Disability Support Pension New Customer Focus Groups

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FINAL REPORT

ALAN MORRIS AND DAVID ABELLÓ

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Alan Morris and David Abelló

Report prepared for the Department of Family and Community Services under its Social Policy Research Services agreement 2004

Social Policy Research Centre

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1 Introduction

Background

In February and March 2004, FaCS conducted a quantitative study of people who had been granted the Disability Support Pension (DSP) between August and November 2003. The study aimed to provide a systematic, quantitative analysis of new DSP recipients' characteristics, their disability and impairment status, labour market histories and aspirations, educational and training backgrounds, pathways onto income support and their service needs. Maximum quotas were planned so that no more than 50 per cent of the sample in each age group would be from amongst those with the most prevalent disability type. The targets for the purposive sampling framework of the quantitative study were as follows.

Table 1.1: Purposive sampling framework for the quantitative study

Research Groups	Age Groups	Prevalent Conditions	Interviews
Young People 16-24 Yrs	16 - 19 Yrs	Intellectual/ learning	100
	20 - 24 Yrs	psychological/psychiatric	100
Developing Age 25 – 34 Yrs	25 - 29 Yrs	psychological/psychiatric	100
	30 - 34 Yrs	psychological/psychiatric	100
Prime Working & Family Age 35 – 49 Yrs	35 - 39 Yrs	psychological/psychiatric	100
	40 - 44 Yrs	psychological/psychiatric	100
	45 - 49 Yrs	musculo-skeletal and connective tissue	100
Approaching Retirement 50 – 64 Yrs	50 - 54 Yrs	musculo-skeletal and connective tissue/ psychological/ psychiatric	100
	55 - 59 Yrs	musculo-skeletal and connective tissue	100
	60 - 64 Yrs	musculo-skeletaland connective tissue / Circulatory	100
Total			1,000

From Wallis Group (2004) *Disability Support Pension New Claimants Survey, Methodology and Fieldwork Report*, prepared for the Department of Family & Community Services.

As a complement to the quantitative survey, FaCS also proposed a focus group study to explore qualitatively what made DSP customers apply for the DSP, their capacities and aspirations for community participation, work and education and training, their perceptions of the information received and the kinds of information, assistance and service support they would find helpful in meeting their aspirations. FaCS was also interested in the focus groups exploring the benefits of participation and the barriers preventing or discouraging participation.

The Wallis Group conducted 1,001 telephone interviews, and during these interviews participants were asked whether they were willing to be recontacted to consider participation in the focus groups, held locally with all participant costs met. Just under half of the cohort (465) said they would participate while another 200 said they might consider participating.

The Focus Group Study

After consultation with FaCS, agreement was reached as to the geographic focus of the study. Areas chosen were Central, Western, Southern and South-Eastern Sydney, the Central Coast and the Illawarra within NSW. Resident in these regions were 96 DSP new customers who had participated in the quantitative study and had agreed to consider participation in the focus groups.

Potential participants were contacted by telephone, reminded of their involvement in the quantitative telephone study, asked to participate in a local small group consultation and advised that all costs would be met and that they would receive a payment of $40 for their time. Drawing the sample proved to be very difficult. Many of the invited participants declined to participate, others withdrew at the last moment and many were not contactable.

Table 1.2: Results of canvassing potential focus group participants

Cohort	Number
Number of suitable participants identified	96
Number who could not be contacted (phone had been disconnected, switched off or was never answered after multiple attempts at various times of the day and days of the week)	23
Contacted but no longer receiving DSP	2
Contacted but too sick or in hospital	9
Contacted but unavailable or unwilling	30
Contacted, invited but no show on the day	11
Contacted, invited and attended a focus group	21

It was intended that there be six focus groups of six to eight participants (36 to 48 participants), and that these be age specific groups. While the numbers of participants fell short there was still some age clustering in the groups. The characteristics of those who participated in the focus groups are detailed in Tables 1.3 and 1.4.

Table 1.3: Age range and gender of focus group participants

Age range	16-24 yrs of age		25-34 yrs of age		35-49 yrs of age		50-64 yrs of age	
Gender	M	F	M	F	M	F	M	F
Number	3	2	2	2	3	2	3	4

Table 1.3 illustrates that 13 of the 21 participants were male and that nine were 34 or younger and one in three was 50 or older.

Table 1.4: Residential location of focus group participants

Region	Central Coast	Illawarra	South-west & Western Sydney	South-east & Southern Sydney
Number	10	2	3	6

Table 1.4 shows that more than half of the participants lived outside of Sydney. The two participants from Illawarra were part of the South Sydney based focus group. Two focus groups were held on the Central Coast, one in Gosford (three participants) and one at Lake Macquarie (four participants). Three Central Coast residents travelled to Sydney to take part in a focus group – two were in a focus group for younger DSP customers and one was in a group of people of different ages.

Focus group participants had a range of disability types, including physical, psychological and sensory impairments.

It had also been planned to include unemployed/employed dimensions in the sampling frame. This proved to be impossible. Only one person who agreed to participate was working part-time. At least half of the participants, however, had had significant stretches of employment. Despite all the limitations mentioned the sampling gave a good spread of participants across age, gender, impairment type and location. The focus groups generated rich data and enabled us to reach a number of conclusions with some confidence.

The focus group topics were organised around four key themes – participation and barriers to participation in a) community / social activity; b) employment and c) education and training. The fourth focus was perceptions of information and how access could be improved (see Appendix A for the focus group schedule).

2 Community and Social Involvement

The level of community and social involvement varied a great deal and, not surprisingly, depended on a number of interrelated factors. Thus the disability, age, family situation and personality of the customer were key shapers of their community and social participation. Social factors such as experiences and effects of poverty, stigma and discrimination also impacted on the capacity and willingness of participants to engage with the community.

Capacity to engage in community activity

For about two thirds of participants the nature of the disability made it very hard to be involved in community activities.[1] A customer in his early fifties had the following observation:

> I would love to be able to do community. I used to do it before, going back a long time ago. I used to help the elderly out at the community centre. I used to drive the bus. I'd like to be able to do that, but my partner … she said with my hearing she doubted they'd let me because I'd be struggling to hear somebody from a distance. Plus … with my balance, I find it hard, so basically I don't. You sort of withdraw.

A young person with a mobility disability, who has a great deal of difficulty walking, spent almost all of her time at home:

> I don't go out. I never really go out. This is an outing for me … I mean I don't, as I said I don't go out because everything is so difficult. Like just getting into this building was a mission ... Just little things like even getting in the lift is not as simple as it is for other people, so you know, I don't go out that much. I have everything delivered and all that sort of thing.

A woman who had been very active but had become ill over the last couple of years had the following observation:

> I'll say something. I found it [becoming ill] has really changed my whole life around. Because I worked full time, I had three daughters and all three wanted to go through university. One is a nurse, one is a social worker and one is a bank officer now. But I always thought that I would be the one doing the charity work, doing meals on wheels and all the rest of it. I can't even look after myself, how can I help somebody else. And it really, it goes against the grain when you want to go and donate, or do something, and you can't.

An older participant with heart problems had to give up her voluntary activity at the local library because she found it too exhausting: 'I worked as a volunteer last year

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[1] The people who took part in the focus groups are referred to as participants. All the names used are pseudonyms.

with the local library which was lovely. But I was too tired to do it for long. Our branch is only run by volunteers. And it was just too difficult'.

The psychological state of customers is also fundamental to their propensity to engage in community activity. Several talked of their increasing isolation and withdrawal since the onset of their disability. A woman in her mid-twenties who had had a serious accident in her teens commented, 'It's just everything changes, you know. We used to go out a lot. I'd never be at home if I could help it. And now I don't want to leave the house.' A man in his thirties who lives by himself observed,

> So I do get a lot of time on my own. I just have to learn to be comfortable with my own company. You get used to it and you just have to like it. … You just have to live with it. You have to adapt. It's pretty hard because one minute you have a life and then the next minute... it could change in a minute...

A participant who has a psychological/psychiatric condition described how she 'sometimes can't get out of the house …'

Customers who were mobile and who were not depressed were more likely to be involved in community and social activity. The interviews suggested that older individuals who have children and / or grandchildren and who are mobile physically and psychologically are more likely to be integrated into a social circle and to partake in everyday activities. A man in his fifties had the following response to the question of whether he 'gets out much': 'Ah, yes I do a lot. I see people, I've got good neighbours. .. I have a lot of friends. I have my grandkids now, so, I enjoy myself.' A woman who requires dialysis spoke of her need to remain positive for the sake of her children. She also had the responsibility of maintaining the household:

> Yes, for myself I like to go out, not to the pub or nightclubs or that, I like to go shopping for my kids, you know, go out to my cousin, whatever. I don't like to stay home … I'm sometimes sick. Everybody said, 'Why are you walking around if you're sick'. I say, 'inside of me I'm sick, but I'm here, I have to be strong because of my kids, you know.' I have to show my kids that I'm strong. Because if I'm weak, my kids, they're young.

Besides the ability to be mobile, the disposition of an individual was also fundamental in shaping their capacity to partake in community and social activity. A middle-aged male participant who has a physical disability but who appeared to be very active, had the following comment, 'you have to be strong inside … If not, that's it – you're dead.' An older female customer who is visually impaired and is waiting for a cornea transplant, was involved in a range of activities: 'I am [a] volunteer for Cancer Council, Royal Blind Society, Red Cross…. I go to Heart Foundation. I can't sit at home, I have to go out.' This customer was optimistic that she would regain her sight and had a very positive disposition.

Financial constraints to community and social participation

Those customers solely dependent on their disability pension often had to severely limit their social activity. Their capacity to partake in voluntary activity was constrained sometimes by transport costs. A man in his thirties outlined how limited financial resources had affected his social interaction:

> It can get pretty lonely sometimes. You're home a lot. You can't really... I mean it's hard to go anywhere and find entertainment without it costing you any money. Even just going to a football match, it could be 15 dollars to get into the gate and then there's food and drinks. The whole experience could end up costing you 40 or 50 dollars. So you tend to sort of not want to go. That's a fair chunk of what we earn. We don't have a lot of money. I mean, you find yourself having to count every dollar that you spend whereas before you didn't really have to worry about 10 or 15 dollars. So I have to count every single dollar in my wallet. … And even your family think that you're abandoning them. They ask 'Do you want to go out?' or 'Do you want to go to the football?' and you tend to sort of not want to go because you haven't got the money. I feel embarrassed that I don't have the money to do things even on the weekend. You end up being less active and you become isolated from other people.

A man in his late forties who had previously had a fairly high income as a truck operator sketched the impact of financial constraints in the following way.

> But of course you earn good money before you could go to the golf club, you're playing the poker machines, you're having a bet on the horses, you're doing this, having a drink. If I go there now I can't put any money in the poker machines. … and the bloke that I know really well will say, 'Come on we'll play the pokies'. And I say, 'No, I can't Bill', and I just say I don't feel I'm sort of participating in it, so I don't go.

A participant in their mid-thirties with two children had become more and more home bound.

> It's hard to go out. I have two kids. It's hard to buy them things that other kids have. I don't go out too much, I just sort of stay at home. I don't have the money to go out or communicate with people. That's about it.

A married woman in her fifties who had worked her whole life and whose husband is also on the DSP commented:

> We don't have a social life any more. I think partly that's a little bit of a problem with us because we had a wide range of friends. You know but we'd ring on Saturday afternoon and say do you want to go to a restaurant tonight for tea. … And plus the money and we can't afford to go to a restaurant any more. … We wouldn't want to go out every day, but it would be nice to go, to afford to go, but you think well it's going to cost $60. Can we afford that?

The lack of finances combined with the disability appeared to often lead to depression and ever-increasing isolation. It was particularly bad for DSP customers who lived by themselves and were totally dependent on the DSP for their income. Partners or adult children often played a major role in helping customers financially and in everyday life. The gentleman in his fifties recently referred to spoke of how his adult daughters helped him when he needed it: ‘If I need something, I don’t have to say anything. They do it. Because I looked after them since they were little, you know.’

The disability as the shaper of an individual’s social / community activity

For a few of the participants their disability played an important role in shaping their social milieu. In the process of dealing with their disability they encountered a range of individuals. At least four of the customers with psychological/psychiatric conditions were involved in group and individual therapy. A participant with serious depression had the following view on community involvement:

> My main sort of involvement in the community is doing the … job, [and] going to these appointments. I go to a group regularly. It’s mental health. I got introduced to Mental Health in the hospital I think and then I had a social worker there who suspected that I might fit the criteria for this group and we did a really long assessment and yes, so it’s a 12 month group, and it coincides with individual therapy once a week. You can’t do one without the other. You have to do an hour of counselling and the two-hour group.

A woman who has physical disabilities and rarely goes out viewed her weekly group physiotherapy sessions as a social activity: ‘I do go to hydrotherapy which is MS hydrotherapy, and that’s just once a week. And I guess that is an outing. Yes. But I’m not in any clubs or anything.’

A customer who is a recovering alcoholic said that because she was not working she is able to regularly participate in Alcoholics Anonymous and Narcotic Anonymous groups. Another participant was a member of Australian Survivors of Child Abuse and intermittently went to their group meetings.

Reluctance to participate in the community / stigmatisation

Participants, especially younger participants, often found it difficult to be socially engaged because of their disability. The fact that they did not work meant that their self-esteem and sense of identity was often severely affected. This appeared to be most acute when they did not have an obvious disability. An added burden was their limited financial resources which made it difficult for them to engage in social activity. A man in his thirties who has chronic fatigue syndrome had the following perception:

> I find it’s hard for me to meet new people because I sort of feel ashamed that I don’t have a career at my age or I haven’t started a family or something like that sort of thing. When you first meet people, the first thing they want to know is what you do. And so I feel embarrassed to tell them that I’m on a disability pension. So it’s hard, you know. I don’t feel very good about myself. It affects my self-esteem and I tend not to want to meet other people very much.

> Before my disability I used to be pretty outgoing. Now I tend to sort of just do small talk and not really engage in a long conversation or get to know the person really well and I just stay away from them. Also, because of how much I earn... I don’t earn a lot of money. For example, you might be with friends and they’d want to go out to dinner and it might be your turn to buy the drinks and pay for the food. And you might not be able to do that. And you don’t want others to always pay for you because they might think that you’re a taker and not a giver. Socially, it’s pretty hard in that way.

A woman in her twenties who had no visible disability commented:

> Well basically I think, I’ve often, people still tend to look at you as basically a dole bludger. … Should you come out and say, ‘You know, I’m on a disability support pension’ … people are like, ‘Ah, shouldn’t you go out and get a job? What’s wrong with you?’ and that sort of thing. And they ask those sorts of questions. It’s not their business. Again people just think that you know you’re a dole bludger or something like that.

A young man stayed at home because he found it ‘easier’.

> Like I have to push myself to be with my friends because it’s so much easier being at home and in your comfort zone because you can just be with yourself and there’s no expectations because you know you can’t reach the expectations that you think that they have of you. So you’re happy just to stay on your own and that’s, I reckon, that’s what I do at the moment.

About a quarter of participants expressed a generalised anger and/or an active disinterest towards the community. They were very disengaged. This is reflected in the following interaction:

> Participant A: I haven’t watched the news, and I don’t get newspapers.
> Participant B: Good idea.
> Participant A: A friend rang me the other day and said ‘Have you been watching the Olympics?’ I said, ‘What? … Are they on?’ I truly didn’t know they were on.

The impact of the neighbourhood and having children on community participation

Those participants who had children of school-going age appeared to be more likely to have members of the community giving them support and urging them to participate. A participant who had had been in a serious car crash and suffered head injuries, gave the following response to the question of whether she participates in community activity:

> I try to, but yes I don’t get [out] much. My kids go to school so I try, I try and … a lot of the mums up there try and get me to do things because they know that I’m not getting out of the house, so they say,

> ‘ah we need you to help us with this’. Because they know I won’t come out otherwise. I haven’t had much help from the pension

She described her neighbourhood as a ‘great’ source of support. She also did some voluntary work in the school: ‘I mainly do like tutoring. And reading and stuff like that. The canteen is just a [voluntary activity] ...It’s all voluntary. I won’t let anyone pay me.’

The positive impact of community activity

There is no doubt that those customers who did voluntary work found it beneficial. A young woman who does a significant amount of voluntary work felt that it kept her going: ‘Well otherwise I don’t know. I’d just be a blob. I wouldn’t be doing anything. I’d have to push myself to get out’.

A couple of the participants mentioned how they now had more time to participate in voluntary activity and that this was very satisfying:

> Well, I’d say yes, it definitely affects my, the way I participate in the community in a positive way, because I find I have a lot more time on my hands, and I am doing voluntary things that I never would have if I’d been on the set career path, and that’s a real positive I think because you meet a lot of different people, different types of people. And it affects, conversely, friendships in a way that I suppose you form new friendships with those different groups.

This participant felt that the voluntary work kept her ‘spirits up’.

For another participant volunteering was central to her life now that she could no longer work. She worked for a number of organisations. Volunteering gave participants the opportunity to talk to other people and fill up their time with what was sensed to be productive activity. The following quote captures this:

> I’ve got a friend who’s got Alzheimer’s and she’s getting 24/7 care. … She used to be sort of a mother to me. So I spent a lot of time there at the nursing home. I’ve spent time with the other patients and talked with the other patients. Some of them don’t have families that come to see them. … Sometimes I could help around and make coffee or just little things like that. Maybe an hour at a time, just little things. So I can’t stay home and do nothing all the time. You know, there’s no time constraints or anything. No one is expecting me to do anything. I can just do things as I like, come and go as I please. Sometimes I come across other people there with families or other loved ones there so I can talk to them. That could keep you busy sometimes, a little bit. I’ve got to do something to keep my mind stimulated and I find that helps quite a bit. … It puts my life into perspective, you know, to see that some people are a lot worse off than I am. It’s not a cheery atmosphere. You’re not having fun or anything like that. It’s sort of hard for me to be around positive energy.

For some participants it was the only time they moved out of their own neighbourhood.

Volunteering, in a couple of cases, had also led to the learning of new skills. A woman who drives from Sydney to the Central Coast once a week to visit her grandmother and work at her voluntary organisation commented, ‘Well what I’m doing now, I’m in an office and I’m learning about changing web pages on the internet and different computer systems that I didn’t know about before and my confidence is kind of gone up a bit’.

Participants often mentioned that they were able to engage in voluntary work because unlike the formal sector, it was far more flexible. As a young woman who does a substantial amount of voluntary work commented, ‘the local coordinator understands my position. And she’s really good and she sort of gives me free rein and it’s flexible which is what I need sort of in my situation.’ A participant who works in the Salvation Army store once a week said it was only possible to work there because the person she worked with respected the fact that there were a range of things she was not capable of doing:

> I work at the ….. [voluntary organization] down at ….. And the lady I work for out there, I catch two buses to get out there, but she drives me home in the afternoon which is a welcome relief for me by the end of the day. But she knows, she lets me do what I want to do, because she knows what I’m capable of myself to do. So I don’t get down on floors and start picking up things on the floor because I know it’s too difficult. And she knows that she can’t have me reaching up, because I find that hard. So everything is sort of at eye level that is easy and whenever I want to have rest she says you go and rest Jane, which is good. So I can go all day, and know that I can stop any time I want to, to rest, because I don’t have to, well as I said, I’m not getting paid to be there. And that’s really my only outlet, is going there once a fortnight. Because I can’t...

She loved her voluntary work in the shop: ‘And I like being there. I like it. Meeting people. So I enjoy that …’

3 Work and Disability Support Customers

The inability to work

About two-thirds of the participants wanted to work but their disability made it virtually impossible. A young (mid-twenties) participant expressed this in the following way:

> But that’s a thing too, the disability. A lot of times, most of the time, you have no choice whether to work or not. It’s not like you’re on the dole and this is supposed to just assist you through a period where you’re looking for work.

A woman who had a range of psychiatric and physical problems had the following response to the question of reentering the labour market: ‘No, I’m very lacking in that area. So like, it really doesn’t interest me to get into the workforce. I’m just happy to do my bit of voluntary work I do each time’.

The psychological state of a participant in her mid-twenties made it impossible for her to contemplate seeking employment:

> Well if I can get everything delivered, I’d never leave the house. Well like she said, I’ve changed so much since my accident, like that happened six years ago in August. … and I’m just not the same person I was then. My whole life has just totally changed. I’m nothing like the person I was. Not even recognisable to look at, to the person I was. I mean a little over two years, I’ve put on 80 kilos, you know, that makes a huge difference. People I see look at me, go, ‘Don’t I know you from somewhere’? ‘Okay, imagine me 80 kilos lighter. It’s me.’ You know. It’s just everything changes. You know. We used to go out a lot; I’d never be at home if I could help it. And now I don’t want to leave the house.

A man in his fifties who had had a stroke said that he spent his days looking for employment:

> I don’t know, I thought … when it first happened I thought well that was it. I won’t be able to drive any more. So I went back to school, like Tech and did a course in logistics management, which I’ve nearly finished. I’ve got next year to do. But I don’t know, even if I finish it, whether I’ll be able to get a job … because I can’t steer straight still, sort of I walk into doors and walls. That’s just not concentrating. Like if I concentrate really hard I’m right. I still fall over and I’ve done that all my life. I had a brain tumour when I was very young and it affected my balance. I’m used to falling over, put it that way.

Despite his disability he persisted in seeking employment. It appeared to be his main activity:

> But I spend most of my time looking for a job. I don’t tell anyone I’ve had this problem. …Ah well, two years worth of nothing so far.

> But the bloke has promised me a job, but well that was a month ago. I rung him up yesterday, he said he’s got to see his boss next week. So we’ll see how we go. When I get it, I mightn’t be able to do it anyway, so.

Constant or intermittent exhaustion was a common problem for most of the participants. This often made it difficult or impossible to contemplate entering the work-force:

> What came up [in the focus group] and seemed to be a major thing, problem, was the fact that all of us have trouble sleeping. Getting to sleep, or waking up through the night, or two of us said it’s sometimes 5 a.m. before we actually crash out. Well when it comes to 9 o’clock, you’re either in a deep sleep or you’re buggered. You just don’t want to get up, or you get up and you kind of walk around and your brain is not working properly, so you go crash again. And apparently it’s affected all of us, from what I heard. And so our sleeping patterns have been shot to bits.

Other participants were fearful of taking on work because of prior experience. A number mentioned how they had had to leave their previous jobs because they had been unable to cope with its demands:

> And I got incredibly tired, and anyway I was going into remission, and I got this job, fantastic opportunity, and it was like very stressful. And I got sick at the end of it and I thought OK I’d have to wait until I’m back on top before I make another commitment. I finished my contract, but it really made me realise that I need to be well and have a certain amount of resilience before I make a commitment. So that really counts me out about going to work. Is it [setbacks health-wise] going to happen again? Because you never know when you’re going to get really bad (young, female participant).

About half of the participants who said that they wanted to return to work and who had been out of the workforce for an extended period felt that they needed a period of transition. One participant had the following sentiment:

> If the getting back to the workforce thing… there’s a lot of pressure to get you to a job straight away. It should be a case of getting you into a training program without having the pressure of having to work at the same time. Centrelink is always about getting you a job. If you haven’t worked for five years they can’t expect you to just jump into a full-time job. That’s a massive change. There has to be some sort of transition.

Those customers who had become ill but who felt that in time they would be able to overcome their disability, were more prone to be optimistic about their work future. A man in his forties who had been a tradesperson before developing lung disease was confident about returning to the workforce:

> … I'm waiting for an operation for my lungs and when that's fixed I'll be getting back into the work force. The job I used to deal with, … I might not be able to go back again because it's underground. The next step is to go and look at something else. Education maybe or something else. Also, with the transplant, the big step is... with the work I will be looking at... fresh air, open air. I will be looking at full fitness, full work in a year. It's nearly 12 months waiting for a transplant; my life has been on hold. I'm hoping to be off disability after the transplant. … Work-wise I'll change my work or re-train or something else or go back to school.

A woman in her fifties who required cornea transplants could not wait to get back to work. She 'hated' being on the pension. Work for her had been a central feature of her life:

> … I love working and I love socialising. … I was working for S ….. … I loved it. I really, really loved it. … I hate to be on a pension. But there's nothing I can do about it. I just have to wait my turn, and when I have good vision I can go to work. I really, I hate bludging. But I'm not bludging ...

She had no doubts about reentering the workforce. Her willingness to do anything and the fact that she had worked for most of her adult life contributed to her confidence:

> A job I will always get. I know I will always get. I'm very positive about it. … I don't care if I'm a cleaner, if I'm cleaning toilets, work on a farm. I don't care what as long as I will have my vision.

Another participant who was waiting for a kidney transplant was also confident of eventual reentry to the workforce:

> If I get a transplant, I'm thinking of going back to work. … A lot of people like me come back after the transplant, they go back to work. They lead normal lives, like other people. And I'm strong enough, if I go back to work if I get a kidney, yes. I want to help my kids. They're still young. If they were a bit older, I won't go to work.

Perceived discrimination of employers

Some of the participants who had worked or were looking for work, reported that they were discriminated against by would-be employers and constantly denied opportunities. The sense of being discriminated against and stigmatised was a common theme:

> My life has really changed since going on the pension because then I was, I mean I've had my disability for about six years, but I've only been on the pension for a year. I was still looking for work up until then because I truly believed that someone would give me a job because of anti-discrimination and all of that. It's just not true. As soon as they see you walk in with a cane, you haven't got a chance. That's my opinion anyway. I've tried for years and years, and I can, I can do heaps and heaps of stuff on the computer, and

> I've had jobs like the girls out here on the desk. I can do all of that stuff. A sitting down job, telemarketing, you don't get anywhere if you've got a disability because they automatically think you're retarded or something because you can't walk properly.

This participant described what happened when she went for a job interview with a government funded agency:

> The interview was with the manager, and she could see my trouble like with getting in and out of a chair and stuff like that. And I said, 'This is all the problem I have. Once I'm sitting down at the desk I can do all of this. And you can't even tell I've got a disability.' And I felt that if anybody will give me a job, it's them. You know. But no, I don't know. I can't explain it, but the way she treated me was awful. You know, when I tried to get up from the seat I had a lot of difficulty and things like that, and I said 'Well I can't do anything about that.' As long as I'm in a position where I don't have to get up and down all the time, I can work just like anybody else.

There was a fear amongst some participants (at least three participants mentioned this concern) that once their disability was known they would be looked at differently. They were frightened of exposing themselves to possible humiliation:

> I suppose looking at me, I don't look different. I don't seem to have any disability. I could probably get a job but after a few days they'd know something is terribly wrong. They'd probably think I am nuts or something. It's a physical problem I've got. If you look at me and you could tell that I have a disability, I don't know how people would react to that.

Perceived lack of flexibility by employers

At least a third of participants mentioned that they would seek work if they knew that the employer would be flexible. A common sentiment was that employers were not prepared to employ a person who was not able to work consistently at full pace. Participants mentioned that their capacity for work on a daily basis was unpredictable so they had to have a flexible, empathetic employer:

> You don't want to let anybody down either, you know. … And again it scares you because you' know, I don't know about you guys, but I wake up in the morning and one day I feel great and I'm thinking I could get a job, and I'll do this and that, and the next morning I wake up thinking, there's no way I could go to work like this, there's no way in the world (participant in her mid-twenties).

A young man had the following view:

> The thing that's stopping me mostly from working is having to complete tasks within a time constraint. I can't do things when things have to be done or when the person in charge wants them done. I could say, for example, fix that tape recorder. But I want to do it in my own time. I wouldn't be able to do it… say it needs to be

> done in half an hour's time. Or it's something that would usually take half an hour to do. I might sort of start doing it then I'd find that I'd have to get up or go lie down or I'd have to leave it for half an hour and come back to it. That's my main problem when it comes to working.

There was strong sense that a lack of flexibility in workplaces makes the obtaining of employment very unlikely:

> But they're looking for people who can work around their business. They don't want to work around your disability. They prefer to get someone else and they worry about whether you exacerbate the problem at work if whether you'll sue them. And when you're a casual they don't have to find an excuse to let you go. So I find that I can't even do any casual work.

A young male participant was prepared to do anything if he knew that the employer would be accommodating:

> I'd sit down and sort nuts and bolts if I had to, just to get some extra money, as long as I could say 'I can't sit much longer in that spot, could I come back in half an hour or lie down for about 15 minutes' or something. But I can't see workplaces having that flexibility. If there were special workplaces… One of the jobs I did, I was making deliveries and I delivered something into this place where there were people with intellectual disabilities. And that's what they were doing. They were sorting out nuts and bolts. They were getting paid to do it, they were full time jobs. And I was only a casual and they were probably earning more money than I was. That's probably more of a normal life than I had. And that made me really upset.

All of the participants felt that they would not be able to cope with a full-time job. A female participant with a psychological/psychiatric condition had the following sentiment:

> Well I find it difficult to, having to work, you know, all the time. I don't think I could handle a job where I worked every day of the week. My depression makes me tired. I have all the appointments that I have to go to in terms of treating my illness.

Impact of the labour market on the ability to obtain employment

There is no doubt that the strength of the labour market is an important determinant of the ability of people who are DSP customers to obtain jobs. In a strong labour market employers will be more pressured to employ workers with a disability. A woman on the Central Coast with tertiary qualifications who wanted to work part-time had the following observation:

> And I'm looking at, I've got some incredible people and friends who keep an eye out for me for work, say part-time work, and my field is media and public relations and there's nothing like that in the Central Coast. … All of the jobs, like part-time things that

> would be appropriate, are in Sydney. And the thing is, I can only work part-time so I can't afford to live down there [Sydney]. So then that completely rules it out.

About 80% of the participants had given up looking for employment. They felt that in the current labour market they had no hope of finding a suitable job.

> I think it's probably difficult to find suitable employment that caters to one's plight. And that's probably the major issue, finding a job that you can handle, and that will bring in enough money for you. You see that's the problem. Like I've got a room mate and nothing wrong with her, she's got the breeze coming out of her ears, she can't get a job, she can't get people to call her back. You know she's been looking for about two months now, but I mean she goes in every day and essentially raids the things, gets on the computers, rings around people, just cold calls people, anything for a job, and she can't get a job. And she's totally normal [sic]. What chance have I got? (a male participant in his twenties)

A DSP customer based on the Central Coast felt that the ability of employers to be choosy was far greater in the Central Coast area:

> And they [employers] can be just so choosy. They can just, you know, you can ask for it, one-armed, one-eyed, green-headed monster, and you have the first person come in and you can pick from the applicants and get one. You can get whatever you want because there's just so many people looking for jobs. And you've already got a mark against you when you've got a disability.

The participants on the Central Coast emphasised that they could not afford to come and live in Sydney.

The importance of work for the participants and the impact of not being employed

In a similar fashion to becoming involved in community activity, obtaining employment was generally very beneficial for the individual concerned. A woman in her thirties who had not worked for 12 years and had recently found a job as a 'lollipop lady' had the following observation:

> … I just recently started working as a …lollipop lady as they call us. … It was very anxiety provoking to start with. You know. Self-esteem issues and just fearing that because that I might be discriminated against. … So the job's boosted my self-esteem and it's made me feel better about myself. I'm contributing something. And the kids are pretty proud.

The activity has also allowed her to meet and 'chat to other mums at the school'.

Participants saw work as a fundamental part of their identity. The lack of work or inability to work often resulted in a poor self image, anxiety and a sense that life lacked purpose. This perception, not surprisingly, appeared to be more intense among younger participants. ‘Your days are empty. I mean if it wasn’t for the kids why would I get up in the morning. Just you’re useless’ (female participant in her thirties). A male participant in his early thirties spoke of his intense frustration at not being able to work:

> And you know what you want and what you’re capable of. And you feel as though you’re not achieving. And that’s the hardest thing really. That’s what hurts me the most. Not being able to do what I know I can do. That hurts me a lot because I was pretty ambitious when I was younger. Where I thought I’d be now is not where I am. I get a lot of anxiety and worry about what the future lies ahead. I get very,very anxious about the future and I tend to not want to look too far ahead. But you have to. You’ve got to plan and I just don’t know what to do.

A male participant in his thirties had the following analysis of his situation:

> Yeah, I feel like I’m on the sidelines, you know? I don’t sleep in. I’m up early in the morning even though I don’t have much to wake up to. I don’t have a job but you’re still up early. You see people going up to their cars, on a hurry to go to work. When I walk outside I see people in a hurry, people doing their hair in their cars or what have you. I feel like I’m not out there. I’ve got nothing to aspire to. I think ‘What am I going to do?’ and you feel like the whole world is revolving. People are moving on with their lives and yours is just still. And even though you’re at a standstill, because other people are progressing, you feel like you’re moving backwards at times.

He went on to say that when you’re working ‘you’re a lot more confident and self esteem is much better. You can start buying things again …’ Not having much money was a constant refrain.

Another participant described how she missed work:

> I do miss working. I really do miss it, when I come into somewhere like this and I see the girl behind the desk, I think well I used to be able to do that. I used to be able to run around like that. I miss that. But there is no going back.

For at least half of the participants not having employment was viewed as a major disappointment and often had a dramatic impact on their self-confidence. A young man in his mid-twenties had the following observation.

> I find that I’m far more, I’m not the person I used to be. It’s changed me, because I’m sort of like, I don’t want to talk to that person, because if you start up conversations, ultimately the question always comes up, what do you do. And it’s like I don’t want to have to answer that question. Because it’s too involved. And it’s personal. And it’s just [that]career is such a huge part of life. Yes, and like if

> you’re not working, you don’t have a job, you’re not going anywhere ... and you’re not a person basically.

Participants mentioned that work was more than a way to earn an income. What they missed terribly was the social contact: ‘Even though I was doing such a small amount of hours. I miss the contact, the social contact very much. Yes, so I have not only finished work, we then moved, so it was total loss of contact.’

The focus groups suggested that the impact of not working was shaped significantly by the age and circumstances of individuals. Thus, a participant in his fifties who had worked for many years and had adult children had no desire or need to work. He owned his house and knew that if he needed something his daughters were in a position to help him. Besides being financially secure, he felt that he had worked hard for at least 30 years and was now entitled to relax. The feeling of accomplishment was reinforced by his sense that his adult children were all doing well.

Counselling as a way of getting people back into work

Enabling DSP support customers to receive counselling was mentioned by at least a third of the participants as the way in which government assistance could help customers back into the work-force. The following comment from a younger participant captures the need by some DSP customers for counselling to help them set goals and get back into employment:

> Counselling would be good. I’d really benefit from counselling. *[pause]* Maybe self-help programs, something like that. Just helping you, maybe they could teach goal setting skills, along those lines. Because when you haven’t been in that frame of mind for a long time it just doesn’t come naturally to you anymore. You need encouragement and you need someone to, sort of, give you a [pause] like a template to improve your life or to get ahead. I don’t know how else to explain it. But things like that don’t come naturally anymore.
>
> … I don’t know what I want to do with my life. I’m 32 and I still want to do with my life. … I never really found anything that I wanted to do. It’s hard to set goals in terms of work and future because I still don’t know what I really want to do. All I know is that I don’t want to be the way I am right now. I sort of have to find out what I don’t want to figure out what I want. I could really do with some counselling, I think.

This participant said that at Centrelink he had requested counselling but had never received a response:

> With Centrelink, I’ve seen questions like ‘would you benefit from a rehabilitation program’ and I’ve ticked ‘yes’ and I’ve even asked
>
> about it but I’ve gotten no feedback whatsoever. I don’t even know why they ask the question because I don’t think they can facilitate it to be honest. I’ve never heard of anything, any programs they have.

4 Education and Training

Surprisingly only two participants were engaged in education and training at the time of the focus groups. Four participants had been doing courses but had dropped out.

Desire to pursue training and education

About a third of the participants were keen to obtain education/ training. There was a feeling that it could help restart their working life and improve their financial position.

> I'd like retraining, to be able to do something more. I mean [my job is] good for a start, but it doesn't bring in much income. You know. I find it difficult trying to do all the expenses of raising a family. I feel like, you know, I rent through Housing Trust and at this point I feel like the idea of ever owning my own home is just impossible.

A participant, who has two young children, was desperate to find something to study but had not been able to. Her comment reflects enormous frustration:

> And how can I use the time that I can't work to do something, that's what I couldn't understand. Maybe I might not be able to work now, but can I learn something while I'm unable to work. Can't I use this time instead of sitting at home twiddling my thumbs and inventing things to do. I've repainted the cupboard twice.

She was keen to get back into the workforce but realised that because of her accident she would have to retrain:

> Because I can't go back to what I was doing. So, I need something else to go back to. I mean I may be able to go and get like a receptionist job, but I need to know to know MYOB, or what's the other thing, QuickTax I think it is.

She clearly needed assistance finding a course.

The inability to pursue education / training

For at least half of the participants their disability made the notion of doing a course too daunting. In a similar fashion to participation in the community and work, an individual's disability was itself a crucial shaper of their capacity to partake in training: 'When you're at a low point you're not really going out … and you give up after a while. I was going okay for a while, but ...' Again, the issue of flexibility emerged as a key requirement for participating in education and training programs. A participant had tried a TAFE course but found the rigid schedule and the perceived remoteness of the lecturer too difficult to manage:

> Well I found it hard. One of the teachers I had, I found it hard keeping up with the content of the class and having trouble understanding and he wasn't a very approachable teacher. And you know I just didn't know where to go to get help and clarification. It just got too hard for me. You know, to get things clarified, to get the

> assignments done. … The course I was doing was more business management. I was hopeful of even taking it further, maybe I would like to do business at university, but I need some advice. And like I used to talk to the course coordinator, and say, 'look I'm struggling, I've had time off, I've been in hospital', but she never gave me, well for a start it was very, very hard to get a hold of her and get phone calls returned, and she never sort of gave me any information on who I could go to. She just said, 'Talk to your teacher'. And my teacher was really unapproachable and was not somebody that I'd like to disclose my mental illness to, so.

A male participant felt that he could not contemplate doing a course because it would be too demanding physically. If, however, there was flexibility, he would consider it. He was also concerned about the impact of studying on his payments:

> Yeah, I was just thinking if you can do a course at your own pace while you're on the pension so there's no pressure. If I go to TAFE I would have to change from disability to Austudy and if I'm not keeping up with the class I might have to go back to disability. And I don't know whether they'd accept that or whether they'd think that's just me not trying or, you know. If I could just stay on disability and do a course at my own pace… as I am now I'm on disability, I'm not studying or doing anything. If there was no pressure on me then I could still study while I am on it. A couple of years down the track I could pick up a whole lot of education at my own pace. If I am not doing anything at all, two years could go pass and I might not learn anything.

Clearly this student required flexibility and intensive assistance that the TAFE was not able to provide.

More than half of the participants had no desire to pursue education and training. The reasons for this were mixed. Some felt that they did not have the intellectual capacity to undertake any further training. For others, there was simply no desire. They were too ill and / or exhausted to contemplate training.

Confusion about how to go about finding / doing a course

Most of the participants who expressed the desire to do some training could not contemplate how they would do it in view of their limited resources: 'How to get there, to get into retraining. I mean I see … but how am I supposed to do it on my own. You just don't have the resources'. Another participant also expressed a strong desire for guidance. He was also fearful about losing his payments:

> There must be a lot of people that need retraining to make a complete career change. I've always had physical work but now I can't do physical work so I need some education because I don't have any qualifications in order to work at an office or do something with my mind rather than my body. It would be good if there was some sort of scheme where rather than people stop working and end up long-term unemployed or on a sickness benefit. Maybe there

> could be some sort of educational program, something that doesn't impact on your pay if you don't go. You know, where there's not a lot of pressure placed on you to fulfil an obligation.[2]

At least three participants were adamant that they did not want to be pushed into any training.

> I think that's really hard, to say what can they [government] do, because you also don't want them pressuring you because it should be up to you. Like when you feel strong, and when you feel healthy and when you feel right about it. Where if it's like something like being on the dole or something, they basically say well if we think you can do something, get in and do it. And they basically, if you're in my situation, they're forcing a breakdown. And it's not going to happen. Yes, I think there's a fine line between having the options there, and forcing people to take them.

The benefits of education/ training

For the couple of participants engaged in education/ training, it was absolutely central to their lives. Their inability to find work meant that they put all their energies into improving their educational qualifications. A woman in her mid-twenties who had battled for a couple of years to find work is now putting all her energies into education: 'I kept saying to my parents I can't stand this. I can't do this. I have to work. I was getting really like bored. But then I just sort of grew into all these courses and things and now I'm really happy.' She was very enthusiastic about the Pensioner Education Scheme which had helped her access courses:

> … And that [education] is the best thing I've ever done because I don't go out, I never really go out. This is an outing for me. I study all the time, and the pension helps me to pay for my course because I get extra money for doing full-time study.

She was hopeful that ultimately the skills she attains would help her find a job and overcome the discrimination she felt at present hampered her possibilities:

> Yes, so basically I just spend all my time now studying and studying one thing after the other. And sometimes like three things at once, because my thought on that in the beginning was I'll have so many skills that they'll be able to look beyond my disability. And I don't know if that will happen or not though. That's what I believed.

Another participant was completing a certificate in Auslan and was confident that she would be able to get a job as an interpreter. She had found out about the Pension Education Supplement which had helped her afford the $1800 course fee.

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[2] DSP recipients can study full-time without losing their payments. Supplementary payments, such as Pension Education Supplement and Education Entry Payment, are available to assist DSP customers with the costs of study. The participant was informed of this at the focus group. More information on these payments can be found on the Centrelink Website at www.centrelink.gov.au or by contacting Centrelink at 132717.

5 Information

Lack of knowledge

Not many participants were positive about the information or help received from Centrelink. A common sentiment was that there was a negligible amount of information available. At least two thirds of the participants claimed that they received no useful information and had had no counselling when they went on to the DSP: ‘I got no information. I was on Newstart with incapacity to work and it was just a payment transition. One week I got this payment and the other week I got another payment’. This participant felt that counselling at the point of transition could have been extremely useful:

> When I changed over to DSP they were sort of like ‘okay this is the end of the road’ sort of thing. Like this is going to stop, that’s it. Like, there’s no more to life after this. That’s what it felt like. When I got home I just put my head down and said ‘Is that it, where do I go from here?’ Maybe they could have given me a lot more information at the time… I think even maybe I could have a one-to-one with a counsellor. Maybe they could sit down with me and ask me where I want to go from here or if I want to stay on this for the rest of my life or if this is a temporary thing for me. Something like that could be better. It could give me more hope.

Some participants were critical of the material sent through the post: ‘Well they send us all these ridiculous pamphlets with cruddy information and they are the same pamphlets every time. They’re not useful.’ At least a third of the participants claimed that they did read the material sent to them: ‘And occasionally I get some Centrelink letter or pension letter or something. I never read it’, was a typical response. A participant followed up this comment stating ‘Same here. You just see all this rubbish and don’t even understand what they’re talking about.’ Participants commented on the enormous drop in communication after they moved from Newstart:

> … And I think perhaps they [Centrelink] could improve communications … And yes, I really notice the difference in the drop in my mail after I finished the Newstart. And then it went down to nothing. It’s good in one sense, but in the other sense its like, well I hope the money is still going into the account. You kind of think they’ve forgotten about you.

Younger participants, especially, claimed that much of the material that was sent was not relevant:

> … if it was better targeted and they send you something that’s relevant to you, you’re more inclined to read it and not just throw out the wad of paper, and chuck out the useful stuff which is in the paragraph at the bottom at the back.

It was alleged that much of the material was aimed at older people and did not relate to their situation: ‘Well most of it tends to be aimed at really old people. That’s all the brochures, you know. It's old people, hip replacements, you know, so most of it is not really that relevant.' (participant in her mid-twenties).

About a quarter of participants alleged that Centrelink failed to respond to their enquiries:

> I've made a lot of enquiries and I get nothing back. I thought I'd get a phone call or a letter or something but I get nothing. There must be something for me. *[pause]* I don't know if there's nothing out there or they're just not doing their jobs, I don't know.

About half of the participants mentioned that they had no knowledge of FaCS and its role:

> You'd think they could just do a bit of public relations. Like I don't even know the name of the organisation. Like I just know that it's government and I don't know who they are, and if they just sent me a letter every now and then, going '[Good] on you trooper! Keep going', I'd feel like I'm being supported.

Knowledge of specific programs and services available to those receiving DSP

Participants in focus groups were canvassed as to their knowledge of specific services, both state and federally funded, that assist people with disability to access community, education, training and employment and improve health and wellbeing.

- Provisions within the DSP that encourage part-time work (higher income threshhold before a review of entitlement, maintenance of fringe benefits entitlements after the benefit stops) – as mentioned earlier, almost all of the participants were unaware of these provisions and consequently feared the loss of the pension and secondary entitlements – returning to work was perceived as a risk.
- Centrelink social workers and occupational psychologists – less than a quarter of participants appeared to be aware that they could access help from Centrelink social workers and psychologists.
- Pensioner Education Supplement (PES) – only a couple of participants were aware of the PES and had accessed it. All of the other participants did not appear to be aware of the payment.
- CRS Australia – about a quarter of the participants were aware of the CRS through their involvement in secondary rehabilitation programs following acquiring their disability.
- Disability Employment Assistance – only one participant was aware of disability employment programs and was able to name a service. Participants were unable to remember such services being described in their contacts with Centrelink staff.
- Area Mental Health Services (AMHSs) – Participants whose main impairments were psychiatric were familiar with the services of the AMHS and were accessing them. Those with affective disorders (mainly depression) whose primary impairments were other than psychiatric were accessing General Practitioners for

mental health support and were generally unaware of Community Mental Health Services (such as free drug and alcohol and psychological counselling).

- TAFE disability support services – one participant had had the assistance of a TAFE Disability Consultant while doing a course. Others were unaware that such assistance was available.

Assistance in accessing the community, employment or education and training

Only a couple of the participants could think of an instance when government assistance had played a role in encouraging community participation or reentry into training or work. This was the response of a female participant in her thirties:

> I just think that certainly Centrelink haven't helped me at all in terms of getting out into the community and treatment with disabilities or anything. All the help I've had has been through, [a family support service], but Centrelink, I haven't had anything from them in terms of help getting around looking for a job or getting involved.

When asked how government assistance could help DSP customers into training and education, one participant had the following response:

> Well one thing, inform us. … [Give us] all this stuff that's available. Everything that is involved with it, like costs involved, time involved, where we go, what we do, everything, not just a little thing that says call this number. So that you know what you, because you sound like an idiot when you ring up and say I want to find out about this. If you knew before you rang, you'd be able to say OK, this is what I want to do, you know, instead of sounding like an idiot.

Desire for a case manager or more personalised approach

The desire for a case manager type system amongst some customers was strong. About half of the participants spoke of how they felt that there was no one individual they could turn to and that they did not feel that they were being treated as individuals. For some participants this was terribly frustrating:

> Just I don't seem to be getting a lot of information, because and I'm on disability, waiting for a third party to be settled. And I don't seem to be getting any information about how it's affected, what I am allowed to use Medicare, what I'm not allowed to use Medicare with. I was getting a script that I get from the chemist and I was saying to him its third party, but they were charging me the Medicare rate. And it should have been charged to the private rate because the insurance company are reimbursing me for that. So nobody seems to be telling me what I am allowed to do, what I'm not allowed to do, and I am so scared that at the end of it all I am going to get into so much trouble because I didn't know how it all works. … So things like that, you don't know about them. What you can and cannot do in a whole lot of situations.

When she was asked if she would like somebody that she could see and with whom she would have a personal relationship she responded, ‘Yes. that’s what I thought I would get with CRS. I’d have a case worker who would help me be rehabilitated. Get me the right kind of help that I needed. In the areas that I needed. And point me in the right direction.’

In response to this comment another participant commented that she also desired a case manager:

> I think a case worker would be ideal. Especially in terms of the problems I’ve had dealing with TAFE. I’d really appreciate having someone to go in to bat for me so to speak. You know, to explain the situation and help me out with what I need.

There is no doubt that the couple of participants who had had a lot of help from Centrelink and had a positive perception of the assistance received, had generally found somebody in the office who was able to go through things with them and respond to questions and make suggestions.

The potential impact of a lack of counselling and knowledge

As has been mentioned the ignorance about access to counselling had serious implications for some participants. At least a quarter of the participants had no one to turn to, to help them resolve personal difficulties or get back into the workforce. Anger and frustration were common sentiments:

> … I get depressed real easily about small things. Little things annoy me and I get in a bit of a rage over small things. I didn’t know that they did the counselling either. Little things annoy me maybe because I am bored (male participant).

The lack of knowledge potentially had serious implications. Thus a couple of participants were reluctant to seek employment or study as they feared that if they found a job they would immediately lose their benefits. One participant expressed this in the following way: ‘I think people must have a fear that if they do something like that [work or study] they they’ll say to you, ‘ah if you can do that you shouldn’t be on disability’’. A woman with two young children had the following comment:

> I think one of the barriers to work too is that if you do get a job, a lot of the time it’s not that highly paid, you lose your healthcare benefits, you know your transport subsidy, and for me on the income that would lose all those benefits for me. I couldn’t afford going to my doctor as often as I do, the kids’ doctors, the counselling, so it’s a bit of a like, it’s not an incentive to work in that respect I think.

A couple of participants feared that too much participation in education and training would result in a loss of benefits.

Positive experiences

A couple of participants had had very positive experiences once they went on to the DSP. A lot appeared to depend on the personality of the DSP customer, the worker initially encountered and the Centrelink office used. One assertive participant who has the capacity and confidence to ask the right questions, gave the following account of her experience:

> The girl I spoke to at Centrelink, …when I first went on the pension she was really great. …went through everything with me. That's how I found out that the pensioner education scheme, the live in allowance, PADP, occupational therapy, she was really thorough and she was a really young girl.[3] So she was really trying hard. … So she gave me all the information that I needed. And yes, also the doctor there was really good as well. Yes. They were all really good to me, as opposed to when you're on the dole.

This participant is now in regular contact with that Centrelink staff member, 'just to find out if there is anything new … I'm doing the PES, Pensioner Education Scheme which as soon as I got on the pension I found out everything I could'.

The only other participant who had obtained the PES found out about by pure chance. Asked how she had found out about it, she responded, 'standing in a queue, and I saw a piece of paper. ... And I'd already been doing the course before for six months. And I couldn't get back-paid for that'.

Guaranteed payments and freedom from scrutiny

Several participants mentioned how moving from Newstart to the DSP was an enormous relief as they perceived that were no longer under constant scrutiny and required to do activities even though they had a disability. Also payments were now guaranteed:

> Before I went on a disability pension, there was a lot of time that they just stopped paying me, I don't know why. … That happened probably six times in about three years. I don't know if it's a systemic thing or whatever. I don't know. Maybe I've got bad luck. I haven't had a problem since being on the disability pension.[4]

A participant who resisted going on to the disability pension for a long time had the following comment about shifting from Newstart to the DSP:

> But since being on the pension I've been treated differently. Like because it's now accepted that I've got a disability, being with Centrelink it's not like they treat, they just treat me differently. When I go in there now, it's like, take a seat and they sort of serve

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[3] PADP is the Program of Aids for Disabled People.

[4] It is possible that a failure to return a Newstart Allowance form may have been the reason for this participant's payments being stopped.

> me, whereas when I was on the unemployment benefit, it was different. I can’t explain it. … There’s a lot of people looking for work on Newstart who are disabled in one way or another, but they still have them in that same category. There are no exceptions. You’ve got to stand in the line you know.

She described one particularly bad experience when she was on Newstart in some detail:

> I had an interview when I was on the Newstart allowance, you know, when you had to put the form in, and you get your money the next day. This day I had to put my form in, and I live like a fair way from the Centrelink office, and it was a very stormy day, and my car doesn’t go on wet days, OK. And I had to walk with the cane, and I was disabled then, but even though I was on the Newstart allowance, it was like trying to explain to them over the phone that I can’t get there because I’ve got to walk and it will take me an hour and a half in the rain, my car won’t go. Just to put a form in. Can I please do it over the phone and I got put on to about five different people, and got a no in the end. And I had to walk with my cane for an hour and a half each way to put the form in because I needed the money. And it’s like, I just couldn’t believe it. They were their rules and they can’t go outside of those lines. I got so irritated.

Three participants said that moving from sickness benefits to DSP was a huge relief. A single mother with a psychological/psychiatric condition, described her experience:

> I have two children and because I was in and out of hospital I kept losing my sole parent pension and having to go on sickness benefits and fill forms in every fortnight, which I was finding really hard to do because my mental illness was quite acute at that time, anxiety, panic attacks, depression. So getting on to the DSP for me was a relief, it meant that I didn’t have to keep running around filling in forms. And remember … because my memory was pretty foggy at that stage.[5]

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[5] Under Parenting Payment (single) eligibility rules, a customer becomes ineligible for payment if their dependent child is absent from their care for a period of eight weeks or more.

6 Conclusions

The focus groups succeeded in providing detailed information about recent DSP customers' capacities and aspirations for community participation, education, training, employment and other forms of participation and the barriers experienced. The discussions also gave insight into the kinds of assistance and service support that participants would find helpful for meeting their aspirations.

Social / community participation

For almost all participants their impairments constituted the most significant barrier to social participation. At least half said that they had had to abandon or dramatically scale down social activities (including volunteering) because of their disability. Often the disability was physical and psychological. Those who expressed the greatest capacity for social participation tended to be older participants and those who had adjusted to their impairments over a long period. Those with work histories, lengthy experiences of independent living and networks of supportive family and friends had the cultural capital and financial assets to make the best of their circumstances and remain socially connected.

About a third of participants said that their social participation was also restricted by their financial situation. Participants spoke of how they had become increasingly isolated because of their inability to socialise because of the costs attached.

The issue of stigma and disability was raised in a number of the focus groups, especially in those with younger people. Several participants spoke of their withdrawal from community activity being motivated primarily by a sense of being stigmatised. By staying at home they no longer risked the verbal barbs of contemporaries and others.

It was evident that for at least a third of the participants being alone had become a central part of their identity and they now found it enormously difficult to engage with the social world.

The five participants who were involved in community activity were clearly benefiting from their engagement. They spoke of how it made them feel 'worthwhile' and helped them meet new people. In a couple of cases community activity had also led to the acquisition of new skills. Participants enjoyed the flexibility of the voluntary sector. They felt that in the voluntary sector their disability was taken into account and they were able to structure their time and work activity so that they were able to cope.

Work

Although only one of the participants was currently in paid employment (an unskilled, part-time position), at least half had had substantial experience of the labour market. All of the participants under 40 were keen to be in paid employment but, at the time of the focus groups, none could contemplate full-time paid employment. The barriers to work were similar those that stopped participants being engaged in the community. About two thirds of participants said that although they would like to be employed their disability meant that they were unable to contemplate working in the formal economy. Most felt that they would be able to cope with formal part-time employment if employers were more flexible. This would involve employers taking account of their disability and allowing them to rest during the day when they needed to and to take whole days off when they could not contemplate going to work. A common perception was that the possibility of finding an employer who was prepared to entertain this mode of working was remote.

There was a perception that discrimination was common and that employers were reluctant to employ a person with a disability. About a quarter of participants told of their struggle to find employment and how they were constantly disappointed. The strength of the labour market was perceived as important. Participants from the Central Coast felt that they had very little possibility of finding employment, especially part-time work.

Not being employed was a source of anguish for at least half of the participants, especially the younger participants. Most of the participants under 40 felt that they were being left behind and were fearful that they would never be able to get back into the mainstream even if their health improved. The focus groups suggested that the self-esteem of these younger participants had been badly affected by their lack of employment. They saw work as a central part of one’s identity and the lack thereof made them feel insignificant. For older participants, especially those who had had a long working life, not being in the work-force was often not significant. Participants who had children and were in a relationship with a partner that worked also appeared less stressed about not being employed. Their children and partner kept them occupied and helped give them a sense of place in the world. Those participants who had been working but were now receiving the DSP due to what was perceived as a temporary health setback, generally had a positive disposition and were confident that they would be able to return to work.

Several of the participants, especially younger participants, expressed a strong desire for counselling to help them return to the labour market.

Education and training

Only two of the participants were engaged in systematic studying/ training. For these two participants education was a fundamental part of their lives. It provided them with temporal organisation, stimulation and hope for the future. Both had been recipients of the PES. A number of participants felt they would like to do some training mainly as a way to strengthen the possibility of finding employment. There appeared, however, to be a good deal of vagueness as to what to do and how to go about it.

At least two thirds of participants felt that because of their disability they could not contemplate doing a course. Others felt that it would only be possible if there was a good deal of flexibility and support. They would not be able to cope with set deadlines for assignments and an inflexible administration.

Information

Participants were generally unenthusiastic about the information they received from government. Many said that they did not read the material sent out and that it did not relate to them. There was a good deal of ignorance about what Centrelink offered. Thus very few participants knew about the counseling services available, the impacts, if any, of working or studying on their benefits and payments, the Pensioner

Education Supplement or Disability Employment Assistance. The lack of knowledge was potentially significant as it made a few participants reluctant to seek employment or engage in training for fear of losing their benefits. At least half expressed the desire for a more personal service – a case manager type approach. There was a feeling that more could be done to help DSP customers into education / training and into work.

A couple of participants had had very good experiences and been given sound advice and all the relevant information they required. These cases appeared to be the result of good fortune and the personality of the customers rather than because of procedures in place.

Appendix A: Domains and topic guides for focus groups

Issues/purpose/ requirements	**Domains**	**Sample discussion points, questions, subquestions and prompts**
Relax participants, begin group formation, signal the boundaries for discussion, advise participants of the intention of the data collection	Group formation Purpose of the data collection	Introductory comments: Thanks for attending The discussion should go for about 60 minutes – so we should be finished by (time). We are from the Social Policy Research Centre. The Social Policy Research Centre is an independent research centre that is part of the University of New South Wales. You are all here today because you began receiving the Disability Support Pension in the last year or so and did an interview over the phone in early March this year. The survey has been very useful and your contribution is greatly appreciated. This is a follow up of the survey and we really appreciate you again giving us your knowledge and time. The Department of Family and Community Services (FaCS) commissioned the telephone survey and has also commissioned us to conduct consultations with people who have been granted DSP in the last year or so. FaCS funds rehabilitation and employment assistance services for people with disabilities and funds the DSP and services available through Centrelink. FaCS wants a better understanding of the type of help and support that people claiming and receiving DSP might want. The information you provide us will remain confidential. Your privacy will be totally protected. Your participation in this group and your answers will in no way affect your payments.

Issues/purpose/ requirements	**Domains**	**Sample discussion points, questions, subquestions and prompts**
The implications of disability and receipt of DSP on participation in the community.	Social participation Awareness and acceptance of social norms Labour market knowledge and work contacts Affects of low income on social participation	Question: We're wondering about whether your disability or being on the DSP has changed the way you participate in the community. That participation may take the form of volunteering or being a part of social groups or associations or community organisations, going out to social or cultural or sporting events, having friends, talking to neighbours and so on. So the question is: Does having a disability or being on the DSP affect the way you participate in the community? If yes, how? Subquestion: One aspect of being involved in the community is about having some social contact. Could we talk about the benefits of activities like volunteering and being involved in the community?

Issues/purpose/ requirements	**Domains**	**Sample discussion points, questions, subquestions and prompts**
Aspirations to employment, training or education	Motivation Self-esteem Job seeking ability Current employment Employment ambitions Current education and training Study ambitions Knowledge of potential supports in these processes.	Question: As you may know, people can work up to 30 hours a week at full award wages and still remain eligible for DSP. We know that for some people on DSP it is not possible to be thinking about working but for others it is possible. We would like to know what your thoughts are about working. What do you see as the advantages of work? Is this based on your own experiences or the experiences of others? Do you think there would be disadvantages to working? Subquestions: What barriers or disincentives have you experienced or do you think you might experience in taking up work? Prompt: I can see how your disability might be a barrier to that but do you see any other kinds of barriers? What are the sorts of things that may help you to find work? Question: We are also interested to know about your plans about education or training. We're interested to know if anyone is studying or thinking about studying at TAFE (mention location if appropriate) or university or doing an adult education course (pause – look for signs of intent). Subquestion: So do you see any barriers in your way to achieving this goal? Prompt: I can see how your disability might be a barrier to that but do you see any other kinds of barriers? Subquestion: What do you see as some of the advantages to studying? Do you think your studies will help you find work?

Issues/purpose/ requirements	**Domains**	**Sample discussion points, questions, subquestions and prompts**
Test the provision of information about disability services and participant comprehension of these	Centrelink provision of disability services information. Participant understanding Third-party information provision (carers, parents, disability advocacy and information services, disability employment services, school transition to work advice and support, DSP-recipient initiated research)	Question: When you were going through the process of applying for DSP what information did you obtain about programs and services that may help you get work or get into study? Have you sought or received information subsequent to receiving the DSP? Sub-questions: Do you feel that you received enough information? If nor, what sort of information would have been helpful to receive more of? Did anyone get this sort of information from anyone other than Centrelink? Probes: School or TAFE advisers? Employment services? Personal Support Program providers? Friends or family members? From your own research? Mental health case managers or rehabilitation advisers? Community Health Centres? If you have used any of these services, were they helpful?