

TRANSITIONS FOR TARA

The journey from childhood to adulthood will be as diverse for children with Kabuki as it will be for typical children. There are simply too many variances in individual abilities and life experiences. Never-the-less, when one's child is young, there's an inherent curiosity about what other individuals with Kabuki have attained in adulthood. Although we cannot be certain of what even our typical children will achieve, we have a vague idea of what is possible, barring unforeseen circumstances. In the case of Kabuki, that vision is somewhat blurred. This is a brief account of our experiences. To form a balanced impression, it's important that you read the accounts of numerous families. This article is not about the development and implementation of a transition plan. For that please see: <http://kabukisynndrome.com/content/kabuki-synndrome-transition-adulthood> . This is simply our personal journey.



Tara's Abilities/Disabilities

Over the years we have personally met somewhere between 40-50 individuals with Kabuki. Based on this personal contact, we know that Tara is on a higher level of intellectual and sensory disability compared to the average individual with Kabuki. It's important to prelude to since her capabilities as an adult may be vastly different from those of the average individual with Kabuki.

The Process in a Nutshell

We are believers of the importance of planning ahead – *to be proactive vs reactive*. As such, we initiated the transition process when Tara was approximately 17 years old. In Saskatchewan, individuals with special needs can attend secondary school until age 22, so we had approximately 5 years.

1. DREAM

We began the dream. Based on what we knew about Tara, what did we wish for her in adulthood? What would allow for her to have quality of life? For some of you that process will involve your child with Kabuki. For us that was not possible, but we were beginning to have a good understanding of Tara's abilities/disabilities.

2. INFORMATION

We began informing ourselves about what was presently available in our community in relation to Tara's abilities. What housing was available, what day programs were in existence, what kind of financial aid was available, and so on? We visited the programs, we spoke with other parents, we attended conferences, and we read about what was available in other provinces.

3. ANALYZE

We compared our dream to what was available.

4. ACTION

We slowly began taking action.

1. DREAM - What was our dream?

- That Tara live in her own home that she would share with 1 or 2 other young ladies with special needs, and support staff. That this home be filled with loving individuals who truly care for her well-being.
- That she have a personalized day program that includes both volunteer and recreational activities, and that those activities give her joy in life.
- That she continue frequent contact with her family.
- That she develop friendships with people other than paid staff.
- That she have breaks from every day hum-drum life (holidays, entertainment opportunities, etc)



2. INFORMATION - What was present in our city?

HOUSING

- There were numerous organizations that managed group homes, but the openings were few and far between. There were other options, but they did not fit Tara's needs.
- We learned of 2 families who had purchased homes near the University of Regina. In exchange for room and board, 2-3 students lived with their adult child, enabling him/her to live independently. In speaking to the parents, although successful, the arrangement had its challenges. It required approximately 20 hrs/week to manage - book-keeping, hiring, scheduling, etc. Ideally they wished for it to be managed by an independent organization. They questioned: What happens when we want to go on vacation? What happens when we can no longer do this ourselves?

DAY PROGRAM/EMPLOYMENT

- There were 2 main day programs in our city. Depending on the individuals' abilities, they could attend these programs Mon-Fri and participate in various activities. The programs had relatively high client/support-staff ratios and required that the individual could tolerate a high volume of interactions in their day.
- During this time a new organization was established in Regina - Creative Options Regina (COR) - that supported personalized support services. Their aim was to provide both supported living and community-based day programming.
- There was a supported employment program which helped transition adults to the workforce and provided job coaching.

FUNDING

- Group homes were funded by social services.
- The day programs were based on 'block funding'. Block funding means that funding, depending on the level of ability of the adult, goes to an existing day program to enable the adult to attend.
- Although the provincial government was beginning to adopt a more client-based module of funding, in reality, this was not yet in practice.

3. ANALYZE - How did our dream and Tara's abilities/disabilities compare to what was available?

It's unlikely the two will ever perfectly mesh. Funding will forever be an issue. However, it's also true that often it's not that the dollars don't exist, but that *creativity is lacking*.

HOUSING

- We knew that Tara was not capable of semi-independence with 'supported living'. She needed 24/7 care.
- Most homes were more uniquely designed for individuals with physical disabilities than those of Tara's needs.

DAY PROGRAM

- We knew that traditional employment was not in the picture for Tara. Employment requires a certain level of expectation in terms of production and social skills. Even with major support, it would have been virtually unattainable for Tara. She is unable to participate in task-oriented activities that need to be repeated over and over. She will simply refuse. Tara needs to see very concrete purpose to her activity. To understand (or even care) that the shelves in the grocery store need to be stocked so that people can buy food is much too abstract for her. In addition, she has limited social ability *in the typical sense*.
- After several visits to the existing day program centers, we were convinced that Tara would not do well there. Tara's sensory and high anxiety disabilities were only allowing her to attend high school for very few hours/day and even at that rate, she was having minimal success. Although we 'immersed' Tara into many activities in her growing up years, we knew she had severe limitations in her ability to cope with noise, rigid structure, too little structure, and boredom.
- She required activities in her day that were tailor-made for her abilities and interests. It needed to be flexible, but not so flexible that there was no structure left.



FUNDING

- We needed to convince the funding agencies of her needs. One little sentence – a monumental task!

4. ACTION - What actions did we take?

HOUSING

- It happened to be that when Tara was about 17 yrs old, there was pressure on our provincial government to provide additional funding for the purchase of new group homes for the then 440 individuals on the waiting list. We were encouraged to add Tara to this list in the event that funding were to become available. Although we were nowhere near ready to have Tara living anywhere but with us, this was to become one of our wisest decisions. We put her on the list. When funding was eventually approved, a

set amount of dollars was very specifically attached to each individual on that list – Tara being one of them. We had to make a decision whether to move forward on purchasing a home (with the government grant) within 5 or 6 years. During the last year, we decided we would go ahead with this opportunity. We met with the various agencies and began the process of discussing Tara’s needs.

- Based on Tara’s needs and our wishes, Creative Options Regina (COR) would manage her home.
- Tara was matched with 3 other young ladies and the search for a home began. We had direct input as to which house was purchased.
- Many meetings (and complications) later, Tara moved into her new home at the end of June 2012.
- We do not call Tara’s home a ‘group home’. This infers the home was in prior existence and she moved in when an opening appeared. This home was purchased with Tara and the other young ladies in mind. It is THEIR home. We call it a ‘shared home’. No different than roommates living together. Better yet – their home comes with 24/7 staff!



DAY PROGRAM

- We began to think in terms of volunteer and recreational activities. As there were no official existing individualized day programs in Regina, we would need to develop it ourselves. We preferred not to personally manage it, as it would leave us with the same dilemma as the parents managing their children’s homes.
- We visited COR and discovered they were still in their infancy. As we shared their philosophies, we decided they were a good future fit.
- We informed the government funding agency that we would like COR to provide Tara’s day programming (still 4 years in the future).
- To move into a shared home situation, Tara required a day program/employment. So while the wheels of government were sorting out funding issues, we began developing a personalized day program – which we address further on in this article.

FUNDING

- An individualized day program would require individualized funding vs block funding. To recap: block funding means that funding goes to an existing day program to enable the adult to attend. Individualized funding means that funding goes directly to a person (or guardian/managing agency) to arrange and manage the individual’s own support services. From our research we knew that neighboring provinces were already using this type of funding but it had not yet been officially adopted in Regina. In cases where it was occurring, it was essentially happening under the radar for particularly challenging individuals.
- Initially, the government was only willing to provide 12 hours/week funding for a one-on-one support for Tara. It took another year of many letters and meetings until further funding became available. Following Tara’s move into her new home, in ‘government’

care, her needs now became documented (not simply our ‘subjective’ input), which helped progress the need for additional funding.

- Tara has now been designated as having Complex Needs, which allows for additional funding to help support her needs.

Complications

- The initial lack of sufficient one-on-one support left large portions of Tara’s day with inadequate support and boredom, resulting in numerous anxiety breakdowns. There were many days we needed to go to the home to help settle Tara. In addition, she needed us to take her on almost daily outings.
- Tara, admittedly, has very unique needs. As much as we tried to explain these in advance, it’s not until the staff needed to deal with them that learning truly began. I often spent time at the home to model how we speak and behave towards Tara to help keep her anxiety at bay.
- Tara’s home went through numerous growing pains during the first 1½ years for various reasons. All 4 young ladies were new to one another, 3 of the 4 had never lived apart from their families, the girls were not adequately assessed as to their true needs, and COR had its own growing pain issues as a new organization.
- Eventually it was decided that four individuals in one home was not working. In the summer of 2013, two of the young ladies moved to another newly purchased home. The positive outcome of this decision was immense.

Tara’s Day Program

At present, Tara qualifies for 5 hours of one-on-one support Mon-Fri. We have decided that 10 am – 3 pm are the best hours in her day.

Developing Tara’s day program is an ongoing process – as it should be.

- We began with the idea that her mornings would include volunteer activities and her afternoons more recreational-based.
- Matching Tara’s abilities with true needs in the community was very important. Tara recognizes ‘busy work’ from a mile away!
- We made a list of activities Tara enjoys – going for drives, listening to music, gardening, taking photos, going for a pop, swimming, grocery shopping, going on errands, and so on.
- We began phoning and visiting agencies to see if they needed assistance.
- We emailed our friends and our kids’ friends.
- We posted ads on online classifieds – Kijiji, Used Regina.
- We put together a schedule based on the outcomes. Some of the activities change week to week, in particular the recreational activities – to keep it fresh and interesting. Others require commitment and are therefore regular activities. However, if Tara is having a few difficult days, volunteer activities provide flexibility.



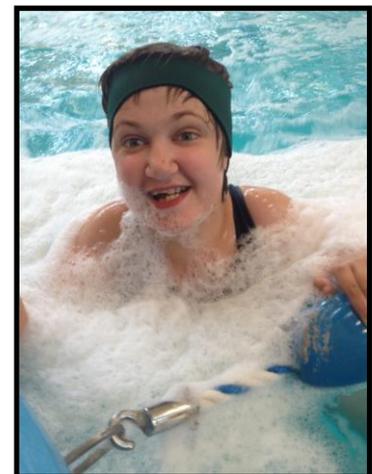
Volunteer Activities

- Delivers Meals-on-Wheels to seniors 2-3 times per week. Tara and her support staff drive to a seniors' complex to pick up pre-prepared meals which are wrapped in warming bags. They deliver the meals to the homes of the 3 or 4 clients on their list and then return the warming bags to the seniors' complex. This activity is absolutely ideal for Tara – drive, music, requires some social contact, but not overwhelmingly so.
- Recyclables – collects refundable recyclables from various businesses and brings them to the recycling depot. At present they service 4 organizations/businesses.
- Buys groceries for her home once a week.
- In the summer has various jobs watering people's private and community gardens.
- Plants and waters her own garden in her backyard. We will build raised garden boxes this summer.
- In the spring does park clean-up.



Recreational Activities

- Swimming – both public and hotel pools
- Photography. Each week she has a different theme – round things, red things, buildings, smiles, shoes, the topics are endless. It's photography 101 – forces Tara to look at her environment in new ways and fosters discussion between herself and support worker. Each week Tara completes different activities with her photos – collages, mails a few to family, photo books, digital frame, etc.
- Mall walk – does a couple of laps, checks out the toy department, stops for a drink.
- IMAX and regular theatres
- Bounce house
- Chuckie Cheese – plays games there
- Science Center and other museums
- Bowling, miniature golf, gymnastic center with trampolines
- In the summer there are various outdoor parks and playgrounds (Tara still loves to swing), outdoor walks
- We peruse various websites for once-in-a-while activities – musicals, concerts, park activities, etc.



Other possible activities

- buying and delivering groceries for seniors
- picking up prescriptions for seniors
- wheel seniors to their activities at senior centers
- watering/planting at gardening centers
- caring for animals at animal shelters
- helping at soup kitchens or food banks
- volunteer opportunities at churches – cleaning, folding, bible school, etc
- library activities
- there are many recreational activities - sports , crafts, music, cooking – that may interest our adult children

Pertinent Elements

- At present we meet monthly with COR and the funding agency to brainstorm and assess successes and needs. These meetings will eventually decrease to a few times/year.
- COR prints a weekly visual calendar of activities.
- COR produces a weekly tracking document which assesses Tara's willingness to participate and strategies used if not. This is obviously a very useful tool!

Email to Friends

As many of you know, I've developed a day program for Tara - volunteer activities in the am (Meals on Wheels as an example) and recreational based activities in the pm. I'm trying to fill one morning/week with a recycling activity. Presently once a month Tara picks up the recyclables at SGI. She and her support staff go to the 15th floor of SGI, pick up the cans, and then bring them to SARCAN. In this particular situation she's allowed to keep the proceeds, but she could also return the profits during next pick-up. I'd like to find additional places of employment that would be willing to have Tara provide this service. Please pass the word around and forward email to co-workers/friends!

Online Ad in Classifieds

Our 23 yr old daughter is a delightful young lady who has an intellectual & autistic disability. As such we are developing a day program for her that includes volunteer opportunities that are within her ability. She would be accompanied by a support worker and is available in the morning. We would prefer activities in the northwest Regina. Do you have recyclables you'd like picked up once a week? Meds or a few groceries that need picking up? A garden that needs watering while you are away? Or a community garden you would appreciate having one less time per week to water? Maybe you have other simple jobs in mind?

Further Ideas

- Sometimes I tag along and become the paparazzi, snapping photos of Tara in action. I use them to create social stories on her iPad app Pictello to reinforce how proud we are of her!
- Don't be afraid to ask organizations for a discount. I explain our situation - that Tara will be coming with a support worker and that she often stays for very short periods – would they be willing to provide a discount rate for her. Many of our city-run programs provide free admission for the supporting person. I explain this and ask for the same at privately run places.
- Check to see if your area provides a free supporting person movie admission. See:
<http://www.cineplex.com/Theatres/Access2Entertainment>
- We have indoor pools, but they quickly become old news. I contacted various hotels with pools/slides, explained our situation and asked whether they'd be willing to allow Tara and her support worker to swim at their pool free of charge (during the weekdays when it's virtually empty). Success!
- Some activities which require a lot of walking and/or are in crowded places are extremely difficult environments for Tara. However, she does very well if in her adult-sized stroller. We've successfully taken her through the crowded streets of Vegas and countless other on-foot touring in this manner. The stroller provides a feeling of safety - it's her personal space.

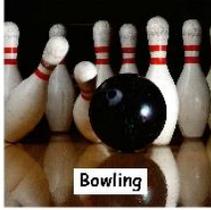


In Conclusion

This account may give the impression we simply followed steps 1 to 4 and by doing so achieved what we had set out to. Obviously that was not the case! None of us live in a vacuum. We were raising 4 girls. We had weddings to plan. We had university tuitions to pay. We had to work for a living. We had ailing parents to tend to. Tara had almost daily anxiety meltdowns that we needed to deal with. We had to spend countless hours advocating for Tara in letter-writing and meetings. All these things took a tremendous emotional toll. But the alternative of no action was not an option for us. Hard work now meant a quality life for Tara and assurance for us.



We were very fortunate that our journey occurred during a time that our provincial government was moving from a block funding module to an individualized module. In addition, greater resources are being made available for individuals with complex needs. Saskatchewan has much still to improve, but we've made strides. We are well aware that for many living in other provinces/states or in rural areas, services are wholly inadequate. Each family needs to work with and invent their own programs/supports that will enable their adult child to succeed. We would very much like to hear what has worked for others.

|  <h3 style="text-align: center;">Tara's Day Program</h3> <h4 style="text-align: center;">DECEMBER 16 - 20</h4> | | | | |
|--|---|---|---|--|
| Monday | Tuesday | Wednesday | Thursday | Friday |
|  <p style="text-align: center;">Grocery Shopping</p> |  |  |  |  <p style="text-align: center;">Recycle</p> |
| Lunch | Lunch | Lunch | Lunch | Lunch |
|  <p style="text-align: center;">Photography</p> |  <p style="text-align: center;">Chuck E Cheese</p> |  <p style="text-align: center;">Swimming</p> |  <p style="text-align: center;">Shopping Mall</p> |  <p style="text-align: center;">Bowling</p> |



Our 24 year old daughter has Kabuki Syndrome. As such she has an intellectual disability and autistic-type sensory impairments which limit her job options. However, we have found some ideal activities that give her purpose and a sense of fulfillment.

Among those are delivering Meals on Wheels, watering community gardens and picking up recyclables.

We are looking for businesses that need someone to pick-up the office recyclables. In exchange we ask that she can keep the proceeds as an income for herself. She would arrive with a support person who is an employee of Creative Options Regina.

Please contact her mom, Margot at 306-543-8715 or margot@kabukisynndrome.com

Or Andrew at Creative Options at 306-546-4441 or ahettema.cor@sasktel.net