VISITOR, PARENT, OR PARTNER? A father's perspective with Mental Health.

In a three year journey with my daughter Allanna through BC Children's Hospital and the Vancouver Coastal Health (VCH) Willow Pavilion Tertiary Mental Health program, I have at different times been treated by staff as Visitor, Parent, or Partner. This proud father will give examples of each of these, and conclude with how I have seen an evolution in this 'treatment' over my three plus years of engaging with the system. In addition to my engagement as 'Visitor, Parent, or Partner', I have also been engaged as a family participant in the Tertiary Mental Health & Addictions leadership council, as well as affiliated work groups.

Allanna is a 20-year old who has been 'committed' to treatment for the last three years. Prior to that, she was in and out of the mental health system. Roughly one year of her committed time was at Children's, while the last two have been at the Willow Pavilion. After little progress other than stabilization in the first 2 ½ of those three years, her progress in the last 6 months has been nothing short of miraculous (in her words below).

As a parent, the greatest de-stressor for me has been as a Partner with her team in Family Conferences. My greatest stressor was when these were not occurring. I consider Family Conferences the most important part of the process in engaging me as Partner. The second most important part of the process was ongoing updates by nurses between these quarterly meetings. At the risk of not mentioning others, Clifford Kaseke has been outstanding in this regard (Allanna calls him Papa Bear), and is representative of the high level of compassion I have encountered in the team.



Some of the Team: left to right - Greg Tatchell (Parent), Dr. Manjunath,
Dawna Richardson (Social Worker), Clifford Kaseke (Primary Nurse), Jacky Siu (Clinical Pharmacist)

At Children's, Family Conferences occurred a minimum of once a month, often every two weeks, and at times of crisis, once a week. After Allanna's transfer to Willow, the Culture Shock into the adult system was profound. It was four months later, and only after some persistence, that a Family Conference finally occurred, just before Xmas 2012.

Relative to my theme of 'Visitor, Parent, or Partner,' until that first conference happened, I suspect I was viewed as just a visitor; certainly not as a partner; probably at times as a nosy parent. The first conference happened 10 days after I first met Clifford. Those four months of what felt like exclusion and diminishment were the most stressful of my three year journey with Allanna; indeed, a true low point, especially by contrast with the intimate partnership at Children's Hospital.

- The day she transferred from Children's to Willow, I will never forget being told by a flustered junior nurse "we don't usually deal with families." What a contrast from the policy two years later that welcomes Parents as Partners; 'Welcome to the Team.'
- Once they finally got started, Family Conferences were regular (quarterly at a minimum), and interactions with Allanna's
 nurses frequent and collaborative between those meetings. Again, Clifford involved me regularly, keeping me informed
 of Allanna's progress, highlighting when/where I could help, and at all times lowering my stress levels.
- In parallel, at the Family Conferences, Dr. Manjunath was an excellent coach, always begining Family Conferences with "What would you like to share first?" It was very empowering.

I still had occasional experiences of being treated as a 'nosy parent who needed to be scolded and put in their place.' The few occasions I experienced this upsetting treatment were with new staff who didn't know me. It taught me that indoctrination of new staff to respect Parents as Partners could be strengthened.

The breakthrough with Allanna was multi-faceted, but two aspects stand out. The first was Allanna returning to a learning environment once a week, evolving to twice a week over time. As Allanna needed accompaniment, and the team wasn't always able to support this, the occupational therapist enquired whether I might partner with them and drive Allanna (happily). Her Special Needs school provided highly personal attention, and tailored their support to her evolving capabilities.

The second breakthrough was supporting Allanna in returning to Church, a recommendation of Dr. Manjunath.



June 2014 CONFIRMATION: Allanna on the left, the Rev. Paulina Lee on the right, and Bishop Melissa Skelton in the middle

- The Rev. Paulina Lee, who has a monthly service on the first floor of the Willow Pavilion, has an equivalent weekly service at her church. In the last twelve months, she has seen Allanna 25 times. Parent as Partner was achieved in this case by Dr. Manjunath's gentle, respectful encouragement to support Allanna's propensity in this area.
- A learning in this area for the system to wrestle with is the question "why is spiritual care not a more prominent part
 of patient care?" In a year of services on the first floor of Willow, Allanna & I were often the only two there,
 although this has changed somewhat recently; at the weekly services, I haven't seen anyone else there from Willow.

When I read this article to Allanna, she asked me to include her belief that the weekly prayers she was receiving from three different churches were a very important part of her recovery.

However, for her parent, without the Family Conferences, I don't believe Allanna's journey of recovery would have evolved as quickly as it did. At the October family conference, Dr. Manjunath described the extent of her progress to date as "very uncommon, especially for someone as seriously affected as Allanna."

In Allanna's own late September words:

"I was thinking about how for a while i was considered a "vegetable" from all the drugs but i muraciously (sic) got better but if i had been a couple years older i would have been a veggie for life so i am SO SO SO grateful for the hospital getting me off of drugs before it was too late."

As the team knows, this represents a sea change (broad transformation) for Allanna. For as long as she had been in hospital, she had been chillingly honest with us all that as soon as she got out, she was going back to the drug scene. The words above, written out by her after she had expressed the same sentiments to her priest and Clifford, gives all of us hope.

In the spirit of constant improvement of the Family Conference process, the Institute for Patient and Family Centered Care (IPFCC) recommendation regarding 'documented meeting summaries and agendas' would be welcomed by this parent.

As a final observation, the 2014 IPFCC Conference held in Vancouver, which VCH supported me to attend, taught me how advanced VCH's Tertiary Mental Health & Addictions (TMHA) family focus is relative to many other jurisdictions across North America. The first sign of this to me was Sharon Marmion (Consumer & Family Co-ordinator for TMHA) asking parents one evening if there was interest in acting as family advisors. In my role as Family Advisor that this led to, I have seen the intense intentionality around institutionalizing the family as part of the process. It seems that my first four months in the wilderness at Willow is not likely to happen to another family.

As a bottom line, the positives far outweigh the negatives, with people like Clifford and Dr. Manjunath and Sharon leading the way from this parent's perspective. A very visible sign to me of the evolving focus on a 'Family Culture' has been the open willingness of TMHA to listen to observations and apply some of them in their ongoing efforts to continually fine tune/evolve the system. The regional leaders for TMHA, Kim Calsaferri and Dr. Peter Gibson, have both been especially welcoming and encouraging in this regard. As an example, it was Peter who suggested this article.

And the ultimate benefit? Possibly job satisfaction. Certainly parent involvement. But beyond a doubt the recovery of patients like Allanna. This family can't thank the Clifford's, the Dr. Manjunath's, the Sharon's, the Rev. Paulina Lee's, Kim & Peter, and all the many others, ever enough.

Proud Father of Allanna Greg Tatchell