

Wade's Story

Wade's mother Vasilka told Wade's story in a recorded interview. This is the transcript.

Wade is 30 years old and is one of three children. He's the middle child. I was told the morning after he was born by the obstetrician that he was abnormal and I said, "What do you mean?" I was thinking something physical like kidneys or heart or whatever, but he said, "Down's Syndrome", and I said, "What's that?" He said "Mongolism", and I said, "What's that?" That's how naive I was.

We had no experience of disability before Wade was born. There wasn't a lot of information around at the time, but one of the sisters in hospital actually had a son who had Down's syndrome, and she brought photos of him in for me.

And I really liked that because I really needed to see photos of someone at home and not in an institution. Wade already had a sister and I wanted him to experience and have the opportunities that she did.

So, he went to his local kindergarten for a bit and then we moved. When it was time for him to go to school we visited all the local schools and were told, "Have you thought about putting him into Minda where he belongs with others of his kind?" and all that kind of stuff—it wasn't good.

So Wade went to a special school for a while, and he kept pointing to his sister's school. And when his brother came along, he pointed to that school as well and said, "I want to go here".

Eventually, things weren't working out at the school Wade was attending. He wasn't enjoying it at all, and lots of revolting things had happened. So we took him out of there and he was home schooled for about eight months while we negotiated with local high schools.

First we visited all the year seven classes and then moved onto first year high school. Wade was about 12 or 13 at the time. We chose Unley High which was the closest one to us—even though it was a very large school and they had no experience of disability.

We spent quite a few months negotiating with just about everyone from the Education Department at some time, and Unley High, and writing letters, and they finally accepted Wade part-time—a very conditional acceptance.

We had some help at the time with an advocacy agency, and they were the ones who were able to get some funding together to have Wade home schooled while we were waiting to get him into school.

We found a really good teacher to home school him, because one of the things the special school said after six or seven years of Wade being there is that he had ADD (Attention Deficit Disorder).

The teacher home schooling Wade found the opposite; once Wade was focused on something she couldn't distract him. You don't sit there for two to three hours if you've got attention problems. There were behavioural problems—don't get me wrong, there were lots of them—but lots of things happened to bring it to that point.

So we got him into Unley High—started him off part-time, with full support. That's the only way that the school would accept him. We had to write lots of letters—to ministers and the Education Department and they finally agreed the Friday before school was to start, at the end of January or beginning of February, that he could start school. We were quite unprepared because they hadn't given us an answer in all that time we were expecting the answer to be “no” because they hadn't gotten back to us.

It was a bumpy road to start with. Wade came from a school of 40 students to a school of 1200 including staff. It was a huge adjustment. But Wade had been such a dynamic personality.

He had some problems settling in. Having gone to a special school he didn't learn the norms that you do when you're at school, like behaviour and appropriate language. But he became popular with the kids very quickly. He ended up going through and finishing Year 12 with a standing ovation at his graduation. That was pretty incredible. We were trying to take photos but we all were quite emotional.

So we experienced a huge difference in the environment from special school, where Wade was quite invisible outside of that school. No-one knew him. No-one saw him. No-one asked about him. He was kind of invisible.

As soon as he started wearing the Unley High School tie, everyone started talking to him. And other parents started asking me about him. We would go out or go to the Show or somewhere, and everyone was always saying hello to him and that had never happened before.

Wade responded really well too. His behaviour started changing and modifying. He started working out when it was okay to say “yes” and “no”, and how to say “yes” and “no”, and so I think he learned a lot of new skills. It was a very quick learning curve for him. And I think it was really important for us as a family.

It was really important for Wade to get into mainstream education because there was no way he was ever going to get anywhere in segregated settings. He would have gone to a segregated high school or he would have stayed at this other school until he was 18, 19, 20—which would have led to a sheltered workshop, or business services (whatever they're called these days) and we could see that his life would never improve and opportunities would pass him by.

His behaviour was deteriorating, he had no social outlets, and he didn't have options that other children have when he was at special school. You know, kids with disabilities are dependent mostly on family and other people to do things.

We could see that his life was going to get narrower and narrower and narrower if he stayed in a segregated setting. It just opened it up for him going to the local high

school and learning what was acceptable behaviour, which he really learned very quickly. It just opened up his world a lot more, on so many levels.

For us there is no comparison between the two schools. It should all be open, because lots of things can happen behind closed doors and people like Wade are a lot more vulnerable. They can't always speak for themselves. You don't always know what's going on.

Whereas I think that if you're out in the public system things are going to be detected a lot quicker if something isn't okay. I'm not saying nothing can ever go wrong, but things would be talked about a lot quicker. So the decision of putting Wade in Unley High School had impacted on all of us in a positive way. It was a hard slog to get but it was good because it led to open employment.

When we hit rock bottom with special school, we thought "Right, there's nowhere to go but up now". We were at the bottom of the heap really, with special school, and I could see it wasn't ever going to change and get better. So his life dramatically improved, his quality of life dramatically improved once he went to high school. And he always had kids come around for his birthday, some really nice kids.

In his last term of school Wade did work experience at a library, and that was the only one he did. I can't remember exactly how this came about, but someone at the school had heard about an agency (I don't know if they still exist) that only did open employment, and they did it really well. So Disability SA and the school, paid for him to do this course and become part of an agency.

The agency did a really good job, and we were really happy. They did a little bit of general work in administration with him. He had a couple of work experiences and then he ended up working at Coles for nine years.

Wade really liked his job at Coles and was part of the community at the group of shops where it was located. I think he was the third person that Coles had ever employed with a disability at the time. He got Employee of the Month in his first year, and he did like it and he was very well received amongst some of the staff and also customers who were really happy to have him there too.

Wade now works at the Adelaide Convention Centre. He is very proud of his job there. Wade finds it very cool because he's got a greater level of independence there.

He gets the tram to and from work, and when he was at Coles he would walk to work and then wait for a taxi—which often wouldn't turn up to bring him home. So I think he's got that level of independence now where he just gets the tram in, and feels really confident doing that, and getting the tram home.

It was such a huge achievement for him. He is working with nice people. I think it's always who's heading it up that makes a work place successful, and HR is very supportive of him being there.

[Apart from his work, Wade also goes to Tae Kwon Do Tuesday and Thursday nights, and has been going for several years now. He has obtained the red belt with

two black stripes. Wade mentioned that this level is very close to the top; another two black stripes and he will be a black belt. Although, it takes him a bit longer than others to achieve these levels he goes through the same type of testing as everyone else. But Wade is quite determined in achieving his next level. *Added by Researcher*].

Wade also used to swim, but he no longer does it as everything together became too hectic for him and for us.

We always wanted Wade to be connected with his family and I think it just evolved. I think a lot of time has been taken up, through school and education which was pretty horrendous and pretty rigorous.

There wasn't a lot of let-up with education; whether it was in special school or the local high school, but at least with the high school it was progressive and heading in the right direction, whereas with special school it was always a dead-end, and even though it was supposed to be a special school with experts, my husband and I were always devising programs for them with the behaviour stuff.

I think his brother and sister—I mean you'd have to ask them—I know that they love and adore Wade and I am careful to try and include them as much as possible in any decisions around Wade, and also honour their own commitments as well so they're not feeling like it's all about Wade and not them. So I think they've all grown up together fairly well.

In matters of seeking support from service providers, we had to work at that, because we've asked for services from time to time, but we've never accepted them because they've not been able to offer us what we have looked for.

Even when Wade was at school as a teenager we asked for people that might be able to come along and just take him out and do what other teenagers do, like go to the pictures or whatever, but it always comes back down to some disability church group or disability community group on a Friday night that's not connected, and it still meant that we had to take him.

Our whole aim to be included in the community is to start making links so that people who are able bodied and able minded can be a resource for Wade—a friend for Wade and a natural resource. Wade doesn't drive and is limited to the kind of transport that he can take so he's not always relying on us.

For the first time in ages, we reconnected with Disability SA because I heard that Individualised Funding was coming out, but we weren't eligible because he doesn't receive any services, and the Individualised Funding was only for families already receiving a service so that money could be set aside.

We still don't have anything, and what they're offering us again is a segregated setting. So I'm just trying to work out how to renegotiate that, because I don't want to lose the little, tiny kind of gain that we've made.

But it would also be nice to have Individualised Funding because his next step would be to leave home, and he wants to do that. We would have done that by now but

he's going to need some kind of support. I don't want to leave him isolated and alone. So, how to be creative about how we're going to do that? There are a few options, but also it's going to take some resources as well.

Wade currently barracks for Port Power. No-one else in the family does, just Wade. And so last year we took Wade to banner making on Friday nights and then he either got a lift or the bus to the games.

They're a really lovely bunch of people, and they're just happy to have people come and support them. So this year or next we're going to try and work out how he can go on a bus trip with them to Victoria to a match. Wade has found a friend this year that attends games and is happy to pick him up and go with him in her car or they get the football bus together.

[Wade mentions that his favourite player is Matthew Primus now and last year it was Warren Tredrea. Involvement with the Port Power has been positive for Wade. Added by researcher.]

Wade's other issue is that he won't use the phone as I believe he's a very strong visual person, and relies strongly on those visual cues. And so he can be talking to you and he will be nodding, and the person on the other end of the phone isn't going to know that he's going "yes".

So, I think that's what his real block with the phone is, and he doesn't realise that it's quick and easy for the rest of us if he would use it. One night he went out and I was expecting him at 8:30 pm and he hadn't come home, so I rang and he just refused to answer. Finally one of his work buddies rang me, after about two attempts of mine just to say that they were waiting at the tram station with him and they were going to put him on the next tram. That's all I needed to know.

We always had it in our minds that Wade has as rich a life as we can provide, and as many choices as possible and a quality of life. Sometimes it's been a bit of struggle. I think what would be helpful is to get support in the way that you want it and not just what's available in the services.

I would love to use services but they just don't offer what we want as a family for Wade, and for Wade himself. So I think that services should be asking people's perspectives and be prepared to work towards that as well. I think Individualised Funding will start to change that.

In regards to Wade having his own place and sharing with a friend, I think would be nicer than living completely on his own. Once he is used to living on his own or has established himself, it wouldn't be so difficult, but initially to be sharing with someone would be better for him.

With regards to giving advice or suggestions to other people in similar situations, I think everyone's got their own motivations but I think that once we left the special school system—it was with determination, I was not going to give up until we got what we wanted for Wade.

Although the initial step was very difficult it's been easier since. Education's a pretty hard slog anyway, but then you just have to be determined. You really have to believe that that's where your son, daughter or family member belongs.

And I've seen it again and again. I've met people who were raised in institutions who now drive cars, who were never even taught to read and write, and that horrible era when people of my age were shut away, back then weren't even given a choice.

Does it matter if you can't reach the goals of everyone else? No-one should be denied opportunities and possibilities. You never know what's inside someone, ever, until you give them a chance.

Wade has a wonderful personality once you get to know him, and once he feels comfortable with you, and he does have a quick, cheeky sense of humour. He can be so quiet and then is surprisingly spot-on with some of the runaway lines that he comes up with. It's quite amazing.

Wade has a kitten called Smokey; we got her because Wade really loved our cat Tisha who died of age related illness. Tisha was quite a companion to him. He would come home and talk to her about what his day had been like and she would sit there and look up at him, as though she was listening to him or as if to say, "Tell me about your day".

Wade is also very emotionally connected to his family. When his sister was away in England for 18 months, as I said earlier he doesn't like the phone, but even when she was away it used to break her heart because Wade didn't talk to her.

Anyway he finally agreed to say hello to her on her birthday, and all he did was say hello and then he had this strange look on his face. In the end I took the phone from him and I said, "What are you saying to him?" and she said, "I haven't said anything, I haven't stopped crying since he said hello". So that's what he does to us. Family integrity has been a major resource for him; it has led him to get on with his life.

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