

## Spotlight

Celebrating the rich and diverse contributions made by Canadian individuals and organizations to the enrichment of life, and the building of a better society. This month, the Spotlight is on ...

### **Al Etmanski and the Planned Lifetime Advocacy Network**

By Nicole Zummack

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VANCOUVER, BC – No parents want to outlive their children, but when your son or daughter has a disability, the prospect of leaving him or her behind can be a huge source of concern, to say the least. Although there are social services available, nothing can replace the love of family and friends. This is something that **Al Etmanski** came to understand all too well during his eight-year tenure as Executive Director of the BC Association for Community Living. Although he was already a leading advocate for people with disabilities and their families, Etmanski realized that more was needed. So, in the spirit of social entrepreneurship, he joined forces with Jack Collins and Vickie Cammack in 1989 to establish the **Planned Lifetime Advocacy Network (PLAN)**, an organization that helps parents with a disabled child answer the question, "What will happen to my child when I die?" In 2002, **Ashoka Canada** recognized Etmanski for his groundbreaking work, making him one of the first Ashoka Fellows in the country. CharityVillage spoke with him about the origins of PLAN, the entrepreneurial spirit that drives it, and his vision for the future.

**CharityVillage:** I first heard about PLAN when you became an Ashoka Fellow in 2002, but it was founded three years prior to that. How did things get started?

**Al Etmanski:** We didn't realize it at the time, but this is really the first time in history that a generation of people with disabilities are outliving their parents. So, that is the demographic phenomenon. The way it came to me was at a Christmas open house for the organization I was Executive Director of at the time, the BC Association for Community Living. Some older parents came to me and said, "Look young man, we're a lot older than you are and we know something that you're probably not even paying attention to now, which is that we're going to die

sooner rather than later. Even though there are a lot of services out there, nothing that is available for our sons and daughters with disabilities gives us any confidence or peace of mind."

So, that was really the initial motivation. Our thinking was about the future, people dying, and that wills and estates would be a good place to start. We started to run some will and estate workshops for families and realized that we didn't know much about it, and neither did the lawyers or trust officers. There was really nothing available to help families figure out how to deal with the safety, security, and well-being of their sons and daughters after they were gone. We were also confronted with the reality that the will and trust are just tools. They are the knife and fork, but not the meal. The meal, for us, became relationships. If people with disabilities weren't in relationships that were caring and trusting and loving, then when their parents died they were going to be left alone in a very impersonal service delivery system. That's when it clicked for us.

CV: How did becoming an Ashoka Fellow impact the work you're doing?

AE: In the early stages, the money certainly helped. We had set PLAN up to overcome a number of hurdles. We were going to reframe disability; we were going to change the paradigm from one of rehabilitation and rights, to relationships. Our contention was that the biggest handicap wasn't the disability; it was the isolation and loneliness. That was one threshold we had to overcome. The other one was that we were going to finance our organization without taking any government money. So, right from the very beginning we operated without money from government, which forced us to become a social enterprise. The practical support from Ashoka - the money - helped in the first three years of the fellowship.

Probably more relevant was the collegiality. Ashoka is a very supportive organization. I would say that they really understand how to nurture you. They will do anything for you if you can think of it. The other side is that they are real intellectual 'pushers'. I come away from Ashoka meetings sometimes and my head hurts! They are so stimulating. They are just blowing all the icebergs away and uncovering this new territory constantly. It's phenomenal.

CV: You mentioned that PLAN is a social enterprise rather than a nonprofit. Can you elaborate on what being a social enterprise means to you.

AE: We use the form of a nonprofit society, although I wouldn't call us a nonprofit. To me, it's almost like a nurse saying, "Hi, I'm a non-doctor." It's such a negative framing. We would say we come from the civil sector and we earn most of our revenue through a variety of social entrepreneurial means. For us, social

enterprise means delivering on our social mission and our social program goals, but doing it in a way in which we earn money as well. Social enterprise, for us, means creativity, ingenuity, and earning your own way to fulfill your social mission.

**CV:** One of the ways you earn money and fulfill your social mission is through publishing. You recently published *The Company of Others*, which tells the stories of different people who have formed their own networks of support. What has the response been like for this initiative?

**AE:** It's been very good on the whole. We do have a publishing strategy that earns us money, so we've learned to become publishers. This was our first joint publication, but our first two books have already gone through several editions. We developed our own distribution system to sell them, and any profit we make goes back into PLAN. So that is one strategy we have to earn revenue.

We work in four different arenas. We do the work at PLAN; we do the social networks that you see in the book, *The Company of Others*. We also share what we've learned here in Vancouver with over forty replications around the world—in Canada, the United States, Australia, the UK, and Europe. We're also changing, so that's the changing of the law - public policy reform. The fourth thing that we do is try to inspire people by creating a new theory of disability based on citizenship. We're working at all four levels all the time.

It's not good enough to just have an interesting social enterprise, like PLAN. At some point, if you don't change the laws and the structures and the institutions in Canadian society and try to address cultural attitudes, then your little social enterprise will not survive. It will be an interesting model but it won't affect the hundreds of thousands of people who are in similar circumstances in Canada. You have to look at it from a broader sustainability perspective.

**CV:** So, what advice might you give to aspiring social entrepreneurs or those just starting out?

**AE:** One thing is to understand how money works. Money is a very important lever of change in society. I wish I'd spent more time understanding how money worked sooner in my life, because once I did, we began to look at the economic assets of families and combining them for public policy change. The other thing is to stay bold. Most of the younger people I meet have fabulous ideas.

*For more information about PLAN, visit: [www.plan.ca](http://www.plan.ca).*

*To learn more about Ashoka, visit: [www.ashoka.org/us-canada/main/canada.cfm](http://www.ashoka.org/us-canada/main/canada.cfm).*