Stories from

 *Shaping our future:*

*Discussions on disability rights*

APRIL 2017

My name is Alastair McEwin and I am the Australian Disability Discrimination Commissioner.

Thank you for sharing your stories and experiences with me throughout my national consultations.

Together, your stories create a picture of everyday life for Australians with disability.

I am sharing these stories, both positive and negative, in the hope that they create a strong case for change that will ensure people with disability can enjoy their rights and participate in all aspects of society, just like anybody else.

# Employment

Ben

Ben has worked at a laundry facility since he completed school. The staff at the laundry are a mix of people with and without disability and Ben enjoys the social work environment. Ben has made many friends from work and he spends time with these friends after work and on weekends. His co-workers respect Ben for his methodical approach to each task he undertakes and his friendly nature.

Ben’s favourite day of the week is Friday because work usually finishes early and the workers go for a few beers after work at the local pub. One Friday night whilst they were at the pub, Ben and his co-workers were talking about asking for a pay rise. Ben was shocked to find out that the workers without disability were paid over three times as much as he was paid, which is $6 per hour. Ben’s wage was assessed via a productivity based wage assessment tool. This assessment found that he was not as productive as other employees and should be paid less.

Ben works hard and wants to be paid the same wage as other employees.

Mike

Mike has a number of certificates in testing and tagging electrical equipment and has worked for various test and tag companies over the past 5 years. However, every time Mike moves to a new company, he is required to undergo an assessment of his productivity to determine the wage he should be paid.

This assessment involves Mike performing a test and tag while being timed by a stopwatch. Mike feels under pressure and feels like he does not always do his best when he is being timed. Anyone would feel this way when they are being timed. Unlike everyone else, however, for Mike, the results of his work when he is timed will determine how much he is paid.

Mike feels that the focus should be on the quality of his work not how quickly he does it. Mike does not like the use of the stopwatch and thinks that the assessment he has to do is unfair.

Andrea

Andrea has a background in administration and is an experienced executive assistant. In the Philippines, she was an executive assistant (or ‘EA’) to a senior executive at a large multinational company. Andrea is deaf and used the equivalent of the national relay service to communicate when using the phone, although using the phone was just one part of her role.

Andrea has been searching for an EA job in Australia since she arrived two years ago. She has the qualifications and experience to work as an EA, however none of the DES consultants she has had believe that she can work in this kind of role because they believe that she will not be able to use the phone. They have tried to suggest other jobs to her, like cleaning.

When Andrea has approached employers directly, they have been unwilling to engage with her and talk about how she can use the National Relay Service to ensure she can still take and make phone calls. Andrea has lost hope that she will find another job as an EA. She feels it is unfair that everyone always focuses on what she cannot do instead of what she can do.

Luke

Luke loves music and has always dreamed of working in a music store. After school, Luke completed a certificate in Retail at TAFE and started looking for jobs. Luke thought it would be easy for him to find a job in this industry as he received great results at TAFE and was passionate about music. Luke applied to over 20 music stores, some many kilometres from his home. In his applications, Luke disclosed that he has an intellectual disability and that he would be happy to talk to any employer about the support he needs. Luke did not even receive an interview for majority of the positions.

Fortunately for Luke, a new music store recently opened close to his home. Luke applied and progressed to the interview stage. Luke and the interviewer had an open and honest discussion about the kind of support Luke would need. The interviewer had never employed a person with intellectual disability before but was open to listening to Luke’s needs and making sure Luke had what he needed to succeed.

Luke has now been working at the music store for six months. Luke’s employer laughs when he thinks of how worried he was about employing Luke because he thinks that Luke is the best employee he has ever had. Luke is diligent, attentive and hardworking and the customers love him. Other employees have become more tolerant, understanding and empathetic and it shows in the way they interact with customers.

Joel

Joel is in his final year of school on the mid north coast of NSW. Recognising the importance of getting his transition from school to employment right, the school and his parents have worked together to source some paid work experience for Joel in local businesses. Joel has done work experience at a local café, at the butcher shop, at the local council and at Woolworths.

Joel particularly liked working at Woolworths and now works there one full day a week, on a Wednesday. Joel has Down syndrome and is largely non-verbal, but he is able to communicate through facial expressions. Joel’s manager at Woolworths recently noted a trend where many people come to buy their groceries on a Wednesday when Joel is working. He always has a queue of 3-4 people when the other registers are empty, and people are happy to wait so they can interact with Joel and get the best customer service in town.

Joel finds it difficult to deal with cash and provide the correct change so he receiving training after work hours. In the meantime, Joel’s manager has made his checkout EFTPOS only to make it easier for Joel.

# Education

Sophie

Sophie has Down syndrome and trauma from past medical operations and experiences. She lived on an isolated rural property in NSW.

Her family always wanted her to go the local school, which was about 15 minutes’ drive away. During primary school, Sophie enjoyed an inclusive education, participating in classes with other students and receiving support from a teacher’s aide to assist her build her literacy and numeracy skills.

Sophie’s mum began researching high schools for the future. She found that many high schools established separate classes for students with vision and hearing impairment and challenging behaviours, and that there was a possibility Sophie might be transported to another school so she can attend a specialist class. The local high school informed Sophie’s mum that they were establishing specialist support classes and if, Sophie chose to go to school there, she would have to be in one of these classes.

Sophie’s parents decided to move to a regional coastal town to give Sophie better opportunities and an inclusive education. They chose a new school that they thought would offer Sophie an inclusive education. However, after a few months, the school advised they would be starting a specialist support class and Sophie would be placed in this class.

The Principal was not committed to providing the support Sophie needed to stay in the class with other students and the teacher found it difficult as she did not have any support. Sophie told her mum that the teacher would sometimes put her in the room next door to the classroom and close the curtains, and other students confirmed that this would happen when the teacher thought Sophie was being distracting or was not staying on task. Sophie received two formal cautions from the school that threatened to suspend her.

Sophie’s mum did not want her to move to the specialist support class, and is currently looking for other schools, but is finding that all of the Principals she has met have very low expectations of Sophie and her ability to succeed at school. Sophie’s family have already moved once to try to offer her better educational opportunities, but now it looks like they will have to move again until they find a school that will offer her an inclusive education.

Taylor

Taylor is nine years old and has Autism. He recently moved with his family to Hervey Bay in Queensland. Taylor’s mother was told that her son would be given use of a time out space at school, and that this would be an open space with beanbags.

One Friday, Taylor accidentally left his favourite toy at school. Taylor was very distressed when he realised this. His mother took him back to the school late on Friday afternoon to get his toy so he would be able to play with it over the weekend. All other staff had left for the day, so the school cleaner let Taylor and his mother in and took them to the classroom. The cleaner told Taylor’s mother about the time out space for Taylor and unlocked the door so she could see it. When she opened the door, she saw a small empty room, with only a thin mattress on the floor, boarded up windows and two bolts on the door in addition to the door handle that also locked.

Taylor’s mother took photos and made a complaint to school. She found out that Taylor had been locked in the room with the light off and door closed and locked around 20 times that year. When in this room, Taylor would cry, scream, and bang his head. The schools response was to provide evidence to Taylors ‘poor behaviour, blaming Taylor for the seclusion.

There was an internal investigation but the only result of this investigation was disciplinary action against the cleaner who gave Taylor’s mother access to the room. For Taylor, like many of the children who are victims of restrictive practices, the emotional and psychological effects are life changing, debilitating and ongoing.

Hannah

Hannah attends her local school. She has Down syndrome and attends regular classes with her peers, receiving extra support from the teacher and teacher’s aide when she needs it. When asked about her favourite part of school, Hannah always says the school musical that takes place every year. For 2 terms of the year, students from all grades, including Hannah, stay back at school on a Monday until 7pm to rehearse and prepare for the musical. They order pizza, hang out, and relax during the rehearsal breaks.

There are no extra teachers or parents at rehearsals. Rather, both the teachers in charge of the musical and students present just accept that Hannah might need some extra assistance learning the dance and song routines and are happy to help.

Hannah now has friends in every grade of the school because of the bonds she has been able to form at musical rehearsal. She feels like she belongs and she is happy.

Lara

Lara is a final year law student at university. For the past four years, she has found herself in a constant battle with lecturers and staff to get the adjustments she needs to complete assessments. Lara has invisible disabilities, being anxiety and a learning disability.

The nature of Lara’s learning disability means that it is difficult to understand and structure complex material. It can take Lara weeks just to analyse assessment tasks and to try to understand what the task is asking her to do and her anxiety often intensifies when she is faced with the task of completing an assessment. Lara’s university has an inflexible policy about allowing extensions to assignments. This means she often has to apply for extra special consideration and negotiate with her lecturers. Many of her lecturers simply do not believe that it is a disability that restricts Lara from completing her assessments in time. Rather, many of Lara’s lecturers believe that it is ‘perfectionism’ or some other ‘trait’ over which she has control and can ‘fix.’ They focus on the disadvantage or unfairness providing extensions on due-dates could cause to other students, rather than the positive impact extra time has on Lara’s ability to complete the assigned task.

Lara feels that the lecturers has confused allowing for reasonable adjustments with providing an unfair advantage to her because they do not understand how much support she needs to be on a level playing field with other students. On one occasion, the lecturer refused to accept Lara’s application for an extension. Further, after receiving a high distinction for a piece of assessment, her mark was downgraded to a pass because it was late.

Lara is a genuinely bright and articulate student who, with the right support and adjustments, can succeed in her chosen degree. Lara hopes that in the future other students will have access to a more inclusive education where university staff genuinely support and understand the needs of all students.

Belinda

Belinda wanted to increase her knowledge and stakeholder management skills to further her career. To do this, Belinda enrolled in an online stakeholder management diploma with a higher education provider. However, after navigating her way to the part of the online learning environment where recorded lectures were kept, Belinda found that she was unable to play the videos. This was because the controls to play, pause and stop were not compatible with her screen reader technology.

Belinda asked for the lectures to be sent to her in another format. This request was denied because it was against the higher education provider’s policy. Belinda had to withdraw from the course because she could not listen to the lectures and access the information she needed to complete the requirements of the course.

Alicia

Alicia had just started Year 12 at school and she was nervous about the end of year exams. She has a learning disability and ADHD. Alicia finds it difficult to concentrate for long periods and it is very hard for her to complete assessment tasks and exams within the required time limits.

Alicia applied to her school to support her application for final exam disability adjustments. She had supporting evidence from professionals and evidence from tasks she had undertaken both with and without adjustments to demonstrate the positive impact of adjustments to her education.

Despite this, her school refused to support the application. The Principal said that Alicia does not have a ‘real’ disability. Rather, the Principal said that she just needs to learn to concentrate more. The Principal said that allowing Alicia to have disability adjustments would let Alicia think that she is entitled to special treatment at school and that she will not get any special treatment at University, or in the future, so she should just ‘get used to it.’ The Principal also said that other parents would complain and that Alicia’s parents were encouraging her to ‘cheat’ by paying for professional reports recommending disability adjustments.

Alicia did not receive the adjustments she needed for her final exams. Alicia did not receive the marks she needed to gain entry into her preferred course at University.

# Housing

Meg

Meg is a wife, mother and grandmother in her late 40s. She has multiple sclerosis and requires 24-hour per day support. She wanted to stay in her home, close to her family and friends, but the only option available to her to receive the support that she needs was to move into an aged care facility.

Meg has lived in an aged care facility for over seven years now. She shares most her life with older people, doing activities like bingo and watching black and white movies. Meg’s cognitive ability has not deteriorated and she uses an iPad and mobile phone competently and likes to keep up to date with the latest news.

Meg she feels isolated. Many of her friends and family do not feel comfortable visiting her in an aged care facility or have just stopped visiting her. It is not an option for Meg to visit them because their homes are not accessible. The psychological impact on Meg of having to live in a place that she has not chosen to live are immense.

Tom

Tom was living in the community. However, Tom’s needs were unmet due to inadequate funding and inappropriate supports. As a result, he started to display behaviours that the service provider deemed as challenging and they withdrew from providing support.

Contrary to the appointed guardian’s requests, a decision was made to place Tom in a secure facility. This meant that Tom was contained 24 hours per day, seven days a week. Subsequent to the move, all activities that Tom had previously enjoyed ceased, as did his personal mobility and freedom.

Due to boredom and an inability to move around freely, Tom began to self-harm and lash out at staff. Additional Restrictive Practices, such as seclusion and chemical restraint, were enforced against Tom. No positive strategies were not as rigorously applied to assist Tom. Tom began to spend large amounts of time in seclusion. It was 18 months before activities that Tom enjoyed were re-introduced into his daily routine.

Tom has now been at this facility for 12 months and continues to have Restrictive Practices applied against him.

Laila

Laila has lived in various group homes over the past 15 years. She has always wanted to live independently with people she chooses but has not been able to get the support that will enable her to do so.

Laila found out about the concept of home sharing, where a person with disability shares his or her home with another person who provides negotiated informal support. Home sharers generally assist with daily living tasks like cooking, cleaning and shopping and stay home an agreed number of nights per week to provide support. This arrangement reduces the cost of paid support for these tasks and overnight support.

Laila placed an advertisement in the paper looking for someone interested in home sharing. She had many responses and met with different people until she found someone she thought would be the right fit.

Laila has successfully lived independently in a home sharing arrangement for over a year now. She is happier, more confident and she has expanded her social circle due to her relationship with her housemates and their friends and family.

# People with disability and the criminal justice system

George

George has an intellectual disability and frequently finds himself homeless because he cannot get access to the supports and services that he heeds. Due to his disability and his frustration at his situation, he often calls out and shouts in public places.

George has a history of arrests for public nuisance when the police have caught him yelling on the streets. He also has a history of resisting arrest from the times when he did not understand what was happening and tried to escape from the police.

George now has many minor charges against him and a long criminal history for behaviours that, rather than being categorised as criminal, could be recognised as being aspects of his disability.

Chris

Chris has a history of poor experiences with the criminal justice system. He has an acquired brain injury and is very vulnerable to coercion. Chris has a fascination with trains and often spends time around train stations after work. On numerous occasions, police officers at the train stations have questioned him about various crimes.

On one occasion, police questioned Chris very aggressively about a crime. Chris did not know how to respond or how to deal with the situation. He admitted to committing an offence that he did not commit just because he was scared and wanted the police to stop questioning him.

Chris was then required to go to court to defend the charge against him. Chris was found not guilty after trial. Chris has experienced a number of mental health issues since his experience with police and in the court room, and is now unable to work. He is scared of leaving his home and feels isolated, lonely and disconnected from society.

Matt

Matt lives in a group home in an outer suburb of Sydney and he has an intellectual disability. Without access to a NDIS package, a group home is the only financially viable option where Matt can live. On one occasion, Matt suddenly became acutely unwell and started vomiting. He was very distressed because he did not understand why he could not control his vomiting. Matt was waving his arms and moving around a lot. Instead of calling his parent or the ambulance, the support worker called the police.

The police came to the property immediately and called an ambulance. The police insisted on handcuffing Matt to stop him from moving. Matt did not understand what was happening and tried to resist being handcuffed.

It was 40 minutes before Matt made it to a hospital to receive medical attention. The focus was on arresting Matt, instead of ensuring that he received the medical attention that he clearly needed.

**Violence**

Melissa

Melissa lives with her husband and son in a regional area. Melissa is a wheelchair user and her husband assists her with showering, getting dressed and cooking. He often makes her wait before he assists her to get ready for the day. He also controls all of their finances and limits the things that Melissa can buy with the money that she earns.

Often, when Melissa falls from her chair, her husband leaves her and does not take her to the doctor or hospital. Even when she complains about her pain, he will not take her to the doctor. Although Melissa’s husband knows how to use sign language, which is her preferred form of communication, he rarely uses it and instead chooses to yell at her.

Melissa feels like there are not many people she can tell about the way her husband treats her. She is scared that if she tells someone, her husband will leave her and she will not have any support, she will not have anywhere to go and her son will be taken away from her.

# Implementation of the National Disability Insurance Scheme (NDIS)

Vanessa

Vanessa is an avid cheerleader and she is now in her second year of Journalism at Edith Cowan University in Western Australia. She is passionate about human rights and wants to travel the world, get a job as a journalist and continue to compete as a cheerleader.

Vanessa also happens to be deafblind. She is able to participate in her lectures at university and learn her cheerleading routines because she has the support of tactile Auslan interpreters and communication guides. She also has a Braillenote device with a keyboard attached that helps others to communicate with her.

Vanessa is able to participate in all aspects of university life because of the support of her NDIS package. She is achieving her goals and she was named Western Australia’s Young Person of the Year in 2016.

Simon and Andrew

Simon and Andrew are both blind and use assistance animals to help them move safely around the community. Simon is 64 years old and Andrew is 66 years old.

Simon is able to access the NDIS and, through his plan, the costs associated with his assistance animal, including vet bills and food, are all covered. The costs of the personal care support he receives in his home are also covered. The support he receives is not means tested.

Andrew is ineligible to access the NDIS because he is 66 years old and beyond the cut off age for edibility for the NDIS. He accesses services and support through the aged care system. He has to contribute financially to his home care package and pay for the costs associated with his guide dog, as this assistance is means tested.

Callum

Callum loves video games and his favourite place in the world is his local video game store. Callum completed a short questionnaire about accessing the NDIS and, after he was found to be eligible for the NDIS, met with a planner to talk about his goals and support needs.

Callum told the planner that he wants to be more independent. He talked about how much he loves video games and wants to work in the local video game store.

Callum’s plan includes support to help him develop his decision making and planning skills, to learn to budget and to learn to navigate public transport. It also includes support to help him build his skills and confidence in the workplace.

Callum now works full time in the video game store. His next goal is to open up his own online video game store and the supports in the NDIS plan are enabling him to build his skills and confidence to do this.