

# Alec's Story (full transcript)

a culture of inclusion

I am Michelle Morrice the mother of Alec who is 11 years of age and currently in Grade 6 at Ferny Grove State School. Alec has a fatal genetic condition called Sanfilippo Syndrome – this condition is progressive and will result in Alec slowly losing all his abilities such as speech; mobility; cognitive function etc. This diagnosis was not made until a few weeks prior to his entry into Grade 3 at Ferny Grove State School in 2015.



Photo Credit: MPS and Related Diseases Society Australia

#MPSRareBeauty

Our pathway into the education system was a difficult one. Alec had been a precocious child with no definitive diagnosis. In preparation for Alec's school, my major concern was his behaviour and how it was going to impact his education and that of his fellow students. In the lead up to his entry into school he had been given a diagnosis of ADHD with ODD and was suffering from bi-lateral senso-neural hearing loss. We were advised by specialists, to investigate dual

schooling and as such approached a special school but were told that he wasn't impaired enough to be accepted into the program. We had no choice but to start Alec full-time in a fully integrated primary school. Unfortunately, my concerns were warranted as over the next few years Alec's teachers struggled with his behaviour. We changed specialists, revisited his diagnosis, and instigated the trialling of medication all to assist him in the educational setting – a new diagnosis of Autism was given. Unfortunately, this was to no avail as things were not improving and were continuing to deteriorate. The school he was attending had very strict policies and their inability to understand/cater to the needs of children that didn't fit the mould ultimately led me to look for alternatives for Alec's education. Through word of mouth I approached another school that I had been advised would have the capacity to assist with Alec's education but after a face to face interview (which Alec attended) I was told that there was no room for him as they didn't accept enrolments from outside of the catchment. I walked away devastated as I was so hopeful that things were going to improve, this was the only option I thought I had left and we had been denied access. I didn't know where to turn, however the one thing I did know was that I could not leave Alec where he was as it was just not working. I kept seeking the advice of the community around me and was told that Ferny Grove State School might warrant investigation.

I cannot remember precisely who it was that pointed me in the direction of Ferny Grove State School – but I am so grateful to whomever it was. I can honestly say that this school has changed the life of my child and my family, I have never felt more a part of a community than I have because of the way my child has been embraced by the community that is this wonderful school. I was put at ease from my very first contact with the management team of the school. The integration of Alec from his initial entry to his movement through the grades has been thoughtfully considered to ensure the best outcomes for both himself and the students who surround him. I am kept informed through regular planned and nonplanned meetings about those things that are important and am kept sheltered from those things that the school feels they have control over. I am told of/and shown his accomplishments however slight. Every class at Ferny Grove State school would have at least one student with diverse needs (generally more than one) and it is because of this that all

other students have learned and exhibit extreme compassion and inclusion. I never once walk through the school and not have a child say hello to Alec or give him a high five. I was privy to a game of handball where Alec was included even though he didn't play well – yet not once was he asked to leave the game. In fact, he was encouraged to continue playing. He is never held back from participating in any activity and has been awarded for success as other students are. Due to the thought put into the best way of making Alec successful within his educational environment he has significantly decreased the amount of time he spends in the SEP unit. Therefore, engaging and socialising just as any other student would. Alec does not feel ostracised, he feels just the same as all the children surrounding him – he no longer fights going to school, he enjoys the engagement and feels absolutely loved by the students who surround him.



I have nothing but praise for this school and can honestly say that I am blessed that Alec and my family are a part of it. This is absolute testament to the management team (led by Brett Shackleton) and the way they have chosen to respect the diversity of their community and embrace the differences of their students and to pass on these beliefs to their entire school community. In my eyes this school is one that needs to be replicated so that no parent needs to go through the difficulties I had to, to find a fit for my son. Alec is in his last year at Ferny Grove State School and I again facing the daunting task of finding the best fit for him in his secondary schooling – the problem now is that this school has made me realise what I should demand in a school for my child.

***Michelle Morrice***