

# The Compass



Family Alliance Ontario

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## Planning For a Good Life in an Uncertain Future

By Al Etmanski

Then, when he had flown a while longer,  
something brightened toward the north,  
It caught his eye, they say.  
And then he flew right up against it.  
He pushed his mind through  
and pulled his body after.

-Skaay, Haida poet and storyteller

Even before the current global economic crisis/recession there were dark shadows over the future of Government supports for our sons, daughters and friends with disabilities.

The first is a demographic challenge. Simply put Governments are losing a big share of their tax base because baby boomers are retiring. Here is one telling statistic. In 2005 there were 44 children and seniors for every 100 Canadians of working age. By 2030 there will be 61 children and seniors for every 100 working Canadians.

The second is more competition for smaller budgets. A reduced tax base means a smaller government fiscal pie. There will be a greater requirement to fund elder care, environmental clean-up and to repay future financial debt. There may also be increased health care expenditures. You don't need to be an economist to figure out that taking more pieces out of a smaller pie could leave a much smaller slice for disability supports.

### **New Solutions for Changing Times**

I don't list these concerns to unduly alarm anyone but to suggest we begin rethinking how to ensure the well being of all people with disabilities. Like every other sector we cannot rely on the way things are. This requires us to think and act differently.

Being different or doing things different is hard work. There aren't any formulae to rely on. There are few examples to use for inspiration. You can feel alone.

Sometimes all you have to rely on is your thinking. As the great Haida storyteller Skaay exclaims above, it is our minds which pull us through. However, thinking is strengthened by **innovation, resilience** and **abundance**.

**Resilience Thinking:** This way of thinking assumes we are capable of solving our own problems. It assumes that when the going gets rough we rely on each other, on our own ingenuity and creativity first. It means we don't rely on external resources unless or until we have taken stock of our collective expertise, experience and assets. Resilience thinking assumes that we as families, our sons and daughters, our neighbourhoods and communities are not passive recipients of outside support and intervention. That we have a built-in capacity to transform, adapt, heal and survive.

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## **Planning For a Good Life in an Uncertain Future** (cont. from page 1)

Resilience thinking suggests our job, and the job of funders, programs and services is to build the capacity of individuals and families to solve their own problems.

**Abundance thinking:** Abundance thinking means focusing on assets and strengths rather than deficits and needs. It does not mean looking at the world through rose colored glasses. There are tough challenges out there and being Pollyannaish won't help. However, it does mean not losing sight of what we already have and making sure we know all the resources we have at our disposal. It means rediscovering the resources already present within our families and communities and to build on what we have.

For example, we can look at the financial resources available to support our sons and daughters as only coming from Government. Or we can include the discretionary trusts and RDSP's that are being set up. We can also look at our purchasing power – that is the billions individuals and their families spend every year. This power can be used to create employment for our sons and daughters and to change attitudes. When we expand our perspective we become richer than we think.

### **Innovation – the hallmark of families**

Nature has a lot to teach us about resilience and abundance. Reducing the vulnerability of all diverse species strengthens the resilience of the eco-system as a whole. The same is true for our society. Dr. Frances Westley, a colleague of mine, has drawn important lessons from nature. She sees the involvement and engagement of our sons and daughters and other vulnerable groups as indispensable to our society's overall health.

*Re-engaging vulnerable populations in our mainstream economic, social and cultural institutions, not just as recipients of services or "transfer entitlements" but as active participants and contributors is therefore intimately tied to socio-ecological resilience. And the way to ensure this participation is by introducing, nurturing and accelerating innovation and creativity!*

Well, that's a challenge we are up for. The hallmark of the disability movement is ingenuity, resilience and abundance. Families since the late 40's early 50's created something out of nothing – the majestic support system we now take for granted. And there is not a day when our sons and daughters don't display remarkable innovation and resilience just to get ready to meet the day.

A good life includes building a future with some certainty. The times and the future are most certainly going to look different than the status quo. As families, we hold the values and strengths inherent in our **innovation** of day to day tasks and visioning, our **resilience** in building relationships and ongoing advocacy, and our **abundance** to draw upon the resources around us. Even in an uncertain future, this doesn't have to be scary, just approached with eyes wide open and hands clasped in shared experience and encouragement. create.

*Al Etmanski is an author, advocate and social entrepreneur specializing in innovative, multi-sectoral solutions to social challenges. He is President and co-founder of Planned Lifetime Advocacy Networks (PLAN), assisting families, across Canada and globally, address the financial and social well-being of their relative with a disability, particularly after their parents die Published with permission <http://www.planinstitute.ca/?q=gettoknowus/executiveteam/aletmanski/blog>*

## A Vision Unfolding...

I'd like to share how this last year has unfolded with our autistic son Kyle.

In January 2009, my husband and I sat down with our daughter and started dreaming about our son's future. Kyle was diagnosed with autism at age 3. He was 18 at the time and still in school. We spent a few hours that afternoon putting on paper what we envisioned for him... even things we weren't convinced he'd ever be able to do. It felt so easy to dream. It gave us hope and lessened what felt like a huge stress, worrying about "the unknown" that was his future. We put the paper away expecting miracles to come. To us, it seemed like this was the only way our dreams for him could possibly come true. We prayed that he receive everything he was meant to have.

We felt that Kyle was ready for something different. He had been in the education system for 15 years. I had pretty much made up my mind that he would be graduating in June 2009, which was only 5 months away. I had even picked a date in April that I would announce this news to the classroom staff.

That day in April came and my daughter gently nudged me to take action like I had promised to do. I knew that I needed to make that call and announce the news. My heart ached; I didn't know how I was going to fill my son's days with meaningful activities once he'd be at home full time for the rest of his life. I could not imagine where to begin looking for what he needed. I felt the weight of it all. I felt torn knowing what I had to do that day. The school day ended and I had not made the call.

Early that same evening came a call, informing me of issues at school that caused us great concerns for our son. I wondered what all this meant. Why now, why today? Without hesitation, we decided we could not send him back, at least not right away. Almost a month went by. With each passing day I knew I could no longer keep going like this, with Kyle only unofficially out of school. I had to take a leap of faith for him and not look back. I had to let go of everything I knew and look ahead to the future we had dreamt about for him just a few short months before.

The next three months were spent letting go of what had been. We didn't know where to turn to next. Letting go of the fear that was blocking us was huge. I knew that God surely had a plan for us and somehow, if we could only trust He would get us through this trying time. We held on to faith.

In July, I spent many days writing a Passport funding application so we could receive what was needed to help Kyle. Luckily he was still receiving the SSAH funding and I had something to work with. The application was mailed out at the end of July. I knew what the reality was: 375 or more individuals with a developmental disability in the Ottawa and surrounding regions still on a long waiting list to receive this funding. No money seemed to be flowing to these individuals; everything seemed to be at a standstill. I tried not to let myself be discouraged. I tried to imagine and feel that we were on the right path.

August came and I knew that I had to get something rolling for him. But what? A friend suggested ABA Therapy (Applied Behaviour Analysis). It was very important to me that our son continue to learn. We hired a Senior ABA therapist who helped us plan, coordinate and implement his learning program. We have to pay for this service out of pocket.

The search for a suitable worker began. We had to find someone French-speaking. Living in a rural area always poses extra challenges because of the distance that workers must travel to and from work, as well as to and from activities within the community. A chunk of the funding is spent paying for travel expenses. We hired a young woman a few years older than our son who had experience working with people with autism. She began learning the ABA programs, all the while getting to know our son. I felt really good that he was continuing to learn.

More things started coming last fall... one was at a Therapeutic Farm, for a total of 6 sessions. Our son has a great fear of animals. I honestly didn't know how this would work out. After having met the two ladies who ran the program, I felt confident enough to have Kyle give it a try. When he started, he spent much of the time with his hands over his ears. He was very unsure about grooming the ponies; terrified of the cat and less fond of the donkey's singing. This farm was a totally new environment for him with many new sights, sounds and smells.

Within 6 short sessions, he was able to bring his hands off his ears most of the time so he could work (except maybe when he knew the donkey was about to make noise); he was able to eventually tolerate the cat at closer proximity: he would brush the ponies and walk them outside: feed the chickens, ponies and horses; gather eggs and one day, he saw one of the ladies taking burrs off the 1100 lb. horse and immediately wanted to help. He stood inches away from this huge animal with little fear and was willing to help to get this important job done. The last day at the farm he groomed the large horse and then led him around

the padlock and through an obstacle course. It was amazing to see him progress out of his intense fears and all within such a short period of time. I truly felt that God was leading us to the people that needed to be in Kyle's life at that time.

After the experience at the farm, we adopted a dog, whom we named Russell (after the little boy in Disney's UP! one of Kyle's favourite movies). Russell is nothing short of amazing in his interactions with Kyle. Kyle is working hard to overcome his many fears of being around animals.

On December 2<sup>nd</sup> 2009, a call from the March of Dimes office, telling me that our son was one of two people who had been chosen to receive Passport funding in our region. I could not believe it. I was shocked, thrilled and so grateful for this beautiful gift that came much faster than I had ever dreamed possible. I felt that all that dreaming we did back in January 2009 was starting to unfold for him. At the same time, my heart ached for all the many individuals and families who were still on the waiting lists for funding and better services.

It felt like the dreams we had acknowledged almost a year earlier no longer seemed so impossible or so far away. We hired a second person, a nephew close to Kyle's age, to help with some community outings. We felt that a male role model was very important for Kyle.

Kyle enjoys many things: snowshoeing, cross-country skiing, skating, bowling and just this spring he curled in a bonspiel with his sister, cousin, and dad. He has expressed that he wants to go alpine skiing. We are going to look into getting him private lessons next ski season. Other ways we have used the Passport funding for Kyle includes going grocery shopping with assistance, shopping, eating out, going to museums and cinemas.

Kyle also goes for regular massage sessions. The relaxation benefits for him are great and he loves it. We make full use of my husband's health care plan to help cover a part of this expense. Then I stumbled upon another gem in the health care plan booklet: speech therapy is covered up to \$2,000 a year. It is very important to us to try to get him the help he needs so he can learn to communicate better. We will be meeting with a new speech language pathologist this week. She will come to our home for the sessions. We feel her role will be more on an ongoing consultation basis, as well as teaching us and his workers what needs to be worked on with Kyle. Kyle's worker recently started introducing him to her life on an organic dairy farm. One day a week

he will go there and she will teach him some of the skills needed around the farm and see how he will adapt to working with his hands. Kyle will have many opportunities to learn his ABA programs in a real hands-on environment. His worker will also do animal-assisted therapy sessions with him there once he's more desensitized to the animals she will use to work with him.

Kyle loves going on the Internet, where he does his own research on everything that interests him, from tornadoes (his passion), to music, and movie trailers, and anything else he decides he wants to learn about, even at his basic level of understanding. He has an interest in languages even though he has limited communication skills. He likes to have things translated from French, to English, to Spanish, to Italian, to German, to Mandarin. We taught him where to go online to type in what he wants translated and get his information independently. He recently discovered that he loves to draw. We want to introduce him to painting and allow him to express his creativity in that medium if he so chooses. Kyle loves being in the spotlight, performing, singing and otherwise entertaining people. He has a great sense of humour. We are keeping our eyes and ears open for singing or acting classes, where he can do some of the things he loves and be part of a group at the same time.

Kyle seems happy and is adapting well to these numerous changes in his life. We see his potential and the possibilities as being unlimited in his life, and we are helping him reach as high as he can for those dreams, that vision.

Having a child with special needs has had many challenges but it also has brought us much joy. The most frustrating part is trying to navigate our way around the systems that are in place. So often, it feels like an impossible maze. There's no doubt, it's a full-time job that is exhausting, time consuming and emotionally draining at times. When our son turned 18, it was disheartening to discover the lack of services in place for young people who still have the same complex needs they did when they were younger.

We have felt hope since we have allowed ourselves to start dreaming about our son's future. We are learning to look outside the box (outside the systems) as much as possible and carve the life our son wants and deserves.

We believe this is just the beginning of the unfolding of this vision for our son.  
*Suzanne McRae and her family live in Moose Creek, north of Cornwall.*

# Transformation Trends

## Independent Facilitation- Our Family's Experience

Our 34 year old daughter Nancy, the oldest of four, is a wonderful woman who lives with significant developmental and physical disabilities. Since age 21, she has accessed community-based supports - a combination of residential support, through New Visions Toronto, and direct funding for community participation support, for which she became eligible in the same year. Nancy grew up with her 3 brothers, experiencing the fun and challenges of any large family, involved with her peers in camping, guiding and community activities.

In 1997, Nancy became one of 50 individuals, transitioning from school programs, to receive support from the Individualized Quality of Life Project, which since 2000 has operated as OPTIONS Planning and Supports for Inclusive Living, a program of Family Service Toronto. We have had access to a Community Resource Facilitator who gets to know Nancy through opportunities to meet with, listen deeply, and guide discussions for planning purposes with Nancy and her support network: a group of family and friends (including a number of former assistants), whose relationships with Nancy are vital to the good life she leads. An independent facilitator, and there have been 3 over the dozen years, encouraged and supported us to get Nancy's Network started. It is a forum for developing a shared vision for her life, dreaming and considering possibilities for Nancy's meaningful participation in valued roles in the community, and helping to mobilize social connections with Nancy. The community development and capacity building, which occur through this networking, have proven valuable to everyone involved.

While our family is among the few who currently have access to independent facilitation in Ontario, Transformation policy development by MCSS is showing encouraging signs of recognizing the value of this support. Unlike case management, the support we receive is unrestricted by program guidelines, and the facilitator is responsive and accountable to Nancy and her network. The combination of effective support to keep her network vibrant, developing plans grounded in community with emphasis on relationship building, **and** the adequate direct funded resources for implementation is essential. Support with fiscal management, including budget reconciliation and payroll functions, is another key to the success of the direct funding Nancy receives.

Based on our experience, we feel facilitation should be available to any individual and their family once eligibility for supports is determined, and over the continuum of life experiences. Facilitation encourages community inclusion and not a life in service. Planning independent of the service system enables Nancy to live her life without any pressure to select one agency or program over another, and conflict of interest is avoided. People, together with family and friends, need independent facilitation to guide and identify the goals and strengths that will enable them to move more deeply into the typical community. Person-directed planning like this is key to citizenship and self-determination, when it is based on the principles and values of the Common Vision for Real Transformation, and is quite different from planning for traditional programs.

Research completed by John Lord and his colleagues shows that when facilitation is combined with individualized funding for disability supports, very positive citizenship outcomes are the result.

*Family Alliance Ontario recommends that individuals and families have the option of working with independent facilitators from a publicly funded organization (not a direct service provider) or a facilitator of their choice, as part of a direct funding agreement. We want families to have support to develop and sustain a support network, and to realize the person directed planning process – lifelong, as needed.*

Christy Barber, FAO President/Co Chair 2008-2010



**Nancy Barber  
and Melissa Silva**



**Daniel and Jordan Strickland  
with Cabbie**

all  
included



**Karen Inwood and Cindy Mitchell**



**Carolyn Calligan with family**



**Barbara McCormack  
and Sarah Baldock**



**Brian, Jeremiah Shell and Barbara Ostroff**



**Vici and Rob Clarke and Muriel Grace**

## Networking News

**Waterloo Region Family Network** is a not-for-profit, family-driven resource centre dedicated to providing the support, knowledge and assistance families need in order to make informed decisions. The Network assists families of children (all ages) with special needs, regardless of diagnosis or lack thereof.

This parent engagement initiative to support families took root during the KidsAbility Centre for Child Development strategic planning process in 2007/08 after family focus groups indicated a need for greater support during what parents referred to as an holistic life journey. In particular, parents wanted opportunities to meet and chat with other parents going through similar situations to share information. They also expressed interest in a variety of seminars/workshops to help educate them on resources and programs available to their children.

In the beginning, this initiative was called Parent 2 Parent and was housed and supported by KidsAbility. Over the course of a few months, a group of lead parents emerged and took on the responsibility of daily operations. In April 2009, the group changed its name to the Waterloo Region Family Network to be inclusive of all family members affected by a disability within their family. The inclusion of the word "network" also better represents what we are all about with regard to our advocacy efforts and to connecting families.

To date, over 240 families have joined the Network. We also have community membership from various parent groups and community agencies and organizations. We have trained 13 parent mentors to support the families who request one-on-one mentoring support. This is, and will continue to be, the core of our program. From fall 2008 to spring 2009, we hosted 10 educational seminars on a variety of topics such as toilet training, sleep disturbances, tax information, summer recreation program opportunities and advocacy. We have had up to 80 participants attend some of our evening sessions. This past fall we co-hosted an Independent Planning and Facilitation event along with another organization called Planned Lifetime Networks. Seventy people attended, indicating an interest in pursuing further discussion about independent planning and facilitation in Waterloo Region. We hope to co-host other events with community-based organizations in the future. We also hosted two sessions on school advocacy in October, appropriately timed to offer an in-depth understanding and support of Individual Education Plans (IEPS).

We will be offering the toilet training and sleep disturbances sessions again this year along with new sessions on Financial Education, Music Therapy and a Natural Approach to Treating Autism Spectrum Disorders presented by a local Naturopathic doctor. All of our sessions offer opportunities for parents to meet and chat over coffee in an informal setting. We have also created and continue to build wonderful partnerships within our community. Through a partnership with the Ontario Early Years Centre we are running Saturday morning social programs for children with special needs, ages 4 – 12, twice per month. This allows often-anxious children an opportunity to meet and play with other children in a comfortable environment. Parents also have the opportunity to connect with other parents while accompanying their children.

Extend-A-Family (EAF) Waterloo Region has been very supportive of the WRFN and involves us in many community-based meetings and events. The Network arranges to have parents share experiences with EAF families related to school advocacy and Autism Spectrum Disorder issues. We are involved with the Autism Spectrum Connection – an online community created by EAF for families affected by Autism – through the commitment of two expert parent bloggers from the Network.

The WRFN is participating in a number of regular community meetings and initiatives with the Alliance for Children and Youth, the New Story Group and Autism Spectrum Disorder Service Providers. We continue to build a relationship with United Way, keeping them up to date on our activities. It is our goal to further increase community development and awareness of the Network throughout this coming year. A significant component of the WRFN involves current advocacy issues. As a newly recognized advocacy group with a strong voice, we have become involved in issues related to School Health Support Services and Special Services at Home –

## Networking News

two very "hot" topics in our community and across the province.

We are pleased to announce that WRFN has received a grant of \$95,800 (over two years) from the Ontario Trillium Foundation. In addition to a grant of \$75,000 (over three years) received from the Frank Cowan Foundation last fall and funding from KidsAbility Centre for Child Development, the Trillium grant will allow the WRFN to benefit hundreds of families with children with special needs in Waterloo Region. Together, these funds will help build the internal capacity of the Network through the development of resource materials for training parents to support each other and by creating strategies for outreach and networking. We publish a monthly newsletter. Our link to KidsAbility is a key reason why our initiative has such strength. Through this generous financial support, the WRFN has been able to hire two part-time paid Community Resource Coordinators. We have also hired our first student volunteer through the Waterloo Region District School Board's Work & Transition Support (WATS) program. And we were very excited to be opening our own office in north Waterloo at the beginning of March. We have creatively financed ourselves versus relying on government funding. Although we have received seed funding, finding ways to sustain ourselves in the future is a key priority over the next two years. This will include things like social networks and monetization of users, sponsorship of programs, selling advertising space and looking to successful models to figure out how to creatively ensure future viability. The WRFN is an autonomous organization, separate from all agencies. We have undertaken the process of incorporation and have applied for charitable status. WRFN website is [www.waterlooregionfamilynetwork.com](http://www.waterlooregionfamilynetwork.com).

We look forward to the continuous growth of our Network, strengthening our voice and developing the resources necessary to support families throughout their life journey.

*Family Alliance Ontario celebrates how WRFN is establishing itself as an autonomous family directed group, and welcomed their affiliation with FAO in 2009.*

With great regularity, people with disabilities and their families will find themselves having to deal with professionals, bureaucrats and others in roles of authority. Not uncommonly the authority figure tends to overshadow the authority of "small people". It helps sometimes to remember that families have a natural authority of their own which can go a long way to reducing this imbalance of power.

Families need to appreciate this natural authority and be willing to act on it. What follows is a brief description of some of the common sources of authority that families can call on when they are acting in the interests of a family member.

### NATURAL AUTHORITY OF FAMILIES

♥ The general public recognizes that families have the authority to be fully involved because they have greater responsibility for the well-being of their family members.

♥ Families know their family member the most fully and over the longest period of time. Therefore they have the authority that arises from long term observation, insight and personal relationships.

♥ Families typically care about or love their relatives more than would be true of others, however committed the others may be. Not only do families usually care more but they are also expected to care more.

♥ Families have to live with the long term consequences of service failures to a greater extent than any other party, except the person themselves.

♥ Families are granted considerable presence in the decision-making processes affecting their family members.

♥ The family is an authoritative witness to the performance of professionals and systems and may have special insight into events that take place.

♥ Family members bring to their role a wide range of talents and experiences which can give them additional authority on many matters. For example, a parent might also be an educator.

♥ Families are often best positioned to see how everything, in its entirety, adds up in a person's life. For this reason they can often see the incongruencies of different interventions.

♥ Family members are often free of the vested interests which call into question the credibility of other parties. Frequently family members are granted a degree of independence which highlights their credibility and purity of motive.

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