TRANSCRIPT #1 “When the rubber hits the road” - EMPLOYMENT AND DISABILITY

TESSA DE VRIES - Welcome to One in Five, the Melbourne Disability Institute podcast, bringing you the latest in disability research from the University of Melbourne. I'm Tessa de Vries.

In this series we will be looking at how research can tackle some of the biggest issues facing people with disability and their families. Join us as we talk to a range of people about new research findings, possible solutions and policy ideas.

Before we start, we just want to let you know that this episode features Allison Milner who died in a tragic accident not long after we recorded this interview. With the permission of her family we are sharing her research here and continuing her legacy.

While both the supply and demand of employment in Australia have generally improved over the last 20 years, when it comes to employment for people with disability we are not doing so well. In fact Australia has one of the lowest employment rates for people with disability in the OECD. The United Nations Convention on the Rights of PWD, of which Australia is a signatory, recognises that people with disability have a right to work, on an equal basis with others. Beyond the fundamental human rights argument for increasing employment of people with a disability, there is an economic argument to be made also.

Increasing employment for people with a disability to OECD average levels would add $11.9 billion to GDP in Australia by 2030. That is a modest and seemingly achievable target of 0.8% increase in employment.

In this two-part episode we explore what is causing such poor employment rates for people with a disability and look at key initiatives to improve the quality and availability of work.

ALEX WALLACE - I’m looking for work constantly, and there's a huge gap in my resume from all times throughout the duration of when I seek so it gets a bit anxious walking into like a job interview,

TESSA DE VRIES- We’ll look at the figures.

ALLISON MILNER - So Australia's employment levels for people with disability systematically below those people without disability.

TESSA DE VRIES - And we'll unpick some of the contributing factors revealed by research.

STEFANIE DIMOV **-** A third of people said that they experienced discrimination, applying for a job going to a job interview and at the workplace.

TESSA DE VRIES- We'll look at what works to better engage and sustain employment for people with disability.

JESSSE OLSEN - Really best practices do have certain features and one of those features is that this would be a more formal system

TESSA DE VRIES - and explore projects designed to address low levels of disability employment.

KEITH MCVILLY-So what we're doing is we're building a model to support the Victorian public sector to onboard, train and provide long term careers for people with intellectual disability.

TESSA DEVRIES - But stay with us now as we're joined by Associate Professor Allison Milner.

ALLISON MILNER - I'm Deputy Director of the disability and health unit

TESSA DEVRIES - for a rundown on how disability and employment interact.

ALLISON MILNER - Well, I think all people with a disability face issues at different stages of the life so it depends a lot on the life stage. We know that people with intellectual disabilities have particular problems as do those people with psychosocial disabilities, and that's shown through some of the statistics around the DES system or the Disability Employment Services system. These people tend to sort of churn through the system, which means they tend to be placed in a job then drop out of that job probably because the jobs not suited to them then they go back into the system to be placed again and again. So this is the group that tends to be unemployed again and again and again.

TESSA DEVRIES -Employment rates for people with a disability are only about 47% compared to 80% people without a disability. And when thinking about those low employment rates keep in mind that people are considered employed if they work for a minimum of one hour per week.

ALLISON MILNER - Our work generally tends to focus on the conditions around a person with a disability. So operating from more of the social model of disability, which would argue that it's sort of the conditions around somebody's ability to interact with a workplace that determines whether they are able to stay at work and are well enough to work.

So within that, we think about things like the psychosocial characteristics of job. So for example, levels of control you might have over when and how and who you work with. Whether you're able to have flexibility about when you go into work, and when you stay at home to work, for example, another big one is if you're having trouble in housing that will then impact the ability to which you're able to get to a job and be able to get to a job say on time, or it being, for example, a long way away from where you're living. So we know these two things are quite closely interrelated, precarious work and precarious housing.

But on top of that how demanding the job is both in terms of physical demands and psychological demands, and one big stressor, we found his job insecurity. So feeling that you know, you may not have a job tomorrow is not very good for your health and is not very good for staying in a job either.

So, a program can be effective for placing someone in employment. But really the rubber hits the road is whether it's good for health, because work that's good for health will ultimately be good for economic productivity, social productivity, and someone's overall well being. So really, we need to be considering these two things in tandem.

TESSA DEVRIES- We’ll explore these ideas further shortly when we look a bit deeper at some of the research around disability employment services.

But first we'll talk to Alex

ALEX WALLACE **-** My name's Alex Wallace. I was diagnosed with bipolar back in 2005.

TESSA DEVRIES - To get an idea about what it's like trying to find work with a psychosocial disability.

ALEX WALLACE – Yeah, So basically, I was working as a cake maker in like an industrial kitchen, and I was living in the fast lane like burning candles at both ends, and I knew nothing about mental illness, nothing at all. And in 2005 December, I had a massive breakdown, a massive psychotic break, elevated psychosis mania, like delusional thinking, all that sort of thing, yeah it led to hospital admissions, in and out of hospitals. Really, really extreme stuff like, like crazy stuff. You know, I was very lucky to survive and be like talking about it today. I think the main, why I sort of got better was just by surrendering to the services and people who are professionals and just letting everything go and saying I am in your hands. Tell me what to do. But it was a lengthy recovery. So it took a while until I started feeling comfortable going back into the workforce. You know, or I could think about going back to work.

So yeah, so I'm looking for work constantly. I've had to work stop start jobs. I've no problem with my work ethic. I can work quite hard and, and quite well, I think, but there's some days where I'm not as on the ball or on the money. Some days I'm feeling very lethargic, very anxious. Even though I feel like I've recovered a lot, I'm still crippled by some things on certain days. And I don't think that's really ever going to go away.

I used to be a bar manager in the UK when I was in my 20s. But that was before I got sick. And now that I'm sick the anxiety is too much to deal with, being out there serving like lots of people dealing with that sort of stuff. I just, I can't do that anymore. So along with the illness, there's been restrictions that have come with that. As far as going back into certain roles in the workforce, even ones I've done before, when I was younger.

STEFANIE DIMOV - That's probably one of the most notable findings coming out of the studies that there's this real broad range barriers to employment for people with disability that it's not just associated with, with getting them sort of job ready. But then I think there's maybe a broader discussion needed around, you know, recognising those barriers and then also supporting people.

I'm Stephanie Dimov, and I'm a project manager on a number of projects looking at disability and employment at the unit for disability and Health at the University of Melbourne.

TESSA DEVRIES - One of the projects is the improving disability employment study, otherwise known as IDES. IDES is a research project looking at the ways in which people interact with disability employment services – known often simply as DES. DES providers are organisations that help job seekers with disability find a job, and also provide whatever support that person needs to keep their job.

The IDES project is the first of its kind to examine the experience of the people looking for work, by conducting surveys and interviews across the range of DES providers.

We talked to Steph and her colleague Alex

ALEX DEVINE - Hello, my name is Alex Devine

TESSA DEVRIES **-** about the project.

STEFANIE DIMOV - So IDES was really born I guess out of the understanding and some of the statistics around the unemployment rate for people with disability. So we know that that's at twice the rate of that for people without disability. And so we know that increasing those rates is really important, but we also know that improving the quality of work for people with disability is equally as important.

The aim of the study was to recruit people with all types of disability, we found that the majority of people had a psychosocial or a psychological disability. So that was almost 45% of people in this study. And then we also had people participating that had physical disability, sensory disabilities and also almost 15% of people had a cognitive impairment or an intellectual disability as well.

TESSA DEVRIES - The IDES project interviewed

ALEX DEVINE- around 350 people with disabilities.

TESSA DEVRIES - That's Alex now

ALEX DEVINE - to better understand their social and economic conditions and how that relates to their engagement with employment services.

TESSA DEVRIES **-** Alex's work within the project focuses on the experiences of people with a psychosocial disability.

ALEX DEVINE - So I guess in my research that refers to a disability associated with someone's lived experience of mental illness, not all people who experience mental illness will experience a disability. But given that people with psychosocial disability, in many contexts within Australia and the world are more likely to experience socio economic inequities, more likely to experience discrimination and have a lot of unmet need for both mental health services, but general services in terms of housing, can mean that mental illness can become a disabling condition.

TESSA DEVRIES - Psychosocial disability produces some of the highest rates of disengagement from the labor market with unemployment rates of 19% compared to 5% for the general population. But the reasons for such high unemployment levels are complex.

ALEX DEVINE - So we know for example from our findings, some of the major barriers to employment that people with psychosocial disability are reporting are actually issues around homelessness or insecure housing, or poverty, or the fact that they're not able to address their both their mental health needs and their general health needs, which makes looking to work and maintaining work much harder.

And these are not necessarily areas where disability employment services are well resourced to support people. DES providers often have very high case loads. There might even if they are aware of housing support community organisation, that community organisation might then not have enough resources to support people with disabilities to find housing.

In a lot of places where we're speaking to people such as in rural areas, there might just be a limited number of appropriate jobs that people feel that they're able to engage with, either in terms of their other coexisting physical conditions, or the hours that's expected of them or the environments that they're expected to work it so it's this confluence of, of barriers at different levels that people with psychosocial disability are experiencing, more those structural barriers to employment that the DES program are currently not able to address.

So I guess the main finding is it's hard to say how the DES program can be really effective for people with psychosocial disability if we're not addressing those underlying barriers.

NATALIE - Hi, my name is Natalie, I’ve been engaged in lots of different disability employment agencies. They've helped me like make a resume, to apply for jobs and get on Seek. They helped me with attending a job interview, like accompanying me to the job interview, staying there through the interview with me, cos yeah, sometimes I get in a really good place. So, I feel like I can work so I have worked and stuff. And then there's times where I'm not so….. And when I'm when I'm going through periods of being quite unwell, I can't hold a job at all.

With mental illness, it's like, every day can be different. So a job, it's like consistent, you have to go there on time. You have to do your job, it doesn't matter what's going on with you, the job is not waiting for you, you have to go and do it and you always have to be good. And that's the thing with mental illness people, you're not always stable like a job. So yeah, with mental health, it can be hard.

STEFANIE DIMOV - We did ask people about the kinds of things that would be helpful when thinking about their next job. And so one of the things that was coming out quite strongly was understanding from co-workers about their disability or their health condition. So over 50% of people said that that was important to them. We also found that receiving a supportive approach to training would also be important for people with disability. And then other important things included, you know, having flexible work hours, for example. So 85% of people said that that was important to them. And having the option to have duties modified almost 70% of people said that that was important, which I guess lends itself to this concept of job quality and having more control over the kinds of things that you do at your job.

Something that we're recognizing is that this is particularly compounded for young people with disability, for young people that are transitioning from school into employment. Young people with disability, you know, whether they're attending a mainstream school or a special school, generally face more limited opportunities around sort of developing work readiness skills than people or young people more generally. So, you know, some of the things that are identified as helping young people into work are things like having access to volunteer experience, but also paid work and after school work, part time work. So there's some research looking at young people with intellectual disability. And so for those young people, if they don't, you know, they're not in a job by the age of 21, it's sort of much more difficult for them to be in open employment moving into adulthood. So it's really important, particularly for young people with disability to be developing some of those work ready skills or those employment skills early on, and certainly before the completion of high school.

ALEX DEVINE - Other things that DES participants have valued in the past is that really one on one engagement where they've got good intake processes. So the DES consultant takes time to understand the person's needs and their aspirations in terms of employment. And then they really work to match that individual with a with an appropriate employment consultant. That can be challenging for other DES providers to do. Not all, there are some amazing employment consultants out there that have a really good understanding of psychosocial disability. And they match that understanding of psychosocial disability with a good understanding of the local labor markets as well. So they've got good relationships with local employers that are willing and able to recruit people with psychosocial disability and provide supportive environments. But we know often enough people might get referred into employment situations that don't meet their aspirations or their needs. And when that does happen it can have a very negative impact on someone's mental health.

NATALIE - You know I can have days where I'm so flat can't function I can't make myself something to eat I can't do anything I can't leave the house. I don't want to lie to an employer and say I’m reliable, I’m good, I’ll always be here and then I don’t, because then I'll just see myself as a failure and make me feel worse.

ALEX WALLACE -I think your number one priority is not to relapse and end up back in a psychiatric hospital you know that that's you know, main goal. I think when you have a mental health condition, and when i get sick, I may be seeming sort of okay today like, but when I get sick, I get so sick is so so sick.

I think protecting your mental health is vital, and it's the number one rule and anyone around you who cares about you should understand that, and not push you into work that is unsuitable, and it could stress you to the point that you'll relapse and yeah, get sick again, because it sometimes it takes a long, long time to recover.

And some people don't even recover fully.

ALEX DEVINE - So even before the introduction of the NDIS, and we see this in a lot of social policy programs within Australia there is this move to marketisation. So previously in the DES program before the July 2018 reforms, all DES providers were sent or referred a market share from Centrelink. So if a Newstart recipient with disability went to Centrelink, Centrelink would refer them on to a DES provider.

While that's still happening Centrelink do still refer people and income recipients or DES participants now have more choice and control in which service they go to. And if they're not happy, they can change.

I guess some of our other work, though, has looked at whether people do change. And we know that there's a lot of reasons why even if people aren't happy with the DES service that they're receiving, they still experience a number of barriers to changing.

It's too early on in the reforms to see if that changes, but we know sometimes people are not aware that they're, they're able to change. They don't have the information about what other providers are available. Enacting change can be difficult. Sometimes people don't want to offend their current DES provider even if they know that it's not meeting their needs, and then other broader issues in terms of housing and poverty and health conditions where their engagement in DES, it's difficult for them to prioritize when they're trying to address so many other issues in their lives.

TESSA DEVRIES - That brings us to the end of Part One of this episode. In part two we will look at the other side of employment; the employers. How do we get employment right, what is the government’s role in increasing disability employment rates and why we need to think long term as well as immediate solutions. In the meantime you can visit our website at disability.unimelb.edu.au to find more information about the research we talked about today and some useful resources. And you can join our mailing list there too.

I’m Tessa de Vries, thanks for listening to One in Five.