

Record

334

File Number

10299

Author: Noone, Bobby

Title: Families making changes

Original source: QPPD

Resource type: Written

Publication Date: 01/01/93

Publisher info: QPPD

**Abstract**

In this article, an Australian mother writes about her twin daughters who have intellectual disability and high support needs. She describes the impact on the family's life of the individualised funding that has enabled her daughters to have their own attendant carers. For the daughters it means that they have a degree of independence and autonomy and a chance to pursue their own interests and lifestyles. **Keyword: Individualisation**

# ACCOMMODATION AND INCLUSIVE COMMUNITIES

## FAMILIES MAKING CHANGES

Bobby Noone

As a start I'd like to share some things about my family. This may be boring because they have censored all the good bits. We are not the typical family as we have three children, not the 2.5 model. My husband is of Irish descent and that helps a great deal because of his outlook on life. Our son, Matthew, has his seventeenth birthday on St Patrick's Day and shares a room with three loud guitars. Kelli and Tammy share a birthday but not the same taste in clothes - that makes life bearable. If you have a daughter of around twenty-one years of age, you'll understand, perhaps even sympathise with me for having two.

Kelli and Tammy are our twin daughters who have an intellectual disability. At the age of six months they suffered a severe reaction to the triple antigen vaccine - epilepsy and brain damage were the outcome. This is part of their past, however, and it is their future which I would really like to share with you.

This picture of the dependent child [see end of article] mirrors my worst nightmare. One day they might move out, take their clothes, their pets, their collection of stuffed animals, all the musical instruments, not forgetting the boxes of shoes. So far our daughters and son still live at home; in the future there is every possibility for that to change.

In the past, we might not have seen moving out as being an option for our daughters, because of their high support needs. Kelli and Tammy both received Consumer Focused Funding in October 1991. This funding has enabled them to employ their own attendant carers to assist them to live at home and to have some autonomy and choice in their lives.

The nature of the funding is individual so Kelli can employ her own workers and the same for Tammy. Sometimes our house is very full, five family members, four workers, a cat, dog and a budgie. Especially in the morning when all family members are trying to leave the house by 8.00 am. It would be unusual to have four carers working at the same time as Kelli and Tammy's personal and social requirements vary. The nature of Individual Funding enables them to have their own lives and interests.

### The impact on the family

I looked up impact in the dictionary. It means collision. In some ways that is what happened when the funding arrived. To be honest, sharing our home with other people did take some adjustment. Our family dog became a bit cross with one of Kelli's carers, they were invading his space in the hallway. He was bought off - he started getting very large peace offerings in the shape of bones. Having people other than family members did take some getting used to. This highlighted other areas such as:

Accommodation: Should we move to a large house to give us more room for the people Tammy and Kelli would hire?

Did both our daughters still want to live at home?

These were choices that had become available for Kelli and Tammy which previously were only thoughts and dreams.

The big issue was, that there was a choice. It is possible. Tammy and Kelli started to develop their own lives, extend their friendships and experiences. We went through the exercise of looking for larger premises but we decided against moving and to do one thing at a time. Consumer Focused Funding first. Plus we didn't want to make home too comfortable, they might never leave.

### The impact of me and my role

Looking back now, I can remember thinking have we gone from "the frying pan into the fire". Especially with hiring of people and training etc. The funding has taken a lot of stress out of our relationship and the relationship I now have with my daughters has changed. We have matured, been able to function as three different identities. I have been able to develop my own interests yet still keep my hand in being a mum. (Although, come the revolution.) Jim and I went away for a weekend, when we came home Kelli had taken over the house. Now I have a new thing to worry about; what time will they be coming home. Should I wait up and look cool, reading this great book, asleep.

### **The advantages and disadvantages for Tammy and Kelli**

Obvious advantages are that both the ladies are able to enjoy independence in their lifestyles, e.g. going to the movies instead of going to the football. Develop their own interests and personalities ,e.g. visiting a tarot card reader, who confirms "your income does not suit your lifestyle". Be individuals in their own home and community e.g. be a volunteer shopper for an elderly lady who is housebound.

Set up new friendships and networks, e.g. go to parties and have social life other than family and work friends. To have new opportunities, e.g. go overseas to Ireland. At the moment both the ladies are in holiday mode in Cairns.

They have a support system other than being totally dependent on their parents, therefore they are less vulnerable.

Having choice in their lifestyles has inspired them to be more adventurous.

Kelli has a good excuse to buy more clothes because she goes out more.

The disadvantages are: It is difficult when carers move on, especially if a friendship has developed.

Personality clashes.  
Invasion of privacy.  
Training of carers.

Learning to get along with other people and trust them.

### **The Future**

Kelli and Tammy are working towards setting up a secure environment for the future. Security could mean a home of their own and a lifestyle of their choice. At the moment they are establishing the base for that to happen. By extending their network of friends and carers. Developing their own interests and lifestyles. Taking on responsibility and control of their own lives.

## The Present Situation

