Submission on my personal experience with DES service providers

Personal Situation

I am a 46-year old woman with moderate disability, that is not immediately visible. I have a number of medical conditions, including myalgic encephalomyelitis (ME/CFS), type 1 (insulin dependent) diabetes, post-traumatic stress disorder (PTSD), adenomyosis, endometriosis, bilateral carpal tunnel syndrome/trigger fingers/RSI, Irlen syndrome and osteoarthritis in my knee, all of which have differing impacts on my ability to find and sustain suitable employment.

I experience daily pain and limited mobility, insomnia from pain and anxiety, extreme light sensitivity and frequent severe headaches, memory issues, at times debilitating anxiety, digestive issues (diarroeah, nausea, occasional vomiting, some from the side effects of pain medications), fine and gross motor control issues and extreme exhaustion.

I am on Jobseeker, and have been since being removed from the single parent pension (PPS) in December 2020, when my youngest child turned 8. Jobseeker is extraordinarily hard to live on as a disabled single parent with three children – even with Family Tax Benefit, we struggle to afford basic expenses after rent and bills are paid. Undoubtedly, having to choose between diesel to travel to DES provider appointments, pain medications and nourishing food (such as fresh fruit, vegetables or meat), has a negative impact on my health and my ability to find or sustain work, especially given the added and significant stress I am under just because of this.

As a single parent (who escaped family violence) with three children, aged 13, 10 and 9, I am very motivated to find work, and have almost completed an Honours degree program at the University of New South Wales, which I started while on the PPS, first attending TAFE to qualify for university entry. I have a grade point average of 81.2 and have worked hard for this, in spite of significant pain, exhaustion and other barriers to study. I am not eligible for AUSTUDY while I complete my program, given my limited, part-time capacity.

I am now completing a professional experience unit, my final Honours degree requirement, which is an internship where I am helping build a website for my supervisor. I have completed approximately 90 hours' professional experience, and have 60 hours left to complete my degree. I consider this professionally relevant: I will have a current verbal reference from my supervisor, as well as job-ready skills following this.

Unconscionable handling of my temporary medical conditions by my ESAT assessor

I am on a public hospital waiting list for two surgeries, and I am sure this is not uncommon for people with disability to have temporary incapacity while waiting for surgery, or when their medical conditions worsen. First, I need a hysterectomy for my adenomyosis and endometriosis, having exhausted all non-surgical options and an endometrial ablation in early May 2021. Although I do everything I can to mitigate my pain and exhaustion medically while I wait for surgery, these conditions have been steadily worsening since 2017. I have asked my surgeons to expedite my surgery, but this is up to them, and I am still on a public hospital waitlist, and I cannot change elective surgeries in NSW being on hold because of Covid-19.

Following the failed ablation last year, I am now, at times, struggling to sit up for more than a few minutes, and perpetually in exquisite abdominal, pelvic and left front shoulder pain (a strange central nervous system glitch but present all the same), physically weak, chronically inflamed, anaemic, exhausted, and with unmanageable blood loss and clotting during my periods (24-26 day cycle), where I am left for 2-3 days either slumped over the toilet (my blood loss is so heavy and fast, this is all I can do), or in bed, too weak to move. I am really fighting to look after my children and do 2-6 hours' internship work weekly, although I am proud when I manage this, too.

My second upcoming surgery is for recurring bilateral carpal tunnel syndrome and trigger finger releases, meaning I am also limited with my fine motor control. I experience burning pain and numbness in my hands, wrists and arms, which affects my ability to sleep, write, use a keyboard, turn taps, drive and carry out normal tasks around the house, and so on. This also clearly negatively affects my current ability to find and sustain work.

My GP is supporting my temporary incapacity until surgery via Centrelink SU415 medical certificates. That said, my ESAT assessor in mid-January 2022 (while on an active SU415 medical certificate) advised that Centrelink will no longer accept these while I wait for surgery, even with elective surgeries on hold due to the NSW Omicron outbreak.

The assessor cited that I had had a medical certificate in 2018 – this was on 17 December, 2018, for my previous ESAT assessment in February 2019 – and that I could not stay on medical certificates indefinitely. I was not on SU415 medical certificates from 2018 to 2020. I have been on SU415 medical certificates since after my unsuccessful trigger finger surgery in December 2020, then again, before and after my unsuccessful endometrial ablation in May 2021. I obviously could not control the success or failure of either of these procedures, nor my needing them, nor my incapacity following them and leading to my upcoming surgeries.

After my ESAT assessment, I called Centrelink, who said they will still accept my medical certificates at this stage. However, I have no control over the elective surgery waitlist and its suspension due to Covid-19, and I do not know when I will have surgery. The uncertainty over whether Centrelink will continue to accept my doctor's medical certificates makes me more incapacitated by extreme stress triggering my PTSD, including elevated anxiety and experiencing more frequent, debilitating and exhausting panic attacks about whether I will be supported until I can have surgery and recover, even though my doctor supports me.

My ESAT assessment is as limited capacity, for 8-14 hours' work weekly, which, when I am not sick and waiting on two surgeries, I would agree I am capable of doing.

That said, my ESAT assessor told me, several times as I failed to understand why, that means I am supposed to do 15 hours' weekly. Given I can barely do 2-6 hours' internship weekly with my current temporary incapacity, the assessor's assertion that I must now do 15 hours' weekly made me contemplate suicide. I am despondent and panicked about my medical certificates being rejected and working 15 hours, when I am clearly unable to work even 8 hours until my surgery.

Please note, I have not been able to work 15 hours' weekly since I was 24 and, even then, I was unable to sustain this. During my degree program, I had significant extensions via the UNSW Equitable Learning Services and Special Consideration processes to manage three-quarters full time study, and that was before I experienced a significant downturn in my health since late 2019.

After my ESAT assessment, I called Lifeline and then a DES advocacy lawyer, who advised to wait until Centrelink sends me a letter rejecting my medical certificates, upon which time I may take action, appeal Centrelink's decision and lodge a formal complaint against Centrelink and the Commonwealth Ombundsman.

All the same, I remain extremely stressed about the prospect of my SU415 medical certificates being rejected, when I am too sick to work 8 hours, yet alone 15. I have no idea what I will do if I am required to work beyond my capacity, at 15 hours, when I can barely sit up or stand. It also makes me feel hopeless and a failure.

Despite the ESAT assessor's adamant claims that I need to now work 15 hours' weekly, Centrelink reassured me that the wording of "8-14 hours capacity, working towards 15 hours within the next two years" is standard for an ESAT assessment of limited capacity of 8-14 hours, and it does not mean I actually need to achieve 15 hours weekly. They also indicated that adding this wording to a limited capacity assessment of 8-14 hours' work weekly causes significant distress to many Jobseekers with similar, permanently limited capacity.

I would like to know why "working up to 15 hours within two years" is stated in my ESAT, and standard. It sets up unrealistic expectations of failure – I will most likely never be able to work 15 hours, even if I dearly want to do so. It also seems to give my ESAT assessor and DES provider an excuse to push me beyond my capacity, before I have even found and sustained successful employment for 8-14 hours. To me, this is unconscionable.

Centrelink also did not advise me there was a time limit to my SU415 medical certificates and that, even if I am so sick I can barely stand, I will be required to work beyond my normal capacity once they decide to refuse accepting them. I had a panic attack during my ESAT assessment, when the assessor began by saying that Centrelink will be rejecting my SU415 medical certificates until I have a surgery date. Surely, this is not my fault? However, I was made to feel this was the case and was genuinely shocked when I was told they would be rejected. How is my doctor wrong about my temporary incapacity, and how does my ESAT assessor or Centrelink decide that I am not incapacitated, when I am?

The assessor also referred to my serious medical conditions as "your women's problems" and my myalgic encephalomyelitis as "chronic fatigue syndrome"; ME/CFS is far more than just fatigue. I was offended that my disabilities were thus diminished linguistically by the ESAT assessor, when they have significant negative impacts on my wellbeing and my ability to work.

When I asked the ESAT assessor, in a very distressed state because I am unable to do 15 hours' work at present, what I could do other than kill myself, her answer was to apply for the Disability Support Pension. I stated I would not be eligible for this, because my conditions are fluctuating and not stable (they should improve with surgery), and that, normally, I want to work 8-14 hours a week. The assessor advised I could 'buy time' while waiting for surgery by applying for the DSP, but I have applied for and been rejected for the Disability Support Pension before. It is a significant and stressful process, and it feels terrible to have my disability be rejected and shunted down to Jobseeker, with its connotations of laziness and bludging (I am neither, I am permanently partially incapacitated, and temporarily fully incapacitated, however).

I will note that, at no point did the ESAT assessor discuss my functional limitations or employment barriers based on my disability, nor what workplace adjustments I might require, and cut me off when I attempted to do this. Nor did my assessor confirm the number of hours I was assessed to work for; I had to do this with Centrelink after the assessment. The assessor seemed intent to bump me off medical certificates for my temporary medical conditions and push me to work beyond what I am able to do normally, let alone now, while incapacitated and waiting for surgery.

In spite of my stating I was having a panic attack and trying to manage this during the call, the assessor repeatedly threatened to terminate the assessment, in spite of my not swearing nor threatening them, although at one point I did ask them, albeit politely, whether they could live with themselves for doing this to people with disability who were clearly too sick until their surgery to work 15 hours' a week. I did not feel believed nor validated by the ESAT assessor, even though my incapacity is real.

Degrading and unethical treatment by my DES providers, exacerbating my disability, including my anxiety-based mental health disorder

My experiences with DES providers themselves has been similarly terrible, and I find I am often calling Centrelink or referring to the Social Security Legislation guides to cross-check facts with which they have misled me. I have also had to indicate in writing that I will take matters to the Commonwealth Ombundsman, in order to avoid their harassing me and adding significant stress, which, in turn, adversely affects my health and my ability to work.

My DES provider is aware of my anxiety disorder (PTSD), yet has at times persisted with causing extreme stress and making me feel literally sick with worry that I will incur demerit points and lose my Jobseeker, with serious consequences of not being able to afford rent, bills, medicines or to feed my family.

My initial DES provider representative in December 2020 did accept my study course towards my mutual obligations and was kind, but left their job. They also insisted I include details of my medical conditions and treatment in my Job Plan, even though this is not necessary nor appropriate in the context of my job seeking or studies. I found this aspect embarrassing and demeaning, as I do not always disclose my medical conditions to others but obviously need to as part of this system. I did question this but was not given the option to say no to having these private medical details included in my Job Plan.

My first DES provider representative's replacement in early 2021 was an awful person towards me (see this section), so I changed DES providers, only to find the next two DES providers were just as bad. Because I am only able to change providers five times, I am trying to stay with my current DES provider, even though many of their actions have been, to me at least, degrading and unethical. Regardless, because I have only had one, relatively short-lived, mostly but not completely positive experience with a DES provider, and three extremely negative ones, I do not have a lot of faith that changing DES providers again will help.

I believe my DES provider and ESAT assessor act unethically when they consistently say that being assessed for 8-14 hours' work weekly means I must immediately find work for 15 hours. Not only does the Social Security Legislation indicate, but Centrelink have confirmed four times with me, that 8-14 hours' weekly work capacity means exactly that, 8-14 hours.

I can only assume that my DES providers and ESAT assessor do this because, according to the Social Security Legislation, I am actually voluntarily at a DES provider in the 8-14 hour capacity band and, officially, could do a Job Plan and fulfil this direct through Centrelink. I am unsure about this, however, because this has never been offered to me by Centrelink and I have always been referred, automatically, to do my Job Plans and mutual obligations via a DES provider.

It will be noted that Centrelink and my DES provider often seem to ping matters to and from one another, indicating responsibility for certain decisions around mutual obligations to be with the other party and, therefore, absolving themselves of any responsibility. It took the human services advocacy lawyer's advice for me to understand that Centrelink are the final authority with decision making around my mutual obligation requirements. I really do not think I should have to read social security legislation, nor consult lawyers, to have the rights to which I am entitled be followed by my DES provider.

I also think that DES providers that mislead clients about their rights and mutual obligations requirements should be penalised for this. It is very stressful to be pushed to do more work than you will ever be physically capable of doing. It exacerbates my medical and mental health conditions and disabilities, and makes it far less likely that I will succeed in finding sustainable work, appropriate to my work capacity.

As another example, my DES provider refuses to acknowledge that I am entitled, under the Social Security Legislation but not to mention common sense, to complete the degree program that I have been working towards while on my Single Parent Pension. I have spent 7 years completing this, and am almost finished. My UNSW internship is directly job relevant. My DES provider simply says yes, I am legally entitled to complete my studies, but no, they will not put it on my Job Plan and consider it as hours towards my mutual obligations requirements.

Bearing in mind I have limited job capacity, so, if my internship is not considered mutual obligations, I am unable to do it and find work to 8-14 hours as well (or outside my capacity, at 15 hours, which is what my DES provider keeps saying). The legislation also indicates that this study *should* be included on my Job Plan. Why does my DES provider refuse this?

When I asked Centrelink what I could do to have my UNSW degree internship included in my Job Plan, they advised me twice to go to my doctor and get SU415s to complete this without the strain of active job-seeking mutual obligations as well. I am honest, and did not like the idea of misleading Centrelink by being on medical certificates without medical need, and could not understand why I would need to resort to this to complete my degree program. It transpires that I needed medical certificates anyway, following my failed surgeries while I await my next ones, but I am still outraged that my only option to complete my studies is to get medical certificates and circumvent my DES provider.

I am a constant tenterhooks about this, in that if I cannot complete my degree because I am busy doing other job-related mutual obligations requirements, it will break my spirit, or what little remains of it after just one year of navigating the Jobseeker mutual obligations and DES provider system. I am extremely anxious about being allowed to complete my studies. This anxiety slows my study progress because it exacerbates my PTSD and medical conditions and makes me sick, thereby blowing out the time it is taking me to complete my degree.

All I can think is, my DES provider does not profit from my completing my studies independently, so does not wish to support it. They really do not seem to care about my individual needs and goals professionally. It has gotten to the point where I do not trust them at all to actually help me find appropriate work when the time comes for me to do so, when I finish my degree program and have recovered from at least the first of my two upcoming surgeries, hopefully this year.

My DES provider has also harassed me to complete Job Plans and attend phone interviews while I am on approved Centrelink medical certificates exempting me from mutual obligations, including once while I was in a waiting room for an ultrasound-guided cortisone injection for bursitis in my hip, and not allowed to be on my phone. Another time was on the day before my endometrial ablation, while I was busy preparing for surgery, packing my and the children's bags, and stressed enough about the surgery the following day, yet alone thinking about Job Plans and mutual obligations requirements. I attempted to reschedule this for a week after my surgery – not unreasonable given I was having general anaesthetic, which may have affected my ability to reason and make decisions afterwards – and my DES provider refused this, continuing to coerce me into making a Job Plan when it was clearly not an appropriate time to do so.

I will also note that the mutual obligations quota system, of applying for a certain number of jobs each month, adds significant stress, which exacerbates my anxiety disorder. Having an arbitrary quota like this actually immobilises me with anxiety and makes it harder for me to function to find work. I would far prefer not to have quotas but be encouraged to apply for jobs; that way I will most likely have the capacity to apply for more. The pressure quotas put on me as a Jobseeker with an anxiety disorder – not to mention, the pressure of mutual obligations generally – does the exact opposite of helping me to succeed in finding and keeping a job.

I really do believe finding work with a DES provider and Job Plan should not exacerbate my mental health condition, and in turn, my physical disability. There must be a way to encourage me to find work without putting in punitive quotas and making me feel overwhelmed with anxiety about my ability to physically meet them, or whether I will be able to continue to receive Jobseeker to house and feed my children as a single parent.

My DES provider also advised I need to attend (pointless) training courses, for example a CV writing workshop, when I have almost completed a degree program, and have written a CV and portfolio as part of this.

I am very hesitant to attend DES training programs, as I attended one voluntarily in 2011 and it was run by Christians, who forced their religion upon me. I advised my DES provider at the time of this, but I find that unacceptable – while I appreciate many charities are Christian, I do believe religious beliefs and DES employment training programs should be kept separate.

Additionally, my current DES provider's training courses are an hour and 20 minutes' travel each way from my home, costing me significantly physically and energetically, a big factor with my disability. Under the social security legislation, I should be allowed to decline this training activity because of my status as a single parent Jobseeker because it is more than an hour each way away by my regular transport. Yet, my DES provider indicated I would lose my Jobseeker if I did not attend.

I would note that, I voluntarily attended a UNSW Employability Careers Expo for my industry in late October 2021, in spite of my poor health at the time. The workshops I attended had CV and portfolio writing tips, identified goals and career paths, interviewing techniques and seminars from industry leaders and professionals. I did this, in between resting in bed, from home on my computer, at times watching recordings when I could not sustain my attendance. I believe this shows I do intend to find suitable work, but I would like to finish my professional experience and degree program, and recover from my much-needed surgery, first.

I would also like to attend suitable and necessary training only, in an appropriate format – online? - that allows me to rest and not have my health exacerbated by attending. How is this so unreasonable to my DES provider?

Furthermore, where we live, there is no outside school hours child care available for my primary aged children. Meanwhile, my high-schooler has serious chronic illness and needs significant medical management, and there is no child care available outside school hours for high school aged children. It is not safe to leave her unsupervised for long periods, although her condition is not considered serious enough for the Carer benefit. These represent additional barriers to employment, and fulfilling my mutual obligations requirements under Jobseeker. I am unsure why it is not okay for single parent Jobseekers to look after their children during school holidays, given my 13-year-old is at risk of coma and death if unsupervised for long, and that none have access to childcare, but my DES provider indicated all my mutual obligations would continue for that time, and that, even with my limited capacity, I could juggle DES provider appointments, mutual obligations and looking after my children adequately.

I would also note that, after Covid-19 restrictions were lifted and mutual obligations requirements were tightened, in March 2021 (?), my DES provider required me to travel 1 hour and 20 minutes to their in-person interviews, in spite of this being possible online or over the telephone from home. Despite my being a single parent Jobseeker, and therefore, legislatively, able to decline this or find alternatives, given the significant physical strain and expense of driving more than an hour from home to attend, my DES provider required it and did not let me use alternative interview formats, such as telephone or online meeting.

I mentioned to my DES provider, who did not seem to care, that such travel to DES provider interviews impacts my ability to do my UNSW internship or attend job interviews. I would rather use my strength, energy and money to attend a job interview than an appointment with my DES provider that I can do over the phone.

I also brought up that I am vulnerable to Covid-19, so would prefer not to attend in person. My DES provider declined to take that into consideration, but I think this should be considered for people with disabilities who are vulnerable to Covid-19. The fact is, we are vulnerable and should have some option to attend in alternative ways that do not exacerbate our disability and medical conditions, nor increase our risk of Covid-19, severe illness and death.

Conclusion

Although I look forward to finding work after my degree and surgery is completed, I am also feeling very downcast that I am not able to wait to complete either of these things, even though I am clearly incapacitated.

I feel like I fall through the cracks, being not permanently disabled enough for the DSP, yet also not well enough to keep up with my mutual obligations requirements under Jobseeker. It causes me significant stress and has made me feel suicidal at times, after just over one year using DES providers. I do not think attending a DES provider should mean I am traumatised, pushed to suicidal thoughts because I have no hope of fulfilling my mutual obligations with them, and experiencing the sense of hopelessness I now find myself in, in spite of being motivated to complete my studies and find work. I have, frankly, enough to contend with as a single parent with disability, and I do not need more. I would like real support in helping me find a job, rather than the seemingly constant threat of losing my Jobseeker, forcing me to ignore my legal rights and disability needs, even though it seems impossible I will meet my DES provider’s requirements. It feels like I have no choice but to fail, when all I want to do is complete my degree, heal from my surgery, and then find a suitable job.

Thank you for reading this. I feel helpless in the Jobseeker system and with my DES provider, and this has helped me to feel heard.