

Interviewee Name: Asphyxia

Interviewer Name: Annie Rolfe

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Transcript

Annie: All right. First question, can you tell us a bit about yourself? What do you think we need to know about who you are? Where you are from? And what experiences have helped you become the person you are today? To help us understand your artwork.

Asphyxia: Okay. When I was a child my main ambition was to be a ballerina. I enjoyed ballet, loved dancing. I also liked writing. I loved creating stories. But back when I was 18 I thought I'd like to be a professional ballerina. Unfortunately, though, my teacher said, "As much as your skill level is good enough, the fact that you're deaf means you cannot become a professional ballerina." This was obviously very disappointing. My deafness didn't prevent me from dancing because I could understand the rhythm by watching the timing of other dancers. If I was doing a solo performance, I would have someone stand in the wings and count the one, two, three, four, so I could see the rhythm. I could hold that time, and dance in time. So I didn't think dancing in time would be a problem. But that was my teacher's attitude. It would have been good if I had challenged this, but I didn't think to, and my family didn't encourage me to fight the system either.

Asphyxia: So I guess I just accepted that I couldn't dance professionally. I then moved on to circus performing. This is the sign I use for 'circus,' for those who aren't familiar with the sign. I think I was drawn to the circus because I could make use of my ballet skills, but in a context that celebrates diversity. The circus embraces human freaks - short statured people and the bearded lady and that sort of stuff. So I really embraced the circus, knowing that my Deafness could be an asset rather than a hindrance. I took up swinging trapeze. I would sign while I was swinging and people loved it. They found it really beautiful. It was a way to express myself while using my Deafness to an advantage rather than it being a disadvantage. I worked as a circus performer for ten years. I worked freelance, performing for various festivals and events. It was wonderful. But before I became a freelancer, I hoped to work for a circus company, like Circus Oz. I was talking with the director of Circus Oz about the possibility of my employment there, but there were many barriers and I couldn't quite see how it would work.

Asphyxia: They would need to hire an interpreter for group discussions, and they couldn't afford this. Back then there was no NDIS, no EAF, the Employment Assistance Fund, so there was no easy way to source interpreters. So it was not easy to be part of a circus company. I ended up establishing my own business as that was the best fit for me given my deafness. I could make my own circus and set

up a deaf friendly environment. So I hired a person to make phone calls and do bookings for me, because at that time the internet wasn't widely used. Emails weren't the way to communicate as they are now. So I had a person ring and make bookings for me. I spent a lot of my own personal money to do that, whereas a hearing person could just make calls themselves. I didn't use agents. I think agents weren't really confident that I could present as a professional, which was disappointing. But I managed to deal with the barriers I encountered. I worked hard. I had repeat bookings at many festivals because they loved my shows.

Asphyxia: Once I got my foot in the door I was able to show them my skills. There was always a way around barriers I faced. I travelled overseas with my circus show as a backpacker. One time I went to Guatemala, where I saw a guy performing on the street. His name was Sergio Barrios. He was a puppeteer, his show was beautiful. I fell in love with his puppets. There was no talking. It was wonderful because when puppets talk, obviously you can't lipread what they're saying. He performed with puppets that communicated entirely with body language. You could see them breathing. This perfectly matched the way I like to work and I was in love with the idea of performing puppetry like him. After his show, I asked, 'Can you please share your skills with me? Can you teach me how to do puppetry?' He was more than happy to help me, which was wonderful. So on the streets in Guatemala, he taught me how to operate puppets. I said to him, 'I'm going to go home to Australia and make my own puppets to perform with.' He warned me that you need to be very specific in the way you build a puppet - you have to give them knee joints that are correct, that bend in the right way, so that the puppets don't flop in the wrong direction.

Asphyxia: You have to make sure that the puppets move properly. That is a skill within its own right. He was speaking Italian - he didn't know English. I only knew English and Auslan, so we had quite a language barrier. But that was fine - we just drew pictures to each other, and that was a beautiful way to communicate. So I came home, and I made my puppets. I loved performing with them. It felt like when I was a child, playing with dolls. I love playing with dolls. It's not something I've ever grown out of, strangely enough. Sometimes I would perform on big stages. So I made a larger puppet show to fill these stages, called The Grimstones. That show actually became a big and successful show. More than I thought possible. I had bookings to tour constantly for five years straight. I just lived on the road. I loved all the work - it was wonderful. But I never realised how exhausting touring could be. It was a bit of a shock to the system, but I'd already accepted bookings a year and a half in advance. Five years of constantly being on the road, as you can imagine, was exhausting.

Asphyxia: Eventually I said, enough's enough. I needed to retire. I was actually able to retire before I was even 40 years old. It was nice that my show was that successful. But actually, I didn't quite retire. Back when I was actually performing, a person from the book publishing company, Allen and Unwin, came along to see the show. She loved the show and thought it could make a really good book. So Allen and Unwin approached me to see if I would like to write a book based on my show. Of course, who wouldn't!? I had been posting on my blog, so they could see I could write well. As I said earlier, when I was younger I loved writing stories. I had good English and writing skills from that. When I was about 18, though, I set the bar really

high for myself, and I no longer enjoyed the fun of writing as I expected myself to be good at it. So I stopped. In hindsight, I'm disappointed about that. I wish I had not been so hard on myself back then. But at least I did keep writing in a blogging form.

Asphyxia:

I also loved to write in my diary. So I was writing a lot and honing my skill. The publisher saw my blog and knew I had good English skills and could write well, so they were confident to sign me up. They offered me a two book contract for books based on my puppet show. This was really exciting. When the books were published they did well. Later, I became inspired to write another book, 'Future Girl.' I wanted the character to be Deaf, and given the environmental issues we face, I wanted to explore them in a book too. So I was able to email my publisher and asked what they thought of my idea. I told them I'd love to write Future Girl based on a Deaf character, and I'd love her story to be told in the format of an art journal. It wouldn't just be text, but presented with visual art as well as the story. This felt natural to me as I was working this way every day in my own journal. And I thought to myself, if I can explore my own story through art and text like this, why not do the same for a fictional character? The publisher wasn't sure, as it had never been done before. But they were game to give it a go and see how it was received. So we dove in and went for it. I got some funding to create the artwork for the book, as that was a very time consuming component.

Asphyxia: It took eight years to create the book from start to finish. I wrote the manuscript from scratch five times, and I made 384 pages of full colour art. It was a massive project. I wasn't sure how it would turn out when printed, but when I received my first copy I couldn't believe it. I cried. It was everything I had hoped for and I was so proud of it. After the book was released it won many awards, not only within Australia but internationally too. It has been translated into other languages. Given that it explores Deaf identity and what it's like to be oral and to discover the Deaf community, I was really excited that so many people would now be exposed to this information. And hearing people would be able to read it and understand us better. To me this felt like a wonderful achievement. I was then approached by three different film production companies who said they'd like to adapt it for the screen. I couldn't believe it. It meant I could choose a company that was willing to work collaboratively with me to produce the film, and I was able to negotiate the role of co-producer.

Asphyxia: This means I have a 50% say in every creative decision made, which is important because these decisions about how to realise the story on screen won't be made from a hearing perspective. I can ensure that the Deaf perspective is authentic. This is just amazing for me. So right now I'm working on this TV series and I'm just loving it. I also do other work as well. I consult about Deafness for other projects, and advocate to make the world a better place for Deaf people. When I began writing Future Girl, I knew I wanted to write a Deaf character, but when I opened my laptop to begin, I realised I didn't really know how to write about Deafness. It was just an everyday part of my life. So to figure this out I started journaling about my Deaf experiences every day. People would come up to me and ask questions like, 'Were you born Deaf?' And I'd roll my eyes and think, *Oh, that old question*. In journaling about it, I'd ask myself, 'Why does this question annoy me so

much?' On other occasions people would be laughing and I couldn't understand what they were talking about. *Should I laugh too? Or just stand there with a stony face?*

Asphyxia: I didn't want to come across as rude. I realised that every day I was making so many decisions about how to handle my Deafness, and I didn't know what would be the best decisions to make. So as I was writing *Future Girl*, a lot of these examples were coming up, and once I had articulated them in my journal, I began posting about them on Facebook and Instagram. The posts got a lot of attention as people really related to what I wrote. Deaf people could identify with these experiences and share them with others, saying 'This is what we go through on a daily basis.' My posts also represented an opportunity for the hearing community to better understand what we Deaf people were dealing with. So this is how I became an activist. I feel passionate about it. I now write articles in newspapers and magazines on this topic. Recently I had a big article published in *Precedent*, a magazine by the Australian Law Alliance, which focuses on how organisations can be more inclusive of Deaf people. I was particularly proud of this piece and glad it was published as it was particularly in-depth and covered a lot of material that would be useful for organisations.

Asphyxia: It's hard to advocate for yourself on a daily basis. So for Deaf people to be able to hand this article to organisations instead would be much easier. So I guess that pretty much sums up what I do.

Annie: That's great. Thank you. Are there any experiences, events or people that stand out in your memory as really formative in terms of getting you interested and involved in your art and music? Tell us about your journey with music. How did you come to get involved with music and what are you working on with that now?

Asphyxia: Well, when I was young I always enjoyed music, like people singing to me. That was the best way for me to understand music because I could both lip read them while they were singing, as well as take in what I could auditorily at the same time. So I learnt the various songs that people would sing to me and I enjoyed that. As I got older, when I became a teen, friends would take the time to teach me new songs. I realised that if I listened to a song first up, I couldn't always make sense of it, the sounds that I was hearing were quite jumbled, but if a friend would patiently teach me what was happening in the song, signing to me repeatedly, I would start to understand the different components of the music and piece it together. Later I could listen to a song by myself and I could mostly hear it and I loved that. I really started to enjoy music. Unfortunately, the friends who had so patiently taught me the songs had to do it time and time again before I could pick up enough to listen to them independently. So they became sick of the songs, and I finally learnt the song and I wanted to play it over and over, and they were like "Oh, enough, I've heard it so many times!" It became a bit frustrating. Especially when I wanted it really loud, I had to wait until I was alone so I could listen to it at the volume I wanted.

Asphyxia: Later, when my hearing reduced even further, I lost hearing capacity completely in certain pitches. This meant that when I was listening to the same songs that I had learnt previously, it sounded like it kept stopping and starting. I

could hear some notes but not others in the music. I didn't enjoy that at all, it was extremely disappointing. I wanted to hear the music! I applied to use my NDIS funds to pay someone to help me access music. So I engaged a musician to work with me to work out what sounds I could hear and those I couldn't. They tried to make music that only included sounds that I could hear and that was fantastic, I could finally hear a whole song again and enjoy it. Throughout that process, there were many miscommunications with the musician. For example, they put sounds in the music and I didn't have the language or the instrument knowledge to be able to articulate my issues with it, to be able to explain which instrument I needed removed as it was making the song fuzzy, or which components to turn down so I could hear the vocals. It was very difficult to communicate, they tried very patiently to teach me. One time they sent me a percussion track that they said they had put in the song, so I could listen to it solo. I realised I couldn't hear the percussion at all, that track was completely silent to me. And I was like "Wow! Some instruments I am not hearing AT ALL!" I needed to work that all out. In the end they started to teach me how to write my own music, that was much better because that meant I could control and pick exactly which sounds and instruments I wanted to hear. I could play it for myself and think, *No I don't want that*, I could listen to something and think, *I want that at a lower pitch not higher*. I could create customised songs myself.

Asphyxia: The first few songs that I wrote were very .. not standard! For example, I made up the melody and the musician listened to the track and said the melody "wanders all over the place", and I thought 'What does that mean?' I was so perplexed by it all. I tried to look it up online but still couldn't find the answers. They began teaching me about music theory, it was very difficult for me to learn music theory as the way it is conventionally taught relies on listening. I was trying to extract the information I needed to understand what was wrong with my melody. I persisted and I eventually got the information needed, I increased my knowledge, and now I know how to write a melody that doesn't wander everywhere. I know how to put a song together following the various musical conventions.

Asphyxia: I feel there is a big barrier for Deaf people to do this because that process of learning was so hard for me. I thought, *okay I will write a music course specifically for Deaf people and I will put it on my website for free*, which I did because I want them to be able to access music. I want them to have the information of how to do it, to learn about creating songs to specifically match their hearing range and capacity.

Asphyxia: Also while I was working I started to develop a theory about why some sounds sound good for me and some do not. I'll give you an example. When I listen to the drums, the kick drum and the snare drum go boom bop boom bop. The kick drum makes a low sound which makes you feel like moving down while the snare makes a higher sound that propels you to move upwards. Boom bop boom bop = down up down up. A nice dance-y feel. But if you add in the hi-hat at the same time, a cymbal, the hearing aid, focuses on this and can't capture the difference between the low and high sounds of the kick drum and the snare drum, which means that I

lose that up and down feeling in the song. I realised that if I remove the hi-hat, I can feel that down-up energy and the piece becomes enjoyable. I was thinking “Is that because my hearing aids are manipulating the sound? Why is that happening?” So I asked other Deaf people, when I tested it on them, they said they had the same experience. I realised, ‘Ok, so maybe we need to change the songs by removing specific sounds that create a problem. With a simple combination of sounds we can avoid overwhelming the hearing aids.’ I had a theory about how that would work. I engaged another Deaf person to make a song that would be suited to their hearing and tested it on her.

Asphyxia: I modified the song to match her hearing and she was ecstatic! She couldn’t believe she could hear so clearly and beautifully. She was crying. We were both crying. She went home and played it on repeat. I could see the impact on her from one accessible song and the impact on me from accessible music. I realised Deaf people out there don’t have access and this is something we need to fix. And now it’s become a passion of mine to find a way to solve this problem. So I’m focused on working out a specific formula of how music can become accessible, for example, removing the hi-hat, and many other similar issues. I’m creating a guide, which I will test on Deaf people to find out what works. I want to see if my theories match everybody or just a few people. And then I want to engage Spotify to require companies that upload music to their platform to also upload an accessible version of that song. The company would follow my guide to create different versions of their songs, modified for Deaf and Hard of Hearing people. That’s my goal. I have applied for a range of funding and am trying to find other Deaf people who can join me in this research. I am also curious about what is happening overseas. Are other Deaf people finding the same thing as me? I haven’t yet found anyone else who is on the same journey as me, not overseas nor within Australia. I have asked around but haven’t come across anyone as yet. So that is what I am working on with music.

Annie: What do you think the public would say are the key milestones or big major happenings in the history of disability arts in Australia?

Asphyxia: Oh I don’t know to tell you the truth, I don’t know what the milestones or major happenings there are in Disability Arts, I really don’t know. I’m not sure where I would access that kind of information, I don’t feel like we have a central hub or somewhere to find that out. The same as I don’t know how to find out what’s happening in the field of music either.

Annie: Is your art political? Do you think art should be political? And by that I mean change in how people think and act and treat each other and is that how we should define success or is it about aesthetic quality and appeal to a mainstream audience or both?

Asphyxia: I feel for me it is both. I am very passionate about specific aesthetics and I want my art to align the particular look that I am wanting to achieve. But I often do

like my art to be political as well. Sometimes I make a picture just to enjoy looking at it, but mostly I make it because I have something that I want to say. I once read a quote "Art should comfort the disturbed and disturb the comfortable." I like that. I feel that my art does that. I like political art. One time, I painted a picture of Tony Abbott, after he talked about how womens' place was doing the ironing. This sparked something in me, so in response I painted him in a frilly apron doing the ironing. I thought that Tony Abbott should try doing the ironing himself, with that attitude.

Asphyxia: Other things that I feel passionate about I paint about. For example, I was frustrated by disability equipment like wheelchairs. I feel that wheelchairs are often quite ugly. The people who design them don't see them as the equivalent of clothing on a person with a disability, nor understand that it affects how they present in the world. They don't think about how the equipment doesn't fit in with the individual's personal style. I feel with clothes we have many options to choose from to match our identity and style, but with disability equipment it's very utilitarian. I got a wheelchair that looked like a lawn mower, and I was like 'That does not match my style at all, it's really embarrassing!' So that's another topic that I've been painting, what I think wheelchairs should look like, to incorporate style with my disability..

I've painted plenty about being Deaf, for example one piece of art states, 'It's not my goal to be normal.' Growing up, we experience significant pressure to pass as a hearing person, and I realise I don't want to. I don't care. I'm not interested in that. I embrace my Deafness and I accept that, which means I receive the accommodations needed to support my Deafness. I'm not going to try to pass as hearing, normal, something that I am not. So yes, my art is very political in many ways.

Annie: Is there something we haven't asked you about that we should. That we really need to know about you.

Asphyxia: No, I think that I've covered everything. Thank you.

Annie: Thank you. It's been great. I just have one last question. Do you identify as a disability artist? Or as a Deaf artist? Or as an artist?

Asphyxia: Number one, my identity is that I am Deaf. I feel, since childhood, that I am a Deaf person, I embrace my deafness and the Deaf community. I feel proud and happy and fortunate to have a passport to the Deaf community because I am Deaf myself. That's a really strong component of my identity. I started using a wheelchair two years ago, but it doesn't really feel like it's a part of my identity. I try to embrace that, the same as I have embraced Deafness but I haven't found the right model for that. It doesn't seem like there is a community like the Deaf community which makes it very easy to embrace Deafness and be proud of. With my wheelchair I'm still on that journey. I recognise and accept that I have a disability, yes, and my art reflects that, but really, overall, I see myself as an artist.

Annie: Thank you so much for your time Asphyxia. This has been wonderful. So I really appreciate it.

Asphyxia: My pleasure.