

Sienna's and Jewels's Story

Jewels, Sienna's mother told their story during an interview on Sienna's behalf.

I love my life

I love my life and I try my hardest to live as normal a life as I can. I have been in hospital many times for chest infections which I get because my muscles are weak, but I always get better. When I get sad, my Mum plays my ukulele to me which cheers me up and makes me happy again.

I love the ukulele and I have always loved music. Mum says when I was a baby she used music to help me relax and be more aware. We used to get help from CanDo4Kids when I was little. One of my favourite things to play with was a wooden box called "A Little Room". It was from Denmark, and it was a little wooden platform that vibrated and helped me to move.

I have a sister named Tallara and she always looks after me. Now that I am 11 years old I can stand and walk, as long as I am supported, but not for very long because my muscles are weak. I spend a lot of time in my wheelchair. But I can have fun in my wheelchair. That's the easiest place for me to have my tube feed. It's also the place I can learn new things and do things that I enjoy.

Good times for Mum and Me

I love going out and Mum used to take us out a lot because she said it is not good to be inside, in four walls. She always took us to shows on Saturday. Mum would put me in my stroller so it was easy for her to take me out. It was so much fun.

Once Mum took me to see a circus. I was so excited because we were right at the front and I could see everything. I can't see as well as other people. It was one of the best times I can remember. I'll never forget that day.

A Bath at Kindergarten

I was born with something wrong with my hips and had to have a special frame on my body. I couldn't bathe and I woke up at night because I couldn't move. I had to stay perfectly still.

When the frame was removed and I was due to have my first bath Mum decided we would have a bath at kindergarten so that it was a community thing. Mum was so excited about me being able to have a bath that she

wanted to share it with other people, like a celebration. It was a lot of laughing, soap and bubbles.

Other people don't understand

Lots of other people don't understand Mum and me. They don't realise how hard it is for us. Even things like going to school. The other kids are sometimes afraid of me because I am different. It hurts me when the other kids don't want to play with me or when they call me names.

I am a happy girl when I can make music, go out with Mum and hear or create stories.

Jewels' Story:

Fighting for Sienna's right to an education

I worked really hard to get Sienna into the same school as her sister. I said, "Well, they're sisters, they need to go to school together." The principal said "Look this school isn't for children like Sienna." That was the first thing he said to me, and I said "Well she is a child first and I'm really going to make sure she goes here."

It was like waving a red flag at a bull! I was determined to prove she was a child before she was a disability. She went to the local kindergarten, and most of the children there were going to this school so they all knew her and I thought that would be really good for her social network.

So we had meetings at the school before she started. I met the principal and one of the teachers. The teacher said to me, "I'm not a special education teacher and I don't want to be. So I'm not sure how your daughter's going to manage in my class." So I just said, "Well, she's going to be coming in to school."

Then there was a really big meeting the teacher organised with teachers' union member in attendance. There were 22 other people, most of who worked for DECS (South Australian Government Department for Education and Child Development).

Basically the man from the union just came up to me and said, "Do you know that your child has a disability, and that there are special schools for children like that?" I could have hit him, but I didn't. I just stood there, and said, "Yes,

well I did give birth to her. My other daughter comes to this school, and I like the idea of siblings staying together.”

In the end Sienna got her own special education teacher because the class teacher wouldn't teach her. So there were two teachers, and she got a health support officer who would come to give her nutrition.

She also had a special teacher assistant to help the special education teacher, but they'd still separate her from the class. One day I found out and said, “Why is she in this little room?” And they said, “Oh, we didn't want to scare the other children because they're asking too many questions, and the teacher didn't feel it was her responsibility to answer them”.

Every day the teacher would ring me and say Sienna's crying, so I'd go and get her and she'd be in the office by the time I got there. She wasn't crying, but her feet were hurting because she had a blister. I got to the stage where I said to the principal, “You don't have to ring me for all these little things. You should try and work them out.”

Eventually, the principal wrote to me to say that Sienna couldn't go to his school anymore because they couldn't find support staff. So I said, “Well, we're not going back.” I made a complaint to the Human Rights Commission because the principal said his school wasn't a school for my daughter, when really it's a public school that anyone can go to – it's not his decision, it's my decision.

We had to wait two terms. The education department kept saying Sienna needed to go to Kilparrin which is a school for children living with sensory impairment. I said, “I don't want Sienna to go to that school because I have looked at it before and it isn't suitable. It's a long way from us. It is not what I want for Sienna. She likes to be around children who can communicate with her because that's how she learns.”

Sienna went to Trinity Gardens Primary School in the end; it has a special unit in a mainstream school, and I had to work really hard to get her into a classroom. I told them I'd write to them every day saying, “Can Sienna please go in a classroom with children her age?” They said they can't do that because children her age don't like children with disabilities. They said to me that “It's not cool”. So they said they could take her to a music class, because all the children are playing music and that was a good compromise because Sienna likes music.

Waiting ... waiting

It takes us years to get things. The school told me Sienna understands things which I had told them from the very begging. They said she writes stories and

knows the right words to pick that make sense. I said to them “Well, yeah, I read to Sienna all the time and she loves stories. So she does understand things, and you just have to listen to her.”

I spent four years getting a computer communication device specifically set-up for Sienna. Sometimes the schools don't know how to use it so I organise a speech therapist to train them. Sometimes I get frustrated when staff miss a training opportunity and then say they can't use it.

Sienna goes to school full-time. Last term she was allocated a nurse because she's on oxygen, she has a jujostomy. Sienna had major surgery in December when they had to close her gastrostomy. She was hardly at school last year because they wouldn't provide any extra support. Her button (feeding conduit) was leaking 300 milliliters of milk a day so I was changing that all the time and we were waiting for surgery. It's exhausting and it's cruel.

My work as an artist

I am an artist and last year I had a studio space with some other artists. As soon as I'd dropped Sienna at school I would go to the studio and paint. I used to work from home with the easel in my lounge room but as people come to support use they'd say “Why are you painting in here?” like it wasn't appropriate, so I found a way to separate my art and my home.

My work as a writer

I've also written a book about flowers which I'm quite proud of, and a collection of poems I've written over the past ten years. I published both books myself. I draw on the experiences I am proud of to understand what I've gone through in the past and to know that I can get through this day.

Building resilience

I learnt resilience as a child - I guess I had a difficult childhood. My parents left when I was a baby; so I was raised by my grandmother. I had two siblings, and I became a carer at an early age. My brother died from cancer when I was quite young. My grandmother ended up with mental health issues, and I used to have to look after the house. I didn't have any support and it was really quite tough.

I had to think on my feet quite quickly, and I was very bright and intelligent. I think it's just my spirit, perhaps. I used to see things differently, and I used to spend a lot of time on my own reading and trying to work hard. I wanted to go to university, so I spent a lot of time studying. I used to have lots of friends, because I was always very social.

Pride in being a mum

I'm most proud of being a Mum! I think what keeps me going is my love for my daughters. Sienna is quite dependent so we are a team. Tallara is very

independent and spends a lot of time with her Dad. Tallara and Sienna are like opposites.

My vision for Sienna

Sienna likes people, and I want a life for her where she's treated like a person, not a disability. She loves music and I can see her in a band with other people living with disability, able-bodied musicians, making music. She has a lot to contribute. She understands things, and likes stories and reading. I imagine her perhaps one day writing.

She is also a teacher. When we're out in the community she teaches people things. Sienna loves libraries. Little children come up to Sienna and ask her what's wrong. I explain to them that she has Cerebral Palsy. Often parents think she's sick and tell their children to stay away. I let them know she is not sick, she has Cerebral Palsy and because of her weak muscles she can't breathe properly which is why she has oxygen. Children like to be around her.

We often find when we're walking down the mall or out, children will come to Sienna and wonder what is happening. They're interested when they are young. Older children have sometimes been influenced by the system e.g. parents, and their fears start to come in, they get scared.

The principal at Sienna's school said to me that children always remember Sienna and it's a good opportunity to educate them. I said to her "Your school is great at integration, but let's focus on inclusion" and she looked at me! I can't help it, you see, I say these things because I'm driven. I've got this passion and it's very direct. It gets me into trouble because I stick my neck out, but I don't care. I care about Sienna and I care about people who need to be part of our society. Sienna does too; she is part of our community.

I want Sienna to have a good quality of life. I want her to be able to access things that everyone else has access to.

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