

Living on the Disability Support Pension

10 case-studies and analysis by Dr May Lam

*Commissioned by
the National
Welfare Rights
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About the researcher



May has worked in the employment and community sectors for the past 22 years, after earlier experience as a secondary teacher and university lecturer. She has a Masters Degree in education, focused on the reproduction of inequality, and a PhD in cultural studies from Melbourne University.

From 1992 to 2005 May worked in policy at Jobs Australia, the national peak body for not-for-profit organisations providing employment and related services. From 2005 to 2008 she worked in employment services policy and research in the UK for the employment services company, Ingeus, and for three months on secondment to the Department of Work and Pensions.

Between 2011 and 2013 May was Deputy CEO and Policy Manager at Jobs Australia. She worked as a consultant during 2014, when she undertook this research for the National Welfare Rights Network, then joined the

National Employment Services Association in August as a senior policy advisor.

May is interested in how government policies shape the way individuals access and use public services, and how this affects their personal identity and the way they make sense of their lives. She is currently Chair of Writers Victoria.

About the National Welfare Rights Network

The National Welfare Rights Network (NWRN) is the peak community organisation in the area of social security law, policy and administration. Its aim is to reduce poverty, hardship and inequality in Australia by advocating for a social security system which is fair, adequate and well-administered.

NWRN members are community legal centres and organisations whose role is to provide disadvantaged people with free information, advice, education and representation in the areas of social security and family assistance. NWRN members operate in all states and territories of Australia. Their services are free and independent.

The NWRN develops policy about social security and family assistance based on the casework experience of our members. It provides expert feedback to Government on new and proposed changes to welfare law and policy. NWRN also works to raise awareness of social security issues to inform the work of other organisations in advancing public welfare.

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Introduction

The National Welfare Rights Network (NWRN) commissioned this research project at a time when the Commonwealth Government increasingly expects and requires people with disability on income support to look for and gain paid employment. In response, the research seeks to better understand how people living on the Disability Support Pension (DSP) manage their disability, their past experiences of learning, work, and participation, and how they see their prospects in the future.

The researcher interviewed people currently on the DSP, resulting in 10 case studies. Though every individual is assessed separately for the DSP and each case is different, the case studies show that DSP recipients share common experiences in trying to study and work, navigate the employment services system, and manage their disability, illness or health condition. From these reported experiences it is possible to form an emerging picture of how the system works for such people; that is, how increasingly work-focussed assessments, referral to employment assistance and expectations of achieving paid employment can affect people such as those in these case studies. It can also deepen understanding of what kind and level of income support is enough to manage disability and increase prospects for participation.

The NWRN is indebted to People with Disability Australia and Mental Health Australia for their advice and assistance in establishing this research project.

The NWRN thanks the people who participated in the interviews, who so generously and bravely shared their experiences.

Employment activation for people with disability 1991-2015

This section provides the policy context for the research project, explaining the evolution of the systems through which the government both supports and challenges people with disability who apply for the DSP.

The Disability Support Pension was introduced in 1991, replacing the earlier Invalid Pension. The Government wanted to reduce numbers going onto the pension, aware that the ageing of the population following the post-war population boom could be expected to swell DSP numbers significantly, along with the overall welfare bill.¹

Since 1991, three complementary aspects of government policy have been designed to address this challenge: tighter assessments to qualify for DSP; the provision of employment assistance for people with disability; and the introduction of increased activity requirements to look for work, with sanctions for non-compliance. The report considers each of these aspects in turn.

¹ Bills Digest No 157 2001-2002: Family and Community Services Legislation Amendment (Disability Reform) Bill 200.2 Accessed from <http://www.aph.gov.au/binaries/library/pubs/bd/2001-02/02bd157.pdf> on 26 September 2014.

Assessment

In 1991, the Invalid Pension was re-named the Disability Support Pension. The reform introduced new impairment tables, which assess levels of disability, and brought in an important new qualification requirement, namely that to be eligible an applicant would not be able to achieve work at full-award wages for at least 30 hours a week for the next two years.

The changes in 1991 were also intended to address concerns that Commonwealth Medical Officers were taking socio-economic factors too much into account. At that time, labour market competitiveness could be factored into the decision to award DSP. From March 1987, for example, guidelines for DSP assessment required that the 85 per cent incapacity-to-work demonstration be made up of at least 50 per cent medically based incapacity.²

In 2006 DSP eligibility was tightened again, limiting it to people with less than 15 hours a week of work capacity. From the beginning of 2012, revised impairment tables defined further conditions to qualify for DSP.

In 2012 a 'program of support' requirement was added to the eligibility criteria for DSP, to demonstrate that a person cannot get a job even with assistance. Although exemptions apply, the change generally means that to qualify for the pension, applicants must participate in a program of support for at least 18 months aimed at securing employment, usually through registration with a Job Services Australia or Disability Employment Services provider.

Activation to achieve paid work

Tightened eligibility for the DSP through the assessment process has been part of a larger policy agenda of labour market activation for all people of working age claiming income support. Participation requirements have similarly extended over time to more single parents and more women who would previously have qualified for the age or widows pension, as well as for people with a disability.

To help deliver the labour market activation agenda, since 1997 all employment services have been contracted out. In 2014 services were contracted through Job Services Australia, Disability Employment Services, and the Remote Jobs and Communities Program, which is intended to address remote and Indigenous disadvantage. Across these three programs, providers are paid higher fees for people who are harder to help. This service system to help people prepare for and find work underpins the government's policies to require attendance at appointments and other forms of assistance, and to apply sanctions in the form of benefits reduction or cancellation where attendance is not achieved after a system of warnings.

Over time, the Government has reduced from 30 to 15 hours the minimum hours of assessed work capacity before someone can be compelled to look for work. As a result of recent budget initiatives, some DSP recipients will have their minimum hours of assessed work capacity reduced to eight.³ At

² Ibid.

³ *Bills Digest No 70 2005-2006 Employment and Workplace Relations Legislation Amendment (Welfare to Work and Other Measures) Bill 2005*, Parliamentary Library, Canberra, 2005. Accessed from http://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/bd/bd0506/06BD070 on 26 September 2014.

the same time, the Government has introduced incentives for people on DSP to work, for example, introducing a provision to allow DSP recipients to work at least 15 hours a week and up to 30 hours a week without losing eligibility for the payment.⁴

Since July 2012, DSP recipients under age 35, with a work capacity of at least eight hours a week, have been required to attend regular interviews with Centrelink to develop participation plans to help build their capacity to work.⁵

Under 2014 Budget measures,⁶ people on the DSP aged under 35 and who are able to work more than eight hours a week will be required to take part in compulsory activities that focus on employment. These activities may include job search, work experience, education or training, Work for the Dole, rehabilitation or engaging with an agency, such as a Disability Employment Service or a Job Services Australia provider.⁷

In a further measure announced in the 2014 Budget, 28,000 people under 35 who were assessed for the DSP between 2008 and 2011 will be subject to reassessment using the new impairment tables.⁸

Compliance and sanctions

To ensure that recipients of working age payments other than DSP attend and actively take part in job search requirements or activities such as Work for the Dole, Centrelink and employment services providers report non-attendance, warn people of the consequences of future non-attendance, and reschedule missed appointments. If non-attendance continues after the required warnings, income support payments are suspended. In the case of serious failures, an eight-week non-payment period can be applied.⁹

Since March 2013, employment service providers have been only required to make one attempt to make contact with job seekers before a participation report is submitted.

At the time of writing, there is a proposal to expand activity and compliance measures for DSP recipients. Under the proposal, people on the DSP with eight hours or more work capacity who are subject to compulsory activities can have their DSP suspended for non-compliance. The foregone payments can be back-paid if they comply within 13 weeks, but not if there is a second instance of non-compliance with activity requirements within a 12-month period. With a third instance of non-compliance in a 12 month period, the DSP will be cancelled and the person will need to reapply and be assessed against the stricter current Impairment Tables.¹⁰

⁴ *Social Security Act 1991* (Cth) s 96.

⁵ *Social Security Act 1991* (Cth) s 94(1)(da), 94A.

⁶ *Social Services and Other Legislation Amendment (2014 Budget Measures No. 6) Bill 2014*.

⁷ Department of Social Services, Budget Measures 2014 Implementation Briefing, June 2014.

⁸ It is estimated that approximately 5 per cent (1,400) of DSP recipients reviewed under this measure will have their DSP cancelled over the 18 months from 1 July 2014. Estimates are based on data from outcomes of medical reviews undertaken against the revised Impairment Tables (since January 2012). Source: Senate Community Affairs Committee, *Answers to Estimates Questions On Notice*, Social Services Portfolio 2014-15 Budget Estimates Hearings, Outcome Number: 1 Question No: 67.

⁹ Information about Activity Test/Participation Requirements, Department of Human Services, sourced from <http://www.humanservices.gov.au/spw/customer/forms/resources/su450-1409en.pdf> on 26 September 2014.

¹⁰ *Answers to questions on notice*, Social Services Portfolio, 2014-2015 Budget Estimates Hearings, Question No. 144.

The DSP claimant population: numbers, characteristics and trends

On the latest figures, from June 2014, 832,454 people receive the Disability Support Pension.¹¹

The largest cohort of people on the DSP comprises people aged 55 to 64, who make up 38 per cent of all recipients. People in the 45 to 54 group make up 25 per cent of people on DSP, the 35 to 44 group 16 per cent, and people under 35, 17 per cent. Those over 65 account for four per cent of all disability pensioners, a rapidly growing age group among DSP claimants, up from 0.9 per cent since 2004.¹²

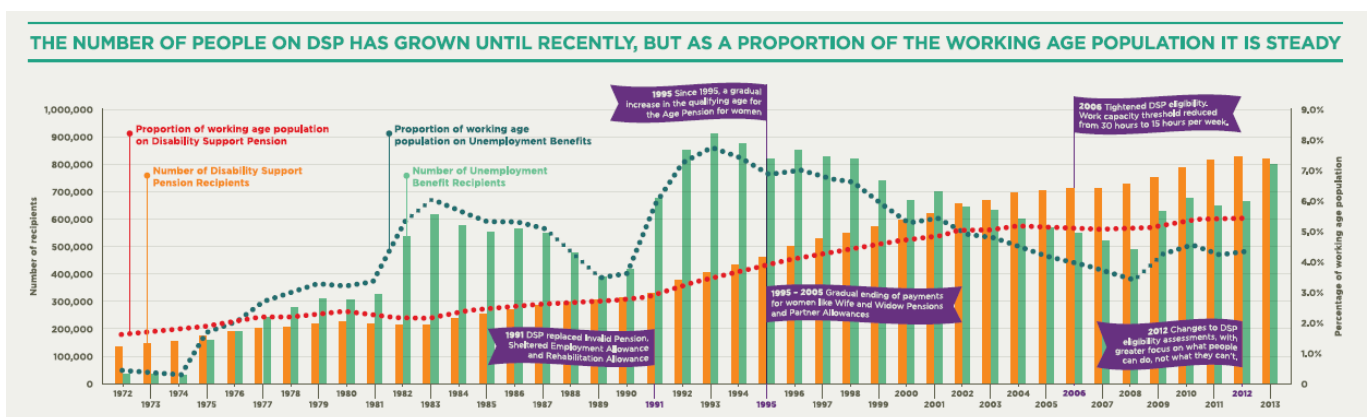
Since 2011, psychological and psychiatric illnesses have topped the list of the main presenting medical conditions for those receiving the DSP, at 31.7 per cent. Musculo-skeletal and connective tissue conditions are next, at 25.6 per cent, followed by intellectual and learning disability, at 12.5 per cent. Together, the top three medical conditions for the DSP account for seven in 10 people eligible for the DSP.

Levels of disability among the Indigenous population are significant. At March 2014, 46,511 Indigenous people were receiving the Disability Support Pension, 6 per cent of DSP claimants.

Around three quarters of DSP recipients are single, at 73 per cent.

It is useful to distinguish between growth in the actual numbers of people claiming DSP and the proportion of the overall working age population on DSP. The proportion of working age people on DSP has remained relatively steady since 2002, at between 5 and 5.5 per cent, as the red dotted line in this infographic below from Jobs Australia shows.¹³ In other words, the numbers of DSP-eligible people have indeed grown, but no more than overall population growth.

DSP claimants as a proportion of all working age people has been contained even while the population has aged and an increase in people in the older age groups, along with the raising of the qualifying age for the age pension for women, might be expected to result in higher proportions of people on DSP.



¹¹ Department of Social Services, Payment Recipients Data, March Quarter 2014. At: www.data.gov.au/

¹² Department of Social Services, *Characteristics of Disability Support Pension Customers*, June 2004.

¹³ Sourced from <http://ja.com.au/Infographics>. This is based on 2008-2012 data from the Department of Families, Housing Community Services and Indigenous Affairs, the Department of Employment Education and Workplace Relations and the Australian Bureau of Statistics.

How the research was conducted

The National Welfare Rights Network commissioned the research in June 2014. It coordinated the recruitment of people to be interviewed, with the help of People with Disability Australia (PWDA) and Mental Health Australia (MHA), both national disability peak organisations. These consumer groups were also consulted for advice about information to be provided to prospective interview candidates, the interview questions, options for interview and the forms of assistance that should be offered to support interviews.

Dr May Lam, an independent researcher, conducted the interviews and wrote up the case studies. All names have been changed and references to places of residence or other identifying information have been removed to protect the privacy of interview subjects.

Recruitment and sample

The NWRN, PWDA and the MHCA provided information about the research to people receiving the Disability Support Pension, along with a form for people to express interest in being interviewed. The form indicated ways that interviews could be conducted (by phone or Skype or in person where possible) and any supports (interpreter, carer to attend) that might be required.

Thirteen people completed forms expressing interest. They were contacted as their forms were received to discuss and arrange times for interviews, until 10 people were interviewed. The sample for the research is thus an opportunity sample arising from those who were provided with information about the research and were willing to take part; it was not a sample constructed to match the characteristics of people on DSP. However, the sample (see table below) covers a range of ages, includes both men and women, and also reflects a range of types of disability or health condition and the stage in life at which these were acquired.

A notable feature of the sample as a whole is the prevalence of mental illness, both as a primary condition and one accompanying the primary disability.

Anonymity

People contacted for interview were advised that their identity would not be revealed in the case studies written up from their interviews. Pseudonyms have been assigned. To ensure that interviewees are comfortable with the level and kind of information to be published, copies of their written up case studies were provided to participants for checking and signoff.

Summary of participants interviewed

Name assigned	Age	Disability/health condition	Year qualified for DSP	Interview method
Kevin	58	Neurofibromatosis, chronic fatigue	2004	Phone
Katrina	52	Chronic pain, anxiety, restricted mobility	2010	Skype
Melissa	32	Asperger's syndrome	2000	Skype
Dean	37	Mental illness (schizo-affective disorder)	1998	Phone
Lauren	20	Chronic pain, depression and anxiety	2013	Face to face
Mark	27	Bipolar disorder/depression	2008	Requested written interview
Anna	50	Psychological issues, chronic ill health	2008	Phone
Lucia	52	Brain injury, depression	2014	Phone
Marie	24	Asperger's syndrome, depression	2007	Phone
Aleks	51	Spinal cord and musculo-skeletal injury	2008	Phone

Interview process

Interviews were semi-structured and lasted in general around an hour. Questions to be asked were established in consultation with the NWRN, PWDA and the MHCA. These are included at Appendix I.

The case studies

Readers of this report are strongly recommended to read the case studies in full in order to understand how the experience of disability, health condition or mental illness has shaped these people's lives and prospects. It is also the best way to learn about the circumstances that led each person to claim the DSP, so readers can judge for themselves the importance and validity of each person's needs to continue on the DSP while they hope to get better and join the paid workforce where possible.

Lauren, 20

I might cry when I tell you my story, but I'm quite used to crying, so don't worry, you won't need to stop, I'm fine to talk while I'm crying.

When I was in Year 10 I started to have some anxiety symptoms. My mum is quite an anxious person, so that was relatively normal for me. I was throwing up a lot, not intentionally, and I lost a lot of weight. That year I also had a lot of joint pain from post-viral arthritis. I started seeing a counsellor.

The next year there started to be violence at home with my dad, and that compounded everything. I started having some depression as well, a lot of problems with my mood, my sleep, my energy. It continued all through my year 12.

In the house I didn't feel safe for about 12-18 months. There was a lot of invasion of my privacy and space, so for example

when I was crying locked in the bathroom my dad got a knife and opened the door, and after that you couldn't lock it. There was no space where I could be upset without him coming in and yelling at me for upsetting other people.

My parents thought it was teenage angst. They complained that I was always crying, always upset, moody, and they asked 'Why are we putting up with this?' I would self-harm after a violent episode at home, but they didn't want to talk about how that was wrapped up in what was going on with me. I was taking my medication in secret and claiming my psychiatrist payments after stealing my mother's Medicare card.

In March last year I moved out into privately owned student accommodation. I went to

Medicare and said 'What can I do to become independent from my parents?' and they laughed. I was assuming that Medicare was the same as Centrelink.

At Centrelink I couldn't get the independent rate of Youth Allowance because I hadn't been independent for a year, even though my parents weren't giving me any money. Centrelink said I could claim Youth Allowance for forced move out of home if it was unreasonable to live at home. But both my parents would have to sign the form. My dad doesn't trust authority in general with private information, so that wasn't an option.

The Centrelink lady said 'If it's not safe for you to live at home, what about your brother? If there's violence at home, DHS will have to come to your house and talk to your parents and your brother and he'll have to be taken away.'

I had a very suicidally constricted mind. I didn't want to make my brother's life hell and I thought 'If I'm

not going to be around for a lot longer, there's no point making him unhappy.' Anyway, with him being a boy, there was less risk of physical violence for him at home: he plays a lot of sport, so he could push back or hold door back.

So I decided not to claim money from Centrelink. I had about \$2,000 saved from the work I'd done before. My rent was about \$600 a month, so I needed about \$800 a month to get by, and I was earning about \$300 a week. All my money from work was going towards rent and bills and quite quickly my savings were going down. I wasn't cooking and I wasn't eating meals. I didn't learn to cook at home. I'm vegetarian and this was an issue: my dad used to try to make me eat meat. Dinner was always chaotic and emotion-filled. Also, with

When I got out of hospital my mum said "We're not going to support you"

my mental illness, I physically wasn't hungry. In that time I ate a lot of crackers.

I went to hospital after a suicide attempt. It was about a week before my 19th birthday, and I had this big thing that I didn't want to turn nineteen. Close to my birthday I kept thinking 'I don't feel safe, I don't feel safe.' I didn't feel safe around trains, around heights. I was quite delusional, I was having arguments with the chemist about how much medication I could pick up, telling my friends about how unreasonable my doctor was being, fixated on finishing the semester at uni – a self-imposed deadline.

At the time my GP kept saying, 'I can't hospitalise you in the public system, I can't do that to you.' I rang my parent's health insurance and they looked at the file and said I was covered until 21, even separated from my parents. I saw that hospital was a better option than to die.

It didn't help that for two weeks leading up to that there had been sexual assault, sexual violence from my boyfriend. And I was worried about money. By the time I went into hospital I had maybe \$200 to my name. I wanted everything to stop.

The CAT [Crisis Assessment and Treatment] team would come to my house and I would seem high functioning. They'd tell me I was so articulate. In the end I got a different CAT team, who looked at all the notes I'd been taking, including about how I wanted to be an organ donor, so then I was put on a list for the first bed that came up in a psychiatric hospital. My best friend came over and was on suicide watch for 48 hours.

In the end I stayed in the hospital for 5 weeks and it cost \$20. In hospital I met some people

who had been on DSP. I had no idea that psychiatric conditions could count: even my friend with cancer who was on crutches with her leg had been rejected for DSP.

When I was discharged from hospital they said 'Your risk hasn't gone down, but neither has it increased.' I got that. When you're agoraphobic, just the ward and a twenty minute walk a day is good. There was a risk I would never want to leave; it's safe in there.

When I got out of hospital my mum said 'We're not going to support you', and gave me \$2,500 of money from my grandma's inheritance. Anyway I didn't want to live with my parents, so I used that money first, then I went to Centrelink. This time I wasn't worried about what would happen to my brother; I had found

out by then that they treat each child's relationship with their parents separately. That could have saved me eight months of trouble.

My mother signed a family breakdown form for an

independent Youth Allowance claim, but my dad refused to sign any form that included the work 'breakdown.' By now mum was keen to be involved, so in the end she sat down and wrote that if I moved back home it would be a wedge in her marriage, and things would fall apart if I came back and she would have to leave.

When I was putting in the claim, I had a nice Centrelink officer who noticed my list of medications. He asked why I used pain medication and suggested I apply for DSP. I said 'It's not the pain, it's my mental health that's stopping me working.' He said 'You're eligible, you should get an assessment.' Because of my friend with cancer, I didn't think I would have a chance, but the man at

I had no idea that psychiatric conditions could count: even my friend with cancer who was on crutches with her leg had been rejected for DSP

Centrelink said ‘You will relapse if you try to find work again.’

When I went to the assessment about a month later I was feeling quite suicidal, so when the assessor asked what I saw myself doing in a month or a year, I just completely broke down. I remember him ticking ‘short term claim’ and feeling happy about that.

A month later I got a call that said I could go on the DSP, though first they wanted confirmation from my mum that she would not contribute to my support at all. I started on it last September and even got back pay. Then I had a complete mental health six months. I started going to conferences on childhood abuse and trauma, wanting to understand my experience and learn how I can help other people. I just came back from a national suicide prevention conference.

It’s only been about 3 months that I’ve had complete perspective. Getting better has just taken time, which is funny because time is exactly what you *don’t* want when you’re suicidal. The DSP has really helped. It was the validation, it was so nice to have someone say ‘This is debilitating, and this is serious.’ They said I had the capacity to work 7 or less hours. That was so nice. I don’t have to go out and look for work, I don’t have to go back to uni until I’m ready.

With the money on DSP I can pay my rent. I decided I needed to live with other people, so now I live with a mum and her daughter. I can buy healthy food, juice, kale, and sit down and have a healthy breakfast without having to force myself. I can have coffee with friends, without having to feel like I’m lesser to them.

When people ask how you are doing for money, they don’t mean they want to lend you money. It’s great to be able to say ‘I’m okay’.

I’m back part-time at uni, doing two subjects. A lot of my uni work is done listening to a speech device because I have concentration problems. A couple of months ago I started volunteering at a childcare centre for children with special needs. I wanted something with structured hours, something with people. I want to work in mental health policy later if I can.

I’m not ready yet to get a paid job. People don’t want an unstable person looking after their children or their files. Occasionally I go for two weeks when I find it really hard to get out of bed. Things that trigger stuff for me can be lighting, or people using certain words, or things like that. I don’t want to be to just suddenly hysterically crying.

I’m not planning to stay on the DSP forever. I just need it now. The idea that I’m sucking out money out of this pool of finite resources upsets me. It’s great to know there’s not the haste, or the pressure. I’m going to get qualified at uni, then I’m going to go into the workforce, and find a job that suits all my sensibilities and sensitivities. Then I’m going to be paying my taxes, and I’m going to be so excited about paying my taxes because I’ll be paying for people who can’t do what I haven’t been able to do.

I’m not planning to stay on DSP forever, I just need it now. I’m going to get qualified at uni, then I’m going to go into the workforce, and find a job that suits all my sensibilities and sensitivities.

Mark, 27

I was born in Australia, then moved with my family to the UK at one year of age, returning

when I was four. I went to the local State School, then got an academic scholarship to a private boy's grammar school. In my final year there I was a boarder. I finished year 12 in 2004, then enrolled in a journalism and business course at university. During Year 12 I worked at a video store, then towards the end of 2004, I started working weekends and graveyard shifts at a convenience store to support myself.

While I was working at the convenience store I started to experience violent mood swings and depression. In a number of incidents I overreacted to shoplifters or vandals, and came close to injuring myself and others. I was unable to balance a 36 hour work week and full time tertiary study, so I dropped out of university. In 2008 the store changed hands and the new owners closed the store at night, so I was fired without notice. After that I applied for similar positions, but without any success.

After failing to find other employment, I applied for Newstart. That year I was diagnosed with bipolar disorder and major depression by my psychiatrist at the time; since then I have had the diagnosis confirmed by another (my current) psychiatrist. In addition I have myopia and need to use glasses or magnifying lenses to see and read. In late 2008, on the advice of my psychiatrist at the time, I applied for the Disability Support Pension.

I understood then and now that Newstart was only intended as a temporary payment for people out of work, whereas the DSP is to provide people with disabilities support for a longer period with some allowance for employment.

Centrelink seemed to create many obstacles to delay and prolong my application for the DSP. Though the staff were always friendly and provided good customer service when I dealt with them in person, it was difficult to know what to ask them and find out how to navigate the system. Resources such as pamphlets available at the Centrelink offices and from the Centrelink website were next to useless. I remember submitting documents from my GP and psychiatrist, bank statements, and forms from Centrelink.

After a long waiting period, I was called in for a Job Capacity Assessment conducted by a third party. I don't remember being aware of the qualifications or expertise of the Job Capacity

Assessor. In any case I wouldn't presume to know what the right expertise is. I don't remember getting information about how the assessment process would work if I did not agree with the assessment. I did not understand the roles of the different people and organisations: outside of my interactions with

Centrelink directly I often had no idea who I was dealing with and what they did.

I did get referred to an employment agency in 2009 and interacted with them, but I got the impression that they were geared to people with substantially more severe impairment than my own. Though the staff were very friendly and helpful, beyond teaching some very basic skills that I already possessed (for example, writing a resume, searching for jobs online) they were unable to provide much assistance. For example, they weren't able to directly connect me to potential employers and they didn't provide any training or work experience. It was not a positive experience: to this day I don't entirely understand who they

Though the staff were always friendly and provided good customer service when I dealt with them in person, it was difficult to know what to ask them and find out how to navigate the system.

were or what they did. Eventually they told me to stop coming.

The DSP covers my medical and living expenses. I am on an effective regime of medications and believe I am managing my mental illness well. I was living in a rented flat, but recently I've had to move into the granny flat at my parents' house. Though I didn't want to move there, I was unable to find suitable accommodation elsewhere after my last rent increase. Currently I pay \$180 a week in rent for the granny flat.

My largest expense comes from appointments with my psychiatrist. I take generic medications that are relatively cheap, but occasionally I'll try a drug for which there is no generic alternative.

I believe there are definite psychological benefits to working, and I'm certainly capable of working. Though currently I am assessed as being able to work zero hours, I do feel I could do some work. I'd like to work in an office environment. At the moment I participate in online and in-person market research studies. It's fun, but I don't make very much, under \$100 a month. Occasionally I provide IT and computer services to friends for a small fee.

I think some work in software instruction or accreditation would work for me. I could do it with just large print and magnifying aids, there would be no other special equipment needed or extra costs. But working under 25 hours a week would actually leave me with less money so there is a disincentive there. After transport and other expenses associated with work, I believe I'd actually take home less each week. Also, I am concerned that working at all would jeopardise my eligibility for the DSP.

I'm very scared that the new eligibility criteria for the DSP won't accurately assess the impact my mental illness has on my ability to find and keep employment. Also I don't want to be accused of malingering or fraud.

If I were found ineligible for DSP, I'd have to go back on the Newstart payment. This would nearly halve my income. It would ruin me. I have no superannuation; the money I have is invested in shares and index funds, which I would be forced to sell. I would no longer be able to afford visits to my current psychiatrist and would have to get treatment for my mental illness from what is available for free or at low cost. Virtually all of my income would be going towards rent. If I couldn't pay that, my housing situation would be affected. I worry that would be the start of a long, slow slide into homelessness.

If I were found ineligible for DSP, I'd have to go back on the Newstart payment. This would nearly halve my income. It would ruin me.

I think the government treats people on the Disability Support Pension with disdain. I don't understand how a disabled person, receiving a payment intended for disabled people, can be

considered a parasite or bludger. Certainly people with disabilities seem over-represented as the cause of some vague economic problem when other groups (particularly Australia's ageing population) are doing what appears to be the same thing.

Some people have asked me "Have you tried not being depressed?" and other moronic questions. Generally I get the idea they resent my not working while they do.

It's difficult to stay motivated. I go for a lot of long walks and I have a good support network in my family, friends, psychiatrist and GP. Although I apply for volunteer positions I never

hear anything back. I imagine that roles like this could be a stepping stone to paid employment, so there is probably just as much competition for volunteer work as paid. I study online using 'Coursera', currently I'm taking an Introduction to Design Course.

Lucia, 52

I grew up in Adelaide and went to local schools in the western suburbs. When I started work I was doing lots of office work and sales. It was a bit of bad luck for me because that was just the time computers came in, so I got retrenched. I got a job in sales pretty quickly, though, then I got work in a dry cleaners. The shoe shop next door had a lot of Italian customers, so the owner got me in to interpret for him, then offered me a job. I worked for him for seven years.

I got married at 27, but didn't have much time off. After I had my two kids, I went back to work part-time when they were two. I've hardly ever been unemployed till now. I worked in retail in shoes. At that time my health was very good, and I was working in two or three jobs in different stores for different companies. But there was too much travel, so when I got offered a more permanent job that was closer, I took that. It suited my life with the kids.

One day my brother offered me a job in his business. It was office work and sales, and was really good because I could be a bit more flexible. I really needed to work. I've been a single parent, always managed on my own after separating from my husband when my oldest son just started high school and the

younger one was ten. I worked for my brother for nine years.

Towards the end of that time, I was getting sick with swelling around the eyes. It was a stressful job, I was getting a lot of headaches and at the time I had a lot of allergies; sometimes it was so bad I couldn't open my eyelids. I tried to see allergy specialists but no one could pinpoint the problem, even the best doctors in the private system. Then I went to a proper eye specialist, someone I had been seeing because of my diabetes. He took a photo of my eye and ordered an MRI scan. Then he rang and said I had a brain tumour. That was in March 2012.

I had to leave work when I had the operation to take the tumour out. It was quite big and they said I might be paralysed and would need rehabilitation. I was in hospital for a month, then went to live with my mum for five months. I was on seizure tablets and blood thinners. I decided I needed to build up my

My mortgage was more than I got on Newstart. I was struggling, I thought I'd have to sell the house.

confidence and get out in the world, I was too secluded at home all the time. As soon as I could drive again, I wanted to work, but I couldn't go back to work for my brother. It was too busy

and would have been too stressful.

It might sound funny, to look for work when you are sick, but it helped me, because I was so depressed. My mortgage was more than I got on Newstart. I was struggling, I thought I'd have to sell the house. My older son works and he helps with bills, and my parents help too. I've been so scared about what will happen. I haven't got a partner who can bring in money.

After a year of physio, my leg was still paralysed. I had to get up slowly to get my leg working. Then I started having spasms. They are like an electric shock, all up my leg. The y were lasting five or ten minutes and could happen anytime, anywhere. I'd have to lie down. I went to the hospital and they said 'don't do too much.'

I used to get headaches very badly and they got worse. I wondered if it was the diabetes, but then I started getting the spasms up into my chest near my heart. When I went to emergency I had another MRI scan. It turned out that the tumour had grown back quite quickly, even though everything had looked alright in the scan I had six months after the operation.

The surgeon said he'd operate again to take out the tumour. They said they got it all out this time, but I won't know till I get my next scan next December. Since the operation I've been paralysed in both feet. I'm walking, but I'll never be the same. I do physio at the hospital every week, but I can't feel my feet and my toes feel as if there are clamps on them. I'm still getting the spasms, I had five when I was in the hospital after the operation and twelve within a month of leaving the hospital. They're not quite so bad now, but I still get them. I can't control my bladder very well. If I'm not close to a toilet, I can't make it.

I applied for the DSP when I first got sick in 2012, but they said they couldn't do anything for me because I was having treatment and I hadn't done more than two years of treatment yet. So they put me on Newstart Allowance. At first I was exempt from looking for work, but when I was still sick they sent me to a Job Services Australia provider. That place said

they couldn't understand why I wasn't on DSP, and they didn't know how to help or train me. I was still unbalanced, and had a swollen face.

In the end, I found my own job, in the spiritual shop where I used to be a regular customer. I only did five or six hours the first time, then worked up to eleven hours a week, spread out so I had a break in between. My work was the best thing and they looked after me; they let me stop or take a break if I needed to because sometimes I'd get the spasms. They were so kind and inspirational. I wanted to build up my hours but the spasms were stopping me.

If I was on Newstart, I don't know how I could manage my health and apply for jobs
person to another, but I didn't fit in anywhere.

Centrelink was trying to push me to work more hours and sent me to a Disability Employment provider. I didn't understand why I was with a DES when I wasn't able to get the DSP. Anyway, when they saw me, they didn't know what they

could do to help me. They kept throwing me from one person to another, but I didn't fit in anywhere. I was having to go in to meet my provider every two weeks for an hour, whether I felt well or not. It was stressing me out going to the appointments. I'd be balling my eyes out, talking about my life. I missed an appointment, and they were going to cut my Newstart.

When I applied for DSP again last December, they rejected it. My GP was away and I got a new GP, but she seemed to think I could work. I think she told Centrelink I could do anything, even though she knew about the spasms and the swelling. It was as if the GP wanted me to work. She said, 'You've not in a wheelchair.' It was hurtful. She was young, she didn't know my history, she hadn't seen what I went through. I couldn't fight it. In the end, the GP got a letter from the surgeon about the second

tumour and how I had to have another operation. She called me in and apologised. She felt bad, and wrote a letter to Centrelink straight away.

I went to the social security tribunal with the help of the Welfare Rights Centre, who said I could apply again. It was about a month after the operation, around July. At the tribunal they looked again at all the medical reports. My friend was there to help me. When I got the DSP, I thought 'Oh my god, finally...'

I haven't been back to work in the spiritual shop since I left in May this year for the operation. They said they'll have me back, and if I could, I'd love to, but I'm not well enough. The spasms can just come on any time, and the pain is excruciating. I get embarrassed, I don't want anyone to see me. The doctors call them mini-seizures. Also, I'm conscious of not having hair, and have to wear a beanie. I don't go out, I can't drive. It's hard when you can't get anywhere.

I used to get into a very depressive state. I've worked so hard all my life, and I always thought once the kids would have left school I could work more, pay off my mortgage. Now I need everyone to help care for me and I feel useless. I'm only 52 but I feel 80.

Katrina, 52

I was born in the UK. My parents died in my teenage years, so I only went to O level and started work early. I did one year of mental health aid training, then I completed my

training as a general nurse. From there I had a serious back injury, so left that to work as an appeals organiser for a charity. After 3 years, I travelled overseas then arrived in Australia in 1988. I fell in love with the country and stayed. I was able to do nursing as a skilled migrant, so was sponsored by my employer and eventually got permanent residency.

Then I went into child protection and family support work, working in a refuge with victims of sexual assault and children 0-5. I went back to TAFE and did a diploma of community welfare, then almost immediately signed to do a double degree in law and social work at university. I was working in a homeless women's shelter and at another family support services, so 2 part time jobs and studying for 2 degrees.

Two years into the course, I was run down by a car on an errand from work. I was 37. I sustained some hip, leg and pelvis injuries and was unable to go back to

university for quite some time. I had some other neuropathic problems and went on to develop a complex regional pain syndrome. I couldn't drive. I was allowed to study and do exams from home. Over time I went from crutches to a wheelchair to two walking sticks, then one walking stick for 7 years. I finished with a Bachelor of Law and a Bachelor of Jurisprudence but couldn't finish the social work degree because they couldn't physically accommodate a work placement for me.

My interest had always been in social justice and Indigenous issues. In the last 2 years of my degree I was offered a placement working in social justice and human rights, this later became a full time position. I had a really supportive employer who made it possible for

I finished with a Bachelor of Law and a Bachelor of Jurisprudence but couldn't finish the social work degree because they couldn't physically accommodate a work placement for me.

me to work full time, even with my physical disability and chronic pain. I was having acupuncture regularly, seeing a pain management specialist, seeing a physiotherapist, and using yoga, relaxation, meditation, and an hour of pool exercise a day. I saw a psychologist after going through some depression. I had gone from being a very fit, high achieving person, to someone very dependent on others.

Then my husband became mentally very unwell and wasn't coping. He expressed a need to not go back to the city after visiting a rural area. We moved to the country. I was able to work on a consultancy basis, telecommuting for three years, till they got funding cuts and I was laid off.

Then my husband's condition deteriorated rapidly with bipolar illness, addiction problems suicidal ideation and a number of hospitalisations. By this time I was working in a bank. But after 18 months I was really struggling, trying to hold everything together. Till this point we had been living on savings and my income. My husband had not wanted to go onto a welfare payment. But when there was nothing left, he was assessed and approved for DSP and I went onto a carer's payment. That was about four years ago.

My husband continued to be unwell, with hospitalisations and recovery programs and at the same time I was getting sicker. About two years ago I was diagnosed with a lung condition, bronchiectasis, which is like an adult cystic fibrosis, the result of having TB as a child. I had to take antibiotics, and to stay well in my lungs I need to use a nebuliser and do breathing exercises twice daily.

Then my husband went into a residential program for 6 months, and with the quiet time at home I realised how unwell I had become. With my lung condition, my breathing, my pain

and trying to manage it, plus driving back and forward to see my husband, I was stressed. I was having panic attacks and feeling quite suicidal. My weight fell to 42 kilograms. It was all too much for me.

A bit more than 12 months ago I was assessed as being eligible for the DSP. I learned that you could do the assessments online. They arranged a telephone interview for me, because I can't drive the sort of distance it would take for the assessment face to face. So the Job Capacity Assessor did a telephone interview. It took an hour and a half.

Not much later they informed me that I was eligible for DSP. It was all a relatively easy process for me because of the paperwork provided by my doctor, all the historical information from the time of my accident, the surgeries I'd had, and the workers compensation claim, which had been successful. I explained to the assessor that I had been able to work for a number of years, and also how complicated life is without the therapies that I used to be able to access in Sydney, like acupuncture. It's harder here in the valley getting access to health services. I've been on a waiting list for 7 months for the pain clinic, and I'm on a waiting list for an elbow replacement. My pain has got worse. I feel I should be able to manage these things but I'm not.

What concerns me at the moment is that having gone through a workers compensation claim I know how stressful it is going through a process where a supposedly independent doctor evaluates what your treating doctor says about you. During the time of my claim for Workers Compensation, I went through seven years of being told I had psychological problems, that there was nothing wrong with me, that it was all in my head. But then it was all found all in my favour.

Being on DSP means I have security, I can focus on being as well as I can. I do have additional costs. We always get the medical safety net, and I pay privately for acupuncture and massage therapy. We're lucky, we own our own home and have no debt and live frugally, so we manage. Travelling costs are pretty high, because I'm four hours (return drive) from my treating hospital. If I was on Newstart, I don't know how I could manage my health and apply for jobs. Being on the DSP means that there are days when I can say that I'm not well today, I don't have to push myself. If I had to work there's a risk I'd become unwell again and fall by the wayside. The anxiety would become overwhelming.

I do voluntary work in the community. I run the local op shop for the school association, coordinating all the volunteers. It's rewarding, because that money goes back into our local school. It's really flexible. I put in about six hours a week, and we have a school association meeting once a month. Before that I was involved in the regional arts program. I've also worked with environmental groups teaching people to grow seeds plants, for restoration of the understory in the bush.

Our municipality has been declared a refugee friendly area, so I'm doing some work to find places for refugees to have holidays. It's important to me to contribute something to the community.

If I had to move to get work I'd be terrified. I've moved to this area and lived here for 7 years and have a really good support network. I've got to have surgery on my arm, so I'm going to

be relying on friends to help me and get me around. I think the social structures you build up are enormous and you can't put a value on that. When my husband was really unwell it

was suggested to me that I move away from home and get employment, because I am well qualified. But it seems crazy: I'd be moving away, paying rent, and then a carer would have to be paid to look after my husband. The flow on costs of that would be

enormous.

I think people with disability are being demonised in the mass media. With physical disability, people can see it and can't argue with it. But when you're talking about mental health issues, it's harder. It puts a strain on you to reach out and ask for the assistance you need. It discourages people from saying they're unwell and asking for assistance, and there's a risk that later we'd be having to pick up people from more desperate situations. It's really like an adversarial system where you have to battle to get the support you need. It worries me that we create an unhealthy non-supportive society. People with ill health and mental ill health can fall through the gaps so easily, and that's exacerbated when you live in

a rural or remote area.

If I had to work there's a risk I'd become unwell again and fall by the wayside. The anxiety would become overwhelming

Being on DSP means I have security, I can focus on being as well as I can. I do have additional costs.

Melissa,
32

I'm from the country and lived here all my life. I went to the local schools, through to Year 12. At school I liked English and History, politics too. I got my VCE over two years though I wasn't really thinking about what I was going to do when I left school. At that time I was too

busy trying to get through every day. I sort of had friends at school and I sort of didn't, though there was a group of girls I used to hang out with.

My parents knew that I've always been different, even though I've always been bright, with general knowledge and stuff. I'm going to be honest, I'm not sure what I'm really good at. I don't take much notice. I was diagnosed with Asperger's when I was 15. It's a condition on the autism spectrum that's higher up. It means it's a challenge relating to people, social skills and things like that. I'm right once I know someone really well, then you can't pick anything wrong, but with anyone new, I'm pretty quiet. When I meet someone new, I try not to stuff up, make an idiot of myself.

When I was at school I didn't have any part time jobs. It was too hard relating to people. When I got my diagnosis it made it a bit easier, to know that there was something, a name for what was wrong with me. It helped me to know how to better myself, even though I can't get rid of it. That's happened through years of counselling and other stuff, becoming more mature.

After doing some research about the kind of jobs it would be good for someone with my condition, we found that data entry was one, so I thought I'd do a business admin course at the TAFE. The first time I did that course it wasn't the best experience. It was bad. I was skipping classes because there were people there that made me feel uncomfortable. The teachers just didn't understand me, the counsellor they sent me to at TAFE thought I'd be better off doing the course with people with

intellectual disabilities, she was associating me with them. I felt absolutely disgusted and patronised. It was insulting. It's hard when your problem is an invisible one. People don't see it.

Sometimes if things get too much I tend to freeze up and not say much. With too much together at the same time I get sensory overload and one of my coping techniques is to shut down to keep calm, so I don't lose it. Or else I put in my headphones for my MP3 player. If I know the work, I put my music on so I'm not distracted, to get it done. I could understand what the teacher was saying but with other people around me talking it was hard. The

breaks are for small talk, and I wasn't there to hear that, I was there to learn and better myself. I'm a 'get to the point' person. I don't pussy foot around. Just tell me what needs to be done and I'll do it.

My parents organised to put me on the Disability Support Pension and I started on it in 2000. I don't really remember a

lot about how it worked. My parents say I was acting dumb in the job assessment, but I wasn't acting, I was just trying to get through school and adolescence without losing it. I really didn't know what I wanted to do.

I live at home with my parents and my sister. After I pay my board and stuff I've still got enough money left. I pay for my antidepressant, which I started when I was 17, and have been on ever since. There have been days when I've forgotten to take my tablet and I feel 'bleah...'

If I went onto the Newstart Allowance it would be less money, less opportunity to do things

I worry that they'll kick me off the DSP. I had two interviews to go to this year in March, and again in June to look at my eligibility. It just makes my anxiety and depression worse and I had to increase my medication.

and try to improve myself. I don't waste money, I'm a saver. I do a fair bit to help myself, to improve myself, with things like cosmetics and clothes, stuff like that. I'm not shallow, I put in the effort to better myself.

I've been to a few job agencies but it's like they don't know where to place me because I know exactly what I want. I went to one, they were hopeless, trying to get me into cleaning jobs. Not that I won't clean, I have tried those through another agency, but it just didn't work out. It was hard finding the people, and they just didn't get me. I'm in the too hard basket.

The first time I went with another agency they got me a paid job, part-time for three months. It was setting up a library for a community health service, and the data base for it, but it was only a four month part-time contract thing. I only got it because the daughter of one of those people had autism, but I'm not sure she really had it because she suddenly got cured. The lady that was meant to be helping me was hardly ever there when I needed help. That's the only paid job I've had.

I did some work for the dole stuff of my own free will, in 2010, just to do something because I was bored. I was doing admin stuff, filling in APRA forms, research, cataloguing for a local community radio station I got that through a job agency. In 2011 I tried TAFE again. I did two courses in a year: got a Certificate I in Community Services /Vocational Preparation, and a Certificate II in Health Pathways. This time everything was so much better, because I'd changed and I'd matured, and I knew exactly what I wanted. One thing I got was an out of school tutor. The disability liaison officer guy really liked me because I was to the

point. He got what I meant, and he understood the whole invisible disability thing. ASD [Autism Spectrum Disorder] is just as debilitating.

Then I thought I'd study for a job in health information technology/clinical coder. The rest of my family work in the health industry: my sister's a nurse, my dad's an orderly and my mum's a cleaner and they both work in the hospital. I figured if I work in admin in the health system they'll be happy and I'll be doing something that I want to do. I'm happy with that. Just give some filing to do, or data entry and I won't complain, I'll be thankful for the job.

They referred me to a Job Ready course.... but finding a work experience place has been hell.

I finished a Cert III Business Admin Medical in 2012. It was a dual qualification: a Cert III in Business Admin and a Cert III in Business Admin Medical. I did my work experience placement with the student services people

at the TAFE, helping with student files, taking phone messages off the recordings. I got a reference from that. At the moment, I'm looking for work.

I'm with a job agency now, I think it's a disability employment program. My assessed work capacity hours is about eight hours a week, but there's not a lot of jobs around here. They referred me to a Job Ready course. I've completed that and just have to do the work experience part, but finding a work experience place has been hell. It's just playing a lot of phone tag with the person I'm meant to contact. She's supposed to find me a placement, but she's not finding me anything, even though I've got a car and a licence and can travel.

The job search stuff I've done has all been of my own free will, because I'm too smart to be sitting around doing nothing. I can work. My

upbringing and my work ethic makes we want to get a job. So I'm already looking for work. I had an interview for a job last week. I think it went well, it was in a nursing home as an administration support officer. I tried my best.

Sometimes it's been hard for me, nobody understanding you, not feeling like you fit in anywhere. But as I've gotten older, it's like 'Either you like me or you don't.' Sometimes I lose motivation. I worry that they'll kick me off the DSP. I had two interviews to go to this year in March, and again in June to look at my eligibility. It just makes my anxiety and depression worse and I had to increase my medication.

I want to work. They can see from my file that I'm looking for jobs. I'm motivated, I'm doing things, I'm trying my best. I get interviews, I dress correctly, I make sure I wear appropriate clothes and do research to try to improve myself. It's harder for girls with Asperger's than it is for boys. It's harder to fit in.

Dean, 37

I grew up in a suburb on the coast. My first couple of years at school weren't too bad and I had some friends, but when I was nine I got bullied. It went on till I was fifteen and messed me up really badly. I had kids teasing me daily, and sometimes punching me. Not punching daily, but I did get hit quite a lot.

At high school, the hitting got worse, especially from one bloke in particular. So school wasn't a fun place for me. I did have some friends, but I wouldn't consider them true friends now, looking back on the way they treated me as a person.

At the beginning of year 9 when I was fifteen I was diagnosed with chronic fatigue syndrome and major depression. So I had to have a year

off school. I saw a psychiatrist, I was very messed up, and he put me on an antidepressant. For the first few months I couldn't even leave the house, I was that fatigued and that depressed. Some people came to see me once, but found it boring and didn't come back. Pretty much everyone stopped coming to see me. I was very fortunate with one good mate who visited and stuck by me.

You don't really recover from depression, but you can learn to live with it. I changed high school and repeated Year 10. I started smoking pot and was drinking underage. I completed Year 10, then after a week of Year 11, I left school. I didn't really care at the time about school, it wasn't somewhere I really wanted to be. I left home and lived with a friend for a while, with his family, then got a place of my own. I worked in the city for a few months, in an office job, but I was struggling. I heard voices, and had paranoid thoughts and was hallucinating, that sort of stuff. So I couldn't hold that job.

After that I went to a youth drug and alcohol rehabilitation centre. I was struggling with marijuana and drinking problems and I had a few LSD trips, so I went off to the centre to sort my life out. I spent a year and a half there. It was in the country, with cows, chooks, turkeys, that sort of thing. We'd study for three hours a day, then after lunch we'd work on the property for a few hours. When I'd been there a year, they took me to see a psychiatrist, who diagnosed me with schizophrenia and put me on antipsychotic medication. It helped a little bit, but not a lot.

I came home to live with my parents and younger brother and started seeing a psychiatrist down here. Throughout all this time I was suicidal on and off; I've struggled with suicidal tendencies for a very long time and I've tried to commit suicide a couple of times but I've been unsuccessful. The psychiatrist had me hospitalised, to try another antipsychotic that's supposed to be very good for people with suicidal problems. I was on it for a very long time. I'm back on it now.

It was so hard to manage everyday life. You've got all this stuff in your head, you're hallucinating, you're hearing all sorts of things in your mind. You think people are judging you, that people hate you. You're trying to deal with life and all this stuff in your head. It was difficult, extremely difficult. It's gone on for years, every day. You get to the point where you just can't cope any more, you just can't do it any more.

I ended up going on the DSP in 1998, when I was 21. To be honest, I don't remember a lot about that; it's all a little hazy. It was a long time ago. I was on the dole before I went on the DSP. As far as I know, I just had to go to my psychiatrist with some forms from Centrelink; he filled them out, I sent them to Centrelink, then Centrelink said 'Yep, you can go on the pension.' Most of time with Centrelink, it's been pretty cool, they've been pretty good.

With the DSP, I don't have to stress out about finding a job. The DSP helps me pay my bills, helps me keep a roof over my head, it helps me buy groceries. I'm on a lot of medication, I think it's about \$60 a month, and it helps me pay for that, and for doctors. Financially, I'd say I get by. I manage to save some money, because I live with my mum. If I didn't live with

my mum, I wouldn't be able to save anything. We pay half the bills each, so that makes it a lot better. I get along really well with my mum. She drives me around a lot. I don't drive and I want to learn how to drive next year.

Every week I go to a place where people with mental illness can go. We go bowling, then out for lunch. Another day a week there a men's group or a women's group, or an outing or a movie. Sometimes I get nervous; I find it easier to talk to some people than others. But it's good to get out and I know a lot of people there now, because I've been going for a long time.

Other things I like to do are hang out with my friends, watch movies, spend time with my mum, and go to church. I became a Christian when I was eighteen. I was in a pretty dark place and God reached out to me. I've appreciated that and I've followed God for a long time. But I still

I get to very dark places. There are times when I get very ill mentally and I don't have a lot of hope, when my illness plays up.

I tried to do stuff at TAFE. About ten years ago, I tried to do a Certificate III in Community Services. I couldn't do it, I couldn't do the work, I couldn't understand what they were trying to teach me, so I stopped. Then about five years ago, I tried to do a Certificate IV in Mental Health. I only lasted a month at that. I didn't understand what they were teaching, so I had to leave.

I also did a literacy numeracy course at TAFE. I repeated it and finished the course. That was hard, that was really hard. I could do the work but it was the illness that was the hard bit.

When I came out of the rehabilitation centre, I worked for a guy at the church, a bit of charity

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work as a peer support person. I got paid, but it wasn't much money, it was about \$6 an hour. I did it for a while, but then I got too sick and I couldn't do it any more. I hallucinate, I see horrible things, violent things, I hear abusive things, putting me down. I have very accusational thoughts. I might think 'It's a nice day' and another voice comes back. 'No, it's not, you're a bloody idiot.' I get paranoid, I think people are judging me.

Having schizophrenia gives me compassion for people. I can look at people and see the things that are happening in their lives that are causing people pain, or insecurity, or anxiety, things like that. I can feel for them, and feel their pain. Other people say 'Pull your head in, get over it' and they don't have any time for them. I understand what it's like to experience bad things and I can say 'It's all right, you'll get there, you'll get over it.' I've understood that compassion is a very good thing to have for other people.

The idea of looking for work scares me because of my illness. It scares me because I just don't think I could do the workload. I couldn't concentrate, I get very fatigued because of all the medication I'm on. I don't think the employer could keep me on, I'd get the sack. On the DSP I don't have to stress out about finding a job.

I think that in the media people on the DSP are portrayed as bludgers. They say 'These people, they don't work, they're getting all this money off the government.' I guess there's people that could work that don't work, but the majority of people are on the disability pension because they can't work.

I'm grateful the government gives me the disability pension. But if I could work and if I

had a trade or an area that I was good at, I'd much rather be working than on the pension. I think that most people that are on the pension think like that.

Anna, 51

I was born in a Soviet country in 1963 and went to school at seven. At seventeen I finished the High School and went to work in a technical library but then studied nursing. Afterwards I was working as a paediatric nurse at a specialised institution for children and teenagers.

I got married when I was 22. I had a daughter a year later and ended up with a divorce when I was 27. I married for the second time four years later. My second husband had high level

technical skills but the political and financial situation at home became too difficult and his salary could not continue. The future seemed bleak. People were worried about future directions for the country and were not getting paid their salaries,

surviving on what their relatives gave them from the country.

My husband applied to emigrate to Australia, passed the immigration exam and arrived to Australia in 1995. I joined him with my daughter a few months later. However, there was some tension in our relationship. The situation got worse and I felt his attitude changed towards us. I was studying English full-time, but my husband had more options, and got an offer to work in the United States with a big salary. He did not invite us to go with him. I cannot really blame him, because our life together was not working properly.

I did not have proper English, and to understand people I had to do everything face to face, so I had to travel everywhere for that, and it cost money.

After he left, I felt relief, but it was also very difficult to manage life. I did not have proper English, and to understand people I had to do everything face to face, so I had to travel everywhere for that, and it cost money. But I feel grateful to the Australian government because my daughter and I could study. In 1998 I started a two-years Certificate in Dental Assisting course. After that I got a part-time job as a dental nurse in a hospital. At that time, my mother arrived to live with us on a six month visa. I was very happy. My mother was well-educated and was active and popular in the Russian community. She married an Italian man and was able to stay. But the next year she became very ill. She had lymphoblastic leukaemia and passed away seven months later. As her condition deteriorated, I was forced to spend more time with her, so I left the work in the hospital and was with my mother when she died.

The next year I was offered a place in a tertiary institution to study for a qualification in dental therapy. I completed three semesters, but during that time I realised I was very ill. It was some kind of stomach upset, but no one could understand what it was. A doctor diagnosed depression and advised me to take up running. I felt I had food poisoning and the doctor did some blood tests but that was all I got. My skin became yellow and I lost ten kilograms. I was really unwell.

When I was lying helpless at home, my friend came to see me. When he saw me, he bought me a ticket to go to a hospital in Russia. At the infectious diseases hospital there, they found out that I had a chronic cause of bacterial infection of gastro-intestinal organs caused by

Yersinia Enterocolitica. They diagnosed it on the second day and treated it with antibiotics. When I came back, it was hard to pick up the intensive studies and I had to do the same study again the next year.

In 2004 we were living in public housing, but there was a problem. My daughter was a teenager then, and the boy next door constantly demanded sex from her. He wrote her horrible messages, destroyed our backyard, and threw rocks at her and the bus she took to go to school. In the end he was prepared to kill her. He was so obsessed. It was not safe for my daughter and she was unable

to live with me. We had two court hearings but we could not stay any more. I was under constant pressure.

I applied to public housing to relocate, but the waiting for a chance to live somewhere else would take months. Then I got a job at a dental clinic further north, so we fled. I got a new place (rent) at the end of the railway line, and I was travelling the rest of the distance to

get to work (1.5 hours one way). At this time I developed significant dental infection but could not address the problem because I had to work Monday to Friday and came back home very late. Combined stress at work and the infection, which had spread my sinuses, took its toll.

At that time I asked a private dentist how much it would cost to restore my oral health. It was \$6,000.00, but I could not pay such money. I had a very stressful and prolonged recovery from the complications of the dental infection.

I am grateful to the Australian Government that at that time the payment for Disability Support Pensioners was able to be continued while they went overseas. This gave me the opportunity to get a diagnosis and the treatment. Unfortunately that three months payment while overseas has been reduced.

Even though I did not want to stop working, I lost the ability to cope. I went onto the Newstart Allowance, because I could not afford to manage on my own any more. In 2008 I went onto the DSP. It was for post-traumatic stress disorder, depression and generalised anxiety disorder.

In the year 2009 I became ill with unidentified illness, after having drunk raw water from a park fountain in the Strathfield Park. My body was covered in bright red spots; I had constant pain in my stomach, lost weight and felt very weak. I attended my local GP and he ordered some blood tests, but was unable to diagnose the illness. I spent 3 months in such a state and lost my hope to be cured in Australia. I bought a ticket to my home country of Russia and was admitted to the State Infectious Disease Hospital on the day of my arrival. I was diagnosed with Giardia infection (a gastrointestinal parasite) and treated.

I am grateful to the Australian Government that at that time the payment for Disability Support Pensioners was able to be continued while they went overseas. This gave me the opportunity to get a diagnosis and the treatment. Unfortunately that three months payment while overseas has been reduced to six weeks.

In 2011 I had an invitation to go overseas to meet someone and I had a relationship with him. When I came home I had pain in my lymph nodes in the groins and vaginal discharge. I went to a GP who ran the test to detect sexually transmitted infections. The result was negative. However, I felt ill and I contacted the man overseas and asked him to go to the sexual health clinic to check for sexually

transmitted infections. When he did, he was diagnosed and treated for these.

I continued to be unwell, but remained undiagnosed. I went to the sexual health clinic, presented my problem and had the test again. This test again came back negative. I suffered for the whole year during 2012. In the year 2013 I went to my home country to see a doctor venereologist at the State Dermatoveneorological Hospital. There I was diagnosed with a number of sexually transmitted infections. The doctor explained to me that the antibiotic course of treatment for those diseases would be prolonged and require follow up appointments, to check the efficacy of the treatment on its completion, first at six weeks, then at twelve weeks after the treatment.

I was forced to disrupt the treatment and come back to Australia because being away for that time had put at risk my community housing dwelling and my disability pension

When the doctor checked me in a follow up appointment, it showed that some of the infections has persisted. The doctor explained that some of those infections were difficult to eradicate, especially in chronic cases like mine, and ordered the second

course of antibiotic treatment. But I was forced to disrupt the treatment and come back to Australia because being away for that time had put at risk my community housing dwelling and my disability pension.

Currently I am experiencing difficulties in my life because I feel ill and need to go back to my home country for diagnosis and the treatment of the sexually transmitted infections. It is possible that a prolonged stay will be needed. It is very stressful, because Centrelink will be paying the Disability Support Pension only for one and a half months while I am overseas.

Also, as a tenant of community housing, I am only eligible to be away from my dwelling for one month.

I believe that the method used to diagnose sexually transmitted infections in Australia (PCR test or NAAT) is the same as in the United States. This is the reason I have not been diagnosed and therefore able to be treated in Australia.

The DSP is a lifeline for me. It helps me with my loan to buy the plane ticket to go overseas and is the only income I have while I am staying abroad. I am so scared that the Government will cancel my DSP support while I am overseas and the community housing might evict me from my home while I am away. I do not want to go anywhere overseas; it is just that I must do it because of my longstanding health problem. But when I come back and feel well, I really will be happy to work.

Kevin, 58

I was born in 1956 so I'm what you call a baby boomer. When I was in second grade at school I got glandular fever and that took me out of school for six months, so that's why I had to repeat second class. When I left school I worked for the Commonwealth public service, then for a big charity at their headquarters, then for a couple of State government organisations.

I was on Newstart between 1998 and 2004, and then they put me on DSP finally in 2004. That was for chronic fatigue and a few other issues. I've always had the chronic fatigue but it acted up really badly in my mid-twenties. I started getting tired all the time, constantly tired, and I had problems with concentrating. I do tend to keep going till I drop, but then

sometimes I get really lethargic. My wife would say I get spaced out and I don't always hear what's being said to me.

Getting the DSP was an uphill battle. I was knocked back a few times, in 1999, 2001, and then 2003. One problem was the Commonwealth doctor who assessed me. He was so rude. I thought if I got him again, I'd put in a complaint. He said to me 'You can get on with things, you can do this, you can do that...' But he wasn't really thinking about how it affected me. I had constant tiredness, I wasn't capable of working long days. They finally did put me on the DSP in 2004, because in the end I got a different Commonwealth doctor, who said 'You should have been on this a while ago' though I had exactly the same condition.

How can you apply for jobs when there's no positions being advertised?

All that time I didn't know I had this genetic mutation, neurofibromatosis Type 1, NF1 for short. We only found out by accident about four

years ago, when my daughter was eight. She had been having problems with hearing things, so when we were at the hospital the doctor noticed some lumps on my daughter's arms and her body; they are these large brownish marks, like a freckle. She said 'How long has she had this?' and sent her for some tests. Neurofibromatosis is caused by an inherited gene mutation that causes tumours along the nervous system, which can turn into cancer. It's often linked to intellectual disability, which is what our daughter has. They checked my eyes and found the brownish coloured nodules you get with NF1. So I only found out because of my daughter.

My daughter also has Asperger's like me. When I was diagnosed with the Asperger's it was like all these boxes were ticked for my wife, explaining what I was like. In my wife's

family there are six out of twelve kids who are somewhere on the scale for autism spectrum disorder, so she gets me.

When I finally got onto the DSP ten years ago it was a relief. I knew I had a guaranteed income, and that I could look for work if I wanted to, but I wasn't being forced into it, I didn't have to be putting in 20 applications for work a week, when usually I wouldn't even hear back from anyone. How can you apply for jobs when there's no positions being advertised? A couple of positions I went for I was told I was too qualified, but what they really means was that I was too old.

Though I was on the DSP I did work part-time for years with the railways as a customer service attendant. I was just working short hours, four hours sometimes, five hours on other days. But it became very stressful because people were jumping boom gates in front of speeding trains. Then in December last year

I had some heart trouble. I thought it was just connected to the frozen shoulder I had in 2000 when they did what they call 'cuff' surgery on the tendons in my shoulder. When the pain came back I just thought it was the frozen shoulder again, but the doctor sent me for an ECG. That's how they found out I had to have heart bypass surgery. When I found out about that I just resigned from the railways. I was retirement age, it was too stressful, and they were putting people off anyway.

Because I was 58, I was able to get all my superannuation money. It wasn't that much money, I used it to pay medical bills. It's good having the DSP, though some of the medications I'm on aren't covered by the PBS

[Pharmaceutical Benefits Scheme]. When I see my heart specialist, I pay him \$100 and I get back \$30 from Medicare. Three weeks after heart surgery, I had to go back in to get a retinal tear fixed on my eye. That wasn't my genetic problem, it was just something that happened. I don't have private health insurance. Can't afford it, never could.

On average a month I'd probably spend about \$60 a month for medication, that's with PBS, then \$40 for the medication that's not covered by PBS. For my daughter it's \$60 with PBS and another \$120 without PBS. My wife's medications for depression and blood pressure are about \$50 month, that's part covered by

PBS. I don't blame the chemists though. For my daughter we have to go up to the city every six weeks to see the genetics clinic. She has to go up to the eye clinic every six months for her eyes, then we have to pay more for the glasses because otherwise she'd be wearing ones that look like Coke bottles.

If I had to go back on Newstart, we wouldn't be able to run the car, which we need to get our daughter to her medical appointments. From a pharmaceutical point of view, we'd have to go without so much.

If I had to go back on Newstart, we wouldn't be able to run the car, which we need to get our daughter to her medical appointments. From a pharmaceutical point of view, we'd have to go without so much. We already have to keep an eye on grocery prices, especially fruit and veggies and meat. We'd have to cut back on food, and school things, like excursions. Our daughter's going to high school next year so we've got to start thinking about her school uniform. Education's not free. We live in community housing, renting. It's the kind of housing you never have to move out of. We were renting before in private rental, but it was costing us an arm and a leg. We're very happy to be where we are.

My capacity to work right now is not as good as it should be. I'm working one day a week, for \$25 a day, for an organisation that supports people on the DSP. I'm doing it to be active again, I don't want to be at home being bored out of my brain. I'm working in the kitchen but I can't do any heavy lifting because of my heart. It gives me something to do, it makes life less tedious, not sitting at home all the time.

My wife is on a carer's pension, to look after our daughter, and studying part-time to get a job, to help support the family and take the burden off me. She applied for the DSP back in 2002 and again in 2005. We lost a baby after we had our first daughter and she suffered really badly with post-natal depression. It went right back to her childhood, because she came from an abusive family, her dad was an alcoholic, and she used to get the shit belted out of her, if you'll excuse the expression. She's got anxiety and depression, and she's a bit obsessive-compulsive. She's talked with her psychiatrist about this habit she's got of pulling out her hair, it's called trichotillomania. She's studying for a Diploma in Community services and does volunteer work at our church office and at the local hospital one day a week as a chaplain.

People with disability in the mass media are seen as retards, not capable of doing things. People *are* capable. You've just got to give them the right incentive to do things. Give them the job they can do, show them, explain how to do the job properly, how it all works, don't treat everybody the same.

Marie, 24

I'm the second of three children. I went to four different schools, I couldn't find a school that suited me, in a nutshell. Primary school was

okay. I had friends, but not as many as I needed to stand up for me. I started getting bullied in the low grades. They'd do silly things. Like, for example, if I was having a conversation with someone, they'd go up to the teacher at lunch and say that I was bullying them. They'd try to make things up and get away with it.

At high school there were a lot more people that bullied me. It was most of the school and it was almost every day. It was so overwhelming I didn't tell my parents, and it kept going till year 12. I left high school in Year 12 at the end of term one. My parents tried a different school to see if that would work better. I lasted a few weeks, but then I had a meltdown. My parents noticed I wasn't behaving normally at home, I was doing strange things, things I didn't do before. Like at

They never asked me if I wanted to do work experience, they just fixed my resume.

form class at the end of the day, I'd do laps round and round the health block. I felt anxious; I was trying to sort my head out.

After that I went to hospital for two months, it was a mental health hospital. They soon discovered they didn't know what to do to help me, so I went to a different hospital. When you're in hospital, you're supposed to slowly get better, but it was horrible. The nurses were very tough with me. If I hit them, they'd put me in seclusion and they'd force me to have breakfast, morning tea, lunch, afternoon tea, dinner and supper. I was fit before I was in hospital, my weight built up, and I got comments from people, from my family, saying that I looked like a balloon.

My parents took me back to school a week after I got out. I wasn't well enough but they told me I should go. I got into trouble but it wasn't because I was naughty, it was because I was unwell. Back at school it was nice, but it wasn't as nice as primary school. I was invited

from a friend to go to the formal. I had been really looking forward to going; I'd only been to a semi-formal before, not a formal. I did not know many people in year 12. I was disappointed, but in the end I just said 'I do not wish to go.'

I started doing work experience placements during Year 12, because I was doing vocational education. At the end of Year 12, my parents arranged lots of work experience for me: in a clothes shop, a coffee shop, hairdressing shop, a childcare centre. I'd do them for about six weeks, trying different things to figure out what I was interested in doing.

My first six week work experience placement didn't work out because I was mentally unwell. People would tell me I was doing strange things. At the restaurant where I worked, someone would tell me to butter the bread, so I would butter it with my fingers. When I worked at the clothes shop, unpacking clothes out of the boxes, there would be these little white packages to keep the clothes fresh. I'd check no-one was there, then I'd eat them. People would tell me later I did these strange things and I'd think 'Why am I such an odd character?'

My favourite work experience was the child care centre. I love kids, though I never want to have one on my own. I wanted to do something with kids, and went to study for a Certificate IV in childcare at TAFE. I didn't know what else to do. I passed one subject and failed another subject then got told to leave. One of the teachers said 'It looks like it's too difficult for you.' I said 'I thought challenges are supposed to be good for people,' and wanted to keep going, but she said 'You failed the easiest subject.'

*One day I'm a nervous wreck,
the next day I'm happy as a
jumping jellybean. I can't tell
how it's going to go.*

After I stopped at TAFE I gave up study for a while, and next I started going around to places looking for work. I looked for a long time. I joined an employment agency and looked for work for years and years. They were useless; none of them would find me a job. They never asked me if I wanted to do work experience, they just fixed my resume. We also did some stuff about what to do if you started your first job. But they never talked to me about what I'd really like to do. I went to Centrelink and asked if I could change. I wasn't really comfortable with my worker.

The only one that helped me was Red Cross. They didn't just help me with jobs. When they saw my face, they'd actually say 'How are you?' They'd be more open, they'd be more there, and showed they cared. I saw different people when I went there; there were four different people, but they all talked to me and I liked them.

Eventually I got a job at a fast food restaurant. I was emptying the bins, mopping the floor, taking rubbish off the tables and cleaning the windows. It was really boring. I did it for a year, as a casual, about 15 hours a week, then I quit. After the fast food restaurant I started to do all different kinds of volunteering. I volunteered at the local museum, at a library. I do all different stuff, to keep myself busy. I do about six or seven hours of volunteering.

I was assessed for the Disability Support Pension in 2007, when I was 17. I don't remember a lot about it. I'm on the DSP because I've got Asperger's and Borderline Personality Disorder, and anxiety. I take medication for both the Borderline Personality Disorder and Anxiety. One day I'm a nervous wreck, the next day I'm happy as a jumping

jellybean. I can't tell how it's going to go. I'm the only one in my family like this.

I still live at home with my mum and dad and my younger sister and pay my mum \$100 a week. I use the rest of the money for Go Card [public transport], juices, lunches when I go out, and for the doctor, like now, I've got a deep cut on my knee. My parents both work, they don't really need the money, but they ask for it anyway. If I had to live by myself, it wouldn't be much to live on.

Other than my family, I've got some friends, and for support I've got a mental health number from a hospital. I can have a chat to a support worker on general occasions, when I feel I need to. A psychologist I go to helps. Mostly it helps me to see a brighter and better perspective.

I don't have problems remembering things. It's just that I take a lot longer than any general person to learn anything. If it takes them a week, it takes me a month. My advice for JSAs and DESs working with people with Asperger's is that they should tell them 'It may be tough in the workplace, today, tomorrow, next year, but with help you could improve your work skills.'

Now that I've got to know the world, I'd like to do something that helps people. I'm not sure what I'm able to do exactly but it would be satisfying to help people. I'd like to tell them that even though you might be suffering from something now, there's always a possibility you'll have a bright future. Even if you're sad today, there's always a possibility you'll be happy tomorrow. Think of the bright side of your day.

Aleks, 51

I was born in Macedonia and came out at five years old in 1968. We arrived on Boxing Day; I still remember it. Dad came out looking for a better life for the family and worked hard all his life. He worked for BHP for more than 40 years and we never went without.

Both my sister and my mum passed with cancer, and I've just found out a few weeks ago that I had it too. There was a growth on my neck, but the first doctor I saw about it passed it off as nothing. I went to another doctor, a skin specialist, and she did a test that showed it was malignant. I've had operations to take away the growths and the test results on the surrounding tissue are coming back clear.

I'd never been on benefits before. I worked 99 per cent of the time, never relied on social security all my life.

That's just the latest thing in my life that's gone wrong. I've been in the wars and given what's happened to me I should be dead five times over. But I believe there's someone

looking after me, something out there. I still pray, I was raised as a Christian. It's hard to talk about it, but I tell you the truth, the way I saw it. Though I tell you no lies, no-one would believe what I've been through.

I grew up in regional NSW. I went to the local primary school, then high school. I wanted to be a radiographer and won a scholarship to pay for the study 600km away. But my parents and my girlfriend changed my mind; they were worried I'd meet someone else out there. So I came back and did a double degree in electrical engineering and computer science. I started at BHP in 1986 working in the strip mill. There were 1700 people there, but then they automated everything so it was all computer operated. I was the first to be chosen out of

1400 applicants for one of the 14 jobs going for computer technicians.

By 1987 I went up to work at a casino in Queensland, installing the security monitoring cameras. I was going out with Tanya then and we thought it would be good to get away. I'd been married before and had two little daughters, but my wife had an affair with her boss, it all came out and we split up. Tanya and I had a daughter in 1991 and she'd be 23 now. They're living somewhere down south of here but I don't know how to find them.

In 1991 when we were in Queensland, my father said 'You should come home.' He wanted me to go over to Macedonia. His father, my grandfather, had some property with trees planted; they would be ready for felling in the 2020s. He was close to dying and he wanted to sign it over to me. I arrived on a Tuesday and he died on the Thursday.

I was at the wake after my grandfather's funeral on the Friday, and we saw some army chaps come into the village. We knew there was a war brewing at the time, between Croatia and Serbia; people were being conscripted. I'd got my Macedonian passport the day before, and registered with the police when I arrived. That was the biggest mistake of my life. They took my passport off me, and made me get in the back of the car.

It was a ground war and I was on the frontline. At first I had no idea where I was. You'd go out for 70 days at a time, carrying everything on your back. When I left Australia I was a fitness freak, I was 116 kilograms at full muscle. By the time I got back 4 years later I was 63 kilograms. In all that time, I couldn't call home. They blew up all the transmitters, everything was dead, there were no phones, no power. I couldn't comprehend what the war was about; I was just an Aussie, I was supposed to be back at home, lying on the beach. But we had to do our

service regardless, and you knew you were expendable.

I was shot from enemy fire in 1993. We were just sitting on a log having a break. We heard a bullet and the guy next to me leant over towards me. When I turned to look at him, I saw he'd been shot in the heart. Turning to look at him saved my life, because the bullet went in under my left armpit when I moved, missing my heart. I spent six months in hospital in Belgrade before getting sent out again. But being shot was the least of it. There were beautiful children being massacred. I saw things I can't talk about, and I still have nightmares.

After I got out of hospital I was sent back to the frontline between Hungary and Serbia. I thought I'd never get out of there. A man driving a truck doing UN food drops got me out to Italy by hiding me in the spoiler up on top of his truck going over the borders. It was minus 26 degrees; I nearly died. In Rome I had to get a re-entry visa to Australia because my passport had expired. I couldn't call home; it was the time they brought in an extra digit on prefixes for the phone numbers, so I was not getting through and I thought everyone had moved away. In the end, I just flew home and went to the house.

I had been away for four years, and my mother had died in that time. I wanted to see my Tanya and my little daughter, but Tanya had got into a relationship with my best friend. My father encouraged her because they thought I was dead. I could not fathom that, I could have gone back to her. I blamed my father for a long time, and didn't talk to him for five years.

In 1997, some work came up over in Port Lincoln working with tuna processors. I wasn't talking to dad, and I got sick of talking to people about the war, with everyone asking questions. So I ended up going over to Port

Lincoln. The job was to insulate the electrical motors in the processing plant but we ended up installing new equipment; it took three years. I liked it out there.

My accident happened in 2000. It was simply because the crane lifting crates of tuna was four tonnes over its load limit. The crane just came off its moorings on the wall, the cage came crashing down on top of me, and I could hear my bones breaking. My left knee was completely shattered; my right knee was damaged too. I had all good teeth, but they had to pull out every one of them because shattered when I was clenching them with the pain. I was in hospital for three months and have had eight operations on my left knee, one on my right. I've got to get a knee replacement operation, but it's still healing, so I still have to wait.

The nerves in my spinal cord are all shot and I am constantly on pain relief, including morphine. I have to take sleeping tablets to be able to sleep. At the moment I'm on four different medications, all trying to do the same thing. The medications have their own bad side effects. I go to the pain each six months, and we review all that. All this has been going on for 14 years. It's a long time.

I went onto workers compensation from March 2000, and had to stay in SA for years because of my WorkCover case. But by 2006, I really wanted to go home. My sister had cancer and didn't have much time left. I just took the first offer they gave me, even though my lawyer said I could have got a lot more. After I paid out the legal fees and medical bills, I had around \$105,000 left. I went back to New South Wales, bought a car, some furniture, then lived on the money.

It was about a year after I got my workers comp payout that I went to Centrelink. I had no money left. I knew there was a six month exclusionary period because of the workers comp, and at Centrelink in South Australia at Centrelink they said it might be five years before you could claim if you'd got a payout. I was under the impression that you couldn't claim till you ran out of money, so I waited till I had nothing left, then applied for Newstart Allowance.

I'd never been on benefits before. I worked 99 per cent of the time, never relied on social security all my life. They put me into Stream 4 and said I'd have to look for work. I wasn't too happy. Then Centrelink sent me to CRS [Commonwealth Rehabilitation Service]. The assessor looked at my medical records from when I was with CRS in South Australia, during

my WorkCover claim, then they put me straight onto the DSP. That was in 2008.

I had no idea you could get a pension for disability, I

thought there were only just the age pension. But once I got on the DSP, it was a big burden off my shoulders. I had enough money to survive. If you don't drink, or smoke, or do drugs, it's enough to live half a normal life. I live in private rental, I'm lucky, I only pay \$135 a week for a one-bedroom bedsit, which is cheap for the area. I had to give up the car when I was on the Newstart Allowance, but I have a car now. The difference between Newstart and the DSP is food, a car, and even being able to save a bit.

I've just got out of prison after serving a four and a half year sentence for an armed robbery I didn't commit. I have no criminal history; the worst thing I got till now was a speeding fine. It all happened because a man I gave a room in

Once I got on the DSP it was a big burden off my shoulders. I had enough money to survive

my house to had a drug problem. I felt sorry for him, he needed somewhere to stay. But I started noticing that my pain relief meds were going missing. One day I got up, the police were at the door, and they said I was under arrest for robbing a bloke at the newsagent. The guy I'd been sharing the house with just disappeared completely. I was sure it was him. It turned out that he went Crown witness against me.

I was so sure they'd know I was innocent that I decided my case should go straight to trial. But after the case was heard, the jury's verdict was 'guilty'. The judge asked the jury to go back and reconsider, and even the prosecutor was shocked.

The guy who set me up was caught later when they pulled a police chase. He already had prior convictions for armed robbery; I don't know why they didn't believe me in the first case. They did a DNA test and matched it to the crime scene. Now they're working out the compensation for all the time I did inside. My parole officer was fantastic. She's always been looking out for me and I feel really grateful to her.

The worst thing about being put away was not knowing when my sister died. My father didn't even ring to tell me. I don't speak to him anymore.

I started seeing a psychiatrist when I got out of jail. I can talk to him. I'm writing about my life too; I'm starting to realise you can't keep all these things to yourself.

Analysing the case studies

The following analysis of the case studies draws together people's experiences under thematic headings. Where relevant, this discussion also explores the possibility of generalising about that experience, in terms of the government services that DSP claimants encounter, and how these systems help or do not help claimants to obtain medical diagnosis, DSP assessment, work or study.

The discussion also reports on people's attitudes and motivation towards learning, development, paid work, and community participation, in order to understand whether and how people have set themselves their own activity goals and attempted, successfully or not, to achieve them.

Readers may also find it helpful to refer to the [table](#) provided earlier to identify the interviewees, though every attempt has been made in the discussion that follows to provide those points of reference. This includes mentions of people's ages, mainly to serve as an aide-memoire.

Going onto the DSP

Disability, illness, health condition

Interviewees suffer from a range of disability and health conditions -- in three cases, from birth. Kevin, 58, suffers from neurofibromatosis Type 1, NF1 for short. This is an inherited gene mutation that causes tumours along the nervous system, which can turn into cancer, and in Kevin's case may be related to the chronic fatigue he suffers, though he also suffered from glandular fever as a child. Both Marie, 24, and Melissa, 32, have Asperger's syndrome; for both these young women it is associated with depression, and for Marie with borderline personality disorder and occasionally severe anxiety. Marie was bullied at school.

For three people in the study, the onset of mental illness was exacerbated by difficult life circumstances. Dean, 37, was diagnosed as a young man with schizo-affective disorder, the onset of which may have been exacerbated by experiences of bullying throughout his school years, as well as experiences of drinking and taking drugs as a teenager. Lauren, 20, first experienced chronic arthritic pain as a teenager, then depression and anxiety associated also with a difficult family situation. Mark, 27, suffers from bipolar disorder, a condition that manifested itself along with major depression after a stressful period when he was working long hours in nightshifts to earn the money to put himself through university, was fired suddenly, and failed in his attempts to get another job.

Katrina, 52, was perfectly well until she was struck in a serious car accident. Years of rehabilitation to improve her mobility led to the onset of depression, a condition arising also from caring responsibilities for her mentally ill husband. Katrina also has a lung condition that needs preventative health care.

Lucia, 50, suffers from a serious brain tumour, which resulted in a year of rehabilitation and was not resolved. After getting worse, Lucia needed a second operation and still suffers from minor seizures, and now also depression.

Aleks, 50, is seeing a psychiatrist for post-traumatic stress as a consequence of his experiences on the frontline in the war in the Balkans. He also experienced a traumatic industrial accident in 2000, when he was crushed by a crate; he has spinal cord damage and has had a series of operations over 14 years to address his shattered knee.

Anna, 50, has experienced two long periods of undiagnosed illnesses, one a chronic infection of the digestive system, the second, chlamydia, a sexually transmitted disease. For Anna, the experience of migration, the desertion of her husband, attempts to study while working and raising a daughter, and sustained harassment in the public housing she was renting have resulted in mental illness.

Diagnosis

Three interviewees found it difficult to get a correct diagnosis. Kevin's neurofibromatosis was diagnosed almost by accident, when he was at a hospital for his daughter, whose hearing problems revealed that she had this condition. This led to Kevin's diagnosis, since the disease is hereditary.

For Lucia, the swelling in her eyes was initially interpreted as an allergy. Several allergy specialists could not pinpoint the problem, and it was only when she saw an eye doctor that an MRI scan was ordered identifying Lucia's brain tumour. Lucia would later have the stressful experience of a GP, who was standing in for her regular doctor, reporting to Centrelink that she was able to work, even during the period when Lucia was suffering seizures and developing the second brain tumour.

For Anna, a long period of ill health, serious weight loss, visits to the doctor and pathology tests did not identify her condition. One doctor suggested jogging. A return visit to her home country gave Anna the opportunity to get a different pathology test, which detected the particular strain of bacteria Anna had, which was then able to be treated. Anna later developed a chronic and rare strain of chlamydia, from which she suffers to this day. This was in part due to denial of any condition by a previous sexual partner, and Anna's initial shame in asking for test.

The elements of chance in three of these nine case studies reveals the risks of failing to get timely and accurate diagnoses when people most need them -- not just to get timely and appropriate treatment but also to qualify for the DSP. Lucia's first application for the DSP was rejected, though she believed she was manifestly unwell, given her seizures. Kevin's application for the Disability Support Pension was rejected three times initially; perhaps in part because his only evident symptom was fatigue and the observation of his wife that he would get 'spaced out'. Anna spent months being unwell and undiagnosed: without the evidence of a pathology result, there was nowhere to take her problem but overseas.

These examples clearly show the connection between an inadequate medical diagnosis and consequences for DSP qualification.

Work and learning experiences and aspirations for people on the DSP

Previous experiences of paid work

All interviewees had previous employment in the paid workforce. Kevin had worked for most of his life, including several years after he qualified for the DSP. Until her car accident, Katrina had been pursuing a rewarding career, including study for two degrees. Anna worked and studied overseas, and also in Australia, studying to achieve the professional level employment she'd had in her country of origin. Lucia had always worked; as a single mother she needed to, and she continued to work even as her brain tumour became more debilitating. Aleks, too, had worked '99 per cent of the time', in technically skilled work relevant to his degree. Conscripted into the army left him emotionally scarred; his industrial accident disabled him physically for life.

The younger interviewees had less experience. Marie, 24, worked in a fast food outlet for a year, on a part-time casual basis, clearing tables, emptying bins and mopping the floor. Lauren, 20, worked in a bakery to support herself while she was studying at university, though she eventually gave up the job because of her mental illness. Melissa, 32, only had one three-month period of part-time paid work arranged by an employment service provider, though she had spent years looking for paid work and doing courses to improve her chances.

Mark, 27, worked until new owners of the business fired him without notice; he has not worked since. Though he has been assessed as able to work zero hours, he believes that he could do certain kinds of computer-based work. Dean worked in an office job after leaving school but his schizophrenia has prevented him from undertaking any more paid work.

For Marie and Melissa, who qualified early for the DSP after secondary school, looking for a job has been their primary goal and the reasons they studied at TAFE. For all other interviewees, getting a job was a normal and desirable part of their lives until their health, or their mental health, prevented them from working.

Aspirations and goals for paid work

Interviewees held strong views that they wanted and expected to work. Mark, 27, who had been assessed with zero hours of work capacity, said:

I believe there are definite psychological benefits to working, and I'm certainly capable of working... I do feel I could do some work. I'd like to work in an office environment. At the moment I participate in online and in-person market research studies. It's fun, but I don't make very much, under \$100 a month. Occasionally I provide IT and computer services to friends for a small fee.

Kevin, 58, kept working even after qualifying for DSP.

Though I was on the DSP I did work part-time for years with the railways as a customer service attendant. I was just working short hours, four hours sometimes,

five hours on other days. But it became very stressful because people were jumping boom gates in front of speeding trains.

For Melissa, being diagnosed with Asperger's Syndrome helped her to clarify what strengths she might bring to a paid job, something she was very keen to get.

When I was at school I didn't have any part time jobs. It was too hard relating to people. When I got my diagnosis it made it a bit easier, to know that there was something, a name for what was wrong with me. It helped me to know how to better myself, even though I can't get rid of it... After doing some research about the kind of jobs it would be good for someone with my condition, we found that data entry was one, so I thought I'd do a business admin course at the TAFE... I figured if I work in admin in the health system ... I'll be doing something that I want to do. I'm happy with that. Just give some filing to do, or data entry and I won't complain, I'll be thankful for the job...

The job search stuff I've done has all been of my own free will, because I'm too smart to be sitting around doing nothing. I can work. My upbringing and my work ethic makes we want to get a job. So I'm already looking for work. I had an interview for a job last week. I think it went well, it was in a nursing home as a support officer. I tried my best.

Marie did a lot of different work experience placements, trying to find out what she would like to do, and put in a lot of time to find a job.

After I stopped at TAFE I gave up study for a while, and next I started going around to places looking for work. I looked for a long time. I joined an employment agency and looked for work for years and years.

Lucia had always worked, and as soon as she could drive after her brain surgery, she really felt she needed to get back to work.

I got married at 27, but didn't have much time off. After I had my two kids, I went back to work part-time when they were two. I've hardly ever been unemployed till now...

As soon as I could drive again, I wanted to work... It might sound funny, to look for work when you are sick, but it helped me, because I was so depressed. My mortgage was more than I got on Newstart. I was struggling, I thought I'd have to sell the house... I haven't got a partner who can bring in money.

For Katrina, even after her accident, she managed to continue working.

I had a really supportive employer who made it possible for me to work full time, even with my physical disability and chronic pain.

For Lauren, employment was a sheer economic necessity.

My rent was about \$600 a month, so I needed about \$800 a month to get by, and I was earning about \$300 a week. All my money from work was going towards rent and bills and quite quickly my savings were going down.

Although she was relieved to get the DSP and have some money to live on until she was well enough to work, Lauren has every expectation of working in the future.

I'm not ready yet to get a paid job. People don't want an unstable person looking after their children or their files. Occasionally I go for two weeks when I find it really hard to get out of bed. Things that trigger stuff for me can be lighting, or people using certain words, or things like that. I don't want to just suddenly hysterically crying...

I'm not planning to stay on the DSP forever. I just need it now. The idea that I'm sucking out money out of this pool of finite resources upsets me. It's great to know there's not the haste, or the pressure. I'm going to get qualified at uni, then I'm going to go into the workforce, and find a job that suits all my sensibilities and sensitivities. Then I'm going to be paying my taxes, and I'm going to be so excited about paying my taxes because I'll be paying for people who can't do what I haven't been able to do.

Dean, too, does not feel ready for work.

The idea of looking for work scares me because of my illness. It scares me because I just don't think I could do the workload. I couldn't concentrate, I get very fatigued because of all the medication I'm on. I don't think the employer could keep me on, I'd get the sack. On the DSP I don't have to stress out about finding a job.

Aleks is not thinking of work at this time, in part because of his chronic pain and his reliance on morphine to manage it. Until his compensation for wrongful conviction and the prison sentence case he served is resolved, he would in any case struggle to explain to any prospective employer where he has spent the past four years. Aleks is writing about his life experiences, trying to make sense of what has happened to him.

Aspirations and activities for volunteering or unpaid work

Many interviewees were doing volunteering or unpaid work. Katrina qualified for the DSP after moving to the country. She has caring responsibilities for her husband but is also active as a volunteer.

I do voluntary work in the community. I run the local op shop for the school association, coordinating all the volunteers. It's rewarding, because that money goes back into our local school. It's really flexible. I put in about six hours a week, and we have a school association meeting once a month. I've also worked with environmental groups, and I'm doing some work to find places for refugees. It's important to me to contribute something to the community

Kevin does some work at reduced wages.

My capacity to work right now is not as good as it should be. I'm working one day a week, for \$25 a day, for an organisation that supports people on the DSP. I'm doing it to be active again, I don't want to be at home being bored out of my brain. I'm working in the kitchen but I can't do any heavy lifting because of my heart. It gives me something to do, it makes life less tedious, not sitting at home all the time.

Lauren volunteers in a childcare centre, learning skills relevant to her future employment.

A couple of months ago I started volunteering at a childcare centre for children with special needs. I wanted something with structured hours, something with people. I want to work in mental health policy later if I can.

Both Melissa and Marie are keen to get what work experience they can. Marie did a lot of unpaid placements.

At the end of Year 12, my parents arranged lots of work experience for me: in a clothes shop, a coffee shop, hairdressing shop, a childcare centre. I'd do them for about six weeks, trying different things to figure out what I was interested in doing.

Melissa was still hoping to hear about the work experience placement she was meant to be getting after doing a Job Ready course with a provider. She was quite willing to travel for it. Earlier, she had volunteered for Work for the Dole because she was bored.

Mark had tried to find a placement as a volunteer, but without success.

Although I apply for volunteer positions I never hear anything back. I imagine that roles like this could be a stepping stone to paid employment, so there is probably just as much competition for volunteer work as paid.

Many interviewees were doing voluntary work, unpaid work, work experience, work at reduced wages, or small manageable work of a few hours here and there. One had even volunteered for work for the dole after doing a Job Ready course with a provider. It was clear that many had aspirations for work and/or voluntary activities.

Living with disability – general implications of the research

From the oldest to the youngest, every interview subject initially held hopes and expectations of joining the workforce. Aleks, Kevin, Katrina, Anna, Lucia, Dean, Melissa, Mark, Marie, and Lauren all expected to work upon leaving school and most did so. Lauren and Mark worked as a way to support themselves to study at university. Melissa and Marie, who struggled to get a job, turned to work experience and persisted with TAFE courses as a pathway to employment, even though this was a difficult learning environment for them. Anna and Lauren worked very hard to combine study and work even while they were ill, and Katrina finished her two degrees even through years of post-accident rehabilitation and pain management.

Both before and after going onto the Disability Support Pension, this group of people manifestly understood the value and importance of paid work. Like the rest of the working population, they see employment as a way to earn money, to support themselves and to be able to afford things. Those who studied followed their interests and aspired to turn them into employment. Some were motivated by clear career goals, some wanted the opportunity to help and be useful to other people, some simply wanted to avoid boredom. Before their illness or accident, none of Aleks, Kevin, Katrina, Anna, Lucia, Dean, Mark or Marie had aspired or planned to be on the Disability Support Pension. Aleks and Lauren did not even know such a payment existed.

How people found out about and were assessed for the DSP differed significantly. For Melissa and Marie, having Asperger's Syndrome seemed to make their qualification for the pension a fairly straightforward matter that was arranged through their parents upon leaving school. For Katrina and Alex, previous workers compensation claims provided helpful histories of evidence about their injuries and acquired physical disability. Katrina had worried that the contested and stressful process of getting workers compensation would be repeated with her DSP claim, but this did not happen.

Some people do not have clear memories of being assessed for the DSP. Dean, who was experiencing both psychosis and suicidal tendencies, said it was 'all a little hazy', but reported that 'most of time with Centrelink, it's been pretty cool, they've been pretty good.' Anna, who went onto the pension (after the Newstart Allowance) for post-traumatic stress, depression, anxiety and systemic health problems, has no particular memory of her assessment process, perhaps a sign that the assessment for DSP went well in her case.

Lauren reported her surprise that mental illness could be grounds to qualify for the DSP, and remembers feeling happy when she saw her assessor tick the box for short-term claim. Yet she believes that she was first misinformed by Centrelink when, making a claim for Youth Allowance for a forced move out of home, she was told that if there was violence at home, "DHS will have to come to your house and talk to your parents and your brother and he'll have to be taken away.' This advice led to Lauren's attempts to manage life on her own and the feelings of impending catastrophe that led to her hospitalisation.

Others found the system of qualification for DSP difficult. Mark, who applied for the DSP on the advice of his psychiatrist, found that 'Centrelink seemed to create many obstacles and prolong my application.' Aleks did not have a clear picture of the relationship between his workers compensation payout and later eligibility for the DSP. Kevin's applications for the DSP were rejected three times. Without the later explanatory diagnosis of neurofibromatosis, his reports of fatigue were evidently not regarded as sufficiently convincing. It was only by being assigned a different assessor that he qualified for the pension. Lucia was obviously ill-served by a temporary replacement GP, who either was not aware of Lucia's medical history, or did not believe her accounts of her condition, or who for some other reason judged that Lucia was capable of working, despite the convulsions and Lucia's anxiety arising from their unpredictability.

The income that people get from the DSP makes them relieved and grateful. Lauren is glad to have the opportunity to focus only on getting better, with a 'complete mental health six months... [to achieve] complete perspective' on her suicide attempt, and to begin to follow a career interest in childhood abuse and trauma so that she can 'understand my experience and learn how I can help other people.' For Lauren, the DSP was also a way to see that she needed help. 'It was the validation, it was so nice to have someone say 'This is debilitating, and this is serious.'

Dean also reported that the DSP gives him a sense of security: 'I don't have to stress out about finding a job. The DSP helps me pay my bills, helps me keep a roof over my head, it helps me buy groceries. I'm on a lot of medication, I think it's about \$60 a month, and it helps me pay for that, and for doctors.' For Anna, who has had so many problems with medical diagnoses, the DSP is 'like a lifeline', giving her 'finally the means to try to manage.' And for Kevin, the DSP helps to pay for the considerable number of medications he is on, along with his wife and daughter. Without it, 'we wouldn't be able to run the car, which we need to get our daughter to her medical appointments. From a pharmaceutical point of view, we'd have to go without so much. We already have to keep an eye on grocery prices, especially fruit and veggies and meat. We'd have to cut back on food, and school things, like excursions.'

There can be significant symbolic and emotional value to DSP recipients in having some kind of 'official' recognition that one is ill, and needs help. This is true for Kevin, after being 'knocked back' three times, also for Lucia, whose expression 'Oh my God, finally...' signals her relief that

her pain and the unpredictability of her convulsions were believed. But by far the most powerful and important value of the DSP is the adequacy of income support it represents. By helping them pay their bills, the DSP relieves them from worry and stress, which in turn supports recovery, or, for people with chronic or worsening illnesses, the ability to simply manage life.

People in general want and hope to be connected to others, to earn money, to learn new skills and ideas, to have routines and something different to do. Being ill, unwell, or 'odd', as Marie described herself, does not change those aspirations, though it might limit their capacity. Katrina and Lauren do voluntary work and Kevin works for \$25 a day. Lucia wanted to get a job as soon as she was allowed to drive. Mark is trying unsuccessfully to get roles as a volunteer, while learning graphic design through a free online university. Maria and Melissa are keen to get more work experience. Aleks is writing about his life. It is clear from their past histories, their declared interests in learning, and (for some) their search for the kind of work that would fit in with their needs and circumstances, that the interviewees in this research have a strong internal drive for 'self-activation'.

That drive towards self-activation is in various ways a source of pride and self-respect for interviewees. Though they have qualified for the DSP and most have no work requirements, they want to be - and wish to be seen as - active, useful, learning, contributing. Past reported experiences of employment underline this point.

The case studies show that many disability conditions are not always visible: people with mental illness, chronic pain, a brain tumour, a neurological disease, or Asperger's syndrome do not always immediately and manifestly present as not operating at full capacity. In addition, most people with disability want to fit in and conceal their difficulties when they can. It is therefore vital that when the Commonwealth Government sets its policy objectives for the DSP, it gives DSP recipients an important role in determining the kinds of activities they might do to improve their work and participation capacity, the hours that could be involved, and the frequency of such activities.

The principle of self-determination in judging the capacity of DSP recipients to learn, look for work or undertake voluntary work becomes even more important when education and employment services do not always get it right, despite their best endeavours. These case studies report instances of TAFE teachers who are ill-equipped or unable to deal with learning difficulties arising from conditions such as Asperger's or mental illness. Some mainstream employment services are reported to be ineffective or unhelpful. Though these services can sometimes open up important and valued opportunities, and (as in Marie's case) be very supportive, compelling people to participate in such services is counter-productive, especially when they are not achieving the employment outcomes intended. Compulsion distorts and demeans the capacity for self-help that the people in this research so clearly show they possess.

In this context, it becomes even more important to recognise the prevalence of mental illness among people on the Disability Support Pension. Among those interviewed for this research, only two people did not suffer from depression or anxiety, though only for three would it have been recognised as a primary disability. This is an indication of the far greater prevalence of mental illness as a secondary condition for people already on the DSP than is represented by the 263,000

(31.7 per cent) of people with a psychiatric or psychological condition as their main medical condition at March 2014.¹⁴

The Department of Human Services has identified approximately 13,350 DSP customers under 35 for review for DSP eligibility who have a psychological or psychiatric condition recorded as their primary medical condition.¹⁵ This number is likely to be far greater when secondary mental illness is taken into account, for reasons identified in the case studies. Though medical diagnosis is a necessary and valid component of DSP assessment eligibility, the lives of the people in those case studies point to the commonsense conclusion that depression and anxiety are likely to follow the kinds of experiences that they have endured: serious accidents, feeling 'odd', shy, socially awkward, in pain, out of control, uncertain about the future, regretting the past. Adding to those conditions the stress of being forced to look for work – using services that can be experienced as ineffective, unhelpful, or 'useless' – is likely to contribute to the risk of greater mental illness.

Finally, there is the hard reality of the labour market. The National Employment Services Association has said of the current labour market that 'competition for jobs is fierce, with 4.4 job seekers in Job Services Australia for every available job, and an estimate of just over nine for every likely suitable vacancy.'¹⁶ Despite significant advances in disability awareness in society in general, and support from the government through disability employment programs in particular, people with disability are less likely to find employment. In 2009, the unemployment rate for workforce age people with disability was 7.8 per cent, compared with 5.1 per cent for people without a disability.¹⁷ This discrepancy points to the need for more consideration of labour market conditions in the determination of activity requirements.

Further research needed

Government policies to activate the working age population have been intended to help people to achieve employment and improved life prospects. But when these policies increasingly apply to people with disability, and when they are linked to the withdrawal of income support, it is vitally important to look more closely at the operating assumptions of those policies. We can identify assumptions in the way people on the Disability Support Pension are increasingly subject to compulsory job search requirements. These are:

1. That DSP recipients are not self-activating;
2. That sanctions will activate DSP recipients;
3. That upon being activated, DSP recipients will get jobs sooner or later;
4. That the employment services system is appropriately helpful;
5. That there are suitable jobs for DSP recipients;
6. That they have a reasonable chance of getting those jobs;

¹⁴ Department of Social Services, Payment Recipients Data, March Quarter 2014. At: www.data.gov.au/

¹⁵ Senate Community Affairs Legislation Committee, Budget Estimates – 5-6 June 2014, Answer To Question On Notice put 6th June, 2014, Department Of Human Services. Topic: Review Measure Of DSP Recipients Question Reference Number: HS 27

¹⁶ National Employment Services Association, *Submission to the Exposure Draft for Employment Services 2015-2020*, August 2014.

¹⁷ *Labour force participation and unemployment rates for persons aged 15-64*, Australian Bureau of Statistics, 2009.

7. That the compliance and sanctions regime and the employment that might result from it will not negatively affect the health and wellbeing of people whose disability or health condition has qualified them for the DSP;
8. That the employment they enter will not contribute to worsened health or mental health for this group.

Each of these assumptions represents a research question needing further investigation.

One line of inquiry is whether, for people with disability and greater likelihood of mental illness, the proposed model of compulsory activation really does help achieve higher levels of employment, with such features as compulsory regular attendance at appointments, minimum numbers of job applications to be achieved, and the possibility of sanctions. An associated question is the potentially negative impact of communicating the system of compliance and sanctions to people whose past and current efforts to get paid employment are already considerable.

Research is also needed on how sanctions imposed – or the risk of sanctions – affect people’s living conditions and subsequent health, mental health and wellbeing.

Another research question is whether assistance provided through employment services programs, both in the mainstream Job Services Australia system and Disability Employment Services, works as it is intended for people with disability and specific research is needed into the suitability of employment support for indigenous people with a disability. This investigation should incorporate a full understanding of the resources and support available from employment services, including:

- The time available for appointments (given caseload sizes and the fees and financial incentives available to providers);
- The degree of expertise among the employment consultants and/or related employment services personnel about the medical/health condition of the person being assisted;
- The variety and suitability of advice and support available; and
- The extent to which exchanges during appointments are compliance-focussed or assistance-focussed.

In this kind of investigation it is important that the research information does not rely only published government information and employment program guidelines; it should be as experienced and reported by service recipients, who might have much to offer and suggest about what would work better. This information is needed to understand how long people with disability can remain engaged, encouraged, and hopeful through months and often years of expected job search and participation activities.

Activation policies also assume that there are sufficient suitable jobs available for all the people with various kinds of disabilities or health conditions who are being activated. Is the system requiring people with disability to look for jobs in a world of employers who are not yet ready to employ people with disability? In tight labour markets, how much is a large pool of other ‘activated’ job seekers, with full health and work capacity, reducing the chances of those less able to compete?

Current government employment policies have emphasised the need for employer demand-driven services. Given this, some investigations into the capacity of employers to take up the labour of those with partial work capacity are warranted. This could support some cost-benefit analysis for all

concerned: for the government, for people with disability compelled to look for work, and for employers rejecting pointlessly repeated applications.

This is a wide-ranging research agenda that would require some investment. It is hoped that the case studies in this small research project demonstrate why the investment is so important.

Appendix I: Interview questions

1. Your life story
 - a. Where did you grow up and go to school?
 - b. When did you leave school and what did you do?
 - c. What work did you think of doing and what happened?
As appropriate:
 - d. How did your disability manifest itself (if not manifest) and how did that affect your aspirations and opportunities?
OR
 - e. How did you come to be injured/unwell and how did that affect your aspirations and opportunities?
AND
 - f. Can you describe your general health and disability condition(s) and whether any secondary conditions are diagnosed?

2. Your experience of the income support system
 - a. At what point in your life did you start claiming income support?
 - b. How did you find Centrelink? (clarity of information about assessment and referrals, how the process would work, helpfulness, anything else)
 - c. How did the process work? (include JSCI, Employment Support Assessment and/or Job Capacity Assessment, any review/challenge and how that went)
 - i. What evidence did you need to take?
 - ii. Did the person doing the assessment have the right expertise?
 - iii. Did you get advice about how the assessment process would work if you did not agree with the assessment and wanted a second/alternative review?
 - d. Did you understand the roles of the different people/organisations/agencies that work with you and how it all fits together? Did you need someone to support you through the process?
 - e. What was your understanding about the difference between Newstart and the DSP?

3. Your ability to live on income support
 - a. What costs are there for you arising from your disability or illness?
 - b. Does the DSP cover these costs and leave you sufficient funds for other living expenses?
 - c. Where do you live? (if this doesn't come up before – i.e. at home pay no rent, shared accommodation & pay rent etc)

4. *(If under 35 and assessed for and granted DSP between 2008 and 2011)* Do you know about the government intention to reassess your DSP eligibility?
 - a. What are your concerns about that?
 - b. What would be the impact on you if not found eligible for DSP?
 - c. What do you know about the payment rates for Newstart compared with DSP?
 - d. What would it mean for you financially to lose the DSP, for example, if you were transferred to Newstart Allowance?
 - e. What would be the impact on you if you were to lose entitlement to money you get from the DSP?

- f. Are there financial incentives for you to work? If you were on Newstart or if you were on DSP?
 - g. What is your opinion about the costs/benefits of working overall? What information is that view based on?
5. Your experience and views about paid work
- a. Do you currently work? What do you do?
 - b. Are there any other kinds of work you feel you can do or would like to do?
 - c. If you had to do some kind of compulsory activity intended to see if you could go into paid work, like skills or training activities, what kind of thing would work for you? And how many hours could you do (compare with assessed work capacity hours).
 - d. Do you/would you have to pay any extra costs connected with your disability in order to get to or to be able to manage paid work?
 - e. What about adjustments/modifications for training and/or work that would be needed to accommodate your disability?
 - f. (subject to manifest capacity to work) If you don't feel you can work, can you explain why?
Prompts:
 - i. Financial incentives to work/costs of working and cost-benefit
 - ii. Past work experiences with employers/colleagues
 - iii. Ability to manage disability/availability for work
6. Your experience of the employment services support system:
- a. Have you ever had help from an agency to help you find employment? How did that go?
 - i. Advice and support
 - ii. Training
 - iii. Employer advocacy/placement/work experience opportunities
 - iv. Anything else?
 - b. What was good? What was not?
 - c. If referred to DES and/or JSA, what was each like?
7. General views about quality of life and prospects (if not revealed through the interview):
- a. What's your opinion of the way that people with disability are depicted in the mass media? What's your sense of how the government sees and treats people with disability in general? Does it reflect your own circumstances and experiences?
 - b. How do you manage your health and well-being? Stay motivated?
 - c. Do you do volunteer work or care for others?
 - d. Are you learning or studying?
 - e. What support networks do you have?
 - f. How do you get around?
 - g. How do community, health and disability services work together in general for you?
 - h. Anything else?