

**PAPER DELIVERED AT THE EDAC CARERS' WEEK CELEBRATIONS
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MY EXPERIENCES AS A MUSLIM CARER

When I was asked by Dr Anne Atkinson to present a speech today on my experiences as a carer, I was suddenly taken down a road of past memories of my struggle to find reasons why my son, Zaemil was falling behind his fellow peers. He is now 16, the eldest of 5 children; but we didn't get a diagnosis of Autism until he was 10 years old, which is quite later than when most children are diagnosed. People ask me 'Why did it take you so long to obtain a diagnosis?' This is a combination of a few factors.

When Zaemil was 4 years old, we were living in Exmouth, approx. 1200km North of Perth. His Kindy teacher had mentioned that he had learning problems and referred him to the Speech and Occupational Therapists. There were many difficulties obtaining therapist services in Exmouth with many months between visits. To us we thought these learning difficulties were minor problems, which he would eventually; grow out of, as we had no other children that he regularly interacted with to compare his abilities with. He liked to entertain himself and didn't want to participate in activities with other children out of school. For us, he was a boy that knew what he wanted.

Due to his other medical conditions of asthma and eczema, and the limitation of adequate medical facilities we felt that we should move back to Perth, where he was enrolled in year one in a private Muslim school. Again the teachers were noticing his learning difficulties and that he had an uncanny knack of disrupting the class with his 'singing' and 'acting'. The teachers found that he could spend hours at a time quietly exploring his fascination over books and not disrupt the class, so they would just leave him there with the books and educational computer games, while we kept taking him to therapists and gave him one on one instructions at home on how to read, write, add and communicate with others.

This continued for many years, with a constant frustration from my husband and myself, trying to understand why he wasn't learning and kept forgetting things we had just taught him. We would ask Therapists why he was having problems with learning and they would say that "it's too hard to answer", "there could be many reasons", "don't worry about the reasons, and just focus on how you can help him". We would keep saying to ourselves that these professionals must know what they are talking about, they are qualified in these areas, so we just kept on with the therapy and home lessons.

It wasn't until my 5th child was born where I was seeing how his brothers and sisters were learning and communicating much faster than him, and getting remarks from teacher assistants that his problems are because 'I'm a bad parent' did I realise that I needed to find an answer to these problems. I felt like all this therapy and home teaching is just a bandaid method if I don't know the cause of his problems. I started to push doctors to investigate this further, it wasn't until I spoke to someone who was a carer of a child with Asperger's syndrome did I start to find similarities in their behaviours did I finally insist the doctors testing him for Autism. I still didn't really understand what autism was, but for me it was something to look into.

When I finally obtain a diagnosis of High functioning Autism, I spent the whole day crying. Not crying because of the grief of him having Autism, but crying due to the relief of finally knowing what his disability was. I would read up as much as I could about Autism and

find myself crying more as I was now for the first time truly understanding my son. I felt for the first time a real connection with Zaemil.

Some of his behaviours and frustrations have now been reduced or eliminated through my understanding of Autism. I had suddenly found simple solutions to issues like his frustration on not having a room to himself for time out because his siblings are interfering with his defined 'space', or his reluctance on trying doing things that he hasn't been trained and mentally prepared for as they are out of his usual routine. I now have more understanding of why he may come home in an aggressive stressful mood because a temporary teacher was taking his class, and have learnt strategies to alleviate that stress.

It's definitely been a struggle to understand Zaemil, but he is my son and like most mothers I couldn't see him any other way. When people get to know him, they always say how charming he is and how he can always cheer people up with his smile. Zaemil has brought so much to our family and taught me so much, such as the need to be patient, not to take for granted the things we can do easily. I have also needed to learn to appreciate the small achievements in life, achievements which we may take for granted. Such as him recently learning to speak on the phone, and not assuming the caller can see him when he asks, "do you like my new hair cut?"

His brothers and sisters frequently tell me how they "wouldn't want Zaemil to be any other way". They believe that his Autism has brought out a characteristic and personality that is funny, carefree and a joy to be around. His love for acting and recreating movies and TV shows he's seen, can keep them entertained for hours. They look up to him and he teaches them about not being afraid to express their feelings. They have learnt that it doesn't matter how a person communicates, dresses or behaves on the outside, it's the beauty from inside that matters, and it doesn't matter what a person can or cannot do, it's what effort they have put into achieving their goals.

Zaemil has also taught me about how people are fearful of things they can't see or understand. I had found when he was 12 years old, he had an accident that put him in a wheelchair for a few weeks, and although people were still hesitant to speak to us we didn't get our usual disapproving glances from people when he made loud noises or the "well intended" advise from people about ways to improve his 'inappropriate' behaviour.

These reactions are especially hard to take when they would come from my Muslim community, where he would be excluded from activities because people believed it was too hard to look after him, or they would unintentionally create feelings of guilt in my husband and myself that this is our responsibility to care for him, as his disability is a test of God and the more we persevere with his care, the greater reward we shall have from God. Some people within the Muslim community have even told us that if we had performed the usual Islamic practice of reciting the call to prayer in a newborns ear for Zaemil he wouldn't have had this medical condition.

It hasn't only been bad experiences though in our community, we have found very caring and supportive people in the community. It was only during last school holidays that Zaemil was taken for work experience at the Australian Islamic College in Kewdale, where he helped in maintaining the school grounds. He was so excited on his first day of work experience, that he told how us they had helped him use the tractor mower, something he usually wouldn't touch because of his fear of loud noises. He had also enjoyed how his fellow peers would make sure they brought his favourite food, which is curry, for them all to share during lunch.

Another aspect of caring for a person with special needs which is frequently forgotten by carers is the needs of the carer.

Like many mothers and carers, I tended to put own needs last and focus on the needs of my children, particularly on the special needs of Zaemil. I used to believe my main function in life was for the care and support of Zaemil and his siblings, and believing that my needs of 'time-out' were signs of selfishness. I would believe that as long as I could maintain a balance between the caring for Zaemil's special needs and the needs of his siblings I was being a good mother. But I have now realized that for me to be the best mother and carer for my children, I need to do things that fulfil my needs as well.

Through encouragement and support from my husband, Zaemil and my other children I finally went back to study about 2 years ago, which initially started as an option for 'time-out'. I'm now finishing my Diploma of Community Welfare and through those studies I have found a way to bring about a more productive balance of my care for Zaemil and my 'time-out', which is doing the work that I love. This balance has been through the Muslim Carers Project with EDAC and the Muslim Women Support Centre where we are working towards addressing the needs and issues relating to Muslim Carers, with a prospect of developing an information booklet for non-Muslims on caring for a Muslim with a disability. I am also doing research on "how inclusive the Muslim community is for people with disabilities". People do question my madness for wanting time-out that seems to be more stressful at times than looking after my family, but for me it's ability to focus on something other than the care and responsibilities of my caring role at home that gives me a clearer perspective of my caring role when I return home.

I will always need to work on keeping that balance between my work, my children, my husband and my care of Zaemil. But with constant support from all that are involved in my life, shall help to maintain that balance. I also know that the caring for Zaemil is filled with many more obstacles than with my other children, but each obstacle isn't impossible to overcome and once cleared, will open more opportunities for Zaemil and joy for my husband and myself.

Thank you for taking the time to hear about my experiences and I pray that there is something here in my talk today that you may relate to.