

Supporting secondary school students with Fetal Alcohol Spectrum Disorder: Learning with FASD

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SPEAKERS

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Elly Fitzgeraldson 00:00

Okay, good afternoon, and welcome to the Positive Choices webinar series. My name is Elly Fitzgeraldson and I work at the Matilda Centre for Research in Mental Health and Substance Use at the University of Sydney on Positive Choices. Welcome and thank you to our audience for joining us today.

Elly Fitzgeraldson 00:25

We are all coming together on different parts of the country today. So I'd like to begin by acknowledging the traditional custodians of Country throughout Australia and their connection to land, water and community. I'm currently on the land of the Awabakal people in Newcastle, and I pay my respects to Elders past and present. I further acknowledge the traditional owners of the land on which you are on, and pay my respects to their Elders past and present. I would also like to acknowledge any Aboriginal and Torres Strait Islander people joining us today.

Elly Fitzgeraldson 01:01

Before we get into today's presentation, I'll go through a few housekeeping points. So as participants, you are currently on listen only mode, which means that we are not able to hear or see you. We are recording this session, and it will be made available through the Positive Choices website, along with the slide handouts, and we'll have a Q and A session at the end of the webinar. So as the session progresses, please feel free to add your questions to the Q and A box you should be able to see on your screen, just noting this is separate to the chat feature.

Elly Fitzgeraldson 01:35

Yeah. So any questions, just put them in here. So if you're new to Positive Choices, let me do a quick introduction. Positive Choices is a website that provides access to trustworthy, up to date, evidence based alcohol and other drug information and educational resources suitable for parents, school staff and students. This website is funded by the Australian Government Department of Health, Disability and Ageing, and was developed by the Matilda Centre in consultation with teachers, parents and students. Some examples of resources housed on Positive Choices include learning resources, fact sheets, videos, webinars and games, also on the website, we have classroom based prevention

programs that are proven to reduce drug related harms. So I encourage you to visit our website and have a look at some of these resources. You can use the QR code here. But now on to today's webinar, which will cover supporting secondary students with fetal alcohol spectrum disorder and learning with FASD. We're very excited to have Associate Professor Louise Mewton, Julia Riches and Georgette Borel presenting for us today. Dr Louise Mewton is an associate professor and public health researcher with a focus on the epidemiology assessment prevention and treatment of alcohol use and related disorders across the lifespan. She is program lead in lifespan and brain health research at the Matilda Centre and the project manager of Learning with FASD. Julia Riches is a research officer at the Matilda Centre and the Project Coordinator of Learning with FASD and Georgette Borel is a research assistant at the Matilda Centre working on Learning with FASD. Thank you to Louise, Julia and Georgette, over to you.

Louise Mewton 03:43

Thank you so much for that introduction, Elly. Alright, so now you can see our slides. So thank you for having us here to present today on Learning with FASD. So this is an online portal which houses new evidence based resources for secondary school educators, for supporting students with FASD in their classrooms. So in terms of the overview of our talk today, first, I'm going to be talking about what is fetal alcohol spectrum disorder or FASD, then we're going to have Julia Riches talking about the development of new resources for secondary school teaching and support staff. And finally, we are going to have Georgette Borel talking about specific strategies for teaching and support staff. Okay, so what is fetal alcohol spectrum disorder? So to start today, what we actually thought we would do is an interactive activity. And what we want to see here is what you know about fetal alcohol spectrum disorder. So we're going to do this through a program called menti. And here, we're going to ask you to join either through the QR code that you can see on your screen there, so you can scan that with your phone, or you can enter that address there, www.menti.com, and enter that code. So you can do that through your browser, and then you will be joining our quiz. So I'll give everyone a minute to join, and don't worry, it's going to be anonymous. No one's going to know what your responses are, but it will be wonderful if we had lots of people participating in this quiz.

Louise Mewton 05:43

Alright, so hopefully most people have joined. Okay, so our first question is true or false? You can tell when someone has FASD by looking at their facial features. So getting lots of responses through there, and most people saying false.

Louise Mewton 06:18

Okay, what's the correct answer? The correct answer is false. So while about 17% of people with FASD do have those three sentinel facial features, most people with FASD do not have those facial features. All right, next question, true or false. In Australia, it is estimated that FASD is more prevalent than Autism Spectrum Disorder, Down syndrome, spina bifida, cerebral palsy, or all of the above. Still getting some responses through, thank you.

Louise Mewton 07:14

All right, if you did say all of the above, you are correct. So FASD is highly prevalent. It's estimated that about two to 5% of Australian children are affected by FASD.

Louise Mewton 07:31

Okay, there are nine neurodevelopmental domains that may be impacted by FASD. How many domains need to be impacted for an actual diagnosis of FASD, we're getting a bit of a range here.

Louise Mewton 07:50

Louise Mewton 07:50

All right, the correct response here is three, so clinical impairment in at least three neurodevelopmental domains, and we're going to go into some of those domains a little bit later.

Louise Mewton 08:19

All right, next one here, we want to see how much you agree with these statements. So the first statement is that FASD is easy to distinguish from other neurodevelopmental disorders like autism or ADHD. So how much do you agree with that response, with that statement? The second is that it is very important that children with FASD receive support from an early age. And the third is that some children with FASD will grow out of it so

Louise Mewton 08:56

Still getting some responses there. Wonderful. Thank you so much for joining in everyone. So FASD is not easy to distinguish from other neurodevelopmental disorders, and it's actually highly comorbid with other disorders as well, which means that people with FASD tend to also present with things like autism or ADHD, which makes it very tricky to distinguish between the disorders. Yes, most of you said it is important that children with FASD receive support from an early age, and that is correct, particularly within the school system, as you'll hear about today, and some children with FASD will grow out of it. No. FASD is a lifelong brain based disorder, and children with FASD do not grow out of it.

Louise Mewton 10:04

And our final question, true or false? FASD is the only diagnostic terminology that should be used to describe an individual who is prenatally exposed to alcohol.

Louise Mewton 10:30

Oh, okay, so people a bit unsure about this one.

Louise Mewton 10:32

It is, in fact, true. So FASD is the only diagnostic terminology that should be used to describe an individual prenatally exposed to alcohol so FASD replaces other terms that have been used previously, so things like fetal alcohol syndrome. So there's no longer an explicit diagnosis for fetal alcohol syndrome, it's now fetal alcohol spectrum disorder. Wonderful. Thank you so much for joining along with that. So now I'm going to give you a little information about FASD in the community. So I first wanted to touch on the prevalence of drinking during pregnancy. So this figure comes from a recent systematic review, which pulled together data from multiple sources to estimate the prevalence of alcohol use during pregnancy internationally. So what they found is that 10% of women globally drink

alcohol when pregnant. But in that figure there you can see considerable cross national differences. So while the highest rates of alcohol use in pregnancy were from countries like Russia, the UK, and Denmark, Australia still has comparatively high rates. So about 36% of women in Australia drink alcohol when pregnant. So it is important to note here that women who do consume alcohol during pregnancy do not do so to harm their unborn child. A lot of alcohol use actually occurs in that first trimester of pregnancy. So before awareness of pregnancy.

Louise Newton 12:06

There is also a lot of mixed messaging around out there about the impacts of prenatal alcohol exposure on the developing fetus, particularly low levels of prenatal alcohol exposure, and this is information that women might find difficult to navigate. And then, because of the high rates of alcohol use in Australia, just more broadly, there is this proportion of women who are alcohol dependent, so they are physically dependent on alcohol, which makes it really difficult to cease alcohol use, even in the context of pregnancy. Okay, so we also know that most women who do drink alcohol during pregnancy do so at low levels. So while there's no safe level of alcohol use during pregnancy that has been identified, we do know that binge drinking and heavier drinking are associated with greater risks of harm. So one severe and lifelong neurodevelopmental disorder associated with prenatal alcohol exposure is FASD, fetal alcohol spectrum disorder. So FASD is an umbrella term. It's a diagnostic term which replaces a range of previously used terms, including fetal alcohol syndrome, as we saw previously, that's no longer in use. We do have very new guidelines for the diagnosis of FASD in Australia, and these were just published in April 2025, and we have those guidelines up there. And the first criterion is that there needs to be evidence of prenatal alcohol exposure. So this can be through direct evidence that there was prenatal alcohol exposure. So confirmation from the birth mother or another source, or it can be through the presence of these three sentinel facial features. So I've got those up there on the screen there. So it says small eye openings. It's a smooth, smooth philtrum, so that area between the lip and the nose, and it's a thin upper lip. But as we saw, only a minority of children have these three facial features. So we often do need that direct evidence of exposure for a diagnosis. So the second criterion there is the presence of pervasive and clinically significant neurodevelopmental impairments in three or more domains. And this will come from direct evidence, so a neuropsychological assessment, for example, and this can also come from reports, from informants in different settings. So certainly, in the educational setting, these neurodevelopmental impairments do result in functional impacts that require significant support, including supports in the education system, the onset of impairments is during the developmental period, so onset during adulthood does not happen, and also the presentation is not better explained by other factors. So this is around differential diagnosis and making sure that the clinical presentation doesn't fit better with another diagnosis. There are also some specifiers there. So that's whether it may be FASD with any of those sentinel facial features, with restriction in size of the head circumference, so something that's called microcephaly, or physical size restriction.

Louise Newton 15:16

So I want to note here that diagnosis of FASD is complex and lengthy. It involves a multi disciplinary team, and there are really very few specialist clinics in Australia that can do this assessment and diagnosis. Those specialist clinics that do exist tend to have really long waiting lists. So because of this complex process, it is recommended that supports are implemented as soon as FASD is suspected, even if that sort of formal diagnosis has not yet been made. Next slide please.

Louise Newton 15:50

Okay, so what we have here are the neurodevelopmental domains that can be impacted by FASD. So we saw that a diagnosis of FASD requires at least, clinical impairment in at least three of these domains. And I want, and I've got them all listed up on the slide there, just so you know that some of these may be very relevant for the school environment. So for a diagnosis, an individual must have clinically significant impairment in three or more of those listed up there, but two different individuals who have been diagnosed with FASD may have impairments in three completely different domains. So one student might experience impairments with attention, memory and communication, whereas another might have challenges with executive function, motor skills and adaptive or social functioning. So you could have two children here with the same diagnosis, but with very different clinical presentations and very different needs in the school context. Next slide, please.

Louise Newton 16:52

Okay, so in terms of FASD, the prevalence of FASD in the community, these are data coming from this systematic review and meta analysis. So it is estimated that one in 13 prenatally exposed infants will have FASD. So most children who are exposed to alcohol prenatally do not go on to develop FASD. From this review, they found that the prevalence in Australia is 6.7 per 1000 live births, and that's pretty similar to the global average, which is 7.7 per 1000 live births. It is important, however, to note that these data contributing to this review were not population based. Data in this area are quite messy. They often rely on things like ad hoc reporting or incomplete data collections, and really we're likely to see underestimation of the true prevalence here. Recent studies have used things like active case ascertainment in the US, and so active cases ascertainment is when researchers actually go into a community and assess all children in that community for FASD. So this was conducted recently in the US, one of these studies, and it suggested that the prevalence rates were about 1.1 to 5% of six to seven year olds, so much higher rates there. Similar findings in Canada using active case ascertainment, with the prevalence of FASD being two to 3% and modeling exercises conducted in Australia also suggest a similar sort of prevalence. So we are potentially dealing with a really prevalent source of neurodevelopmental impairment here. So in Australia, this translates to 6000 babies born each year with FASD. So this is higher than many other neurodevelopmental conditions, as we saw earlier. What this does mean is that most teachers are likely to be interacting with a student with FASD in their classrooms on a day to day basis. So that's whether the student sort of has that formal diagnosis of FASD, or the student may have undiagnosed FASD, and that really goes back to that complexity around assessment and diagnosis, or you may have students with FASD who have possibly been diagnosed or misdiagnosed with another neurodevelopmental disorder. So that's really common as well. Next slide please.

Louise Newton 19:12

Okay, so this the profile of individuals diagnosed with FASD. So these are data from the FASD Australian registry. So this registry aims to collect detailed information about children under 15 years old in Australia living with FASD. So since the registry started in 2015 they have collected data on over 1000 cases, and what they found is that the median age of diagnosis is 8.8 years. 17% had those three facial features, as we saw below. So most children with FASD do not have those sentinel facial features. 18% had microcephaly. So that's the restriction in size and the head circumference. In terms

of the neurodevelopmental profile, the most common neurodevelopmental deficits were in attention and executive function and FASD is also really highly comorbid with other conditions, the highest comorbidities being with ADHD and communication disorders. But a number of other disorders are implicated there as well. Next slide, please.

Louise Newton 20:22

Okay, so we saw earlier that FASD is a lifelong brain based disorder, and children will not grow out of it. So FASD certainly has impacts during the critical adolescent period. So we know that adolescence is this period of intense brain development, and this is often the period when we do start to see some issues associated with FASD first start to emerge. So this brings us to our very first resource from the Learning with FASD website. And what this is is a brief explainer video to give you some information about FASD in adolescence. So we're going to play that for you now.

Voice over 21:02

Fetal alcohol spectrum disorder, or FASD, is a lifelong disability caused by prenatal exposure to alcohol which damages the brain and body of the unborn child. FASD is so prevalent that many educators may not realise they are interacting daily with students who have undiagnosed or misdiagnosed FASD. Those with FASD often experience ongoing challenges throughout life in multiple areas of functioning, including learning, memory, behavior and academic achievement. Adolescence is a particularly vulnerable time for individuals with FASD as societal expectations for independence, educational attainment and employment increase. Young people with FASD often experience challenges, including dysmaturity that make it difficult to meet age based expectations. Dysmaturity refers to varying levels of maturity in different areas of development that do not align with an adolescent's chronological age. It often leads to unrealistic expectations from educators. Adolescence is also a critical time for brain development for all young people, the adolescent brain undergoes significant transformations in brain structure and function, leading to unique adolescent behaviors such as increased risk taking behavior. These transformations are often experienced at the same time as other key changes in adolescence, such as physical maturation and changing hormone levels. All these biological changes also interact with cultural, economic and social factors to significantly impact how adolescents think, feel and behave. Because FASD is a brain based disorder, and adolescence is an intense period of brain development, the stresses of adolescence can have a significant impact for young people with FASD and other neurodevelopmental disabilities, common experiences that may be difficult to navigate for all young people, such as transitions into secondary education or the workforce, the emergence of mental health problems, changing peer relationships or the use of alcohol and other drugs, will be even more challenging for adolescents living with FASD. Although many young people with FASD often experience significant difficulties, they also have unique strengths and resiliencies that can be leveraged to support engagement via a strengths based approach in the school environment and as they transition into young adulthood, early recognition and appropriate intervention are key factors that can improve outcomes for adolescents with FASD or suspected FASD as the pathway to diagnosis can be lengthy. It is advised to implement support strategies as soon as FASD is suspected, effective and appropriate supports are crucial for reducing the risk of secondary challenges, such as a disrupted school experience, contact with the justice system, harmful substance use and mental health concerns. This is why understanding and supporting adolescents with FASD, or suspected FASD in the school setting, is so important. That's where we come in. Learning with FASD is an online portal that houses

evidence based resources such as fact sheets, guides, videos and webinars to help Australian educators understand and support young people with FASD in the school environment.

Louise Mewton 24:41

Okay, so that is it from me. So with that background around what is FASD, I'm now going to hand over to Julia Riches, who's going to dive a little bit deeper into how we actually develop the resources housed on Learning with FASD. Thank you everyone. And thank you Julia.

Julia Riches 24:58

Thanks so much. Louise. Yes, and thanks for providing us with that really great background that kind of sets the scene for me to tell you about the new resources that we've developed. Before getting into that development process in more detail, I just want to acknowledge the research team and the key stakeholders that were involved in this project. And importantly, I want to acknowledge that Learning with FASD received funding from the Australian Government Department of Health and Aged Care, and to thank them for that.

Julia Riches 25:29

So the first iteration of Learning with FASD launched in March 2022, and it focused on resources for the primary education sector. And this is because the earlier a child with FASD receives a diagnosis and those appropriate supports are put in place, the better the outcomes and the lower the risk of those secondary challenges that we just saw in the video. So the primary focus website is organized around three topics, so they're understanding FASD classroom strategies and family engagement. And while it is aimed at primary school students and staff. These resources still have really useful information for secondary school teaching and support staff, particularly because of that concept of dysmaturity that was just mentioned in the video as well. Young people with FASD show varying levels of maturity, so some of the strategies while they are for class, for primary school teachers, will be really useful in a secondary school setting as well. So the secondary school expansion. So in 2024 the Matilda Centre received additional funding to develop resources specifically for the secondary education sector. So the project has been carried out in three phases. At the start of last year, we were in intense sort of research planning and the consultation phase, before we moved into phase two, which was focused on the collaborative development and focus testing of the new resources. And finally, we're now in phase three, which is all about the dissemination, promotion and evaluation of the new resources and the updated website.

Julia Riches 27:04

So to give you a little bit more information, in phase one in 2024 we conducted a scoping review of existing resources that provide educators with knowledge and skills pertaining to FASD, and this had a particular focus on resources for secondary school educators. So we looked at both grey and peer reviewed literature. So grey literature, in this case included FASD organisation websites, government websites, Google, App Stores, streaming services, anything you can think of, really. And we also looked at nine peer reviewed databases. So the team screened almost 4000 resources, and of those, 138 relevant resources for the secondary education sector were identified. We also conducted our first round of consultations with secondary school staff, FASD, education experts and parents and caregivers of young people with FASD. So the goals of this phase of the consultations were to seek

feedback on the currently available resources for the secondary education sector, identify gaps in the available suite of resources, talk to secondary school staff about their needs and sort of key barriers to obtaining information about FASD. And finally, and most importantly, we needed to identify priority areas for resource development.

Julia Riches 28:30

So the scoping review revealed a really critical need for short format, high quality, evidence based resources, so many good quality resources that exist, are these long guides that are 50 plus pages that just aren't suitable for time poor teachers. And the review also revealed that very few resources exist that focus on secondary school aged children with FASD specifically. So this is really important, because adolescents are going to face different challenges than primary school aged children, so it's really important that we have information and resources specific to this age group. Two cross cutting themes emerge from all consulted groups, and the the kind of lighter blue bubbles that you can see here and these were a need for resources that assist educators to understand the impact of FASD on learning and behaviour, but also resources that provide practical strategies to support learning behavior and development. When we spoke to the experts, they highlighted a need for resources that included information on specific challenges and difficulties, so specific topics, and this is the green bubble here, that were flagged by experts included supporting students through transition, so for example, moving from primary into secondary education or into the workforce, and also information and strategies to support mental health.

Julia Riches 29:56

So our consultations with educators, and these are the dark blue bubbles, revealed that in addition to wanting information on practical teaching and learning strategies and the impact of FASD, they really wanted information on how to best support social and emotional development and information on physical modifications that could be made to the classroom environment to support students with FASD. Finally, consultations with parents and caregivers of young people with FASD revealed the importance of information on working effectively with families and other supports. So that might be occupational therapists, speech pathologists was really crucial to support a cohesive learning strategy. So into the development phase, the resources were developed using a multi stage review process, and at each stage refinements were made by the research team based on consultation feedback. So just to explain in a little bit more detail, we used an iterative process to produce the first draft of the resources within the team, and then we, we then engaged two groups of expert consultants to review and provide feedback on these so this included staff from the National Organisation for Fetal Alcohol Spectrum Disorder in Australia, which is the peak body supporting people and families living with FASD. So while I'm here, I'll just mention that the NOFASD Australia website has a wealth of resources on FASD for all kinds of professionals, and I do really recommend that you visit their website if you're seeking further information, it's nofasd.org.au and they also run a helpline, and the number can be found on their website. There's also the FASD hub, which is another really great Australian website that has information for professionals. And so we also engaged with an experienced educator as an expert consultant who had particular knowledge and expertise relating to FASD in an Australian context, and is the author of a number of wonderful resources for educators already. So one is on FASD and complex trauma.

Julia Riches 32:03

So after incorporating this feedback, we also ran a second phase of consultations with secondary school staff, experts and parents and caregivers. So over 30 people provided feedback on the newly developed resources and the updated website during this phase, and this is the final result. So what you can see is the updated Learning with FASD homepage on the left and the secondary school landing page on the right. So I'll quickly talk you through each of the new resources we developed, including just a quick rationale for why we chose those topics. So the ones you can see on the screen, the screen are four new fact sheets that we've developed. So Georgette is going to talk about the substance use fact sheet in more detail. So I won't touch on that too much now, but just to take you through the other ones. So we have information on mental health, and this is because over 90% of people with FASD will experience mental health challenges over their lifetime, and we know that adolescence is a key period for the emergence of mental health concerns, and this was also identified as a key topic by experts, as I mentioned. We also have information on social and emotional development, and this fact sheet provides a really practical framework for educators to explicitly teach social and emotional skills to young people with FASD. And I said this was identified as a key topic by secondary school staff. We also have a fact sheet on transitions during adolescence. So young people with FASD really struggle with changes to routine. So common transitions like moving from primary to secondary education, moving between classrooms at school, having different teachers, and then transitioning out of secondary school. So whether that be into open or supported employment, vocational education, this can be really challenging for young people with FASD. So this fact sheet provides strategies for educators to help support young people through these different transitions, and it was identified as a key topic by the experts.

Julia Riches 34:12

Lastly, we have three additional resources in different formats, so you've already seen the FASD in adolescence video, but what we also have is a short podcast episode on managing challenging behaviors. So challenging behaviors that might include violence, bullying or inappropriate behavior might arise for adolescents with FASD, and this was identified as a really important topic by parents and caregivers, particularly in how schools respond to these challenging behaviors. So we spoke to Christine Brooks, who is the Vice Chair of the Board at NOFASD Australia, a former primary school teacher and a carer to a young person with FASD, and we spoke about some of the challenging things that had arisen for the young person that she cares for and the really helpful things the school had done to support them through that time. And finally, we have another explainer video on FASD and trauma. So as Louise touched on before, trauma is extremely common among young people with FASD. The statistics aren't great, but some of the estimates at the higher end say up to 95% of young people with FASD may have experienced some form of trauma. And what's important here is the challenges associated with trauma can overlap and intensify the difficulties associated with FASD, particularly in the school environment. So we have another brief explainer video that goes into that in a little bit more detail. So that was a very quick rundown of what's on the site, which you can find them all online. But what I'm going to do now is hand over to Georgette to talk you through some strategies for teaching and support staff.

Georgette Borel 35:58

Thank you Julia, and thank you to Louise as well for sharing that really important context on FASD and how we've developed these resources. So now I'm going to go through some of the guiding principles that teaching and support staff can use in the classroom to support students with FASD. We'll then look at substance use in young people with FASD, and some specific strategies that teaching and support staff can use to communicate effectively about substance use. So firstly, as it says here, there is no typical pattern of impairment in FASD, unlike what you might see in autism spectrum disorder or ADHD, and this is because the specific impairments or impacts depend upon a number of factors, such as the timing of alcohol exposure in utero, genetic factors and so on. And this means that each person with FASD will have a unique combination of strengths as well as challenges, and they will require different supports. So if you've worked with a student with FASD in the past, you might already know that what works for one student with FASD may not work for the other. They may actually have strengths and difficulties in completely different areas. Secondly, one of the only cross cutting features of FASD is this concept of dysmaturity. So this means that someone with FASD will have varying levels of emotional maturity in different areas of development. For example, if we're talking about social emotional development, a 15 year old with FASD may have the emotional understanding equivalent to a 12 year old, but the social skills of a 10 year old. So therefore, it's really important to adjust your expectations to match developmental maturity rather than the chronological age. And lastly, a really important note is to not remove supports or scaffolding from students once improvements have been made. So the supports or scaffolding around the student is what's enabling them to improve or to work effectively. If these are taken away, the student just doesn't have what they need to engage in the school environment.

Georgette Borel 38:03

And underpinning all of our strategies are the eight magic keys. So these were developed by Deb Evenson and Jan Lutke and they're guidelines or principles that are considered best practice in supporting young people with FASD. So these keys should always underpin approaches to working with students with FASD and be applied in conjunction with topic specific strategies, such as the substance use ones that we'll go into next. So concrete is the first key. So young people with FASD often have challenges with communication, which includes speech, so articulation and language in terms of understanding and expression. So it's really important here that as an educator, you speak in concrete terms, so don't use words with double meanings or idioms. So for example, instead of saying settle down or behave yourself, it's much more helpful to be really direct and say something like, please stop talking.

Georgette Borel 38:57

The second key that we have is consistency, so students with FASD do experience difficulty generalising learning from one situation to another, so therefore they'll do best in an environment with few changes, which does include language. So teachers and parents can coordinate with each other to use the same words, key phrases and oral directions to help students apply that learning from one context to the next. And repetition is the next key. So students with FASD have chronic short term memory problems. They'll often forget things that they want to remember, as well as information that's already been learned and retained for a period of time. So in order for something to make it to long term memory, it may simply need to be retooled and retaught repetitively.

Georgette Borel 39:47

Routine is the next key. So stable routines that don't change from day to day will make it much easier for students with FASD to know what to expect, and it'll help sort of decrease their anxiety and just from. Better learning. Simplicity is our next key, so remember to just keep it short and sweet. Students with FASD can be really easily over stimulated, and that can lead to a shutdown, at which point no more information is coming in. So keeping a really simple environment is a really good foundation for an effective school program. And next is specific, so say exactly what you mean. Remember that students with FASD do have difficulty with abstractions, generalisation, and not being able to sort of fill in the blanks with instructions. So tell them, step by step, what to do, and again, just keep in mind those concrete terms and specific instructions and repetition if needed. And second last, we have structure, which is the glue that makes the world make sense for a student with FASD. If this glue is taken away, it can be really difficult for a student to engage, and things can start to fall apart. So a student with FASD is much more likely to do better in a school environment when there are appropriate structures around them. And lastly, we have supervision. So because of their cognitive challenges, students with FASD bring a naivety to daily life situations, so they might need constant supervision, as with much younger children, to help develop those habit patterns of appropriate behavior. So we do have more detailed information on these guidelines, which we'll link out to, and we also have a link to a short video series that goes into a bit more depth on the website.

Georgette Borel 41:36

So just touching a bit more on substance use in young people with FASD so people, as Louise mentioned earlier, people have been prenatally exposed to alcohol, are more likely to initiate substance use earlier. Prenatal alcohol exposure has also been associated with greater alcohol, cannabis and tobacco use, even when other factors such as age, sex, education and prenatal exposure to other substances have been accounted for. Adults with FASD are also up to 20 times more likely to develop substance use disorders than the general population, and approximately 46% of adults with FASD engage in risky substance use. So while the underlying mechanisms that drive this risk aren't entirely clear, young people with FASD are more likely to experience certain factors that increase the risk of early substance initiation. So this includes things like co-occurring mental health conditions, stressful or traumatic life events, or an unstable home environment. Prenatal alcohol exposure is also associated with heightened reward sensitivity, so increased reward to drinking or using substances and increased alcohol tolerance due to their altered brain development. So this makes people with FASD more vulnerable to the negative consequences of alcohol and drugs, even at lower quantities. Other challenges with memory, impulse control, problem solving and understanding abstract concepts can also make it difficult to remember and connect the consequences of actions. So the relationship between drinking too much and then feeling sick may not be as clear to a young person with FASD. It can also make it difficult to anticipate the long term effects of substance use, And other social factors such as peer influence and dysmaturity, which again is that behaving in a way that is younger than the chronological age may also contribute to risky substance use. And early substance use can impact brain development and affect cognitive, social and emotional functioning. It's also related to indirect harm, such as lower school completion and negative impacts on mental health. And earlier age of alcohol use is also one of the strongest predictors of alcohol use disorders in later adulthood. So all of this combined makes adolescents a really important time point for teaching and support staff to be ready to have safe, supportive conversations with young people with FASD about substance use. So

given those unique complexities of substance use in young people with FASD, these strategies from our substance use fact sheet have been designed to help give teaching and support staff practical ways to communicate effectively about substance use and the associated risks and to provide appropriate harm reduction information. So firstly, adapting harm reduction education materials to the level of maturity of the young person, as we've mentioned, dysmaturity affects many young people with FASD, or just many people in general, with FASD. So as an educator, this might include observing students asking questions to gauge their level of knowledge and maturity before delivering educational material, just to make sure. That it's relevant and easy to understand. And again, because harm reduction can be quite an abstract concept, students with FASD may struggle to understand and retain harm reduction messages or to engage in meaningful discussion about the risks. So again, tailoring that information is really important. Next is using visual or hands on examples. So again, difficulties with abstract concepts can be really common, so using visual or tactile examples can make this information more concrete. So this could look like, you know, using cups and water to pour a standard drink size to sort of make that information visual.

Georgette Borel 45:43

Similar to this modeling communication and social skills with role play activities also help students engage with complex information. Examples of this might be practicing or resisting peer pressure, or practicing how to ask for help from a trusted adult if they feel that they're in a situation where they need help. Addressing the motivations for substance use is another important factor for young people with FASD so they might be motivated to experiment with substances out of curiosity, peer influence, or to cope with commonly occurring, commonly co occurring risk factors like stress, anxiety or trauma. So being able to discuss these motivations opens the door to talking about healthier alternatives for managing these challenges, such as engaging in hobbies, talking to peers or trusted adults, or using relaxation techniques, classroom discussion strategies like using a fictional case study can also help all young people discuss sensitive topics without fear of personal consequences. So this is sometimes called a one step removed strategy, and it might look like asking students 'suppose this happened to someone or they were in this situation. What kind of advice could you give them? Who could they go to for help?' And it just helps young people feel safe and yeah, open those discussions bit more easily. So next, we have facilitate access to resources and guide young people towards evidence based information, such as Positive Choices. So for young people with FASD, this also might include consolidating these resources into simple visual information sheets, just so that that information is really easy to digest. Collaborating with caregivers in community is also really important, and that ties back to that repetition and consistency in the eight magic keys. So where possible, collaborate with parents, caregivers and community to encourage consistent messaging and strategies between school and home. Another key is to think about your duty of care. So this, of course, will be unique to each school, but it's really important to maintain clear rules and boundaries and know when to refer students to further support, then we have build trust. So keep an open mind and allow students to feel comfortable and safe having conversations with substance about substance use. Students might feel more comfortable speaking to someone in the school community than they would a parent or caregiver. So it's great to be ready to have these conversations, and finally, prepare for individual discussions. So if you think a young person might be engaging in risky substance use, try to find a time to talk privately and communicate your concern in a supportive, non confrontational way, let them know that you're

there to help. So these are all covered in much more detail on the fact sheet online, which we'll link out to, but I will leave it there and hand back over to Elly for some questions.

Elly Fitzgeraldson 49:10

Hi. Thank you so much to our presenters, Georgette, Julia and Louise. That was so informative. And I love all of the tangible strategies for teachers and things that they can be doing in their classrooms. That's so great to hear. So we're now on to our Q and A session. I encourage our audience members to put any further questions into the Q and A panel for the presenters to answer live. But to start off, let me ask you the first question that has come through

Louise Newton 49:46

That's quite a long one. Elly, do I can field that, if you want, it's all around the low access to a diagnosis means low access to supports and low access to strategies in schools, and we really do share the frustration around the difficulties in getting a diagnosis. We do suggest that these supports that we have on the website are in place, whether or not there is a formal diagnosis, many of the supports that we have online really are relevant across different neurodevelopmental disorders. So as long as you have, if you know, if you're implementing those strategies, even without a formal diagnosis, that really is, I mean, the main suggestion from from us and from the people that we work with, just because getting that diagnosis is such a lengthy and complicated process, there are other there are some other things there, like in terms of the early identification, does it need to bring in at prenatal education and at birth? Yes, we, we believe so we are putting together a proposal at the moment looking at sort of prevention programs, so stepping way back and actually developing prevention programs that are delivered to students in school to in order to prevent FASD in the first place. I don't know if you want to add anything there, Julia or Georgie.

Julia Riches 51:16

I think just that messaging that you said really clearly, and that we're trying to get across is because the level of the rates of diagnosis is so low, and it's so under diagnosed or misdiagnosed, and it takes a long time to get a diagnosis. That idea of when you suspect maybe that there are, you know, there's been prenatal alcohol exposure, or you suspect that there is something that's not working for this student implement, implementing those FASD informed strategies can go a long way to supporting that student and helping them engage in the school environment.

Elly Fitzgeraldson 51:55

Thanks, Louise and Julia. So the next question is from Michael, given the potential mental health and correctional connections, what collaboration and roll out of education is occurring/planned for these sectors?

Louise Newton 52:10

So we are we're focused on the education sector. So I'm gathering you're talking about education activities that are delivered to correctional and mental health services, in terms of the national fetal alcohol spectrum disorder strategy, the action plan, these are certainly priority groups, and it's suggested that targeted screening can occur within these settings. But we are, we are very much focused here on developing resources for educators. I'm not aware of anyone out there at the moment

building these sort of education programs specifically for you know, around what is FASD and what can you do about it? How can you support people with FASD specifically for correctional or mental health settings? But Julia, who is a font of all knowledge, may know otherwise.

Julia Riches 53:00

I don't have anything particularly helpful to add to that. Louise,

Elly Fitzgeraldson 53:06

Thank you. So this is from an anonymous attendee. We know that trauma can have long, lasting effect on generations. Has there been any research conducted into how FASD can impact next generations from a medical perspective,

Louise Mewton 53:25

We do have our resources focused on trauma. I think you might be talking here about intergenerational trauma, which I don't know if we do specifically address in our resource.

Julia Riches 53:42

It's one of those difficulties with this area, in that there is kind of a lack of research into a lot of things. In terms of those intergenerational effects, one of the risk factors of a child being born with FASD is the biological mother having FASD. So that is one way that that does have fallen effects to further generations, but I would say I just don't think there's enough research in this area that's been done yet.

Elly Fitzgeraldson 54:15

Okay, thank you. Someone has asked how important is a diagnosis of FASD. So if a high school student has is suspected to have FASD, would it be best to focus on strategies to help rather than to get a diagnosis, and are they likely to need the diagnosis in order to access disability support as an adult?

Louise Mewton 54:41

Unfortunately, we do know that FASD is not covered by the NDIS, which is an issue, as Julia has mentioned, and as I've mentioned, we really want people to be using these strategies, regardless of whether or not there is a formal diagnosis because of the complications around the diagnosis. There was another aspect to that question. I forgotten it.

Elly Fitzgeraldson 55:08

Whether, whether it's better just to focus on those strategies, or to keep, you know, trying to get a diagnosis.

Louise Mewton 55:14

I guess about the importance of a diagnosis, it really is. I mean, having a diagnosis is very important so that you can put in the supports in place that are specific for someone with FASD. So it's really important to get that diagnosis. We just do not have the capacity in the system in Australia at the moment to be diagnosing people, particularly in rural and remote areas, which I know someone else has mentioned in there as well. These clinics are in, you know, urban settings. We do know someone

who we work with closely, Liz Elliott, who, you know, has contributed to our resources. We do know that her and her team do go out to rural and remote settings, actually travel out in order to provide services. But you know, the services home base are in urban areas, so yeah, a diagnosis is important so that we can get those supports that are specific to the diagnosis in place. In the meantime, let's give them the supports that might be helpful.

Julia Riches 56:17

I've got something to add to that too. Sorry, Elly, to jump in just on the point of getting the correct diagnosis too, is that, as Louise mentioned earlier, there are really high rates of comorbid disorders with FASD. So it's really up to 70% of young people with FASD might also have ADHD. And why a FASD diagnosis is really important in that regard is because the treatment for young person with ADHD compared to the treatment for a young person with ADHD and FASD is going to be different to some of the medications that you might prescribe to an adolescent with ADHD and not going to work the same way for a young person that has both ADHD and FASD. So that's just one of the, I know we've talked about how hard it is to get a diagnosis, but one of those things that is really important in ensuring that young people have the full and correct diagnosis.

Elly Fitzgeraldson 57:17

Yep, that's actually a really good segue into the last question, it's about how you mentioned before Louise about the overlap with FASD and ADHD, autism, and how the strategies can be relevant for different individuals. Someone has asked, Are there any key differences to be aware of in these strategies for the FASD population.

Louise Newton 57:46

This is something that we have been talking about a bit recently. We did a sort of training session with principals from emotional behavioral schools last week, and this came up, so it is something that we have been thinking on. And I think Julia, I'm sorry to throw to you inhere, because it's a really tricky question. We know that one of them is this just maturity, dysmaturity. It's something that's cross cutting across individuals with FASD. But as we said, it really depends on when they were exposed, how much was, how much exposure occurred, and things like that, in terms of what individual symptoms someone's going to display. And I know if you have anything to add to that, Julia?

Julia Riches 58:24

Just that these strategies are written to be FASD informed, so they are targeting some of those more common difficulties that occurs, those difficulties with memory is why there's a lot of strategies about repetition and routine and things like that, which, you know, we do know the symptoms of FASD overlap a lot with the symptoms of other neurodevelopmental disorders. So there's not something that stands out necessarily that we would say, do this for a young person with FASD, but definitely don't do it for a child with other a different neurodevelopmental disability.

Elly Fitzgeraldson 59:04

Thank you for that. So thank you to our presenters and thank you to our audience. Please feel free to send through any feedback on the webinar, ideas for future webinars or any extra questions to info@positivechoices.org.au and you can also keep up to date with Positive Choices via Twitter and

Facebook with our handles on the screen here. Thank you again for joining us today, and we hope that you coming out of this. I definitely did.

Louise Newton 59:41

Thank you, everyone you.