



## Article

# Graduating University as a Woman with Down Syndrome: Reflecting on My Education

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**Abstract:** This paper reflects on the experience of being a woman with Down Syndrome who completed an undergraduate degree at an Australian university. This autoethnography is based on a year-long research project completed as part of my studies. I did a literature review about the experiences of other students with an intellectual disability at university. Then, I wrote about my own university experience. I found that the parts of my own educational journey were linked to each other like stepping-stones. Four main things came from my research: the importance of the journey before going to university; the isolation experienced by students in this situation; how stereotypes might affect students; and teaching methods that can be used to support students during their time at university. This experience changed me as a person. I gained skills and confidence whilst being at university, as well as the ability to see where I am going in life. This experience made me feel more part of society. While there were many wonderful parts, it was not an easy journey. People with an intellectual disability have a right to have an education. What makes the biggest difference is the way we are treated by other people. It would be good for students with an intellectual disability to be accepted and treated with respect. People may have a different way of learning, and it would be good if this was recognised.

**Keywords:** university; higher education; intellectual disability; inclusive education; autoethnography; Down Syndrome



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## 1. Introduction

This paper is an autoethnography of a woman with Down Syndrome who has recently completed an undergraduate course at Flinders University, South Australia. This paper is a reflection on my own experience of being a student at university.

This paper was written from work I did in a year-long research project as part of my studies. Sally helped me by supervising this project and writing this paper with me. First, I did a literature review about the experiences of other students with intellectual disabilities at university. Then, I wrote about my own university experience.

In this paper, we talk about how I completed this project, and some of the important things about my experience of university. I found out four main things in my research through both my own experience and by learning from other people's experiences at university. In this paper, the following are discussed:

- The importance of the journey before going to university;
- The isolation experienced by students in this situation;
- How stereotypes might affect students; and
- What teaching methods can be used to support students during their time at university.

## 2. Materials and Methods

The methodology used for this project was autoethnography. Autoethnography is a relatively new qualitative research approach which involves researchers critically analysing

their experiences and providing an understanding of how these compare to the experiences of others from a similar social group (Chang 2016). By collecting personal accounts and reflecting critically on the social meanings of these experiences, it allows researchers to develop an understanding of their own experiences and how they have shaped them (Liggins et al. 2013). Autoethnography also asks the researcher to think about how analysing their experience can help them understand other people's experiences by thinking about social and cultural meanings (Chang 2016).

At first, I found it hard to think about this unfamiliar word and how it related to my own life and experiences. So, I broke it into parts. I thought about it as auto—referring to yourself; ethno—looking at your own journey; and graphy—referring to the research. Therefore, for me this word described the study of my own 'journey of learning' when compared with those of other people.

### *Methods*

This research was conducted in stages. Firstly, I did my literature review. The aim of the literature review was to find out about the experiences of people with intellectual disability at university and their ideas for improving university education. Sally conducted the first review, using university databases. The review set terms to search for qualitative research; literature about the views of students with intellectual disability themselves; and research in university settings. To make the project manageable, we reduced the scope of the literature review and selected the most relevant nine articles for me to read in full. Some of the papers were hard to read because they were very long, and it was difficult to find the information needed. The Read Aloud program on the computer was useful. I am a visual learner, so I worked with my mother to help me understand the main ideas in the papers. She drew diagrams of the ideas, and we talked about how the ideas affected the people who were in the research. I then looked for information which might answer some of the questions. These were selected and recorded on to templates under the heading of the questions. Each author's comments supporting the discussion was combined to relate to the question.

I had a student mentor, Kathryn, who helped by summarising some of the reading for me too. We were interrupted by COVID-19, which made it very hard. We had to go online, which made it very hard to work together when we did not know each other well. When the lockdown had eased, we were able to all meet face to face in the university. This was better because we exchanged easier conversation together, and there was a warm feeling between us. For example, with Sally, we were looking at the paper together and trying to figure out which sentence should go where, and she could write instructions straight on to the paper. This was helpful because we worked as a team. I also audio-recorded the sessions so that I could listen to them again.

All of this work helped us when it was time to start the next stage—my autoethnography. The first step in my autoethnography was that I related the educational story of my life in conversation with Sally. I found that the parts of my own educational journey were linked to each other like stepping-stones. The next step was to write in more detail about each of the stepping-stones on my education pathway. This took a long time and a lot of energy—I worked very hard. I conducted a series of interviews with people who were involved in my education, and I did a lot of personal reflection.

I needed to work out how these ideas fitted together. Once I had words written down in each of my main stepping-stones, we looked together for things that came up more than once, and where my experiences connected to the big ideas that were in my literature review. This is how we came up with the themes.

With the same kind of assistance as I used for the literature review, I critically analysed the themes and compared my experiences of university with the information I found in the literature review. This allowed me to identify the importance of the themes and how they contribute to new ways of thinking about the social world of university education for people living with intellectual disability.

### 3. Results

In this part of the paper, I have written about the major ‘stepping-stones’ in my education. These are about my high school education, the Duke of Edinburgh’s award, starting university life, film studies, the foundation course, and the Bachelor of Arts degree. They are all important because each one opened a door to the next opportunity.

#### 3.1. High School

I lived in a South Australian country town until I was 28 years old, and all my formal schooling was there. In primary school, I was in a special small class but in regular classes for some of my subjects.

When it was time to go to high school, I wanted to be with people I already knew, not just people with a disability. I had the choice of two high schools, and I visited them both to see which one was the best for me. When I arrived at the second one, my friends from primary school rushed over to meet me; so I decided this was the school I wanted to go to.

In high school, I was included in mainstream classes for subjects like English, history, and drama. For other subjects, I went to the learning centre and had a Student Support Officer to help me with the more difficult lessons.

I learnt some other skills: one was using the computer and another was in the drama class. I learnt about work experience and some sports. I learnt how to play basketball, hockey, as well as weightlifting. I felt comfortable with these lessons and enjoyed gaining self-confidence. Some of my friends in high school were Indigenous Australians and they involved me in an Indigenous Australian school club.

In the last years of school, the principal allowed me to go to Adelaide every Friday as one of my school days to go to dance workshops with a well-known inclusive dance organisation.

I had a great time when I went with the school to Mount Hotham in Victoria, during a week’s holiday in July. There was snow everywhere, I had a whale of a time being on the snow and having an instructor teaching me how to ski.

When I left school, I was very pleased to get my modified SACE (school leaver’s) certificate. I then went to TAFE (technical college) for computing and mathematics.

#### 3.2. Duke of Edinburgh’s Award

From ages 14 to 21, as well as schoolwork I was doing the Duke of Edinburgh’s Award Scheme for people with special needs. The purpose of the Duke of Edinburgh’s Award is about expanding people’s vision and introducing them to a wider knowledge of what is around them.

There are four different areas: (1) Volunteering; (2) Physical; (3) Skills; and (4) Expedition, with levels of Bronze, Silver, and Gold.

I volunteered with the Salvation Army and the special needs program where I did secretarial work, copy typing, and photocopying. I helped the teachers by playing with the children, reading them stories, and helping with hydrotherapy. I took up physical exercise and went to line dancing and swam in the Special Olympics.

I wanted to learn how to play the piano and study some classical music. I took some sessions in culinary arts, as well as poetry and theatre. The expedition was about going camping, lighting a fire, putting up a tent, learning to use a compass, bushwalking, horse trekking, and safety precautions if ever we got lost. The last project for my Gold Award was talking to Prime Minister Mr John Howard about the value of arts for people with disability. He was very friendly.

It did a lot for me. It was a lot of fun; I had to learn how to find people in the community to help me with each project. So, I met new people and learnt many new things. I had to meet up with my mentors regularly to work on the project, and I had to write it up and present it to a panel.

### 3.3. *Starting University Life*

After I received my Gold Award at Government House, the Duke of Edinburgh's Award director asked me what I was going to do next. She then introduced me to the idea of applying for the Up the Hill program at Flinders University. This program includes people with disability in classes, with support from student mentors. They participate in the learning by auditing subjects and gain the experience of being at university. People learn what the atmosphere is like and how the student feels by stepping into higher education. So, it was the link for me to the next experience in my life.

I was invited to the university for afternoon tea. I had a conversation with the director of the program, where he asked what subject I was interested in. I said I was interested in drama. I later learnt that the conversation had been my interview for the program. I was incredibly happy to be offered a place.

Over the three years in the Up the Hill program, I audited many subjects—English, Creative Writing, Drama, Poetry, Cinema and Fantasy, Film Appreciation, and Screen Studies. I was totally included in the classes and I was involved in the discussion groups. The film studies class went on location to make a short film. I enjoyed being part of the team and to be included in a filmmaking experience. I helped with the lighting and I played the voice over in the film.

When the three-year course was finished, I crossed the stage in a graduation ceremony with beautiful music playing. I was very proud because some of my teachers from my secondary school came to the ceremony. It was a wonderful experience and I enjoyed it. The program was an inspiring experience for me. Later, some of my friends followed me in enrolling in the program.

### 3.4. *Film*

During my time in the Up the Hill program, I met the lecturer of screen studies, a man named Tom Young. He found out I wrote stories and suggested that I could make a film out of one of them. He said he would mentor and guide me to direct the film. It took me a while to write the film script, it was much more complicated than just writing the story.

After the Up the Hill program, it took me a further two years to do film production. During this time, there were some media students who were involved with me in the making of the film. We were all learning what the filmmaking industry was like. The lecturer worked with me on characters, costumes, music, finding a site, and everything else that was needed to make a film. This film was shown in the cinema and went to film festivals in different parts of the world. The film was shown on television at Christmas time.

### 3.5. *Foundation Studies Course*

It was after this experience that coordinators from the program suggested the idea of me taking the Foundation Studies Course. This course is the beginning of academic study at university. At first, I was not sure if I could do it; however, I gave this a try. I asked permission from the course director for my parents to come with me to the classrooms so that they could help me with the course. The tutors agreed with this, and I went to the classes three nights a week. Some of the topics were Mathematics, the Ecology of the River Murray, and English. There was also a survey on Nuclear Power Stations. I interviewed some people on that topic, hearing their point of view. I also did a topic on China and how it was building up bases in the China Sea.

The study was hard and all very new to me. I learnt a lot about tutorial work as well as having to write assignments. This felt different to going to the Up the Hill program because, when I was auditing topics, I did not have to do any assignments. Now I was working to get a pass in my studies. There was also a lot of homework. At the end of the course, I was pleased to learn that I managed to gain enough marks to apply for a Bachelor of Arts Degree.

### 3.6. Bachelor of Arts Degree

I began attending Flinders University as an Arts Degree student when I was 35 and have undertaken one, or sometimes two, topics each semester. Coming to university as a student became a great thrill to me, but daunting at the same time. From this experience I feel I have learnt so much during these semesters and about so many different topics.

The topics I enrolled in were Drama for my Major and Screen Studies for my Minor. There was the Stanislavski Workshop, this involved about learning the history of the dramaturge himself. He taught that acting is something you do instead of something you show. This motto gave me the inspiration to understand not only myself but to understand the techniques of theatre. There were acting workshops and learning about the history of the stage, including from different nationalities such as Asian Dramatic Traditions, the way both the Japanese and the Chinese use their craft theatrically including the way they use their body movements. These styles of movement are called 'Noh' and 'Kabuki'. This influenced me in my own dance movements. I also learnt about stage and film directors and had to make some short films myself.

In Aboriginal Studies I learnt about the children being taken away, and how much I related to their sadness. I learnt about the history of the Aboriginal Australians, including what they struggled with over the years through their historical art. What stories they brought out whilst crafting their baskets and how the DNA of the original people is connected to these baskets. Some of this I did not know before. Another subject I studied was English. I was very fascinated with writing at the time.

Studying at university was very different to being part of the Up the Hill program, or even the Foundation Studies Course. Now I was studying to gain results, working towards an actual degree. Before the beginning of the first semester, I went to the Disability Office to find out what support was available. I was informed that I could have an access plan towards my studies, for example extra time for assignments and exams. With this, I could have a room of my own to take the exam and have somebody with me to assist me to understand the questions. When I queried about having a mentor, they said they could not provide that. They did not do it for people with intellectual disability, only for people with physical or visual disabilities.

I soon found that at university I was on my own and it was all very different. As a student I was by myself. I had to learn how to get to the university on the bus, and I had to try to find the rooms where lectures and tutorials were located. This became extremely hard for me because I felt very lonely on the campus, and I did not know anyone. People did not talk to me, and every so often I could not find the class or felt too shy to go in. So, I missed some lessons. Being on my own around the campus, at times I felt that I wanted to go home and not come back to university.

Some of the activities I had done in the Up the Hill program with a mentor were going to orientation week, dancing with people at a community fair in the university hub, and trying out the wonderful food they had there. I learnt how to socially interact with mentors outside of the university environment, as an example taking a mentor to a show. Now, I felt very lost without this contact.

The university did not fund mentors for students with intellectual disability. For me to have support at university, my family and circle of support had to raise funds. It took a lot of effort to organise. With this support, I was able to pay a student in the class to be my buddy. This made all the difference to me being at university, I got to know the student as well. I met their friends and I felt happier being safe at university. We also worked on the topics together. We sometimes went to the library to look at my studies, and we enjoyed having lunch together. On a social aspect, we went out either watching a show or just hanging around talking about anything we wanted.

## 4. Discussion

My journey through education has been very rewarding, but it has not always been easy. In the next section of the paper, I reflect on the isolation I felt once I got to university,

how the stereotypes about people with disability affected me, and what helped me in my studies. In this section, I am also using the literature to draw on the experiences of other students who have been in my shoes and have been involved in research projects.

#### *4.1. The Importance of the Journey before Going to University*

From my experience, something that stands out to me is how important it has been for me to have had lots of activities and experience before I went to university.

I have been involved in many community projects as well as drama for many years. Through this I have met lots of people and learned lots of new things. My parents and other people were always finding new activities for me to get involved in. This was fun and it always led onto the next exciting thing to do. Being involved with the Up the Hill program where I was auditing topics and had a mentor with me helped me to get ready for university life.

Other people have said they felt like this too. Philip and Heidi shared their views in [Wilson et al. \(2012\)](#), saying that their early experiences were important in building their confidence and readiness for university study: “They felt that these were difficult but important years in their development during which they matured, volunteered in the community and maintained entry-level jobs” ([Wilson et al. 2012](#), p. 40).

Like me, both Heidi and Philip were supported by their parents to become included in community activities. They both felt that it was extremely important to state how significant the advocacy of their parents had been in their development, especially in preparing them to succeed at school, to access opportunities and supports at work, to participate in the community, gain access to post-secondary education, and to feel ‘normal’. I agree with Philip and Heidi about how lots of experiences in the community can be very helpful before you go into higher education. For me, it was the same.

They thought their opportunities reflected a combination of what their parents wanted for them, what was available, and what they enjoyed and interested them ([Wilson et al. 2012](#)). For me, it was the next thing I was introduced to. If something I was interested in came my way, people guided me along that pathway. For me, it was my parents, but also my teachers at school, people from the Up the Hill program, and other friends and family. So, each of the things I did led me on to my journey to university.

#### *4.2. The Isolation Experienced by Students in This Situation*

When I first started attending university, I found it was different to going to the Up the Hill program. On my first day with Up the Hill, I was introduced to my mentor who helped me to find my way around and build friendships with other students. The mentor attended classes with me, helping me to understand what was being said by the tutor, and supported me with the end of semester presentations. [Rillotta et al. \(2020\)](#) explained that mentors attend university classes with students, and they also support them with social activities inside and outside the classroom. They help them learn their way around the university. Other students with intellectual disabilities also said they felt they developed more confidence when they were supported by mentors ([Rillotta et al. 2020](#)).

In her research with nine college students with intellectual disability, Paiewonsky explained how certain aspects of being new to college affected students: “feeling different, adjusting to new expectations, having a new identity, transportation, new routines, self-determination and new relationships” ([Paiewonsky 2011](#), p. 37). All these aspects needed to be dealt with by the student. This has been a common experience for students, and several studies have shown that students with intellectual disability feel unsure about what to expect, find it stressful, and find it hard to concentrate ([Rillotta et al. 2020](#); [May and Stone 2010](#); [Wilson et al. 2012](#)). This was also the situation for me, because all these things affected me in this new experience. I found it to be rather hard without a mentor to guide me. Even though I had been in the Up the Hill program and knew the university well, now being on my own turned out to be a big challenge for me. I also found it hard to concentrate.

Other students have also found this support to be important for feeling more comfortable in the classroom (Kubiak 2017) and for encouraging tutors and lecturers to be more confident in supporting students with intellectual disability (Plotner and May 2019). This individual support was found to help people find their way around the campus and get settled in, as well as start to discover what their strengths are and what they prefer as a subject (Paiewonsky 2011).

#### 4.3. *How Stereotypes Might Affect the Students*

It is extremely derogatory for people to say negative things about people with disability. This topic matters because to be unkind to others is the wrong thing to do. It is hurtful and makes them feel like a knife stabbed them in the heart. It makes them feel they are the worst thing around, and that they are not important. This affects them emotionally and they feel useless. In my experience when you are new to university and trying to fit in, these comments and being ignored makes people feel very low. I felt alone when this happened to me and I felt I could not speak. I could not concentrate because these feelings made me so unhappy. I did not feel I wanted to be there. I still find this very hard to talk about. It makes me feel ashamed.

Being harassed or possibly overlooked is not a helpful thing to go through in life. This would scare the person with disability, who may not know what to do and would not know where to find the guidance to do something about it. This is not a good way to go for people with disability, feeling alone and as though they are not allowed to be there.

Other students with intellectual disabilities have experienced stereotyped thinking and discrimination as well. These damaging views include thinking that people with intellectual disability are stupid, cannot learn concepts, and are lower achievers (May and Stone 2010); and that they are not able to learn or even to think for themselves, so may not be able to learn at university (Lightner et al. 2012). Some people have the idea that people with a disability sometimes scheme to get extra support so that they can ask for special privileges and pity (May and Stone 2010). These negative attitudes have a strong impact on students with intellectual disability. It is very hard for students with intellectual disability when other students were judging them and behaving badly towards them (Kubiak 2017), and when tutors talked down to them (Stefánsdóttir and Björnsdóttir 2016). Wilson et al. (2012) relate how one student's mother introduced her to the class and as a result she was teased or ignored by other students. Other students agreed that it was not good to point the disability out to the rest of the class, as it highlighted differences, not similarities (Rillotta et al. 2020).

There were some great times when I did not feel dismissed by the students or by the tutors. This was in media. I felt so much involved in this subject because there were people I was teamed up with and we became very friendly: they did not look or seem fazed about me at all. The conversations we all had were basically getting to know each other, and to help each other with the technological areas about the camera. Here I felt I became part of the group; we were learning together.

The positive experience of being on the stage in my subject 'Drama and the Stage' with people I found easy, and a good way to get along with people I barely knew. They were able to be open enough just to have a conversation with me. As I was teamed up with practically all of them, they made it easier for me working on scenes. The comfort I felt made me feel I was on cloud nine. I felt so at ease with all of them; the environment of the stage made me stronger inside because I managed to be able to have new friends. I got along with a man who made me feel included with anything. I felt more accepted in the practical sessions like media and drama, than I did in the tutorials and lectures. In the hands-on experience, it was easier than in the lecture topics. The students included me in these classes.



#### *4.4. Teaching Methods That Support Students during Their Time at University*

The reason this topic is important is because it would be helpful if teachers found a way to understand what things make it hard for students with disability to work out what the teachers are asking them to learn. Teachers using visual aids make it easier for the students to be more involved in the topic.

Most of the time I felt welcomed by all the tutors in their classes, but I sometimes found it hard to follow what was being said. Some of the tutors spoke quite fast, and when they moved around in the class, while talking, I could not hear them, especially when they walked behind me. I also found it harder to follow the lesson if the tutors did not use a power-point presentation: this is where I got confused and could not concentrate. Sometimes they said things I really did not understand; this is because the academic language is too hard. I tended to blank out at times, not understanding the content of the subject.

Some of these points are also highlighted by some other students and teachers. For example, [Kubiak \(2017\)](#) comments that when it comes to communication for people with disability, this can be hard if they were not getting the opportunity to be involved in the class. This would make them feel as though they cannot contribute to be part of that community. To use their own voice and to be heard by other people would be essential.

Other students with intellectual disability told [Kubiak \(2017\)](#) how they can be supported in the class. It was easier for students to learn at their own pace, with non-judgmental teachers. He suggests that for some students, it was helpful if they already had the information before the class so that they were prepared for the lesson. The use of brainstorming on the blackboard in addition to color-coding mind maps was helpful. Additionally, if students kept a daily record of what happened in the class, they could recollect what they had done. Students in both the [Kubiak \(2017\)](#) and [Plotner and May \(2019\)](#) studies found the use of power-point presentations very useful, where students could see the words as well as read them. Including a printout of the power-point slides to remember the lesson was also helpful.

What helped me was having mentors, recordings of the lectures and tutorials, having information before the lecture, and power-point presentations. It helps if the tutors speak slower and stand in front of me because I need to see their faces and what they are saying. Read aloud software on the computer is extremely helpful to learn what the lesson will be about ahead of time, and for the readings. I have a recording device where I record the sessions being given, and I can then listen to them later when I get home. Sharing this information with other people at home makes it easier to understand the essays or trying to get my head around what I was supposed to do for the assignments. In these conversations at home, I can take my time to learn more about what I have to do.

It would be good if the university accepted that students with intellectual disability can manage the study with the right support and teaching modifications. For example, aids for visual learners and extra time to complete studies. It has taken me a longer time than other students to bring together all the information I need to understand the assignment. It took me nine years to complete my studies because I only did one topic a semester, sometimes two if it was a workshop.

#### **5. Conclusions**

I feel I have gained so much from being at university. Gaining this much knowledge is worth it because this is what I want to be. This experience has changed me as a person in ways that have made me more confident in myself. I think I have broken new ground, because the results that have come from the work that I have done have been very positive.

I have learnt to reach up to the point where I could possibly make a career out of some of the new thoughts and skills in my life. I believe I have gained some skills whilst being at university, and the ability to see where I am going in life. I have also learned about how there are different ways to learn about a subject I am interested in. There are so many things I have learnt, and I can talk about, and this has made me feel more part of society.



This can be so educational—for example, cultural theatre. In the future, I will always look back remembering what it was like obtaining that experience.

While there have been many wonderful parts, it has not been an easy journey. The thought of going to university is exciting, but I was not always sure where it was going to lead in the future. There are many things which are confronting when you are the only person with intellectual disability in your lecture or tutorial group. How does a person with disability cope when stepping into the class seeing people who saw them as being different? How do people with disability cope with the loneliness when other students do not talk to them? This was something I had to face every day.

Knowing you are not alone makes a big difference. I remember how it felt when I was with mentors: I had someone to talk to and become friends with. To me, it felt as though someone actually listened and guided me all the way through my university experience. Once they have a mentor with them, people with intellectual disability know they are not alone. The reason is because they feel there is a safety net, but the major reason is that people with disability have someone to turn to.

I was born with Down Syndrome, and it is part of who I am—I do not know anything different. One way I know about myself is the way other people treat me. Sometimes this makes me feel good about myself, when I am made welcome and like I am wanted in class. Other times, I have been ignored or treated badly. This makes me feel there is something wrong with me. There is nothing wrong with me. I know I can learn, I can feel, and I can see the world the way I choose to see it. People with intellectual disability have all the feelings everyone has, and we want to belong. We have a right to have an education.

What makes people with intellectual disability different is the way they are treated by other people. It would be good for students with intellectual disability to be accepted and treated with respect like other students are. People may have a different way of learning, and it would be good if this was recognised.

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