

IPWSO 2016 - TORONTO, CANADA

PLANNING FOR THE FUTURE:

Creating a Lifetime Personal Network of Safety, Security and Love

(1) Why Do Future Planning?

- To deal with our fears about future interference in our sons' and daughters' lives from those who might not act in their best interest
- To be fair to others who care about our vulnerable loved ones with PWS, and who need to know what's going on now, and what has been put in place for later
- To know as parents/families that we have done the best we can, and that we have left a legacy of our love
- To be as prepared as we can to face the unknown, and to be at peace.
(from ***SAFE AND SECURE*** - Etmanski, Collins and Cammack, 2010)

(2) Obstacles to the Planning Process

- Being overwhelmed and fearful; not knowing how or where to start
- Lacking professional guidance with respect to disability-specific concerns - (i.e. legal, financial, tax planning issues)
- Believing that other family members (often siblings) will naturally assume care and responsibility for their vulnerable sib after parents have died
- not having a clear vision for the future
- Getting stuck because of not being able to envision the "perfect" plan
- *Imagining/hoping/wishing* to outlive our disabled son or daughter
- Grappling with the paradox of wanting to keep our loved ones safe, while also wanting them to have a good life where their preferences and choices are respected.

(3) Getting "Unstuck"

- The most useful recognition and motivator for me has been that AN IMPERFECT PLAN IS BETTER THAN NO PLAN AT ALL!

(4) How to Get Started

- (i) Before you can plan for the future, you need to clarify your vision. What future do you desire for your son or daughter? What are their hopes/dreams/preferences for themselves? What does a safe, secure and happy life look like? What do you want future family members/friends/caregivers to know, and how do you want them to be involved?

ii) A personal future plan for a **GOOD LIFE** incorporates:

- caring relationships
- financial security
- a home of one's own - (there are many models of "home", dependent on how much monitoring and support is needed for our individual son or daughter).
- choice and control - balancing our vulnerable loved ones' desire for self-determination with their need for structure in order to live safely.
- the opportunity to contribute in meaningful ways to their community, and to the lives of others.

(5) How Did Our Family Start Our Planning Process With and For Our Daughter?

- (i) Vision of a Future Personal Plan: which we created - in writing, and in as much detail as possible - and shared with family, friends, and other supporters of our daughter.
- (ii) Expert Professional Guidance: we identified and began to work with a team of professional advisors (legal, financial and taxation) with disability- specific expertise and interest.
- (iii) We began to work through our fears, allowing her to experience the "dignity of risk".

(6) The Building Blocks of Our Daughter's GOOD LIFE

- (i) Financial Security:
 - wills set up as testamentary trusts by mother, father and stepmother
 - estate planning
 - planning that ensures our daughter will not have direct access to money in the future - (her vulnerability to exploitation, and the need for controlled access to food)
 - protection to ensure her ongoing eligibility for provincial government disability benefits (*Ontario Disability Support Program - ODSP*)
 - federal government Disability Tax Credit and Registered Disability Savings Plan
 - recruitment of Trustees who are of our daughter's generation, to take over when we as her parents are no longer able to act in that capacity
 - our daughter's own Will and Powers of Attorney.
- (ii) A Home of Her Own:
 - purchase of a small mid-town condo which is held IN TRUST. We wanted to make sure she would have long-term stability, as well as choice, privacy, safety, security.
- (iii) Caring Relationships:
 - we are working to bring together a "younger generation" whom we hope will become long term friends and supporters
 - we have begun a training and succession planning process for our Trustees
 - we have established an incorporated not-for-profit self-directed support organization - (a Board of Directors) - to direct and oversee her safety, security, and quality of life for her lifetime.
- (iv) Choice and Control:
 - Our daughter is able to live independently and safely in the community with a modest amount of daily support and structure.

- In order to ensure her safety, there are many aspects of her life that need to be not within her control - such as access to money and food. However, we have been able to honour her preference to “grow up and move away from home”, and to live on her own without roommates or live-in support staff.
 - By ensuring food security - (i.e. No Doubt, No Hope, No Disappointment -*per The Pittsburgh Partnership - Linda Gourash and Janet Forster*), we have helped eliminate almost all of our daughter’s anxiety about food.
- (v) Contribution:
- We have had to deal with our own biases about the necessity of being “gainfully employed”. This has entailed making a shift from focussing on the socially accepted contributions of **doing**, and learning to recognize and value her unique contributions of **being**.

(7) What We’re Working On Now

Enduring relationships:

- Our daughter is an only child, we (her parents) are in our 70’s, and her mother is the only family member living in Toronto. She has the complex health and disability-related challenges that come with PWS. Many of those issues are not well understood by family and friends.
- We are working with a Community Network Facilitator to build, with and for our daughter, a new generation of current and future friends and supporters.
- My personal five year plan - as her mother, primary care provider, case manager, advocate, loving parent - is to work myself out of a job!

(8) If I Had Known Then What I know Now I Would Have:

- been less self-reliant - more willing to ask for and accept support and help
- realized that enduring, caring relationships are the heart of the matter for all of us. I would have actively begun (at a much earlier age) the process of facilitating relationships with the potential to evolve into my daughter’s own personal friendship and support network.
- focussed less on her vulnerabilities, needs and deficits, and more on her unique contributions to the lives of others.

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Special Note:

Most of the framework for our family’s guidance through the long-term planning process, as well as much of the material included in this presentation, has been taken from Safe and Secure: Six Steps to Creating a Good Life for People With Disabilities, by Al Etmanski, with Jack Collins and Vickie Cammack - copyright Planned Lifetime Advocacy Network, Ontario Edition, 2010

