development Partnerships Program – Disability component. The opinions and interpretations in this publication are those of the author and do not necessarily reflect those of the Government of Canada.