

Case study: interview transcript

Interviewed by the Antipoverty Centre for the Senate Standing Committee on Community Affairs inquiry into the purpose, intent and adequacy of the Disability Support Pension

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Details

Interviewee	#274
Age	32
Pronouns	she/her
Location	Canberra
Payment	recently JobSeeker, now DSP
Program	previously DES, currently student
NDIS access	no
Interview date	4 September 2021
Method	Video call

Edited transcript

Disabilities

For my disabilities it's a bit of a complex web of things. So on the physical side, I have Hashimoto's disease, rheumatoid arthritis, type one diabetes and fibromyalgia. For the mental health stuff I have been diagnosed with ADHD, complex and bipolar.

Diagnosis

I actually have always been very fit and healthy and was working as a roofer doing roof restoration. I was just tired all the time and ended up getting diagnosed with Hashimoto's disease, which is an autoimmune thyroid condition, and got treated for that. Then the fatigue continued. I ended up getting really bad joint pain and had to quit my job because I couldn't work anymore.

I went to see doctor after doctor after doctor. Because of my age and because I was physically fit and looked healthy, I think a lot of doctors sort of, I dunno, thought I was being a bit of a hypochondriac or something. I just got angry eventually and went in there: "These are all of my symptoms. Can you find out what's wrong with me? Can you test me for these things?" And doctors don't really like that.

By the time I was diagnosed with rheumatoid arthritis I wasn't able to walk, or open round door handles. At first it was like, "Oh, well, you know, it's because you have worked." I worked as a roofer for six, seven years. And so I was completely non-functional by the time I got diagnosed.

And then, because I was running ran half marathons – I'd do that once or twice a week and then have shorter runs – they're like, "Oh it's you're running, you've gotta stop running." So I just gradually cut more and more things out. Then I got into bodybuilding. And then that's when my wrists and shoulders went. And yeah, anyway, so that was a long, long process. But I went to see a rheumatologist and by that time it was very aggressive. They make you go through all of these medications that don't really work, but are on the PBS, before they'll give you the ones that work. So then I got on the ones that worked and recovered a lot of my physical functioning. The flare ups happened less often and I was able to move around, I was able to go and get another job and work.

And then the diabetes thing. I was diagnosed with diabetes when I had started studying at the ANU. And that was the same thing. Like, by the time I was diagnosed, I was really, really sick. I actually told my doctor that I thought I had diabetes and I tested it myself by doing things like eating really, really carby meals. She was just treating symptoms. My mouth was so dry that I couldn't sleep so she was just giving me things to put in my mouth to make it less dry. By the time I got diagnosed my ketone bodies were really high and I had to go to hospital. Then I was diagnosed and that was treated.

I was diagnosed with ME/CFS before the diabetes. That was about five years ago. I had a major crash where I couldn't do anything for about nine months. I was working. I had quit my job roofing because of the rheumatoid arthritis and then when I regained my functioning, I started a hairdressing apprenticeship. Then I had this big crash. I had to go and see lots of specialists down in Melbourne and stuff like that. And they ruled out everything else so it was ME/CFS. I recovered and then I was studying. Now it's come back and it's 10 times worse. There's heaps of pain and I have to go and see a neurologist to just double check some things but the diagnosis at the moment is fibromyalgia.

Experience on income support

I have been on income support since maybe end of 2016. I was on JobSeeker [then Newstart] to start with.

When I started studying I was on austudy, but on the long-term unemployed rate, which was slightly higher. When I had to reduce my study load to part-time I then went back onto JobSeeker. It's just been this process of going from JobSeeker to austudy to JobSeeker to austudy. And every time I'd go from austudy to JobSeeker, when I'd go back to austudy it'd be the lower rate, because [constantly changing payments meant] I wasn't then long-term unemployed.

I had to go back on JobSeeker because I was only studying part-time, and so all of the mutual obligations stuff came in. They were obviously making me look for jobs and stuff like that. I'm like, "Well, I've reduced my study load because I can't study full-time. What makes you think I can work full-time and study?"

So it was just back and forth between those payments for ages and I was living in my van for two and a half years. Because I couldn't afford, on the austudy rate I couldn't afford to pay for accommodation and utilities and food and all of my appointments.

Accessing the DSP

I did put through a DSP application. It got rejected as they do. It was a weird situation actually. Somebody called me, and I only picked up the call because it was in between lectures, and said, "Is now a good time to talk?" And that was my assessment, in between classes. The second time I actually went in and spoke to a person. Apparently that's how it's supposed to be but this was over the phone. And it just got rejected based on some wording that I'd used in my phone conversation. I didn't appeal because I didn't have the energy.

The year before last I applied again. This time I was able to get straight on, but only because I'd had that previous experience and had also helped my ex partner and my uncle to go through their applications.

My uncle was rejected. I don't know whether he's appealed or not, he actually is in hospital at the moment and homeless and that's a whole other situation. My ex partner put through three applications. He appealed the first one, and it got denied. Then the second one, he got denied. And then third one, he appealed it and took it to the tribunal. And it was just over wording. That's all it was, he didn't have the right wording said in the right way. Even though they supported him in his application the doctors hadn't used the correct terminology. He is now on DSP. But it took like two years, I think. So it was a long process. He's got schizophrenia and he's pretty bad. Often he does shopping online because he can't leave the house and stuff. He's really not very functional. And so to put something like that on someone in that state was just ... yeah. I'm actually pretty impressed that he went through with the tribunal stuff, because, yeah, it's been hectic.

I knew what they were going to pull me up on so I got so much documentation it was ridiculous. I went through all of the criteria and got someone from community law to help me as well. I wrote out my own letter and then my doctor looked over it and said, "I'm happy with that," and signed it. Otherwise, I would have got rejected again 100%.

In terms of whether I worry about losing access to the DSP, I try not to think about it. With living on payments and with dealing with agencies that have total control over your life and your income, I think it's easier not to think about these things. I get this kind of dread. I haven't been asked to do a review yet. It is there in the back of my mind all the time but I don't even want to think about that. It's kind of stressful.

Although I did get straight on DSP this second time, I mean, it's a long process anyway, by "straight through", I mean it wasn't denied. It still took me so long to get all of the documentation, and then having to go through all of the criteria and make sure I had exactly the right words. Even though it was approved I just don't want to go through that again. So I try not to think about reviews and possibly getting kicked off. I mean, all of my conditions are permanent. They will only get worse or stay the same.

Centrelink's always changing the criteria and all that sort of stuff and tightening down on things. You never know, I might end up not being eligible in the future. And that's kind of scary, because I don't know how I would survive without being on DSP because financially I can barely survive at the moment.

I did have a bit of an issue which ended up getting sorted out. But they have clamped down on things like going overseas if you're on DSP. I got a scholarship for a student exchange, well I got a couple of scholarships actually, which was amazing. And so I went overseas – that sort of covered all of my expenses. I was supposed to be getting paid the DSP for the time that I was there. They were very strict about it. I could only get it for the time I was studying, so once I stopped studying I couldn't travel around for a bit, I'd have to return straight away, otherwise I'd be cut off my payments. They said that your payments will just stop and then when you come back, you can reinstate them, but I did have the fear that cut off means cut off, starting again.

Interacting with Centrelink

The Centrelink website is terrible. It's terrible. It's really difficult to navigate, really difficult to find things. I've had difficulty submitting claims. I've submitted claims incorrectly by accident and then not been able to submit another claim. And I don't know, I don't think it's very user friendly. And when I was on JobSeeker, there were lots of times where it was down. I think the app is better than the website personally.

But I did have a problem with the app recently. I get this education supplement because I'm studying. And I was told that would expire if I didn't update my study details. It just prompted me to go to the app, and you click manage study details. I extended it and submitted it all, but it vanished.

So my pension education supplement got cut off. And then by the time I got it reinstated I'd missed like four payments. That was like to \$240, which is a lot for me and they didn't backdate it. They said they would backdate and they didn't. Then I complained and they said they were going to fix it but I have to follow that up. So they owe me \$240.

'Mutual' obligations

I'm studying so I had no idea you had to do mutual obligations on the DSP. It's ridiculous.

When I was on JobSeeker and I was studying I told the guy who was dealing with my stuff at my JSP, which was APM, that I was not going to be looking for work. And he was supposed to put that on my job plan and that was supposed to be approved. He told me that I didn't need to go on austudy, that I could stay on JobSeeker. I don't know why he told me that. And then I ended up with a six grand debt because of it. I said, "My JSP said I could." He was like, "Yeah, we did say that but we're not going to provide anything in writing to Centrelink," and so I had to fight with them about that. After that, I ended up on austudy.

The activities had a massive effect on my health. This is why I blocked it out. I have been able to get medical exemptions but you could only get one. I think it's three months.

Being linked with a JSP and having to attend those appointments and getting cut off if you forget, or miss the appointments, or are unwell, it took a massive toll. Particularly on my mental health.

I don't know if I've just had really bad luck with JSPs. But the way they treat you when you go in there, it is the most humiliating, dehumanising experience. It just makes you feel shit about yourself, about your life. Also being pushed, like having to sit there and write a resume and look for work when you are not coping mentally at all and are in a seriously bad way is horrible. It's a horrible feeling.

If you're not in a position to work – and a lot of people on JobSeeker are on JobSeeker because they're not in a position to work, they might not be on DSP, but that's just because it's impossible to get on DSP – you're going there and being forced to look for jobs that you

are not going to take. They force you to just take whatever job comes up comes up, they're not interested in what you actually want to do.

If you say, "Actually, I would like to work and I have done this in the past, these are the sorts of things I'd like to do. Are there any courses I could do or something that could help me to get to this point?" they just don't care. If they're going to have these kinds of requirements, even if they just wanted to get people into work, it doesn't make any sense. Why don't they stop to ask why somebody isn't working? It's not just cos they want to be poor. So that was the biggest problem, just trying to explain my situation and having people just not really care.

I don't know if it's the same now but I know they were running on commission. It was kind of like the more people they get off Centrelink and into work, the more commission they get. So they have absolutely no incentive to listen to people, treat them like human beings and try and get them into work that's going to make them feel fulfilled, and not make them feel like just the lowest.

That's my JSP experience. Like I said, the most humiliating, degrading experience. Never had to do Work for the Dole though, which I'm grateful for. I have never had any positive experiences. Mutual obligations are not useful.

NDIS

I am not on the NDIS. I haven't wanted to put in an application because I've recently had my DSP application, and then a housing application. Both of those were really traumatic experiences and I just didn't want to start another one. I now have to take the semester off uni because there are lots of days where my cognitive function is that bad that I can't actually make words. I'm physically incapacitated as well and relying on friends and family to help me out.

I'm very confused about why if you're on DSP and you've gone through all of that application, if you then do an NDIS application, I don't quite understand why the two are so separate. Like why are they not linked a little more? I know there are people who aren't on DSP who need NDIS. That totally makes sense that they've got to go through all of that stuff. But if you're on DSP already, I'm not sure why there isn't a shorter process to get on NDIS. Because if you've been deemed to have a disability by Centrelink, and need to be on DSP, then surely it should be a little easier to get on NDIS. That just confuses me.

I am going to try and put through that application and see what comes of it. I'm really dreading it, but it's gotta be done.

Payment adequacy

I think the payment's too low. But cos I've only recently got on DSP, and it's so much better than JobSeeker, it makes it difficult for me to complain at all, because I know how many

other people are on JobSeeker. And I don't know how I survived on it to be honest. Well, I do. I was living in my car.

But um the payment is enough for me to meet my very basic needs in terms of food, petrol, (as long as I don't drive too far), rent, utilities, all that kind of stuff, and my medications and all that kind of thing. It's not enough for anything outside of that.

So while you're able to support your basic physical needs if you're not able to work, it just kind of means that you miss out on a lot of the things that bring joy to people's lives, like going on a holiday or going out to dinner with friends. You know, things that people enjoy doing like going to the movies and things like that, because you are permanently living on a severely restricted income.

I don't smoke and I quit drinking at the beginning of the year. I mean, I know people don't care about people smoking and drinking, but they are addictions. I'm in recovery at the moment for alcohol addiction. So it's not just like, "Oh, just don't have a drink," or something. For some people that's not an option. So that gets bought before food. And that would definitely be my situation if I hadn't stopped.

The DSP is fine for barely surviving. But if you have to be on these payments long-term, you can't have any sort of decent quality of life. Also, I am very fortunate to be in public housing, so my rent is really low. If not, I wouldn't be able to survive on the payments as they are, let alone as a long-term thing.

Medical expenses

My out-of-pocket medical costs are about to go up massively.

My GP bulk bills, which is great, although I now have to look for another GP because she's moved. Unfortunately, I just go to the closest bulk billing GP and they're usually registrars, which is fine, and they're usually really good, but registrars move around. I'm constantly cycling through GPs. It would be really good to be able to see your GP and have that be my GP, especially because I have lots of conditions. For management it would be easier to see one one GP but financially, it's not really viable because sometimes I'll need to see them once or twice a week. So if I was paying like \$70 an appointment or something I wouldn't be able to afford that on DSP.

My major medical expenses are psychologist appointments. And my rheumatologist appointment once every three to six months is \$150 so that's not too bad. But I've now got to go and see a psychiatrist and a neurologist and a heap of other specialists. Yeah, it's gonna get expensive. That's why I was trying to get on the DSP before I have to have all of these appointments.

Up until recently, whenever I saw psychologists, it would be once a fortnight for six months, and then wait six months for the next mental health care plan, which is not ideal, especially

if you're dealing with PTSD. Trauma work requires regular appointments. Fortunately I am now able to go through victims of crime and get 20 free appointments through them.

Aspirations

In terms of goals and aspirations for the future, I do have a few, though they are a little murky at the moment as a result of my sudden and rather severe health crash.

I have thought about having kids in the future. But in my mind it's always been that I won't be able to have kids unless I have some sort of stable employment. I've never thought about having kids on the DSP. I wouldn't feel like I could meet their needs as well as my own.

In terms of employment, I would love to be able to get to a point where I am able to work at a full-time level doing something I am passionate about in a workplace that is flexible enough for me to be able to work around my health issues.

I would love to pursue my studies a little further over the next few years (honours and postgrad) and a career in academia would be amazing, though probably not possible on a practical level. Realistically, if I were to go down that path, if I wanted a job, it would have to be overseas because there aren't enough jobs here. And because of my precarious health, I would be worried about going overseas and not having access to those supports. And I also have a fear about cutting myself off from DSP and leaving public housing. If I went overseas, and then got six months down the track and realised that I couldn't function and I needed to return home I'd be back at square one.

What I would really like to do is help the invisible people in society who don't get a voice and who don't get seen but who struggle every day just to survive, but I don't feel like I have the capacity to do that anymore. I initially went to university to study psychology with the rather outlandish plan of setting up a not-for-profit organisation that could offer portable mental health support to unhoused residents.

Once I became increasingly physically incapacitated I lost confidence in my ability to achieve anything of any significance, so I switched degrees and now don't really have any firm conception of where I am going and what I am capable of in any practical sense.

In terms of other long-term goals, they are just dreams, really. I want to go hiking in beautiful places, go travelling, ride my bicycle across Australia, train for a triathlon, have a family, buy a house and write short fiction. And I would love to be able to reliably look after a dog.

I think the reason I struggled with this question is (and perhaps a lot of people don't realise this) it is very difficult for someone with complex psychosocial and physical disabilities to conceptualise any sort of a 'normal' future because our society is set up for able-bodied, able-minded individuals who can work 40 hour weeks, go to the gym, socialise on the

weekends and 'manage' life the way we are taught we need to be able to in order to be a successful and functioning member of society.

I would love to be able to have a long-term relationship, socialise with friends without being drained for weeks afterwards, go hiking, travelling, start running half-marathons again, get my garden up and running and be able to do all the things I dream of, all the things I used to be able to do.

Coming to terms with being disabled is terrifying, and just because we can't do the things other people can do, it doesn't mean we don't want to. When I am bedbound and my brain isn't working properly and I'm struggling to survive on income support, it doesn't mean I want to be like that. I would give anything to be able to live the life I see other people around me living, to be the person that our ableist social structures are designed to accommodate. But I'm not. And this is why I find questions about future goals so difficult to answer.