

A day in the life of Tammy and Kelli Noone. 2018

I want to start this morning by introducing you to my twin daughters Tammy and Kelli.

Kelli Noone does like choice and control of her life. She has 10 vibrant colours of vegan nail polish and perhaps 20 scarves for each season. Kelli is not a slave to trends but likes to be noticed and has her own style. Sundays you can find Kelli checking out the farmers markets in the city, local buskers, sometimes coming home with a beautiful new henna design on her hand or foot.

She shares a home with Tammy and a fair amount of negotiation for the front porch plus use of the van. However it is clear Kelli is the host at home. A role she shines in.

Tammy Noone has lived with her sister Kelli in their own home in Bardon for 18 years. Like her brother, Matthew, Tammy is a music lover and collector of vinyl records. She enjoys swimming and getting out and about in her car. A highly intuitive person, Tammy loves to get to know people, and keeps those she trusts around her.

Tam and Kelli both struggle with complex seizures and a significant physical and intellectual disability. For them no two 2 days are the same – due to their ever changing health needs .

How does it work?

As you can see Tam &Kelli live in a house in Bardon, tree lined streets, with a garden, great neighbours, plenty of space to entertain and do their own things.

At the moment we are supported by an organisation who receives the individualised funding from Qld Government. We choose how we want to manage the funding and take on most of the responsibilities of an employer.

Tammy and Kelli employ 8 staff ... two of these are permanent part time and 6 are casual. The amount of hrs each person works could range from 5 – 30 hours per week but there is flexibility to respond to what tammy and Kelli need on that day or week.

We don't employ nurses or **medical staff** but over the years Tammy and Kelli have gathered around them a committed group of professionals who are local, available and responsive who help to keep them as well as possible.

One of these workers Sue is a keyworker and while involved in day to day support she also works with me and takes extra responsibility working alongside others to model quality support. She helps to ensure that the formal support is family friendly.

Tammy and Kelli's Dad and I take turns to spend time with them on weekends ... historically this was necessary due to low funding but now is more about monitoring and keeping in touch.

Being an Employer and the paperwork.

Documentation of the paid roles in a job description has been helpful in being clear to potential workers of what is expected and means we are more likely to find the right person for the role.

Some of the roles require on-going review and adjustment because of changing support requirements.

in a potential worker we look for

- skills and attributes that may be a good match with either Tam or Kelli
- Lives local or has local knowledge.
- Has a car/drivers licence
- Similar age to Tam and Kelli.
- Able to work weekends/evenings/overnight
- Can think creatively
- Practical
- IT skills/eg social networking/skype/

Recruitment and how do we find staff?

Sometimes we engage a Staffing Agency to advertise for us – they would also do the initial screening and short listing. We also ask friends/workers/family networks someone they might know.

The keyworker and myself and sometimes a friend will interview potential candidates. This first interview is at the local library which is quiet and private. (coffee van)Tammy and Kelli do the second interviews, at their home.

Checking Referees, workers visas and criminal history screening is done by the keyworker but we are clear that I am the employer, on behalf of T&K. At this stage I take on payment of wages, tax and superannuation but have backups in place for when I go away eg to Ireland !!

Tam and Kelli and the keyworker take people through the induction checklist. Friend/s will also drop in to say hello to meet a new person. However a very important part of induction is getting clear about how Tam and Kelli want to live their life, who is the decision maker and what is non negotiable in our family.

2. How did we get here – Not by magic.

Getting Started – Self Direction

In 1989 (29yearsago) I had not heard of self-direction, person centred planning, individualised funding, Social Role Valorisation or what a non-traditional service might look like, or even if one existed. . When T&K were growing up we had had some experience of family support from an organisation called Mamre . their founding principles were inclusion, and the importance of

relationships and friendship. We were welcomed there.

The Traditional Large Service provider (so called Educational and Training,????) Tammy and Kelli had been attending for 15 years and this was not working well. We had worked hard to try and make it work but without success. Tammy in particular was clear she did not want to be there. I witnessed Tammy being called a troublemaker and likewise her mother. At the time I was recovering from open heart surgery and we had no other family with capacity to assist, it was a tipping point for me. Tammy and Kelli were very vulnerable to being placed in institutional care.

We were looking for something different .. With the support of Mamre we were able to take a small portion of the funding from the large service provider as a way of having some home support in the interim. Paid support at home was not common place at that time. Tam and Kelli were 20 yrs old .This was overwhelming at first having paid support people in the family home.

At this time I was introduced to a brand new organisation in Brisbane called Lifestyle Options Incorporated –This collective of eight professional people with physical disabilities were initiating a new way of organising funding so that people with disabilities would direct and govern their own service while leaving the management of funding with organisation staff that they had employed.. .An empowering and effective alternative service to the more institutional models at the time. LOI had 3 vacancies and were open to welcoming people who had more complex disabilities and were supported by family. Great opportunity, right place right time, we were ready. The LOI Coordinator helped us work through planning the kind of support we needed identifying what was important to us as a family at this point we established some basic principles which still guide us today : For Example :

- Ensuring paid support happens in a respectful way
- Being a good employer, establishing good working relationships.
- Thinking creatively
- Identifying What is family business what is service business
- Being clear about the Roles, **relationships and non negotiables**

We directed support for T&K for about 5 years before they moved into their own home. They were offered a unit with Public Housing provider. We started with week days living at the family home, and weekends at their unit but this was difficult to sustain so Tammy and Kelli moved in full time to their own home. Short story, unit living was not for them. They applied for a transfer and Tam and Kelli moved to their house in the suburbs. They have grown with the home and it is a great example of what a difference well designed housing can mean for people with disabilities.

Lifestyle Options has closed now, one reason was the governance role was impossible to maintain when drawing upon the same people all the time to take on the governance role. The NDIS was a reality and people chose to take their funding and to move to another arrangement. Alternative

options were now available. Tammy and Kelli chose to move to Staffing Options as the host that I mentioned earlier, so we could continue to self-direct.

More changes coming - NDIS; Tammy and Kelli getting older. (me too)

The NDIS will mean a whole change of funding. We intend to continue to self manage, and have funds paid directly to our account, purchasing support and continuing to engage, support staff.

When Tammy and Kelli receive their NDIS plan Staffing Options will no longer be the host provider for their self directed support. We have three ways to pay for the supports and services funded in their plans. Agency Managed, Plan Managed or Self Managed. We will continue to purchase some assistance with payroll with Staffing Options and self manage.

Safeguards - **Succession Planning – what does this mean?**

I Have asked (10) people, trusted advisors, friends, who know Tam and Kel well to come together to help me to Safeguard what Kelli and Tammy have both now and in the future.

- to keep what I know works best for my daughters, keeping the vision for a good life
- to ensure the general health and well-being of Tammy and Kelli is attended to regularly and with good information
- Making sure paid support does not over take their lives.
- keeping the PizzaZ in their life.
- to keep Matthew a part of Tam and Kelli's life and to be reassured there are others around who will support the vision with him in the future

Roles and Work of the Network

We meet formally three times a year and this meeting is facilitated by one of the members. Most of the people in the network have taken up a particular role and this gathering is a chance for the whole group to hear what is happening. I am still at the centre of all this but we are gradually building the knowledge of members and building the links between them.

- The roles at present are - someone to facilitate the meetings, keep the notes and set the date for the next one; someone else helps with money; another person organises regular social gatherings, another helps with staff training and recruitment; another is my back up on health issues and someone else advises on equipment and workplace health and safety.
- The social organiser arranges a Sunday Breakfast with Tammy and Kelli every two months at their home. Tam and Kelli can be themselves there and it is a relaxed time to catch up. Not everyone can make meetings but people stay connected through the notes.
- The network arrangement is part of the contract Tam and Kelli have with Staffing Options identifying decision makers and roles. Two of the network members have signed the contract with me and Matthew.

Challenges and Learning Being the employer was not an easy role for Tammy and Kelli and I was not a great employer as I was also Tam and Kelli's Mum. Clearly at odds. A tension.

- **. Self Governed Lifestyle Options** LOI Our organisation focused more on being in control of our supports than on getting a life. Coordinating all of this took my time and impinged on other things I had previously done eg even spending time with extended family.
- Some things should never be paid for.
- Negotiation and Delegation is something I learnt slowly. Hard to let go but I learnt no one can do this alone. The role of a key worker seemed a good way to go to separate some of the role of employer and family member. This has worked well and continues today. Sue has worked for Tammy and Kelli over 10 years.
- You don't have to recreate this from scratch there are many examples and different situations that others are only too pleased to share. Start with what works best for your family member .

This is what I do; I don't know another way to get what we have.