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Abstract

This paper is written by the secretary of PATH (Penrith Association for the Handicapped), a parent of a daughter who has a disability. She tells how PATH came into existence and what it has meant to those on the committee in terms of challenging those in authority on an issue, honing their lobbying and management skills and supporting the rights, needs and interests of people with disability and their families. **Keyword: Families**

CHRISTINE'S STORY

I suppose it could be argued that I have always been a person who got involved but this time I didn't know what I was in for.

It all began when we bought our first home in Sydney's West. We moved from an area where support services for my disabled daughter were available and almost taken for granted. They weren't extensive but when you have a small disabled child, in need of fairly intensive care, you don't complain.

When we moved, my daughter was nearly ready to enter pre-school and her independence was minutely and gradually improving. My second child was one month old when my friendly and insistent Early Intervention teacher dragged (literally) me along to a Public Meeting. She was highly disgruntled (to put it nicely) at the fact that she was running a program funded for forty moderately to severely disabled children with eighty on its books, and many turned away. The area she worked in stretched from Ryde to Penrith - the situation seemed ludicrous.

The Public Meeting, in December 1980, was convened by professionals in the field calling for parents to organise an early intervention service in the Penrith region. We all sat around in a big circle - about 20 professionals on one side and about 10 parents on the other. The professionals were very hostile about the poor attendance of parents and forgot that at least those present made the effort to attend. This hostility served only to reinforce the timidity of some parents and to inflame others.

Certainly I became inflamed! and rebellious! Three of us decided that, although we agreed there was a definite and desperate need for an Early Intervention System in Penrith, the number of those who were willing to participate was too small to support such an undertaking. Of course the professionals weren't willing to be involved because they all had full-time jobs!

We set up a steering committee and with the help of a very dedicated officer from the Department of Youth & Community Services, advertised for a Management Committee for a soon to be formed parent support, activist, lobby group. Thus the inception of PATH - the Penrith Association for the Handicapped. My mother had horrors when I announced I was elected secretary and now I know why.

That was over six years ago and I am still secretary of PATH. My experience has been invaluable. I have learnt to stand up and be counted, to feel that the rights of my disabled daughter are as important as those of my non-disabled sons. I have acquired skills I didn't truly recognise until last year, that is management and lobby skills and some experience in public speaking (whether good or bad). I feel I have helped to create a change in the circumstances that affect my daughter's life and lifestyle and indeed all those like her. The changes have been small, tedious and sometimes painful but nonetheless an improvement. After all, Rome wasn't built in a day, and who knows about the Federal and State Governments!

All this positive outcome has not been without its costs. I have experienced new heights of exhaustion, new reaches of frustration, and even greater extents of anger at times. The complexity of the bureaucracy I think is deliberate, so that if nobody knows how the system works, or who is responsible for what, then nobody has to face the enquiries or answer the issues directly, ie the buck never stops!

It takes a great deal of courage to challenge someone in authority on an issue and sometimes I have risked more than I was really willing to risk, but win or lose, the satisfaction of having stated your

opinion and actively trying to create change is really worth the risk. "Somebody should do something about it" just doesn't cause a ripple, unless it is said to someone who usually doesn't want to hear.

I certainly didn't volunteer because I had some free time and energy or I wanted to contribute to my community. These are valid reasons and thank God for those who volunteer for those reasons. In fact I didn't even consider myself a volunteer until I began to come in contact with paid workers, one of whom introduced me as a volunteer person.

Even now I consider myself and all the others on the PATH Committee as unpaid workers because, if we had a choice, I don't think any of us actually has the time to contribute to the community for doing good works.

We feel very strongly about the needs, rights and interests of disabled people and their families and see a job that must be done. I'm sure we would all like to be paid for the not insignificant hours we put into PATH. However, the lack of remuneration will not hinder our motivations and in some ways gives us the power to act as we see fit - without the encumbrance of, or loyalty to, an employer. The power too comes from the fact that our livelihoods do not depend on the outcomes of our activities, that is, politicians can see that our actions are in direct response to an identified need within the community and that ultimately the only way they can shut us up is to address the issues.

T H E E N D