

For and By... A Personal Perspective On Congregational Life

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Introduction

Good morning everybody it is really great to be here today and a privilege to share with you my story. I hope it will be a story that will encourage us all to see how the impact of Gods love and purpose has had in my life and how important it is for us, the Christian Community in reaching out to the community of people with disabilities, like all of us, who are in desperate need of His Hope and Purpose. In my story I share with you my testimony, my first experience of congregational life, how I found my place and my purpose in the bigger picture and then finally will share with you my future vision for the Christian Community.

My Testimony

Growing Up

Eleven months after I was born I developed a very high fever which resulted in me having a convulsion. The convulsion resulted in brain damage affecting the control of legs and left arm. I am one of the very lucky 400 people who are born with Cerebral Palsy each year. I have it real mild.

The doctors told my parents that it might be better if they put me into an institution as I would not be able to talk, think for myself, sit up by myself; I would be mentally retarded (as that s what it was called it back then). The doctors added that since they already had a daughter 13 months older than myself, also born with Cerebral Palsy it would be better to concentrate on looking after her.

My parents did not agree to this and so they took me home and now you can not stop me from talking!

My sister and I commenced our schooling at the age of 3 and a half years of age at the Spastic Centre. For the next 12 years we grew up within the Medical Model way of living. When you live within this type of Model you are constantly bombarded by Physiotherapy, Occupational Therapy, Speech Therapy, Doctor appointments, Annual EEG s and Annual Reviews where along with all

this medical entourage your teachers decided on your future. One learns in this type of environment how to be helpless, the patient, the victim, the one who always received help and never encouraged to give out. Everything was done for us not with us or by us.

First Congregational Life Experience

My first congregational life experience was not in a church but in an institution for country boys and girls with Cerebral Palsy. This hostel was a place I would visit with my sister once a year for the holidays. We would go on different outings for the week with other children. It was a good time for my socialisation.

For me these visits were also a time where I learnt a lot about myself; how to be independent, make my own choices. Small decisions like what I wanted to wear that morning became significant decisions. It was also an unsettling time like any 13 year old. I began to question my place in this world. For me that included questions about the meaning of my disability was. Why me?

It was during one of these deep contemplating moods while sitting on the floor just outside the girls dorm on the floor with my arms wrapped around my bent knees that my girlfriend Jill came up to me and asked me whether I would like to join her at a Bible Study. Coming from a Greek Orthodox background the Bible had always been read and expounded in Greek; Bible Greek for that matter so the chance to see what the Bible had to say in English was an intriguing thought. So I went to find out what this Bible had to say.

A group of young people from the local church down the road from this hostel had decided to bring their guitars, Bibles and some supper and spend some time with us. We gathered in the dining room and sat around a table. Across the table from me was a young woman maybe in her late teens. She looked attractive in the way she held herself. Her face seemed clean, bright and there was SOMETHING about her! She was beautiful.

Later on at Supper, this young woman approached me and introduced herself to me. We started to talk and I sensed she really cared; she really wanted to listen to all my searching teenage questions and concerns that I held at that time. I remember feeling sad upon leaving as she helped me quietly into my bed after all the other girls in my room had already fallen asleep and said goodbye. She was leaving and I was also left wondering what this thing was that made her so attractive and beautiful. Whatever it was I WANTED IT! I don't remember learning anything about the Bible that night; just experiencing this brief but significant impact this relationship with this young woman had on me.

Finding My Place and Purpose

About a year after this experience my family and I went for a holiday to Melbourne and stayed with my sisters' God family. Mum was given a copy of Joni's autobiography *Joni* in a Greek translation. The day before the end of the holiday Mum managed to get me a copy of it in English. She said it was a must that I read this book. From the first page I was gripped and all the way from Melbourne to Sydney lying at the back of my father's orange Ford Falcon station wagon (when wearing seatbelts was not compulsory). I read Joni's story.

Joni's story for me was one of those WOW!!! books. I was inspired and saw something important. If God could love Joni and give her purpose even though her disability seemed more severe than mine then surely God could love and accept me and give me Purpose in my own disability. Joni also bridged the gap between my Two World Theory, where people with disabilities lived in one world and people without disabilities lived in the other world while still having reign over both worlds. Joni's story bridged the gap and made me see that really there was ONE world where everyone of us had some sort of disability; including the biggest disability being our disabled relationship with Jesus.

My attitude since that day swung from Where do I belong to I know where I belong I belonged in the community of Gods people. There I find acceptance, love and a purpose because I know God loves me. At the same time my mother was about to undergo a serious operation and wanted to make sure we had the support and friends we needed. She believed we would find all this at an Anglican Church. Both my sister and I were taken to our local Anglican Church where I began my congregational life.

I made a lot of special friends at church. I joined Bible Studies, joined the choir, went on social outings, church house parties. But it wasn't all easy and some times very disappointing.

Frequently, outings to Café s, the beach...different houses for Bible Study where stairs were involved became hard work. Going to these places involved too much walking and always left me breathless. I was too scared to tell them I was in pain incase I would be rejected. In fact it was on the Sunday night after the long weekend when I discovered my Bible Study group had gone to Australian s Wonderland and I had not been invited. When I asked disappointingly why the reply was, We didn't want to hurt your feelings . We didn't know if we could fit your manual wheelchair into the boot of our car

As more and more of these disappointing events were happening I began to feel disillusioned. I thought Christians were supposed to love and accept me - all of me; even my disability. They should know how to help me. They should know better than that!! I thought.

Disillusioned and discouraged I went to see a wise man who gave me some very good advice. It was so good that I told him that he must write these down for me to remember and to this day I still have the little piece of paper on which he wrote,

Athena

1. *It is important how you see yourself: firstly as person who has contributions to make and plenty to give in relationships and in church ministry. Within that overall perspective to then see how your disabled legs have given you extra insights and character to benefit you and others.*
2. *Seek for opportunities to serve others, asking how they are going*
3. *Let others know how you are affected by your legs and how they can help if need be.*
4. *Be realistic as to what you can achieve!*

I am really excited to say that this person who wrote these important gems for me is the Minister at Glenbrook Anglican which has just launched our Policy Guidelines into Disability Ministry, Rev Wayne Presbury. Thank you so very much for this little precious note. Your congregation I hope knows they have a genuinely caring and insightful person to lead them in such a ministry!

My note from Wayne taught me that I had a lot to give to others and that I had a special place within the Body of Christ. I had to learn that this little girl who grew up within the Medical Model and learnt to be helpless was not helpless at all. I was the one to help educate my friends at church. Although they did love and accept me needed guidance to understand the ways I needed help so that I could feel like I belonged within the Christian Community.

Christianity is all about relationships. That small Bible Study group, down the road from the hostel I frequently visited, brought with them church. They gave me a taste of what church is supposed to be and that young beautiful woman gave me a taste of the love, acceptance and the Hope that only Jesus can give.

The challenge before us today is this:

Are we as the Christian Community doing this work? Going into the sometimes depressing environments and hopeless situations of people's circumstance and bringing Life and Hope into their lives? Are we making it possible to invite these people into our Church Building? Are our church buildings and programs disability friendly?

As I began to teach my friends about my needs and the best way to help me I became aware of a greater need within the Christian Community. Through personal experience and a recent Action Research Project conducted during my Degree at Uni which looked into meeting the needs of people with disabilities within congregational life I discovered that the Christian Community **does** want to help and they **do** want to know how to include people with disabilities within the life of the Church but they need help and guidance from those who know it best.

In 1987 the Australian Government enacted the Disability Services Act(1986), and in 1993 the NSW Government developed the 10 Disability Service Standards to ensure that people with disabilities were integrated within our communities mainly by change within the services sector.

But I want to challenge the Christian Community who also provides a service to people with disabilities to take note of what these standards. What do they mean for us? They cover many areas but the ones that I will focus on today are:

Standard 1: Service Access *Each consumer seeking a service has access to a service on the basis of relative need & available resources*

Are our church's disability friendly? Can a person access the front door in a wheelchair? Can the deaf or hearing impaired come in and listen. Can the blind or sight impaired read the Bible from a Brailled Bible? Is the person with an intellectual disability confronted by a patient and

understanding congregation?

Standard 2: Individual Needs *Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals*

These are much more than just physical access. Are we meeting the needs of each person's disability? Going to accessible outings? Providing signing interpreting services for the deaf or hearing impaired? Are we holding the Bible Study down stairs instead of upstairs this week?

Standard 5: Participation & Integration *Each person with a disability is supported and encouraged to participate and be involved in the life of the community*

Are we encouraging people with disabilities within our communities to take part in reading the Bible, Leading worship?, Welcoming people into the Church? Being on the Prayer Chain? If not, what stands in the way?

My Future Vision For The Christian Community

My vision for the Christian Community for the future is that our attitudes and our understanding of the needs of people with disabilities will be challenged and in the process prove that we can not do without each other if we are to display the glory of the Body of Christ. I want us to all have a better knowledge and understanding of our theology of disability and how this impacts on how we care and love the community of people with disabilities within our Christian community. Because I believe this will make a huge impact. We do not live in separate worlds. I depend on you as much as you depend on me to make sure we make it work.

This song is based on Isaiah 35 about our journey home to Heaven. Our journey is not an easy one at times but the encouragement of Isaiah 35 teaches us to keep going because of the promise of no more disabilities - whether we are blind, deaf, we can't walk or whether we are discouraged and fear we are told to rejoice as the journey to Jerusalem will be grand

I am hoping that this ministry we are launching today will equip our congregations to encourage and strengthen all people with and without disabilities; learning to learn from each other thus helping the Body of Christ work the way God intended.

Athena Pavlis-Goard