

What has made it easier for us to feel welcomed in the church Desirae Pillay (parent of a child with special needs)



Introduction

My husband and I are proud parents to three children, Savannah (15years old), Talisa (8 years old) and Eli Michael (3 years old). Savannah is a person with special needs. She is diagnosed with:

Cerebral Palsy (CP)

It is a group disorders associated with developmental brain injuries that occur during foetal development, birth, or within the first 2 to 3 years of life.

- It is characterized by a disruption of motor skills with symptoms such spasticity, paralysis, mental retardation, seizures, vision or hearing problems. It is no longer considered a disease but rather a chronic non-progressive neurological disorder. www.kznhealth.gov.za/cerebralpalsy
- Autism – Autistic disorder has three major hallmarks: qualitative impairment in social interaction, qualitative impairment in communication, and restricted, repetitive and stereotypical patterns of behaviour, interests, and activities. Onset is very early, normally prior to three years of age. www.autismsouthafrica.org.

Savannah walks with great difficulty and uses a walker. When the distance is too great she uses a wheelchair. She also has difficulty speaking and is an Augmentative and Alternative Communication (AAC) user (www.caac.up.za). With regards to her autism, we have learnt how to manage her autism and how to help her to participate in daily life. She has achieved goals far greater than we imagined and is living a full life as a person with complex special needs.

We have found it helpful to help our congregation understand Savannah's struggles in social settings. This way, we are fully integrated into the

congregation and the atmosphere is one of acceptance where we do not feel self-conscious.

Becoming part of the Congregation

While people are mostly willing to help us in church settings, we found that in order for us to be comfortable in church, people needed to understand how "special needs" defines our family. We explained to the congregation that:

Savannah finds it difficult to:

- To look people directly in the eye. It helps to bend down to her level.
- To be in large crowds of people. It is okay to greet her but not to cluster all around her.
- To speak to unfamiliar people. You can help new people in the church to understand that it will take time before Savannah will speak to them. They can greet her and she will learn over time to greet them. It may be best for them to gradually come into her personal space.
- To adjust to changes. We prepare her for everything. This is done using picture stories and specific conversation techniques. Changes without warning can cause severe anxiety for her. It is helpful to advise us of changes e.g. in the Teaching schedule for Sunday school.
- To focus in a noisy atmosphere. Therefore she is very quiet when we are in crowds and finds it easier to speak to only one person at a time.

We helped our congregation to understand that it is respectful to Savannah to ask her if she wants to be helped before assuming that she needs help. We also shared some of her likes and dislikes.

Our Family's Favourite Biblical Lesson

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And they come unto him, bringing one sick of the palsy, which was borne of four.

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And when they could not come nigh unto him for the press, they uncovered the roof where he was: and when they had broken it up, they let down the bed wherein the sick of the palsy lay.

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When Jesus saw their faith, he said unto the sick of the palsy, Son, thy sins be forgiven thee. Mark 2:3 -6

It Takes Courage

It was a difficult endeavor for the friends of the man with "palsy" to bring him to the Lord. It must have been with great effort that they carried him to the house. It must have also been very frustrating to arrive at the house and not be able to get their friend inside. Often families with a child with special needs feel frustrated when attending church as the normal processes and procedures of services can be exclusive of families with a child with special needs. When this happens, many families do not return. For us who do return, we have to

have courage and determination, just like the friends of the palsied man who found a way to take their friend with special needs into the house where the Lord was teaching.

It is helpful when . . .

- People greet and welcome us as any other family, and do not stare at Savannah or become excessively nice to her.
- People speak directly to Savannah as they speak to her siblings. We find it works best when greetings are short and preferably with a comment rather than a question. For example: "It is lovely to have your family with us today." It has been helpful to us when people say "Please let us know if you require any help during the service".
- People greet us with a handshake as opposed to a hug. Sometimes Savannah does not enjoy physical contact with new people. It is easier when people ask each of our children if they may give them a hug.
- People treat all our children the same. When they give preference to Savannah, it is very hurtful to Talisa and Eli who face being ignored time and time again. We as Christians should aim to do as Jesus did, who gave preference to none, not even His own siblings.

It is not helpful when....

- People say "I know what you are going through." If they do not have a child with special needs, they cannot possibly know what our lives are about, any more than we know what their struggles are about.
- People compare Savannah to someone they know. It may come up in a future conversation, but the first meeting is not the time for it. Sometimes we already feel self-conscious and this type of comment can make us feel even more uncomfortable.
- People assume our child's diagnoses or assume that because they know generally about the condition, they know our child's particular needs. There are different conditions that cause people to have special needs. The effects of these special needs on our families can be the same in some areas and very different in other areas. We find it helpful when we are asked in a respectful attitude, about Savannah's special needs. We believe that it is wise for churches to gain an understanding of disability. We have found that the best way this can be done is for the congregation to be involved with people with disabilities through local organizations and charities by accessing resources on the web, or by increasing awareness by hosting a "Disability Awareness Sunday" or other event.

The Lessons We Have Learnt from Mark 2 :3-6

³ *And they come unto him, bringing one sick of the palsy, which was borne of four.*

My heart skips a beat when I read this. The friends of the man who had special needs carried him to the Lord. What a joy for families to be able to share their challenges and for people to willingly support them. Our family has experienced spiritual and practical ministering but I know that too many families do not share this experience.

⁴ *And when they could not come nigh unto him for the press, they uncovered the roof where he was: and when they had broken it up, they let down the bed wherein the sick of the palsy lay.*

What a lesson! This man's friends were not deterred by the building but were determined to get him to Jesus! Church should be accessible to everyone. In this case the building was not accessible to the man with the palsy, but that did not stop his friends from getting him in. I know that even when the building is accessible sometimes the hearts within them are not. We are blessed to be part of a congregation where we are loved and cared for. How we hope that this was the same for all our friends who are parents of children with special needs.

⁵ *When Jesus saw their faith, he said unto the sick of the palsy, Son, thy sins be forgiven thee.*

Our greatest life lesson has been that Savannah's special needs, reveals who we really are in how we respond to her and the challenges we face. Having a child with special needs also reveals the attitudes and beliefs of the people around us. It is our fervent prayer that all people with special needs have friends of faith and commitment as the man with the "palsy" had.

In conclusion

As parents, we find that the way our children are defined can be very hurtful to us. Through the ages definitions have caused much anger and pain to the nations of the world. Similarly, incorrect definitions about people with special needs can cause much anger and pain to families. For our family, unacceptable phrases are handicap; disabled; retarded; "something's wrong". We prefer to use the phrases "person with special needs"; "people who are differently abled"; "person with challenges".

Our family is in a church where Savannah is indistinguishable from the other children. She is well integrated into this community of believers, but it was a long and difficult road before we found this spiritual home where people are open and willing to grow with us.