

## 1.1 Introduction

### *Children present basic facts about dyslexia*

Jacob: What is dyslexia? Dyslexia means difficulty with words.

Billie: Dyslexia is a learning difficulty that affects a child's ability to develop a strong understanding of written language.

Hayden: This is the child that seems bright and capable yet struggles with reading, writing and spelling.

Elise: Dyslexia is a brain based learning difference. It is caused by a difference in the way a brain processes information.

Teagan: Children with dyslexia have difficulties hearing sounds in words and problems with sound letter associations.

Ashlee: Dyslexia is on a continuum from mild to severe.

Ben R: Reading affects every aspect of education.

Ben R: If you can't read, it makes it very hard to learn.

Deeka Rose: Dyslexia can impact on other areas of learning.

Deeka Rose: It can affect maths, language, attention and memory.

Luke W: Dyslexia is a lifelong persistent difficulty. It cannot be cured and does not disappear with age.

Bailey: Children with dyslexia aren't recognised or supported in our schools.

Bailey: This is because of a lack of understanding and awareness of dyslexia in the community.

Breannah: Dyslexia is a disability that is recognised under the DDA. It is a disorder or malfunction that results in a person learning differently to a person without the disorder or malfunction.

Mason: We need our education system to acknowledge and understand dyslexia.

Madison: We need early identification with screening in the first year of school to red flag children at risk of reading difficulties.

Teagan: We need our teachers to provide explicit instruction in evidence based reading methods.

Ashlee: We need targeted early intervention using multisensory structured language.

Pacey: We need our schools to provide accommodations and assistive technology to help us to succeed.

Luke W: We need our universities to include evidence based reading methods and dyslexia awareness in teacher training courses.

Hayden: We generate new ideas and find different ways to solve problems.

Billie: We are creative, insightful, divergent thinkers

Bailey: We see the big picture and think outside the square.

## 1.2 The Difficulties and the Impact

### *Tanya Forbes:*

These children as early as prep and kindergarten are going into class, they are seeing all the other children learning the alphabet sounds, starting to decode these simple words and they are thinking 'Why can't I do this? What's wrong with me? Am I broken?'

To feel that, at age 5, you wouldn't wish that on anyone.

### **Student Experiences - Negative**

Eliza: All I can say is dyslexia is trouble with everything. Dyslexia is connected to every day of your life, every activity that you do.

Ashlee: Teachers say I need to do better but I can't do better, this is my best work.

Ben M: Try harder, I don't really like that at all. Because it makes me really angry and I have already been trying hard.

Madison: I work extremely hard but never get the score I really want.

Mason: When I have to do tests, it is very hard to read the questions and hard to work them out.

Erika: They didn't really understand. She would just sit at her desk and she wouldn't come over and help me. She wouldn't explain things for me.

Luke W: Making you do all this work. you have to stay in all of your lunchtime instead of going out and playing.

Kyle: I was really struggling with my work. I just wasn't keeping up with everyone.

McAyla: I found class really hard and I found that I wouldn't ask for help at all. I would day dream and keep to myself.

Luke J: I would muck around in class. I just really wouldn't do my work that much.

Luke W: I would rather get in trouble by doing no work instead of doing the work and getting it all wrong.

Dylan: I just hated reading, hated writing. My favourite things were obviously recess and sports, other than that, I switched off. I didn't listen because I couldn't. I didn't know what they were talking about. One of my teachers just wrote stuff on the board. Said 'Do this!' You never know what it means.

Breannah: I know I have to write essays and everything but just to be able to do prac and do something I am good at without putting myself down, trying my hardest but still not getting there because I can't write. I can't put words into sentences and it is just so hard.

Eliza: When you are little, I didn't want to say that I'm dyslexic. You always see the person in the class who is struggling and gets special help and the teacher is always hovering. You don't want to be identified as that person because kids are going to think you are stupid and dumb. That is how I always felt so I tried to hide from that. When the teachers called me out to the front, I didn't want to go out the front. It was horrible, so the way for me was to hide... and it worked.

Luke J: I was very angry with myself a lot. I always used to say, even now I say sometimes that I am just no good. I didn't want to do anything because I am just no good at it.

Breannah: Primary school was the worst of my schooling. I had so much difficulty and no one could pick it up. It is really hard being a student and going to school each day, being terrified to walk through the gate of school, knowing that you just won't get any help.

Dylan: I hated it when people have said, 'You're dumb.' It just made me feel like I was nothing. It made me feel like I was worthless... pointless being at school. I didn't get anything done, that made my confidence drop... dramatically... straight down.

### **Parent Experiences**

#### ***Jo:***

The disadvantage of having dyslexia is, not knowing you have it. The advantage of dyslexia is, knowing you have it.

So as soon as you know about dyslexia, the doors open up for you. It takes away the pressure.

When you don't know what is wrong, you think you are silly.

#### ***Judy:***

Why did it take 5 years? Why did it take 5 years before we got a diagnosis? Why do schools ignore the early warning signs?

I don't know why schools even tend not to like to even use the D-word, dyslexia.

#### ***Karen L:***

When we got her formally assessed, her teacher was shocked she had dyslexia.

She actually said to me, 'I have never taught a dyslexic child before.'

I thought to myself, 'You have, you just didn't know it.'

There is so many out there that have dyslexia and I feel lucky that we do know about Ashlee's dyslexia because we are able to help her. We are able to teach the teachers how to help her.

***Karen R:***

The result came back that he had moderate dyslexia. That was a relief. At least we knew what he had. We could then embark on this journey to find out what we could do to help him.

But then we have the struggle where the teachers are not really well informed about dyslexia and don't know how to deal with it either.

There is this reluctance... to talk about it... reluctance to give him the help that he needs...

***Pam:***

It is very frustrating when you know what is happening and you know what can be done but on the other end, they don't believe you or they don't know what to do. It's an uphill battle.

***Kym:***

Nothing....I am sick of being a nag now. I am sick of constant emailing. I am sick of having to every year when she goes into a new class with a new teacher having to go through the whole rigmarole again. It is very frustrating and upsetting.

I am starting to think after 3 years in a row, 'Why bother, they are not going to do anything for her.'

***Veronica:***

Dyslexia is not a lack of intelligence... it is a lack of access.

Mason is articulate, curious and clever but his struggles with reading and writing impact every area of his learning.

Mason requires understanding, accommodations and access to assistive technology. He needs extra time when reading and writing. I would love for his school to recognise his learning difficulty and provide him with understanding and assistance he needs to realise his full potential.

***Tracey:***

I see so many other families in our school that come to me and ask me 'How do I get that help that you had for your son?'

The answer is that you have to get it privately at this point of time in our education system.

There are some wonderful teachers that go out of their way to help our children because they understand learning difficulties and dyslexia but they are the rare gems and I think the system has to change.

All of our teaching professionals need to be educated and understand what these learning difficulties are.

The small changes... they can make in a classroom make such a difference for our kids.

***Erica:***

It is okay for teachers to take some time to learn about it themselves.

To try and feel what it would be like in a classroom where you are constantly being told, 'Gee you are naughty... I wish you would concentrate more.' They are constantly being told that all of the time. Feeling low about your self esteem already and then you are getting told you are no good.

***Belinda:***

To have problems for so long, the anxiety kicks in and they can't think. It affects their short term memory and processing speed, which are two areas with problems for dyslexics anyway.

They get to a point, why should I try? It is better to muck up and be naughty and pretend I am lazy because people think I am that anyway. Why bother. Why bother putting the effort in if I don't get anything at the end.

***Renea:***

To have self esteem and to have self worth and... now you've made me cry... just to have a voice. For him to be able to go to school and just love it.

To learn, to be successful and just to know that he's okay.

He's perfect. There is nothing wrong with him, it is just other people don't understand him.

***Judy:***

It is so wrong. It can impact on the child so much on their early years... Impact on their self-esteem... Impact on their learning... It shouldn't have to be like this. It doesn't have to be like this.

Liz: Difficulties families experiences with dyslexia.

Our children are hurting and we are hurting too. It becomes a really big issue in families too. We say 'What is going on? Why isn't my child learning?'

The teachers are confused because they are not trained in dyslexia.

Yet we all know that dyslexia is a real neuro-biological difficulty where brain cells don't talk to each other as well as they should be, perhaps they are not as effective or efficient.

It does not mean that our kids are not smart, that's the thing about dyslexia. These kids can be really smart but when it comes to formal learning, that is when it is really difficult.

Nola: Emotional aspects

They go to school feeling confident, as most children do. Then in the first couple of years, they run into this reading situation. They assume in the beginning it will be sorted out.

Their parents and teachers say, 'Maybe you are just a bit slower, it will click into place'. This continues.

If it is not diagnosed, the child fails again and again and nobody explains to them.

Their feeling becomes one of shame, and many people hid it.

They feel marginalised. They are marginalised because they can't participate.

Carol: School refusal as a result of unsupported LDs

Year after year of doing that is very frustrating. Often these children by about Year 9 are saying to their parents. 'I have had enough of this. I don't want to go any more.'

You can strap a little child into a car seat and make them go to school. It is harder to do that with a 14 year old child.

School refusal on the grounds of untreated and unaccommodated disability sadly is a lot more common than we like to think.

Sandra:

We are just saying, 'Oh look, they are failing, they're still failing, they've failed.' and we are not intervening anywhere.

The ramifications for that are the mental health issues, the anxiety, the depression, the disengagement, the social exclusion, the difficulty getting a job, the high rate of incarceration, poor literacy, can't access health care, can't read medication labels, can't vote, can't apply for a job;

Nola:               The impact - social-economic

Once they hit the teenage years, they are at risk of depression, unemployment, underemployment. There are no ifs or buts about it. We know that is the case, it has been measured again and again. The number of people in prison with dyslexia is above the norm by far. There is a problem with individual suffering but there is also a national social problem and also a national economic problem.

It is completely unrelated to intelligence. So what we are doing is wasting talent and causing suffering.

Sandra:

It is a human rights issue. To leave kids... to know that at least 10% of kids are going to fail automatically at school and not do anything about it is nothing short of criminal.



### 1.3 The Problems

#### Misconceptions around students with dyslexia

Sarah A: Misconception - Low IQ

One of the major misconceptions is that children with dyslexia are of low intelligence when often they can have great strengths and be gifted in certain areas.

Suze: Misconceptions

As a speech pathologist, it frustrates me that people equate having difficulties with speech, communication and language, and with learning difficulties as not being intelligent. The same applies to children with reading difficulties. The number of times I have heard people say to me, 'The parents obviously didn't read to them enough at home, or he is just lazy, he should just try harder, he clearly does not have any aptitude for this.' They extrapolate that to everything. Very frustrating!

Sarah A: Misconception- Lazy

Another misconception is they can be labelled as lazy when often dyslexic children often have to work twice as hard as any other child in your class.

Bartek: Underestimated

This is a population of people whose potential is very regularly underestimated. The reason why I think they are extremely capable is because I have been doing this a long time and I have seen some remarkable things happen in the practice.

*B Roll: Nerang SHS girl working hard*

Sarah A: Misconception - Identification

Another misconceptions is it cannot be identify until 7 or 8 or approaching Grade 3 when we can identify their weaknesses and their strengths much earlier than that.

Suze:

People will say to me, 'Oh dyslexia, isn't that when people read things back the front and have trouble with their eyes?' That was from the 1920's and people still think that is what dyslexia is.

Dyslexia was first described by an ophthalmologist by an eye doctor in the early 1900's, and that view has still stuck. To me, that just shows how much ignorance there is about this condition or misinformation there is out there.

Bartek: Visual problems

There really are a few really common misconceptions around dyslexia.

Probably the most common one is that because written language is a visual thing, people assume that reading difficulties must be a visual problem. There is a huge body of research to suggest the problem is to do with a subtle language processing difficulty - phonemic awareness and phonological processing difficulties, the sound structure in language.

When people think about dyslexia, they think about letter reversal and word reversals, they think about tinted lenses and those types of issues. We know for the vast majority of kids, the issue is not to do with visual processing.

Nola: The problem - denial of existence

One of the things I have learnt along the way, even though there has been knowledge of dyslexia out there for a long, long time. It has taken a great deal of time for it to come through into classrooms.

First of all that the phenomenon actually exists, and that is the case here in Australia because we had a senate inquiry in 1972 and the conclusion was the phenomenon didn't exist, it was poor teaching.

Mandy: The National Dyslexia Working Party

The NDWP report came about because of a high level of lobbying, particularly from parents across Australia at a federal government level.

Nola: The Problem - Teacher training

Over the years I have seen so many teachers that were crying out for help about the situation. They knew they had someone in their class but they couldn't quite pin it down. Because there is about 3 people in every class, most teachers would have had that experience.

Mandy:           The National Dyslexia Working Party

The National Dyslexia Working Party report was a package to ensure that students with dyslexia, no matter what school they attended would receive some level of support to ensure they could participate as well as possible.

Nola:            The problem

For many years, I and other people have been trying to call out and say, look this situation is here and there are things that can be done about it. I have learnt along the way, you have got to be able to get knowledge from the universities to the schools and to government, and that is not necessarily an easy task.

Mandy:           The National Dyslexia Working Party Report

The party report was completed and the recommendations were put to the federal government. They were in turn reviewed by departments but as with what happens with many of these very good reports, they tend to end up gathering dust on a shelf somewhere. The reality is, not a lot has come out of it.

#### 1.4 Understanding dyslexia

Liz: Dyslexia is real.

It is something that impacts on 2 or 3 children in every single classroom and that is every single classroom all around Australia. What you have got is kids that are struggling for very legitimate reasons.

They are trying their hardest but they just can't grasp the reading, the writing and the decoding.

Mandy: Description

The reality is there are a lot of children struggling with literacy in Australia. We know that every bit of data indicates that there are many, many children who are struggling to acquire strong literacy skills in reading, spelling and in writing. We are seeing it every day.

The children who continue to struggle despite really good intervention are the ones we would identify as being children with learning disorders. When we talk about reading disorders, we are talking about those students with dyslexia. Dyslexia is a difficulty with words so when we are talking about reading disorders at the word level, then we are talking about students with dyslexia.

Anne: Dyslexia on a continuum

There has been a debate in the field about whether or not we should use the term dyslexia because it medicalises the condition. It makes it sound like some kind of separate syndrome. It is true that dyslexia is not some separate condition.

We are talking about a continuum of reading and they are simply the children who are struggling the most with acquiring that ability. So in that sense, it is not a syndrome but it certainly exists. Those are the children that fall at the bottom of the distribution that we need to identify because they are going to need more intensive effort in order to be able to learn to read well.

There are very many conditions that are a continuum but we still give them a label. Hypertension is high blood pressure. You choose the point on the blood pressure scale where you decide someone has hypertension or not. That does not say whether hypertension exists or not. It just means that we understand that we are talking about a continuum. Identifying those people and understanding how they learn to read will have direct implications for everybody else on that continuum as well.

### Identifying Dyslexia - Key indicators to identify students with dyslexia in the classroom

Angela: Identifying

There are always these children that you think should be getting it. They're bright. They can answer questions in class. They seem really engaged.

And yet when they actually sit down to do their reading and writing they seem to have trouble.

They are very good at distracting you, so when they're supposed to be doing one particular job, you will find they will be doing something else - tidying up or looking for books or something like that. I call them the masters of distraction. They are always trying to find something to take your attention away from what they can't do.

That is when you go, why?

They seem like they know what they are doing. They seem like they seem to understand this story. They seem to have an insight into the story when you ask them questions.

They seem to have this deep understanding but when they sit down to have a go at reading or writing themselves, the connections are just not there.

Anne: Identification of children at risk

Very early on, in pre-school and the first year of school, the red flags you would be looking for would be a child struggling with phonological awareness tasks, who would be struggling with learning their letters, who might be struggling with basic verbal memory or short term memory tasks. Those are the things you might see as being the risk factors.

Moving down the track, it is really important to assess all the key components of reading.

Firstly, the sounding out capacity using a nonsense word reading task. You need to check the child is not learning the words off by heart but the actually know how to do that sounding out process. An early sign might be a child who has difficulty if you give them a list of nonsense words to read. They can't sound them out, they can't say /g/ /o/ /p/ is 'gop'.

The other thing you would want to do is test their word recognition skills. After that sounding out process, children need to move to a more fluent recognition process. Some children struggle with that stage. They are okay learning to sound out but they struggle developing that fluent recognition system. We test that by giving them words they will get wrong in they sound them out. We might give them 'yacht' and they say /y/ /a/ /cht/. Then you go okay, what is going on here. That would be fine if it is a child in kindergarten says that, but if it is a child in year 5 you would think perhaps they need some work on building word recognition skills.

The two things you would look for are sounding out and basic sight word recognition.

Sarah A: Indicators of Dyslexia

The indicators to look for.

Even before they start school you make notice they a difficulty with picking up rhymes or nursery rhymes or pronouncing long words.

They may struggle with sequencing of ideas in stories which then impacts in school for writing stories.

Jodi: Identify and act

Prep, Kinder and 1.

You are looking for the children who struggle to acquire the skills and go onto read. Having trouble learning the sounds of the letter. Having trouble stringing those across to form words.

I don't think teachers need a degree in identification to see and hear the children that are struggling in their classrooms.

We want them to feel empowered that if they can see and hear that a child is struggling that they have got the skills to get in and take them to the next step.

Teach them the alphabetical principle. Teach them how those letters work.

Don't just assume that a sight words list send a pm reader going home is going to help every single child in their class. Even those children that may make that magical shift from reading , we know benefit from understanding a symbol sound relationship.

Bill: Indicators of dyslexia

So you have got this bright young person who is usually pretty articulate, they can grasp concepts.

If you ask them to explain to you what they have learned in words, there is no problem at all.

But here is a gap widening between what they can tell you they have learned and what they can show you when you ask them to put in print.

Then you see the obvious delay in the acquisition of reading.

Sarah A: Indicators of Dyslexia – take 2

They might find it difficult following a sequence of instructions.

The biggest indicator will be for reading and writing and the retention of alphabet names and sounds. They will struggle when they start school with picking up and remembering all of the letters and the letter sounds which then in turn they may be struggling with their reading or their writing.

You might notice gaps in their written work and you might notice that their handwriting will be an issue.

You might notice with mathematics, there might be some issue with regard to remembering facts or times tables or concepts such as time.

Bill: Indicators of dyslexia

You notice these bright bubbly kids hit school ready and rearing to learn to read and very quickly, you see this weight descend on them as they watch other kids in their class rip through reading boxes, move their way through the spelling groups and it just destroys these kids.

Liz: Indicators

You will get a child who will start misbehaving.

You will get a child who will start acting out.

You will get a child who will withdraw.

They will be asking to go to the toilet of all times of the day and night and you know they don't need to go. It is those indicators we need to look for.

This is the child that is not quite grasping things in class. When they are looking at the pages in their readers and their books and they are not decoding easily.

It's just really difficult for them.

### 1.5 Associated processing deficits

Bartek: Weaknesses - phonemic awareness

There is a very important relationship between phonemic awareness skills and decoding ability in particular.

Phonemic awareness, this capacity to understand and manipulate the speech sounds in language seems to be very closely related to the cracking of the code of the language.

Kids who have a very well established concept of speech sounds in the language seem to have a very significant advantage in cracking that code.

Kids with dyslexia have a difficulty with establishing that phonemic awareness skill set.

Bartek: Phonological Memory and Rapid Automatic Naming

These guys also have trouble with phonological memory. So they have trouble remembering what has just been said, not all of them do but some of them do.

There is another skill set under that umbrella of phonological processing, understanding and processing speech sounds of language, called rapid automatic naming. This means being able to look at a set of very simple visual stimuli, like numbers or letters or simple objects like bat, kite that kind of thing, and kids with dyslexia are slower at naming those compared to those without.

Anne: Orthographic processing

Orthographic processing is looking at strings of letters, not just individual letters and sounds. Like recognising that 'yacht' is a word by recognising that string of printed letters and being familiar with it. Orthographic skills are not related to the sounds, but it is more the recognition of those printed letters on the page.

Mandy: Orthographic processing difficulties

Some children struggle with that processing. They seem to not build up the whole store of mental graphemic representations, the knowledge that there are certain patterns of writing in English. These children have orthographic processing difficulties.



Bill: Difficulties - word retrieval

Some kids will have significant word finding difficulties. They don't have quick recall of the word to get the meaning.

You probably see it interviewing some of the kids, they will do this thing called circumlocution. They will use words like 'stuff' and 'this' because they know what they are trying to say. The word is in their vocabulary, it is in the lexicon but they just can't pull the drawer on the filing cabinet to get it out quickly.

Not all kids with dyslexia are verbally fluent and amazing speakers because the word finding difficulty may be there as well.

Angela: Identification - Memory

Memory does come into play.

You find these children have trouble recalling or learning their sight words...

They don't have that retention.

We are also working on that rote memory, like days of the week. They have difficulty remembering and recalling that sequence.

Recalling times tables would become a very difficult thing because it is a rote learning thing.

Getting it into the long term memory seems to be the difficult part.

Liz: Coexisting difficulties - slow processing speed

The thing that marries all of these things together, all of those strengths and weaknesses that a child with dyslexia may or may not have is slow processing speed.

This is the number one accommodation that children with dyslexia will need for their tests and exams is extra time to allow for slower processing speeds. This is nothing to do with intelligence.

A child can be just as intelligent as any other child but they may be slower to decode the letters on the page, they may be slower with their working memory, they may be slower to understand a concept and apply it.

Julie: Anxiety

There is a limited amount of time and sometimes that pressure can build their anxiety. They have had years and years of failure. Struggling at school. They can develop anxiety around that as well.

So before you even walk into a classroom, you know you are going to have to do a reading task. The anxiety is there which then slows down the processing speed even more and interferes.

It snowballs and just makes it harder and harder for them.

When the anxiety builds, it actually interferes with your rapid automatic naming and you can't sequence. Once your anxiety builds, your working memory and your functions shut down. They are less effective and it is a vicious cycle.

## 1.6 Moving Forward

Nola: The future is bright.

What's really rewarding is to see the changes that are happening now, and they are.

At last there is recognition at high government level that this is a phenomenon that really needs to be addressed.

There is at last informed courses for teachers.

The word dyslexia is now used in the community.

There are now many parent groups out there saying 'Yes. We need change'.

It is now on the political agenda at last!

Breannah:

I hope that this message that I am trying to bring out will help students like me in primary school and high school, so they can see, that there is still hope.

No matter whatever it is, just keep on trying because that is what we're dyslexic but just keep on doing it.

Dylan:

I feel like I can actually do it. I feel like I can be as good as anyone else. I can do whatever they try and do.

Eliza:

I want to be able to fight for something. I fight for something I believe in. I have this passion for dyslexia, because I have it.

That's what most people do, they fight for what they have or they fight because a family member has it... and they will fight for it.

I am not one of those people that will stand there and watch kids suffer, because I know how it feels.

I know what they are going through. I may not know exactly what they are going through but I have got the same idea around it.

I don't want to watch people sitting there and hiding because there is no need to hide when there are so many opportunities out there to get help.

I just want to help. I don't know how to help but I am just trying to do the best I can. This is the way I know I can in a way.

Nola: Future - Change is beginning

There is change but it has to go a lot further so a lot of those NDWP recommendations are fulfilled.

But the change is beginning.

We have just got to keep all at it for a bit longer.

### Strengths associated with dyslexia

Liz: Support - define the child differently

What can we do early to stop that happening?

What I would like to see and what we can all do is to help to a child to define themselves differently.

It is amazing how quickly, the child who struggles with reading becomes a champion in the school yard because they are the fastest runner, they are the best player on the soccer team or perhaps they are a gun at chess or maybe they are an incredible singer.

It all comes down to the definition of the child - how that child is defined and how they are perceived by others. Take the emphasis of the difficulty and put it on the strength and that is the thing that teachers need to do. Take that child out of the spotlight for their struggle and put them into the spotlight for their success.

Angela: Strengths

It is the creativity that I am in awe of. Children with dyslexia just think differently. They have these amazing creative minds. they are artistic, or they are scientific, or their maths.

Jodi: Strengths

The child with a clean profile of dyslexia has every ability to rely and succeed. Not only on their capable verbal skills but also their non verbal abilities to read faces, remember places, their visual spatial skills and again they are very good in business because these students are very charismatic.

I have taught many early on before I've earned their trust who could talk me out of nearly everything. So I will say they are charismatic.

So the misconception is they have trouble with reading, they are going to have trouble with everything, it is really a myth that needs to be exploded.

Liz: Strengths - mental

Mental strengths come from having to work so incredibly hard to get through school. What that does, with the support from parents and teachers, people become incredibly resilient. So everyone else have given up, these kids, these adults, these teens are still there working hard.

They are the ones that have the ability to see the big picture... to think outside the square.

Outside the square thinking is critical, they are the mental strengths having dyslexia can bring and are so very critical to moving forward as a human race.