



PLANfacts

“Relationships have the power to transform lives.”



Celebrating 20 Years: 1989–2009



Photo: David Campion, from *The Company of Others*

Planned Lifetime Advocacy Network—better known as PLAN—was born out of love. The love that our founders felt for their sons and daughters drove them to ask the question, “What will happen to our sons and daughters when we die?”

We quickly realized that there were no trailblazers to follow. It was a new question based on an emerging phenomenon: people with disabilities were living longer than their parents.

Our founders hoped that PLAN would enable them to fulfill their responsibilities to their sons and

daughters beyond their own lifetime. When they filed incorporation documents in the spring of 1989, they couldn’t imagine the future impact of their actions. The 20 years since has been a remarkable journey.

Our most important discovery was the importance of relationships.

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The friendships of network members that have bloomed and endured provide the security and quality of life that our loved ones enjoy. Relationships between families have been the glue that holds us together and propels us forward.

You’ve probably heard Chuck and Gordon Walker’s story. We’ve told it hundreds of times. We tell it because it carries a powerful message: **Relationships have the power to transform people’s lives.**



From left to right: Arthur Mudry, Jack Collins, John Ralston Saul, Joan Lawrence, Ted Kuntz

"What a wonderful world my daughter has given to me... Lynn's relationships are so solid, friends she has had from elementary school and high school. They treasure their relationships with one another. Her friends have contributed a lot to my life. The gifts that they have brought to me were unexpected."—Arthur Mudry

Our Four Values

PLAN was founded by a group of strong family leaders—Jack Collins, Joan Lawrence, Al Etmanski, Vickie Cammack...—people who had both worked in the social service system and parents of children with disabilities. Their front row view of the social service system made them concerned about its long term stability and responsiveness to their sons and daughters. They began to imagine life for their child without parental advocacy. PLAN was their solution.

Joan Lawrence, Arthur Mudry and Ted Kuntz, all past chairs recently reminisced about building an organization that would be truly responsive. The following emerged from their conversation about our four values.

1. Independence from Government Funding was our first value. PLAN was founded to last the lifetimes of our loved ones and to advocate strongly when needed. We knew that government funds carry government influence.

"If government gives you money, they have a certain amount of control and there may be a fear of advocating there. If we earned our own money, we could advocate and hold government accountable."—Arthur Mudry

2. Family Leadership became the DNA of PLAN. When we set up our constitution, we required a majority of families on the board. We always want families to drive the organization. It also recognized that we were experts in the lives of our son/daughters.

"We got involved because we wanted certain things for our sons and daughters after we were gone. What we didn't realize were the benefits while we were still alive"—Joan Lawrence

3. Relationships are a key to a good life. This became apparent as we developed our model of personal support networks.

"I think that it was the early experience of networks that demonstrated the importance of relationship and it became clear through that that everything else was possible. PLAN was the first group to make the networks central to their work."—Joan Lawrence

4. Contributions equals citizenship is our final value. Its value counters the unsettling perception that people with disabilities were recipients of services with no contribution to make. By focusing on gifts and contributions, we make the link to full citizenship in society.

"My son was an example; he always had the qualities of a small child, in school he was held back. When he became involved with PLAN, he became a real person that allowed him to contribute. His celebration was a tremendous tribute to him and a reflection of PLAN."—Ted Kuntz

PEACE OF MIND

Our lifetime commitment

"It was PLAN's commitment to maintain Colin's network for his lifetime that drew us to PLAN," says Beryl Sawyer, "It held the promise of peace of mind knowing there would always be someone there for him."

Beryl and Len had heard another parent describe how PLAN created a personal support network for their son so that they would have caring relationships throughout their life. Although they had a close relationship to their son, Beryl and Len understood that having a network for Colin would ensure that he would always be cared for.

After more than a decade, Colin's network is a vital part of his life. Colin's network is comprised of his parents, his two sisters, friends from his church, former support staff and past connectors. Holding it together and making it sing is his current connector Rosalyn, who Colin describes as "a great lady". Listening to Beryl and Len, you really get a sense of the importance of this circle of friends in Colin's life.

According to Beryl, the day that Colin's network got together with him to do a PATH (a life plan) was a real turning point in their lives. "Colin's network had gathered for a potluck dinner. Sitting together, eating good food and listening to Colin lay out his dreams, I really saw a change in him. Once we got started, Colin, who is normally pretty quiet, really got into it and get excited. Everyone was throwing out ideas for how we could accomplish his dreams. It was a powerful moment".

A few years later, most of the dreams Colin described have been accomplished. He has travelled to

Mexico and taken a course in computer programming. He has regular visitors each week. He has a new friend and now Colin's network is beginning to think about doing a new PATH to set some goals for the next few years.



Len, Colin and Beryl Sawyer

Photo: David Campion

"It's really easy to get Colin dreaming about what he wants to do next", says Rosalyn, his current community connector. Rosalyn has been Colin's connector for four years now, and takes real pleasure from being a part of Colin's life. "One of the great things about Colin's network is meeting, sharing, and connecting with this wonderful group of people. The effect of this intelligent and gentle man on everyone is amazing! I am very thankful to be a part of it."

Lee McKim has been a part of Colin's network for six years. "I love how

energetic and excited Colin is when the group is together. We took him down to the Art Gallery and everyone was laughing and enjoying themselves."

Beryl still visits Colin on a regular basis and remains the primary person in Colin's life. But now, Beryl worries a lot less about Colin's future. He lives in a wonderful residence, has friends and family, and is well-cared for. Colin

spends his time on his computer, entertaining visitors, going to church, and doing all the things he loves.

Beryl knows that at some point she won't be there anymore to help Colin and watch out for him. "That's okay," she says, "With his own personal support network that will be there for his lifetime, Colin will always be surrounded by people who love and care for him."

A Look Back...



Jack Collins, Founding President



First edition of *Safe & Secure—Six Steps to Creating a Personal Future Plan for People with Disabilities* published

PLAN secures progressive changes to the use of Discretionary Trusts. Families stage a rally to protect the existence/integrity of Discretionary Trusts

Helen Gardom, wife of the Lieutenant Governor of B.C., becomes PLAN's Honourary Patron

Vancity

Vancity Credit Union, Vancity Community Foundation and Davis LLP become PLAN's first corporate supporters



PLAN Institute for Caring Citizenship incorporated

Launch of CIBC Wood Gundy Spinoza Bear Program. Young families can receive a free planning package for their young child with a disability

First Celebration of Hearts social event honours the person at the centre of the network

PLAN plays lead role in securing proclamation of new Adult Guardianship legislation.

www.philia.ca launched to foster a dialogue on caring citizenship

Planned Lifetime Advocacy Network was incorporated May 26

Expo '86 reunion creates an endowment fund for families: "Lucille Johnstone Endowment Fund"

St. Christopher's Foundation offers Future Planning Scholarships to families

PLAN receives the prestigious British Columbia Association of Broadcaster' Humanity Award

PLAN Affiliates develop in five provinces and one state

Second Edition of *Safe & Secure* published

PLAN launches the Funds to Live By Campaign

Imagine—Canadian Centre for Philanthropy New Spirit of Community Partnership awarded

A Good Life for you and your relative with a disability by Al Etmsanski is published and becomes a Canadian bestseller

PLAN and Vancity Partnership expanded and announced

www.plan.ca launched

1989

1991

1993

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1996

1997

1998

1999

2000



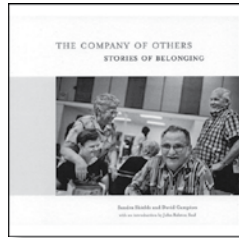
ICBC—PLAN partnership

—Circle of Friends Endowment Fund established

PLAN becomes the first non-profit in Canada to have an externally reviewed Social Audit

PLAN Institute produces a portrait of social network facilitation in Canada, *Reaching Out*

Alberta Edition of *Safe & Secure* published



Meritorious Service Medal by the Government of Canada is awarded to four of PLAN'S founding members

PLAN Institute publishes *The Company of Others*

Second Edition of *A Good Life* published

Registered Disability Savings Plan is announced in the March 19 Budget



PLAN and RBC partner to deliver financial and planning services to individuals opening an RDSP

RDSP Edition of *Safe & Secure* published for BC

PLAN and London Drugs launch the *Safe & Secure* contest to raise awareness of the RDSP and planning information

PLAN partners with London Drugs to distribute books and publications across BC

Institute launches "Weaving the Ties That Bind" an online course in social network development

Quebec Edition of *Safe & Secure* published in French

Dutch Edition of *Safe & Secure* published

His Excellency John Ralston Saul, husband of Her Excellency Governor General Adrienne Clarkson, becomes PLAN's national Patron

PLAN Institute, in partnership with the National Film Board, produces "The Ties that Bind". The PLAN Institute organizes a tour of eighteen cities to reach families across Canada



French Edition of *A Good Life* published

PLAN & Plan Institute receive Arthur Kroeger Award at Carleton University recognizing excellence in areas contributing to the Canadian Society

PLAN develops its first online course—Will & Estate Planning

www.tyze.com, an online personal network service, is launched

www.rdsp.com is launched

Western Australia Edition of *Safe & Secure* published

2001 2002 2003 2004 2005 2006 2007 2008 2009

Sharing Our Experience

It's been an inspiring few days preparing for this 20th edition of PLANfacts and seeing how the vision of the few founding families here at PLAN have touched people around the world.

The logos on these pages represent the many family groups who share an understanding that the key to a good life lies in relationship and from relationships comes a sense of belonging.

As I opened and read the emails accompanying these logos, I heard an overwhelming feeling of gratitude from these families. From our Affiliates across Canada and the US to organizations in the Netherlands,

Scotland, the UK, and Australia, the messages are similar:

We face challenges—finding community connectors, identifying funding sources, and developing organizational capacity—but we celebrate the successes of developing intentional communities. Networks, one by one, are blossoming. To quote Laura from Equal Futures, Scotland, *"The network, which often begins as a small group, wondering what the next*

step is, blossoms into a strong secure group of people, working together, seeing themselves as a group, coming into their own". Laura's email continues, "After three years, based on the powerful results of their networks, I can only imagine what some of your older networks must be like."

Laura, they are amazing, with transformations taking place that we could not have even dreamed of 20 years ago.

Since 1999, PLAN Institute for Caring Citizenship has shared our experience and knowledge with thousands of people, including the two hundred plus participants at our annual week-long



All over the world

**we are making changes and having an impact
It all started with a question and a community**



retreat, "Family Leadership". Immersed in Vickie and Al's fine art of leadership, and nurtured by the values of relationship, contribution and belonging, families have returned home, inspired to create local organizations.

We share our knowledge about nurturing personal networks through our online course "Weaving the Ties that Bind." We've had participants from Japan, the UK, New Zealand, the US, and across Canada share their experiences. The same messages are repeated over and over; we are hungry for belonging and we know in our bones that relationships are at the center of a good life.

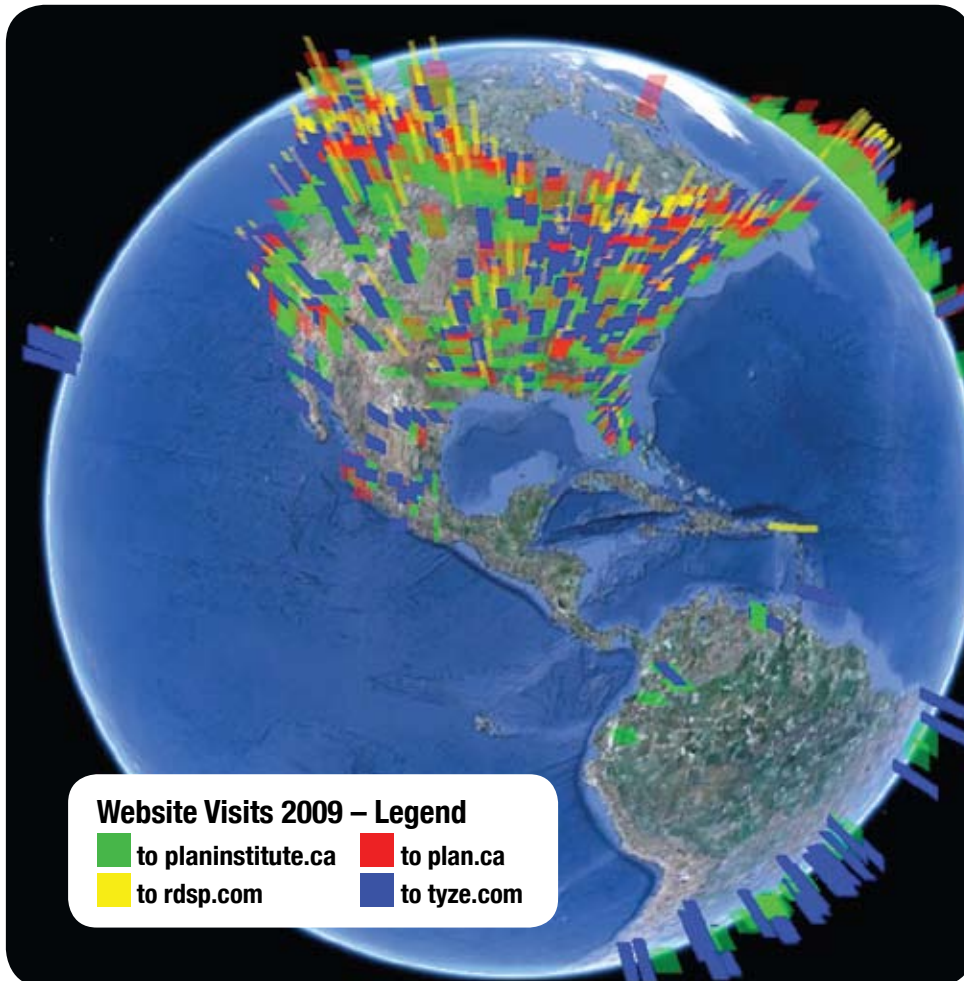
"The course took me on an emotional journey, quite a roller coaster ride" emailed one participant. "I am making contact with a real person in about 2 weeks—so begins a great adventure for me—he or she will already be contributing to the community by beginning to teach me how to do my job". She then finished off the email with the following Maori proverb:

"He aha te mea nui? He tangata. He tangata. He tangata."

"What is the most important thing? It is people, it is people, it is people."

This year we launched Tyze (www.tyze.com). Tyze is an exciting new innovation—social networking software that shares our 20 years of experience in creating personal networks. Tyze provides secure, online personal networks of support designed to strengthen relationships. Many organizations are adopting Tyze microsites for their members, providing new tools to share, plan, build durable relationships and foster belonging.

So hats off to our family leaders, each inspired with a vision for a good life. Thank you all for taking the time to share your successes and your challenges. We look forward to a world where "everyone belongs".



A GOOD LIFE:

Inspiring a new way of thinking

By Jack Styan, *Executive Director*

It was as if I were struck by lightning the first time I heard Al tell the story of listening to a group of people with disabilities who, when asked to dream about their lives, didn't say a word about their services. They spoke about family, friends and lovers, about jobs and vacations, about home and the desire to help others in their communities: about good lives.



After delivering services for nearly 15 years, this was a revelation for me. The shutters were opened from a window and I began to really understand what people had been telling me. I understood that when Phil invited me over for coffee he wasn't looking for a lifeskills worker, he was looking for a friend. When Russell lined up the dominos so he could spend the afternoon with Marlene he wasn't trying to give me a hard time. He was just pining to spend time with the woman he adored. And when Barb insisted on buying lunch, she wanted to be sure that she gave back to me as much as I gave her. People around me were trying to live their vision of a good life.

It all makes sense. Striving for a good life is universal. We all want to be surrounded by caring family and friends. We all want a place we can call home and the ability to influence decisions that are important to us. We all want financial security and the opportunity to contribute.

That people with disabilities and their families also strive for a good life seems obvious. Nevertheless, billions of dollars are spent on services in Canada each year and the people being supported have surprisingly little influence on their services. In fact, we have met hundreds of families who have been so focused on services that they have lost sight of that vision for a good life.



More importantly, we have now met hundreds of families who have successfully pursued their vision for a good life for their loved ones. We've told many of their stories, some in this newsletter. From our collective experiences over the last 20 years we have learned a great deal. For example, we have learned:

- We may not control services but there are many areas of our loved ones' lives that we can plan for
- Developing a future plan will change the present
- Future plans lead to peace of mind
- Having friends can transform our lives
- The first step is the hardest.

Al and Vickie have spent countless hours compiling these learnings in seminars and books that we share with families around the world. We often here people talking about "a good life", "contribution" and "support networks". We are pleased that our vocabulary is entering the water stream. It means our hard work in securing good lives for our loved ones is inspiring a new way of thinking and benefiting people with disabilities and families across the country and around the world.

Policy Reform—A Legacy of Change



"We learned an important organizational lesson in PLAN's early years. Our innovative programs would not have much impact unless they were recognized by society's systems and institutions. We needed our governments to recognize and adjust their regulations, policies and statutes to accommodate the solutions that we were developing. Since then we learned that all social innovations require corresponding structural changes in order to be sustainable, long lasting, and to have widespread impact."—Al Etmanski, Safe and Secure

Using funds from a trust

When PLAN was founded, discretionary trusts were around and being used. They had been tested in the courts in Ontario and Manitoba. In the early 90's, government tried to claw back disbursements from discretionary trusts. We rallied families and advocates around the province. Our efforts lead to reforms that permitted disbursements from non discretionary as well as discretionary trusts. Now trustees are able to use funds from a trust to assist the beneficiary without a loss of income benefits.

Setting up assets in a trust

Even after several years of work to raise the awareness families about planning well, people were still receiving inheritances directly from their parents' and grandparents' estates. When they received the asset, they were disqualified from disability

benefits. It seemed unfair that people were punished because their families had not planned well. Now people with disabilities can put up to \$100,000 in a trust so they can profit from the inheritance over their lifetimes without a loss of income. Being able to place assets in a trust has also been useful for people with disabilities receiving insurance and other settlements.

Representation Agreements

As families developed future plans, they needed a way to assure that their loved ones would be supported to make sound decisions in the future. We co-founded the coalition to reform Adult Guardianship legislation, which lead to the introduction of Representation Agreements. Before Representation Agreements, the only legal tool available was "committeeship", which requires that a person has to be deemed "incapable"

before a Committee is appointed. Today, people are able to designate a Representative to assist them in financial and health care matters. Relationships of trust are used as a criterion for determining capacity. Families across the country are now beginning to look at bringing Representation Agreements to their provinces.

RRSP Rollover

We convinced the federal government to allow RRSPs and RRIFs to be transferred to a son, daughter, or grandchild without having to pay income tax. The current government agreed to permit RRSPs and RRIFs to be rolled over to an RDSP.

Registered Disability Savings Plan

Prior to the Registered Disability Savings Plan, we were alone in planning for the future financial security of our loved ones with disabilities. We proposed, researched, financed, and led the campaign to establish the world's first disability savings plan. We worked with BC and other provinces to accommodate the RDSP by raising asset limits and eliminating claw backs. Today, 500,000 Canadian families will have support from the federal government in their efforts to secure the future. For a young family, an investment of as little as \$30,000 can lever as much as \$90,000 in federal funds and result in an asset of as much as \$500,000 to secure their well-being.

Innovation and Social Enterprise

Independence from government funding provides us with the ability to be an effective advocate and voice for families. It also removes the anxiety many families have about the long-term viability of contractual government funding.

When our founders decided not to accept government funding to assure our independence, we needed to find another way to sustain our work. That way has been social enterprise. Today, people often speak about social enterprise as a new way forward. PLAN has been doing it for twenty years.

Our social enterprise takes place in four arenas:

- Lifetime members, who want to secure a good life for their relatives pay for the services we provide
- We package our knowledge and experience in books, seminars and other products and generate revenue from sales
- We deliver value to corporate partners and professionals who pay us for our services
- Foundations fund us to develop, disseminate and scale-up social innovations.

Corporate Partners

We would like to recognize some of the key community partners that have contributed to our success and more importantly to the future well-being of our loved ones.

Our relationship with Vancity began when Garland and

Vancity

David Cohen met John Meyer, a trust officer at Vancity Savings Credit Union. John joined David's budding network, managed his trust, and remained in his life as trustee and friend until David passed away in 2006.

Vancity put their trust in us before we had a track record. Vancity funded Safe and Secure, sponsored estate planning workshops for families, and has managed trusts as small as \$100,000 for PLAN members.

Eventually, Vancity agreed to share profits from the business that PLAN members conduct at Vancity. This agreement has provided a steady income stream to PLAN.

More recently, Vancity supported our work on the new Registered Disability Savings Plan by hosting several round-tables with executives of other financial institutions, who provided strategic advice. In 2008, Vancity was made an honorary Lifetime Member of PLAN in recognition of their support for our work.

Davis LLP was one of our first corporate

DAVIS | LLP

partners. Davis LLP has been instrumental in presenting Will & Estate workshops, including a regular guest spot in 'Thinking in the Future Tense' annual seminar.

Davis LLP's support has been integral to:

- establishing future planning scholarships to encourage families with younger children to complete their Wills
- funding the production costs of TV and radio ads as part of the BC Broadcaster's Humanity Award
- writing the 'In Trust—how to set up your own trust' guidebook.

Davis LLP has also underwritten the expenses of the Funds to Live By campaign for a number of years, clearing the way for all contributions to go directly to PLAN activities.

We would like to like to single out Peter Bogardus and Mary Hamilton for their ongoing support, whether it be presenting workshops or providing legal advice to us and our families.

Having been at the forefront of the RDSP initiative, we wanted to ensure that the product was in broad national distribution while communicating the opportunity across the country. It soon became clear that a national bank would go a long way to fulfilling these two objectives.



RBC agreed to support this work and we now have a strategic relationship to raise awareness about the RDSP among the relevant national audience. RBC is now PLAN's "Preferred National RDSP Provider".

We are currently developing a communications strategy which includes in-person and on-line RDSP seminars, along with a national advertising campaign to get the word out to the relevant audience. In addition, PLAN and RBC are working closely on some critical policy initiatives such as 'guardianship' to help address legal changes that are necessary for many people to be able to access the RDSP.

Foundations

Many foundations have supported our work over the years. With their assistance, we have developed our knowledge about personal support networks and future planning; to share our knowledge and experience with families across the country, to advance public policy initiatives, to increase our organizational capacity, and to develop our entrepreneurial ideas.

We would like to recognize some of our key supporters.

THE J.W. McCONNELL FAMILY FOUNDATION

Our partnership with the J.W. McConnell Family Foundation is based on personal relationships, shared values and mutual respect.

Tim Brodhead, Stephen Huddart and Katharine Pearson have all been good friends of PLAN. Over the years, their support has assisted us in many arenas, including:

- enhancing our capacity to be entrepreneurial and self sufficient
- spreading the PLAN model across Canada
- creating a global dialogue on contribution, citizenship and disability (www.philia.ca)
- researching and campaigning for the RDSP.

Currently, their support is assisting us transform the ability of individuals, families and the disability sector as a whole to withstand changing economic circumstances and government commitment.

For their significant contributions to our work, PLAN recognized the J.W. McConnell Family Foundation with an honorary Lifetime Membership in 2008.

The Law Foundation of BC has supported numerous PLAN projects such as Safe and Secure, *In Trust*, and our Will and Estate Planning Seminars.



Their most significant investment has been in the Registered Disability Savings Plan. A major grant from the Foundation enabled us to do legal research, learn how Ottawa works and develop strategy. It also sustained our efforts across five federal governments and three Prime Ministers.

The RDSP will benefit an estimated 50,000 British Columbians and 500,000 Canadians. Groundbreaking laws to accommodate the RDSP have been passed in twelve provinces and two territories.

Current support will ensure British Columbians are aware of the RDSP and able to fully utilize it. The evolution of disability benefits across the country has begun. The stage has been set to break the connection between people with disabilities and poverty.

In 2008, PLAN was pleased to bestow an honorary Lifetime Membership on the Law Foundation of BC for its critical support of our work on the RDSP.

St. Christopher's School Society

St. Christopher's School Society has been a consistent financial supporter for many years.

In 1996, 25 St. Christopher's Future Planning Scholarships were made available for families. The scholarships were designed to assist families in creating comprehensive future plans to ensure the security and quality of life of their loved ones with disabilities.

St. Christopher's assisted with educational materials and information to families and provided resources to younger families by contributing to the Spinoza Bear (now Warm Bear) program.

Some of the most valuable assistance was in building the organizational capacity of PLAN. St. Christopher's contributed to the purchase of office equipment, database, website, videos and technology. Recently, the Society dissolved and has designated PLAN as a beneficiary of the annual income from the St. Christopher's School Society Fund—the relationship has evolved into a lasting legacy.



Looking back— looking forward

Susan Whittaker, *Chair*

PLAN is one of those wonderful organizations that draws you in and wraps its arms around you. After tentatively trying the waters, I knew I had found 'home'.

This is where I want to be and where I want to spend my time and energy on behalf of my daughter and others with disabilities. Experience has taught me not to dwell in the past, but to look forward and to work for what will benefit many. It is important to me to work with creative, innovative people that welcome me into the fold and that share our family's values.

Beryl Sawyer once wrote an article entitled 'Hope is spelled P L A N'. There is nowhere else that hope is printed in such magnificently large and welcoming letters! There is nowhere else that has a goal of 'peace of mind' for families.

You have only to reflect on our history to understand how hope and peace of mind are there for all families.

As a mother, I cannot imagine a world without the wonderful founding families who searched for answers to very difficult questions. They had the courage to stay at the table until they had clarity of vision and then they had the courage to follow that vision.

We have considered many possibilities in answering the many questions that have presented themselves. We have evolved and changed over the past twenty years

and certainly in the eight years that I have been immersed, I have witnessed much growth and change. We have been so fortunate to have dedicated and committed families, friends and staff, people who understand the vision and the importance of making that vision real and tangible for our loved ones and families.

We have been fortunate to have partnerships with foundations and corporations that share our vision and trust that we can turn that vision into reality. Our success is founded on those relationships.

We have always set a very high bar at PLAN. It is evident that all that we do has been well thought out. We turn to the experts to educate us and to help us find solutions. No decision is taken lightly.

As the Chair of PLAN, there is nothing more affirming than to hear stories of how the organization has changed people's lives. We have seen the lives of so many enriched by their involvement in PLAN whether it be the individuals at the centre, families, friends or network members.

PLAN's core values will continue to guide us and keep us strong. Future decisions need to be met in the same careful, considerate way in which they have been met since PLAN was just a dream. This dream has swept us up in ways that no one could have imagined.

The poems of Robert Frost come to mind when thinking of PLAN's beginnings:

*'I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I-
I took the one less travelled by,
And that has made all the difference.'*

For the future, his words could be our guide.

*'The woods are lovely, dark and deep.
But I have promises to keep,
And miles to go before I sleep,
And miles to go before I sleep.'*

A salute to everyone that has been a part of PLAN's dreams and success!

A salute to our future!

DISCLAIMER

Any firm or company mentioned in this publication is purely for the benefit of the reader and does not constitute an endorsement by PLAN. It is PLAN's policy that we do not, and will not, endorse any legal firm, financial planner, life insurance representative, or other commercial enterprise.

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