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MEASURING THE MOVEMENT OF PEOPLE BETWEEN SYSTEMS AND FINDING WAYS TO IMPROVE WORK AND HEALTH OUTCOMES

SURVEY AND INTERVIEW REPORT

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For further information relating to this report, or the project “Measuring the movement of people between systems and finding ways to improve work and health outcomes” please contact Associate Professor Ross Iles at ross.iles@monash.edu.

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The views and opinions expressed in this report are those of the authors and do not necessarily reflect the views of the study funders or individual study participants.

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EXECUTIVE SUMMARY

The Collaborative Partnership to improve work participation (the Partnership) is a national alliance between public, private and not-for-profit sectors to improve work participation opportunities for people with a temporary or permanent, physical or mental health injury, illness or disability. The Partnership's aims are to improve work participation rates of people with a physical or mental health injury, illness or disability; and improve the experience and outcomes for people with an injury, illness or disability by improving the benefits and income support systems they access through collaborating across sectors.

The current project, *Measuring the movement of people between systems and finding ways to improve work and health outcomes*, forms one of the five key pillars for the Partnership in its Strategy 2020–2022 and expands on previous research in the Cross Sector Project Report (Cross Sector Report)¹. The Cross Sector Project report generated a national conceptual map of the ten major benefit and income support systems available to Australians whose temporary or permanent injury, illness or mental health condition completely or partially affected their ability to work. These systems included: employer-provided leave entitlements; workers' compensation (short-tail & long-tail schemes); motor vehicle accident compensation (lump sum & statutory benefit schemes); life insurance (income protection & total and permanent disability policies); social security allowances; defence and veterans' affairs compensation & pension schemes; and early superannuation withdrawal entitlements.

PROJECT AIMS

We know that many people access income support from Australia's various income support systems but what is unknown is how and why people transition between these systems, and the impact it has on their health and work outcomes. The specific project aims were:

1. To quantify the movement of people between the ten major benefit and income support systems operating in Australia during one financial year.
2. To identify and understand:
 - the key pathways and significant drivers of movement between income support systems;
 - the health, economic and social outcomes for people transitioning between systems, including people accessing multiple systems concurrently
 - the factors and characteristics that influence health and work outcomes for individuals transitioning between systems including the significant barriers to work participation;
 - changes to income and impact on immediate family relationships as people move between systems;
 - changes to healthcare and welfare use as people move between systems;
 - the economic impact to Australia of people transitioning between systems including productivity losses; and
 - the likely impact of the coronavirus pandemic on the movement, experience and outcomes for people accessing the various systems.
3. To develop baseline data for future use, and outcome indicators including measures for work participation.

4. To make recommendations (for policy makers and income support system designers) that will inform future approaches to drive improved outcomes for people with health or disability.

METHODS

In order to achieve these objectives, three key project activities were undertaken:

1. A survey of previously working people whose health had impacted their ability to work and had engaged with at least once income support system.
2. In-depth interviews with a selection of people completing the survey to better understand their experiences of income supports and transitioning between income support systems.
3. Development of a systems dynamics model to describe inter-relationships between different income support systems (a separate report, user guide and information sheet has been developed as part of this activity).

The approach used for the survey and interview activities is summarised in Figure 1.

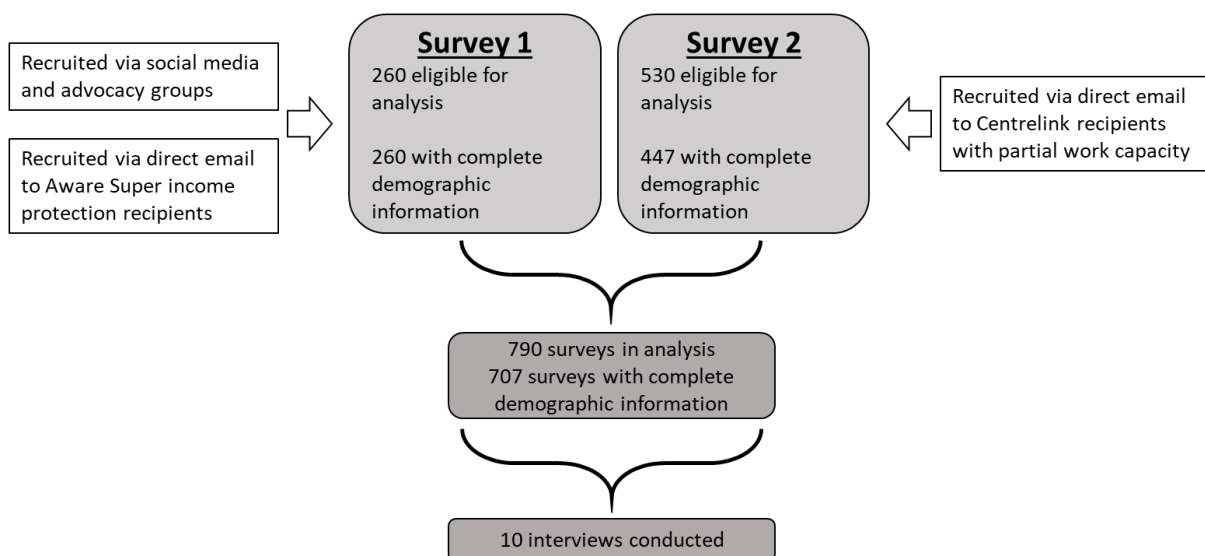


Figure 1: Overview of study: Two surveys utilised three recruitment methods. Interviewees were drawn from survey respondents.

Surveys and interviews were conducted with people aged over 18 years; who were previously in paid work and whose health had affected their ability to work, and who had engaged with at least one income support system. An initial survey was designed to capture details of the experience of people receiving income support. Upon review of responses, a second, simpler survey, was designed to encourage greater completion and validity of data. The original survey was distributed between March 10 and August 6, 2021, through two methods: 1. A social media campaign and engagement with a range of advocacy groups via Facebook, inviting interested and eligible people to complete the survey; and 2. Direct emails to Aware Super income protection recipients to invite survey completion. The second survey was direct emailed to approximately 5,000 Centrelink recipients identified as having a partial work capacity. Survey participants were also offered the opportunity to take part in a follow-up interview, and were purposefully sampled

to provide insights into a variety of experiences of income support systems and transitions between them.

RESULTS

A total of 790 surveys were available for analysis. Different groups could be identified in the data, clearly reflecting the different recruitment methods applied. Survey respondents who were currently receiving the Disability Support Pension (DSP) were more likely to be female and based in NSW when compared to all DSP recipients based on data provided by the Department of Social Services (DSS). Aware Super income protection recipients were older, more highly educated, more likely to live with a partner, and had lower financial distress than other survey respondents.

Interviews were conducted with 10 people who had a variety of experiences of income support systems. Two high level themes were identified: 1. Transition or progression between systems; and 2. Experiences within systems. Common experiences of transition included difficulty adjusting to changed life circumstances, lack of supports, difficulty with paperwork and an ongoing lack of communication. Experiences within systems described the physical and psychological burden of interacting with systems, a lack of awareness of available options, difficulties with job providers and returning to work and an inability to plan for the future. Interviewees described having to advocate for themselves within the systems and relied mostly on informal supports.

The original Cross Sector Report hypothesised transitions based on scheme policy and eligibility rules that effectively determined the pathway through a “cascade” of systems. The findings of this project, from both the survey and interview data, indicated that experiences of interactions with income support systems are highly individualised and non-linear, and that individual circumstances have a much larger influence on the experience of income support systems than can be described by scheme eligibility and system rules alone. For example, the number of transitions between systems was not necessarily an indicator of complexity. Survey results revealed it was most common for respondents to engage with a single system outside of paid employment; usually Centrelink (i.e. to progress from paid work to Centrelink benefits). Interviewees described how complex such a single transition could be, that it could in fact take many months, was highly stressful and involved long periods of receiving no income. As a result, the notion of “pathways” as being likened to simple routes through income support systems is likely to be an over simplification of the experience of transition. From the information gathered in this project there do not appear to be defining characteristics to indicate if a person is more likely to travel in a particular direction or engage with a particular pattern of income support. It is clear that moving from one source of income support to another is difficult and occurs at times when people are unlikely to be operating at full physical and mental capacity.

The most commonly used income support system was Centrelink (85.9%), followed by early superannuation withdrawals (28.6%), workers compensation (21.3%) and life insurance (18.2%) (Figure 2).

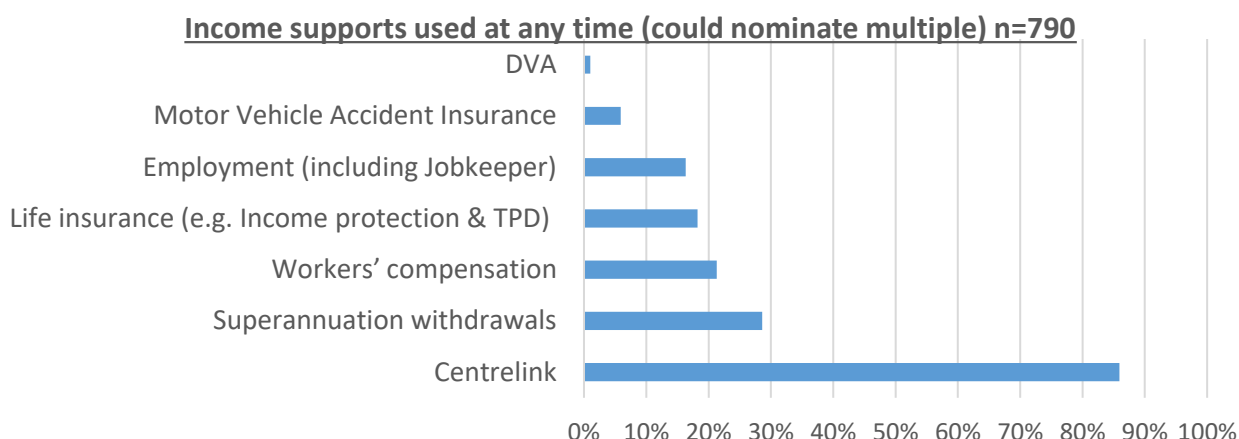


Figure 2: Proportion of respondents reporting accessing different income support systems at any time.

Superannuation withdrawals were most commonly accessed early due to health impacts and financial hardship, and the survey differentiated between superannuation withdrawals and payments through a life insurance component and total and permanent disability (TPD) lump sums. While it was not possible to differentiate between early access of superannuation and COVID-19 pandemic-related access in survey one (the largest dataset), nearly 65% of respondents in the second survey indicated accessing superannuation before 2020 (i.e. prior to access rules changing in response to the pandemic). Interview participants described using early superannuation withdrawals to ease aspects of their circumstances that they would have otherwise been unable to manage financially (such as covering relocation costs or making mortgage payments in advance to ensure future repayments were manageable).

It was most common for respondents to engage with a single system outside of paid employment; usually Centrelink. A little over a quarter of respondents engaged with two systems, whereas engaging with three or more systems was relatively uncommon (Figure 3). Of those who reported engaging with two systems, the majority described using Centrelink in combination with another system (e.g. Centrelink plus superannuation or Centrelink plus workers' compensation). Workers' compensation in combination with life insurance was the most commonly reported combination outside of Centrelink.

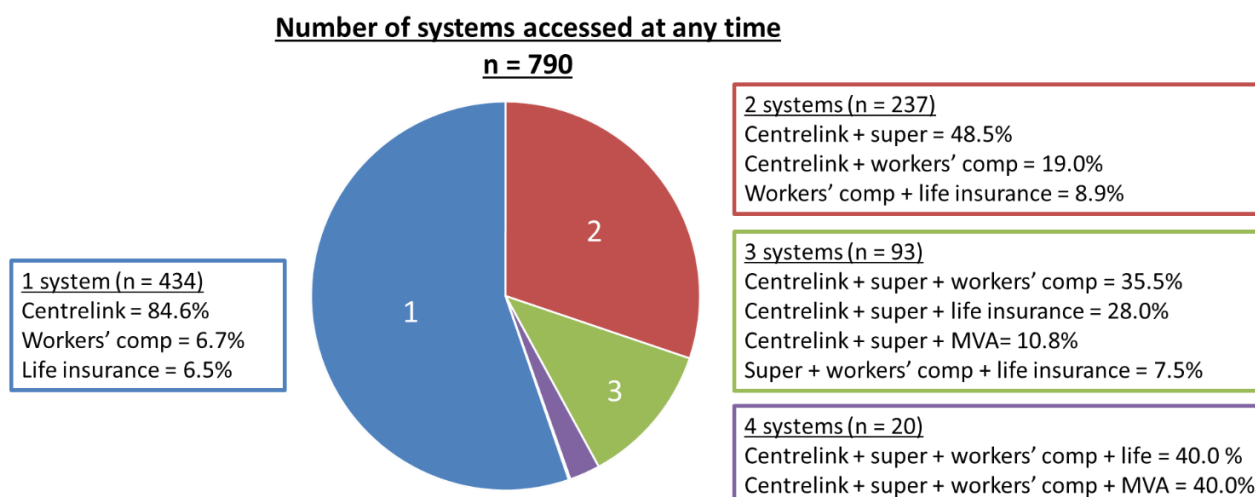


Figure 3: Breakdown of multiple systems accessed by individuals. Note that the combinations of systems are indications only and are not intended to be interpreted as estimates of the true prevalence of these combinations.

KEY FINDINGS

The following is a high level summary of the findings from the survey and interview components of the project:

- While the original Cross Sector Report suggested a “cascade” of systems based on eligibility rules for each system, the findings of this report suggest that there are many other personal and social factors that play a large role in determining how people engage with different levels of income support, including whether they “fall between the cracks”.
- The notion of “pathways” is much more individualised than expected, and from the information gathered in this project there do not appear to be defining characteristics to indicate if a person is more likely to travel in a particular direction or engage with a particular pattern of income support.
- Across each of the systems, paid employment was the most common income source in the month prior and being unable to work due to ill health was the most common reason for moving to an income support system.
- Participants were financially distressed. More than half of the survey respondents reported a period of no income which lasted on average somewhere between 7 and 15 months. People used personal savings, relied on family or sold assets to pay for things with no income, but most commonly went without. Personal savings was not further defined in the survey, but was differentiated from lump sum payments or credit card/personal loan. The financial distress experienced by Centrelink recipients was higher than those receiving income protection benefits.
- While there is often a genuine desire to work, it is often capacity limiting the ability to work. Before accessing each income support system, the majority were receiving income from paid work, and health impacting work was the main reason for seeking income support. Across the survey less than half reported being able to return to work (RTW) at any time, and for those who did report RTW it was common to have attempted multiple times. Employment agencies were described as not genuinely taking into account a person’s limitations when putting forward job roles.
- There is an unintended harm arising from engagement with the systems of income support. As people progress through the systems, the physical and psychological burden they experience increases while their capacity to cope with system requirements decreases. The majority of supports mentioned throughout were informal supports, such as family members or friends with experience of various income support systems.
- Those interviewed expressed dissatisfaction with administrative systems and described them as having a negative impact on their health. People suggested that paperwork should be standardised across medical professions, and should be able to be shared across income support systems.
- Participants described that to improve the experience of applying for income support there needed to be greater transparency and streamlining of the process through providing guidance on how to apply and providing the ability to check the progress of an application (e.g. on the status of an application for the DSP).

SUMMARY OF RECOMMENDATIONS

A summary of the recommendations the research team make is provided below.

1. Make use of the co-designed system dynamics model to investigate the impact of future policy settings and initiatives

The model provides a platform for policy experimentation to determine whether an approach to improve outcomes may be beneficial or otherwise. A suite of resources related to the model has been provided, and A/Prof Thompson will continue to be available to support use and experimentation with the model in this way.

2. Develop an overarching strategy to investigate the issue of system transitions further

To better understand the impact of transitions between systems, two approaches are proposed: data linkage and prospective cohort studies. Both of these approaches can be challenging to implement, particularly across the multiple income support systems in place. A clear understanding of transitions between ten income support systems is unlikely to be achieved in a single study. Therefore a strategy should be developed to identify the most efficient methods to gather appropriate information for key transitions.

3. Provide income support education as early as possible when health impacts the ability to work

In this study the majority of people were in paid work the month prior to receiving income support. It is at this initial point of work disability that it may be best to provide information regarding the income support systems that exist and what the requirements for each system are. This approach will require pooling resources across organisations to not only develop the resource, but also to promote it to anyone who might benefit. Such a development would need careful consideration of who would take the lead, where the resources would reside and ownership of the content.

4. Improve support for employers so they are better able to support people to stay at and return to work

Regardless of the income system encountered, the majority enter the system from paid work. There is an opportunity to strengthen support provided to employers so that they are better able to retain and return people to work. Initiatives, such as “Employ My Ability”¹, are likely to improve the confidence of employers around workers with temporary or ongoing work limitations.

5. Identify approaches to system entry that ease transition and determine how to adapt such approaches across systems

The experience of engaging with income support can be improved. Interview participants identified the need for greater transparency and visibility of available resources. Easy to follow checklists of how to apply, and processes that allow people to readily check the progress of their application would be one way to achieve this. Streamlining the collection and the transfer of information between systems, such as medical diagnoses and

¹ Department of Social Services (2021). *Employ My Ability*. Retrieved from https://www.dss.gov.au/sites/default/files/documents/12_2021/final-employ-my-ability.pdf

specialist reports, would facilitate transition and reduce the burden placed on the individual to meet the specific requirements of each system. Enabling the preparation of documentation ahead of time (for example when transitioning from workers' compensation to Centrelink benefits) may also reduce the length of time that people experience no income.

6. Extend case management capabilities within income support systems

Study participants described a lack of guidance regarding options outside of the system they were currently engaged in. It may be possible to increase the knowledge base of case managers, or select groups of case managers, within each system with a more holistic view of the various systems of income support and how they operate. Such an approach may guide people to access appropriate services across the various systems available to them.

SURVEY RESULTS

DEMOGRAPHICS

A total of 790 surveys were available for analysis, where at least information related to one system of income support was complete. Overall, survey participants were in the later stages of working life, with 65.6% over the age of 45. Almost two thirds were female (63.2%) and most were from NSW, Vic and Qld (26.7%, 26.0% and 22.2% respectively). Just over one quarter had not progressed education beyond high school (26.3%) and just under one third were living with dependent children (30.7%). Combined, the survey respondents reported high levels of financial distress, with a median score of 8 on a scale from 0 (not financially stressed at all) to 10 (as stressed as can be). Demographic characteristics appear in Table A1.1.

The Department of Social Services (DSS) provided demographic information related to all Centrelink benefit recipients to allow comparison with survey respondents to determine the representativeness of the sample. Table A1.2 provides a comparison between survey respondents reporting they were receiving Centrelink benefits at the time of completion of the survey (only identifiable from survey 2) and information provided by DSS. The survey sample contains a greater proportion of people receiving the DSP and fewer receiving JobSeeker benefits compared to the data provided by the DSS. The proportion in each age category is comparable between the survey and DSS data, however the survey appears to over represent females and people based in NSW.

The demographic characteristics of the Aware Super income protection recipients were compared to other survey respondents in Table A1.3. Respondents from the Aware Super mail out generally appear to be older, have completed higher levels of education, are more likely to be from NSW or Victoria, live with a partner and have lower levels of financial distress.

ENGAGEMENT WITH DIFFERENT SYSTEMS

The most commonly used income support system was Centrelink (85.9%), followed by superannuation withdrawals (28.6%), workers compensation (21.3%) and life insurance (18.2%) (Figure 2).

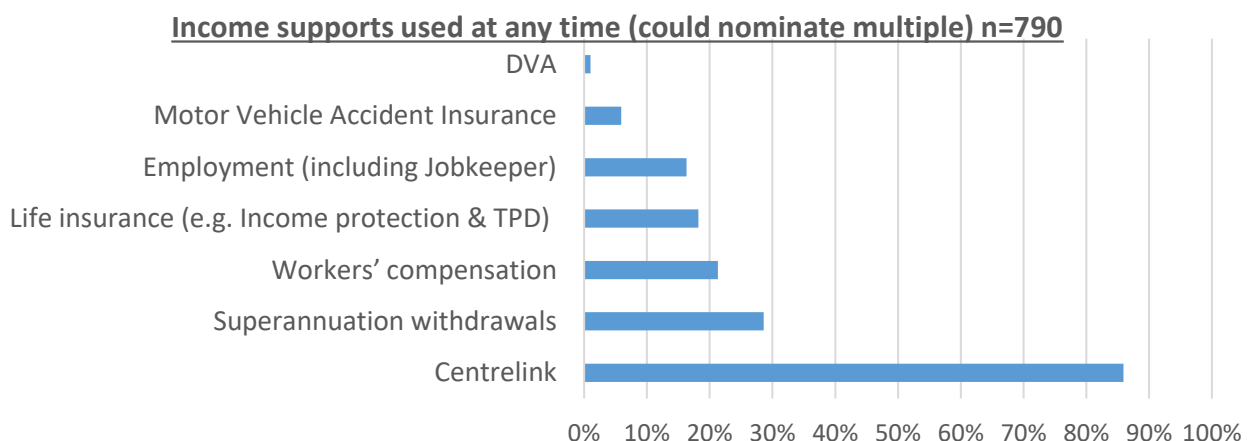


Figure 2: Proportion of respondents reporting accessing different income support systems at any time.

It was most common to engage with a single system outside of paid employment, usually Centrelink. Of the 30% who reported engaging with two systems, the majority described using Centrelink in combination with another system (87.3%), of these nearly half (48.5%) reported utilising a combination of Centrelink and Superannuation withdrawals income supports. Workers compensation in combination with life insurance the most commonly reported combination outside of Centrelink (8.9%). It was less common to report using three, four or five income support systems, with Centrelink most commonly appearing in any combination of systems (Figure 3). Tables A1.4 and A1.5 provide more detail on simultaneous system use and multiple system use.

Number of systems accessed at any time

n = 790

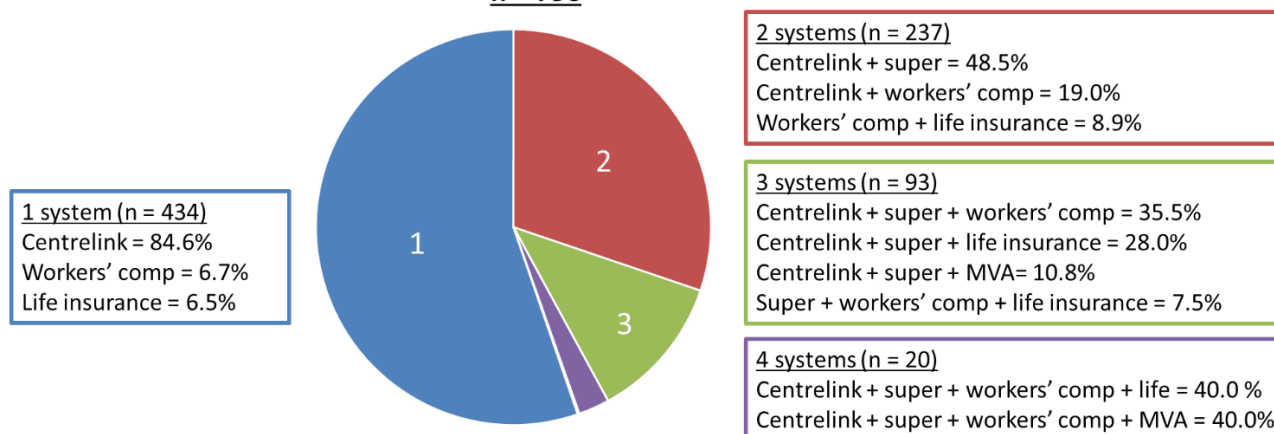


Figure 3: Breakdown of multiple systems accessed by individuals. Note that the combinations of systems are indications only and are not intended to be interpreted as estimates of the true prevalence of these combinations.

Across each of the systems paid employment was the most common income source prior to engaging with the system. The proportion reporting paid employment in the month prior was greatest for workers' compensation, Centrelink and life insurance income protection (93.8%, 76.4% and 75.9% respectively). More than half of respondents reporting withdrawals from super reported previously getting income from paid work (50.4%) and Centrelink (51.3%). Each system had small proportions of respondents indicating various sources of income in the month prior, reflecting the many and varied routes people experienced through these systems. A breakdown of previous income source is provided in Table A1.6.

PERIODS OF NO INCOME

More than half (51.9%) of 779 respondents reported a period of no income at all. For those completing Survey 1 the mean reported duration of no income was 7.4 months (n=137), for those completing Survey 2 the mean was 15.8 months (n=267). Of those reporting a period of no income, 97 (24.0%) reported having received a lump sum payment, which may have been perceived as a period of no income when the lump sum was intended to replace, at least in part, potential income received during that period. Having to wait to be able to receive benefits was the most common main reason for having no income (Figure 4). Note the large numbers in the "other" category in response to this question give some indication of the highly individualised stories reflected in survey responses. A breakdown of periods of no income across both surveys is provided in Table A1.7.

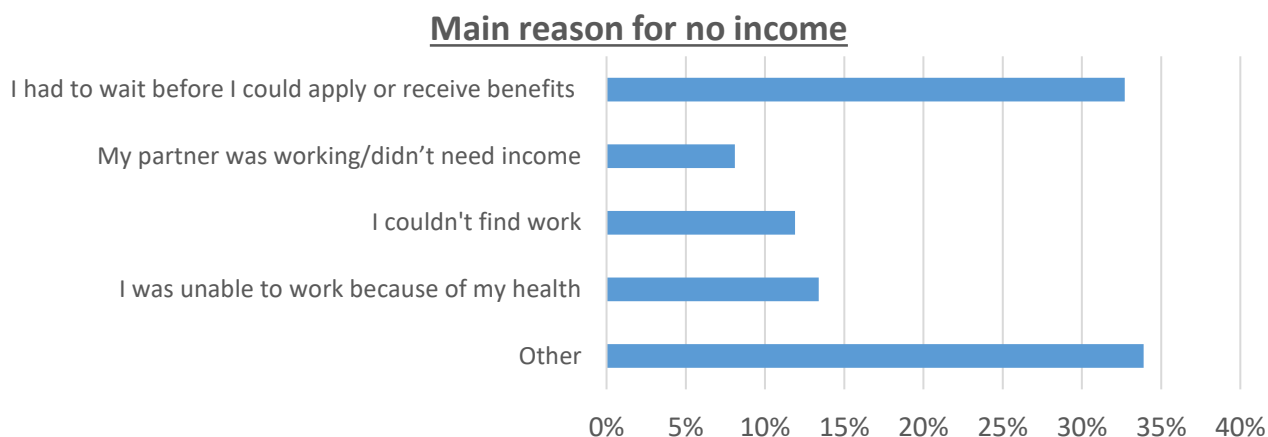


Figure 4: Main reason for receiving no income. Note the high frequency of “other” responses that Did not fit into survey categories, reflecting highly individualised circumstances surrounding receiving no income.

Most people reported using personal savings² (62.8%) or relying on a family member (43.8%) to pay for things when receiving no income. More than half (54.7%) reported they went without.

REASONS FOR MOVING BETWEEN INCOME SUPPORT SYSTEMS

Across all systems, “I was unable to work because of my health (injury or illness)” was the most common reason for moving to the income support system. “I became eligible for” specified system (for example due to waiting periods or eligibility requirements) was the next most common reason for moving between systems (Figure 5). This answer option was included in the survey as a result of the Cross Sector Report focus on eligibility determining access to different income support systems. However, the varied responses to the question, particularly in the “other” response category (see Table A1.8) underline the importance of individual circumstances behind transitioning between income supports. Even with the nine factors identified in the Cross Sector Report, there are many and varied combinations of circumstances that mean even a relatively simple “pathway” (e.g. from paid employment to Centrelink) is difficult to generalise in terms of the characteristics of people making such a transition.

² “Personal savings” was not defined further. However, the response option was differentiated from a “lump sum payment” (including a Superannuation payment) or “credit card/personal loan”

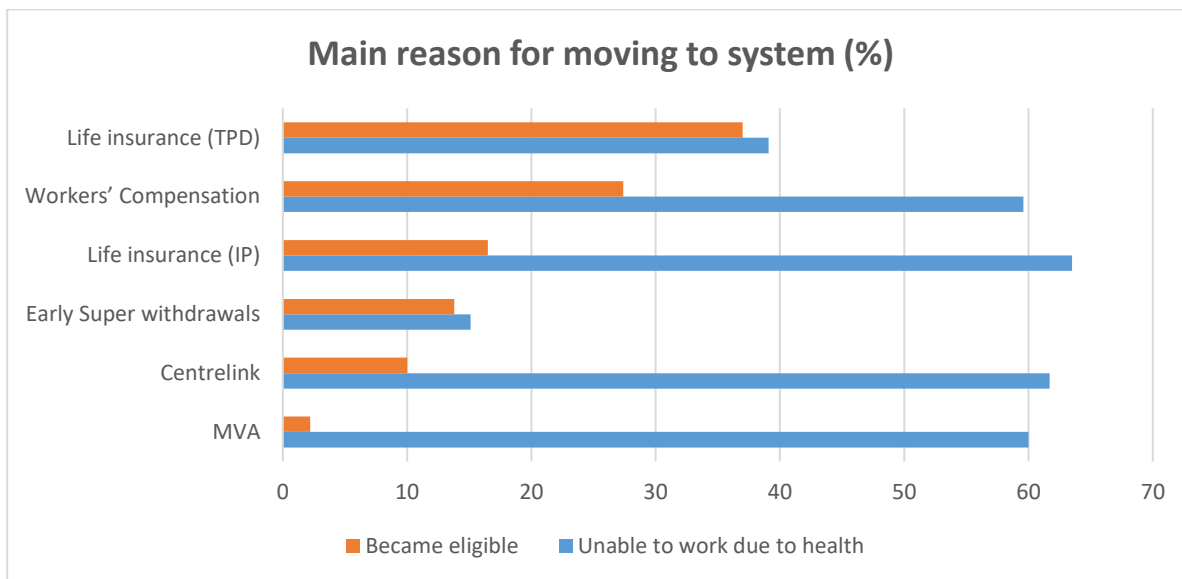


Figure 5: Main reason for moving to an income support system. Respondents had a greater focus on their health impacting their ability to work than meeting eligibility requirements across the income support systems.

FINANCIAL DISTRESS AND HEALTH

Overall survey respondents reported high levels of financial distress. Using the 11 point scale where 0 is not financially distressed at all and 10 is as financially distressed as a person can be, the median score across the survey was 8, with a mean score of 7.1 (SD 2.56). There were differences in levels of financial distress in the groups responding to the survey (Figure 6). Those who responded to the initial social media and advocacy group recruitment campaign had the highest levels of financial distress, and is likely a reflection of response bias, where those in worse circumstances would be more likely to respond to the advertisements and offer of an incentive. The income protection recipients reported the lowest levels of financial distress, however it should be noted that this group still reported considerable financial distress.

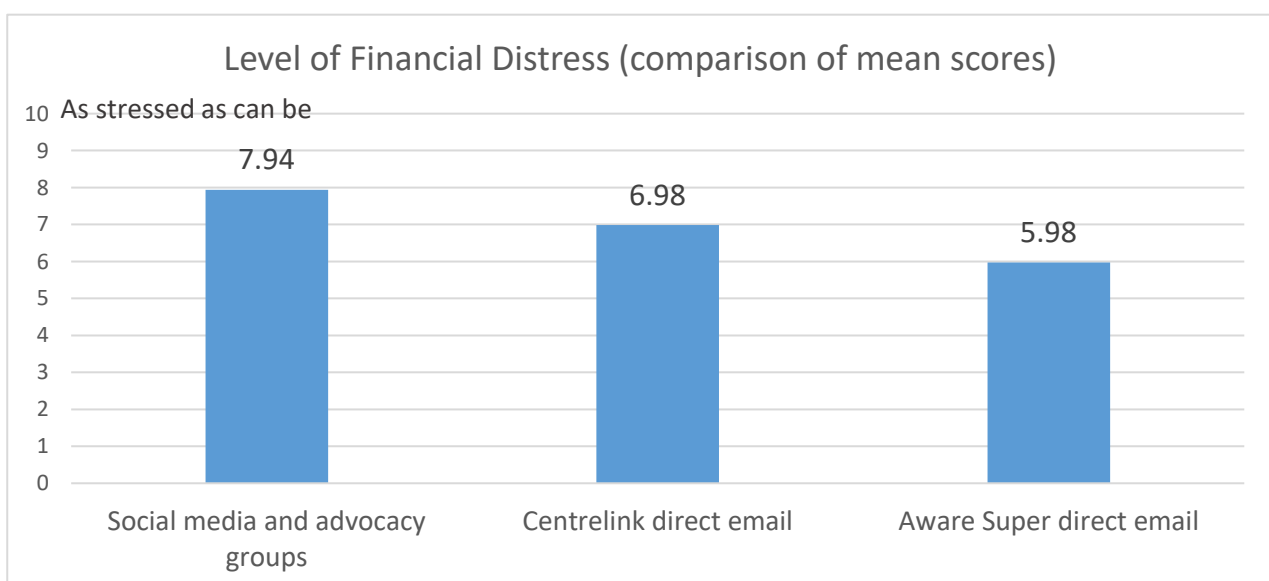


Figure 6: Mean financial distress for the three methods of recruitment into the survey. The Aware Super group reported the lowest levels of financial distress. Response bias is likely to be present in the group recruited by social media.

While these differences are statistically significant using univariate tests, it is not possible to control for other factors that may influence levels of financial distress due to the differences in data between the two surveys. As a result these differences should be considered as preliminary evidence that there are differences in circumstances between groups answering the survey. This is not surprising particularly for the income protection recipients, where benefit amounts are not impacted by partner earnings compared to those receiving income support from Centrelink. Further examination of the levels of financial stress revealed that women (mean 7.23, SD 2.52) were slightly more distressed than men (mean 6.81, SD 2.66), however the size of the difference identified and the low sensitivity of the measure used in the survey suggests that other factors are likely to play a larger role in financial stress than gender alone. Due to the low numbers in each category, it was not possible to compare superannuation withdrawal data between men and women.

A single item was used to capture the self-rated health of survey respondents. Unsurprisingly, responses painted a picture of poor health. Over 80% rated their health as fair or poor (Figure 7), and less than 1% of respondents rated their health as excellent (Table A1.23).

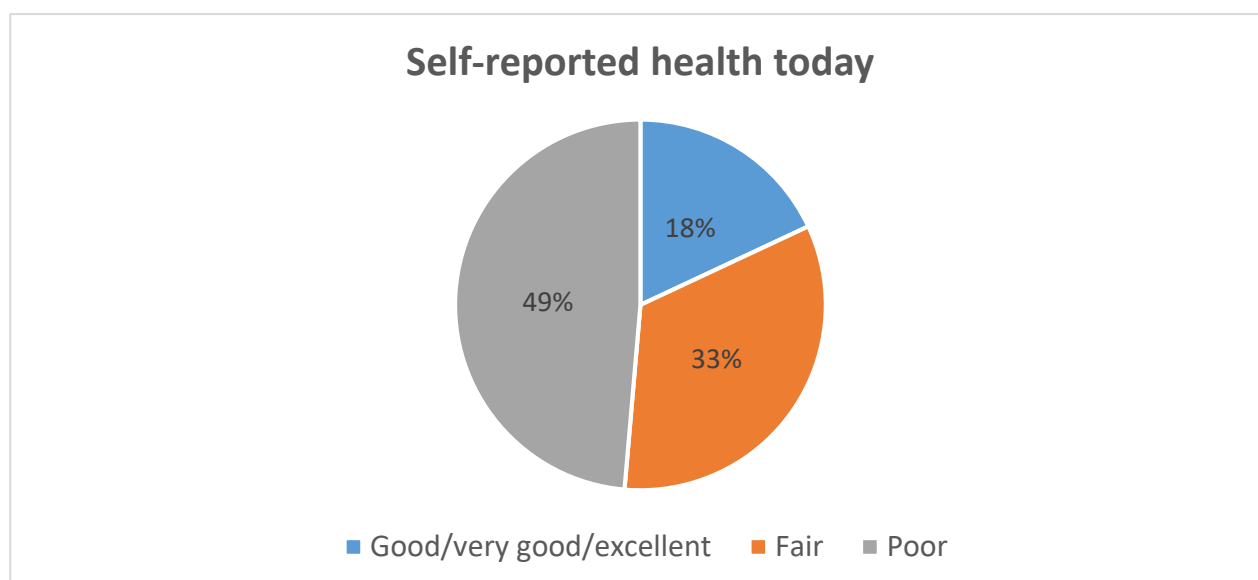


Figure 7: Self-reported health today. Responses of good, very good and excellent were combined and these “positive” responses made up just 18% of the survey sample.

NDIS

A relatively small proportion of survey respondents (26.3%) reported applying for services through the NDIS. Just over half of these (14.0% of the sample) were successful, and respondents reported waiting, on average, longer than six months before hearing an outcome on their application. The vast majority were engaged with Centrelink when applying (88.0%). A total of 34 respondents (17%) reported NDIS assistance in relation to securing employment. Further information regarding engagement with NDIS is provided in Table A1.9

RTW

Less than half (40.9%) of the respondents reported attempting to return to work at any time. Multiple attempts to return to work were common, with over 30% reporting 3-5

attempts to return to work. These respondents reported various reasons for multiple attempts to return to work including health challenges (physical and/or mental health), employer/workplace challenges and a variety of other circumstances. For the majority of respondents the type of work they were returning to was part time (50.7%) or casual (51.4%) (See Table A1.10).

SUPPORTS

A family member was identified as the most helpful support when moving to both income protection and Centrelink income supports. Lawyers were described as most helpful when moving to Motor Vehicle Accident compensation (MVA) and total and permanent disability insurance (TPD) systems. The employer was described as most helpful for just under one fifth of respondents moving to workers' compensation. Further information on the supports used is presented in Table A1.11.

OTHER DATA

The information provided above aims to address the key messages identified in the survey. In recognition of the likely multiple audiences for this report, information captured related to each individual system is reported in Tables A1.12 – A1.20, alongside information related to lump sums and other information captured in the survey not described earlier.

INTERVIEW RESULTS

DEMOGRAPHICS OF THOSE INTERVIEWED

A total of 260 participants expressed an interest in participating in a follow-up in-depth interview. Nearly all of those 260 respondents (93.5%) had accessed Centrelink at some time in their journey, mostly utilising Jobseeker/Newstart (82.3%) or the Disability Support Pension (68.3%). This was not unexpected due to the recruitment method of the survey recipients. An attempt was made to contact 25 participants, with 10 completing an interview. Interviewees lived in New South Wales, Queensland, South Australia, Victoria and Western Australia and of the ten interviewed seven were female. Participants were aged between 18-64 years (one aged 18-24yrs, five aged 35-44yrs, two aged 45-54yrs and two aged 55-64 yrs).

APPROACH TO ANALYSIS

Survey and interview data indicate that the pathways people take between systems appear highly individualised and non-linear. People interacted with different systems concurrently or back and forth until 'landing' in their current system of income support. Many anticipated that their income support could change in the future, for example being successful with an application for the DSP. There appears to be a perpetual pull towards the "downstream systems", i.e. Centrelink, where upon landing there it seems extremely difficult to leave. There does not appear to be a group of defining characteristics that indicate a person is more likely to travel in one direction, challenging the development of personas. Due to this variability in experiences, analysis was focused on the commonalities and differences between journeys undertaken, rather than on the individuals experiencing them. Figure 8 aims to illustrate the differences in experiences across those interviewed. It was relatively easy for interviewees to identify a "starting point" when health was impacting their ability to work. They could also clearly describe their "end point" or their current circumstances. However, people's recollections of the transitions they had experienced to reach the end point varied considerably. Some were able to clearly order their interactions with different systems, while others found it very difficult to recall the order of the systems they encountered, some systems were also identified as being utilised concurrently, such as workers' compensation and TPD payment.

CATEGORIES AND THEMES IDENTIFIED IN INTERVIEWS

Two high level categories were identified in the interview data that had clear alignment with the overall program objectives:

1. 'Transition or progression between systems'; and
2. 'Experiences within systems.'

Each of these categories consisted of a series of key themes, and a summary of these key themes is provided in Table A2.1. The first category encapsulates the interviewees' experiences of any transitions between or into different income support systems encountered. This included discussion of the processes involved, decision making, implications and impacts, support networks (or lack of), any interactions with NDIS and any impacts encountered due the COVID-19 pandemic. The second category encapsulates experiences the interviewees described with the different income support

systems encountered, incorporating aspects of the income support system itself and interactions with relevant staff/professionals associated within each system.

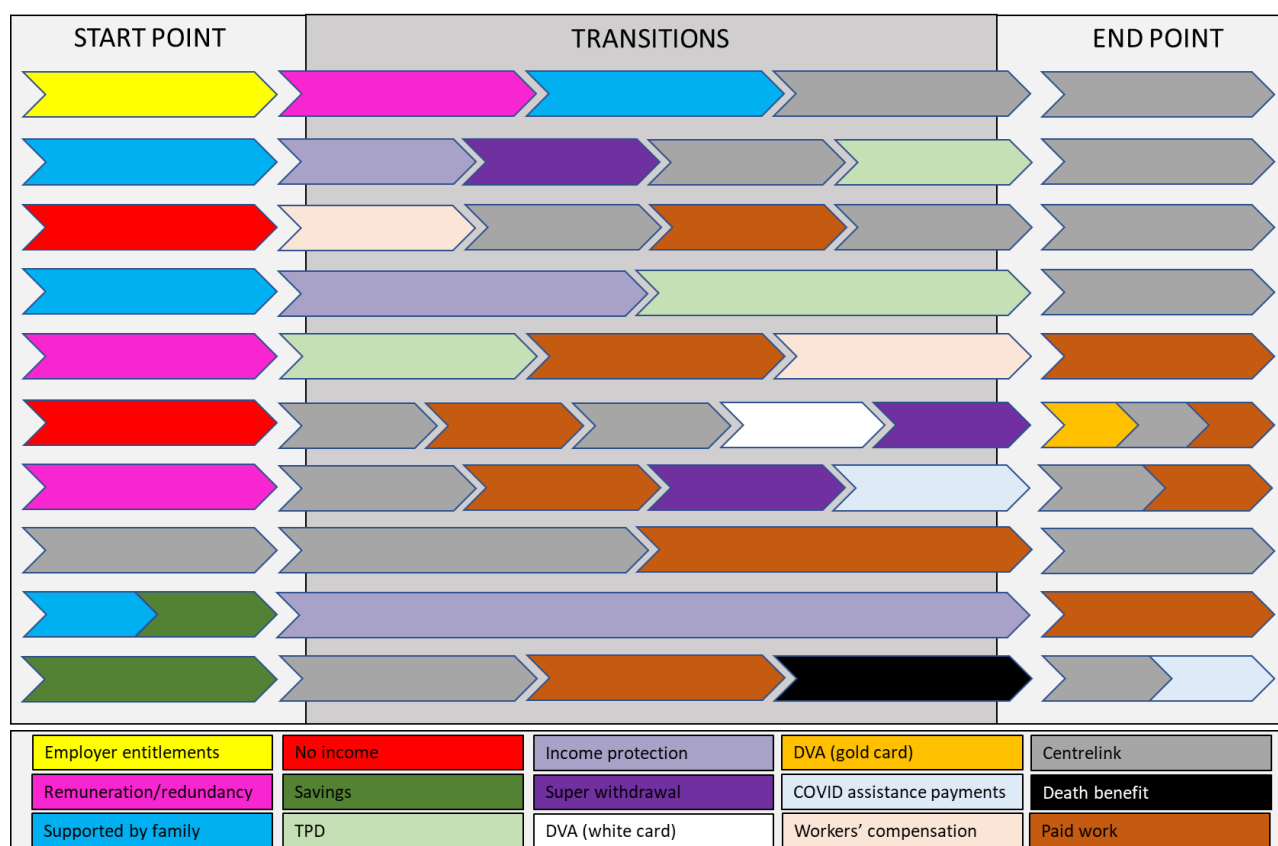


Figure 8: Colour map of the systems experiences of interviewees. Start and end points were easy to identify; However, transitions were less clear, varied in number, duration and the types of systems encountered.

CATEGORY 1: TRANSITION OR PROGRESSION BETWEEN SYSTEMS

Respondents described the following common experiences of transitioning to/or between different income support payments: lack of support navigating the system, uncertainty about how to commence the application process or how to complete required documentation, lack of communication throughout the process, lost paperwork and physically having to attend in person to resolve discrepancies or obtain paperwork that was not available online. There was a common theme that the Centrelink income support system was one of the most challenging systems they had experienced on their journey.

“I might have had a much better health outcome, but the reason ... wasn’t lack of information, it was lack of money...I was on Newstart....I would say most of the problems that have led to inadequate health outcomes for me or suboptimal outcomes for me have been to do with not having the money to see doctors, rather than not having the information.”

Importantly, the challenges that respondents faced created additional health concerns for many of them. Many interview respondents spoke of challenges in the initial stages of their journey. For example, the described difficulties in gaining time off work to attend medical appointments or recounted experiences of “struggling along” trying to come to terms with their disability. Some of the experiences shared by respondents were around the inevitable conclusion of being unable to fulfil work requirements and thus reluctantly finishing paid

employment, whilst others were unable to continue in their position due to employer ultimatums.

“So, I was really struggling in the new role and eventually they said look this isn’t working, we’re going to have to let you go”

Many of the respondents believed their situation was short term and that they just needed to try and get better so they could get back to work. However, often as their situation worsened, they came to the realisation that a full return to work was not feasible. In this situation, the burden was described as both physical and psychological.

“If I had have applied for the pension when I first got diagnosed, it would have been fine. But I wanted to keep working, but apparently cos they’ve tightened up the criteria for everything, um it made it harder. I wanted to keep working. I wanted to prove that I could keep working until I couldn’t.”

Some respondents described initially supportive work environments and flexible work arrangements to cover time required for medical treatments and appointments. However, the implications of the COVID-19 pandemic restrictions were evident in respondents’ inability to maintain work and the subsequent financial consequences of reduced work hours.

In the period following paid employment, respondents utilised formal and informal supports and networks. Informal supports included heavy reliance on family members or a partner for financial, physical and emotional assistance. Some respondents talked of seeking legal or financial assistance to assist with their situation, and it was acknowledged that this process in itself was stressful. Others discussed a feeling of desperation that they had run out of options and financially they were struggling.

Respondents also spoke of challenges faced around obtaining a diagnosis for their condition/s. In some situations there were multiple conditions at play, making diagnosis challenging. Once a diagnosis was made, it was often challenging for respondents to come to terms with their health and related changed life circumstances. Income support systems had a role to play in this: respondents spoke of being overwhelmed by the sheer amount of paperwork and requirements in many of the subsequent income support systems encountered during the next stages of their journey, having already faced a long string of medical and specialist appointments. They believed the focus should be on symptoms not diagnosis, as often their personal situation did not fit into the “tick boxes”; for others, the focus on the diagnosis itself meant they “didn’t have enough points” for an application, even though their disability necessitated income support. For those with complex conditions there was often a requirement to pay for testing or private specialists, which was often reported as unattainable and exacerbated their health burden and financial distress.

“For the amount of paperwork they wanted... all too difficult, basically... I think that’s pretty much how it’s designed... instead of spending my energy doing that and chasing that process it was much better for me to just focus on trying to get better and get back to full-time work”

A recurrent challenge was the time and energy required, both initially moving into and within income support systems, particularly regarding paperwork. The opaqueness of the process was especially challenging:

“...when we were applying, it was bouncing around Centrelink, all over the place, trying to find someone that could give us.....the right form because it’s not obvious on – anywhere, um, what the form is.”

Respondents commented that much of the paperwork was similar amongst systems, yet there was a requirement to have a new set completed for each system touched upon. Forms were described as hard to obtain, those who needed to complete them were often busy or refused to do so, and completed forms often “went missing” in the system. A consistent theme in many of the systems was around the lack of support provided, and not being given advice on the pathway to take or guidance on the progress of their application. As a result, the process was described as “stressful” and “combative”. Some respondents suggested it was deliberately made difficult to apply, as there was no guidance provided and the language used was difficult to understand. The application process was described as “jumping through hoops”, “a nightmare” and a “maze”. Once in the Centrelink system there was a consensus amongst interviewees that interactions with the Centrelink system was a complex process.

“...how does a person...that...hasn’t graduated high school coping with that stuff? Or English as a second language or you’ve just got so many medical things that, you know, your brain’s not functioning or your body’s not functioning or you’re under heavy medication?”

CATEGORY 2: EXPERIENCES WITHIN SYSTEMS

Some described the impacts of being on social security benefits (such as Newstart) as impacting their health outcomes due to financial constraints, but also emotionally due to a lack of information about their application for other benefits (such as DSP). Difficulties applying or being rejected on an application meant some people gave up. When successful transition was made, such as from Newstart payments to the DSP, this was expressed in a sense of relief amongst respondents.

“...when I got on the disability pension I didn’t have to go to the job provider....Like I felt like I’ve been left alone....it was my very first thought.... and I started crying ‘cause I thought, thank god....it was great to have that more money ‘cause now I can see my specialists and I’ve got more money for medication... I wasn’t able to get all those extra medications when I was on Newstart, so it’s not just the money but it’s the money to provide for your medical needs.”

Respondents reported being unaware of the range of income supports available. For example, “stumbling across” income protection by chance after contacting their Superannuation providers to query payment deductions and being advised they were premiums to cover TPD, income protection and life insurance. Or only being made aware of the ability to claim the DSP through the job service provider. It was clearly suggested that there needs to be greater visibility of resources about available support systems and more transparency in application processes. For example, life insurance was described as “a life saver” and one stated they advise everyone they know to start putting into a policy

or ensuring they have a policy attached to their Superannuation, as they felt many people were not aware of what may be available to them.

“...it made a massive difference to have 70 per cent of my income...it meant that we didn’t have the same hit on our lifestyle that we would’ve otherwise”

Commonalities of experiences transitioning to income protection support payments included respondents describing the paperwork requirements as “tick boxes” with most respondents indicating the process was not necessarily onerous but was challenging around health circumstances and commitments.

“TPD – they, they were happy to accept everything no questions asked.”

Lump sum payouts were described as having implications for health, economic and social outcomes when transitioning out of the Income protection income support system towards another system (such as Social Security). This included waiting periods necessitating being frugal and “going without” due to ongoing medical financial commitments “quickly eating up” the lump sum payment.

“...my TPD paid out and I built a house, so I don’t have to pay rent.”

Many expressed a desire to return to work in the future but there were queries about how this could be accomplished. In workers’ compensation, respondents spoke of challenges engaging assistance to return to work and having to “push” to be placed with a return to work coordinator that could assist them to identify a suitably qualified position matched to their work capacity. Within Centrelink there was a largely negative image portrayed of job providers with remarks made around inflexibility, lack of empathy, compassion and understanding of work capacity. People felt that job providers were not working in their best interests, “pushing” them towards jobs or courses that they were clearly not suitable. Respondents were very aware of an unequal relationship, and felt stigmatised when the job providers with power over their situation displayed a lack of understanding and a sense of ableism. Interviewees felt unable to speak up about the injustices and finality of the job plans that did not consider the whole ability of the person concerned. Queries were raised by respondents as to why they had been placed with job provider as opposed to a disability employment provider, and described this as a clear flaw in the system. Respondents wished there had been some sort of advocate to go to for support with the job providers, who had the “power to do something about” how they treated their clients.

“...job providers, I felt so unequal [sic].... there was a lack of equity. Very pushy... sort of very focused on getting you into a job and getting their bonus....I can honestly say the experience I had with the job provider was nothing but negative.”

There were differing accounts of interactions with NDIS. Some respondents spoke highly of their interactions with “well-me” representatives and support workers and a simple transition and approval processes. However, others described unfavorable interactions and an incredibly complex and confusing application process that led to them giving up. This is despite the view that the assistance that could be provided would be “invaluable”. It was suggested that instead of a “goal-based” system it should be needs-based, because some disabilities are not going to improve and people know their limits and abilities.

Interviewees reported that a lack of understanding of conditions may lead to incorrect provisions being made.

“NDIS would make a huge difference if we could have somebody come and clean the house because it also puts an immense pressure on my partner, he needs to do everything”

FUTURE PLANNING

There was a consistent theme amongst respondents that it was difficult to plan for the future when there was so much uncertainty about their situation, both financially and in terms of their health. For some this was described as a sense of despair. Some spoke of financial challenges and considerations for the future as having to take a gamble with investments, or having to make decisions around partners giving up carer payments and support roles to work full-time.

“...it's like a Russian roulette of symptoms with my disease..... looking forward to the future....it kind of makes me a bit depressed so I try and just take one day at a time and live with the symptoms that I've got..... it's hard to make plans.”

PRACTICAL SUGGESTIONS MADE BY INTERVIEWEES

There was a range of advice and practical suggestions put forward by interviewees to reduce the burden faced navigating different support systems. Respondents spoke of a lack of understanding of what was available to them and wishing they had been aware of what was available sooner. For example, only being made aware of DSP through the job service provider or being unaware that there was a disability advocate that could be engaged

“I didn't know that.... it existed, I didn't know I was eligible, I didn't know anything.... it's not so much I wish I'd known, as resources I wish I'd had”

It was suggested there needs to be more transparency and visibility of available resources

In addition, some kind of checklist that someone could work through to prepare all the required parts of their application and the need for a system that allowed them to track the progress of their application.

“...it's like a maze and then it's snakes and ladders and it's like the rules change halfway through, you think you're kind of doing it and then it's like, aha, but you didn't do that, though, did you? No, sorry, begin again, and the clock starts again.”

Providing additional supports was a recurrent suggestion, especially when applying for social security payments (such as JobSeeker). Due to the lack of experience for most people when first navigating the Centrelink system, it was described as very daunting and difficult to understand. Suggestion was made that information could be provided in “simple English” to be understood by someone who may have an intellectual disability or who is not fluent in English. Others reported wishing there had been some sort of advocate to go to for support.

Interviewees identified that there may be a “false economy” at a lot of stages in the process, as making it harder to access income support systems (such as DSP or workers’ compensation) ultimately made it harder to get medical treatment that may enable someone to stay in or return to the workforce. It was proposed by those interviewed that there may be a mentality to limit costs, but in fact the best way to limit costs would be to spend more in the short term (i.e. “upstream”) to save money in the long term (reduce the number of people “downstream”).

“I think that there’s a lot of false economy at a lot of stages in the process. So, um making it harder for people to access worker’s compensation or the DSP makes it harder for people to get medical treatment which might let them go back to the workforce or stay in the workforce”

There was a consistent theme of respondents suggesting they had to advocate for themselves throughout many of the processes they encountered. As such, respondents suggested it was important to “know your rights” and be as prepared as possible and ensure applications are “bullet proof”. For example, respondents described that if an application for DSP was not approved that it was possible to request a copy of the report, but they were unaware of that at the beginning of their application. The importance of this knowledge was described as “you don’t appeal something if it’s not in the rejection letter”. Informal supports, including advocacy and social media groups, were a valuable source of guidance through processes and learning what was required to make a successful application. It was described that without a support network it is very difficult for someone who is ill to obtain required paperwork for many of the income support systems.

“...the fact that I found it so difficult (moving between different income supports) was actually why I decided to agree to do the follow up information (interview), because I thought people who haven’t been through this don’t realise how hard it is.”

CONCLUSION

The original Cross Sector Report suggested a “cascade” of income support systems that was primarily based on eligibility rules for each system and circumstances related to the person’s health, such as the mechanism of injury (e.g. work-related or not), and their individual circumstances (such as their partner’s income). Both the survey information and the interview findings suggest that individual circumstances beyond those described in the Cross Sector Report have a large influence on the experience of income support systems. While the survey suggested that it was common to progress from paid work to Centrelink benefits, the interviews revealed that even what appeared to be a simple “pathway” consisted of a range of complex circumstances that impacted the person’s experience of income support and their health. As a result it was not possible to easily describe how people moved through income support systems, apart from being able to say with confidence that the longer people are engaged with income support, the more difficult it becomes.

Prior to conducting this project, the notion of “pathways” through the income support systems was one that fitted the notion of eligibility rules that governed where people could receive benefits. The number of systems of support in place, and the multiple variations of systems (e.g. by state) result in a multitude of ways people can experience income support, even before consideration of personal circumstances such as specific medical conditions, family relationships and an individual’s desire to work. As a result, the concept of common “pathways” through these systems is likely to ignore important aspects of people’s actual experiences. Emerging from this research is that moving from one source of income support to another is difficult and occurs at a time when a person is unlikely to be operating at full physical and mental capacity, and much can be done to make it less likely that the experience of transition is deleterious to health.

Along the lines of the recommendations of the Cross Sector Report, it appears the best opportunity to intervene is early, or “upstream”. Regardless of the income system encountered, the majority enter the system from paid work. The first line of action should be to support employers to retain employees with a temporary or ongoing work limitation wherever possible. When maintaining work is not possible, interviewees described a low awareness of what supports might be available, the processes required to apply and a lack of transparency regarding their application. There may be opportunities to provide support to all employees through developing easily understandable and accessible descriptions of income supports available and what is required to be able to access them. Consideration of who develops, owns and promotes such resources is needed. An alternative approach would be to provide more “active” support through enhanced case management, where the case manager is able to provide guidance on the various systems of support and their requirements to prepare for and support transition. Trials of this style of case management are a feature of Pillar Two of the Collaborative Partnership. Providing comprehensive formal supports is likely to reduce the reliance on informal supports and discovering information by chance. It is also more likely to allow a person to match the income supports available to their own personal circumstances. Perhaps the most important aspect being that when people are required to transition to a system of income support, information is readily available, support is provided as early as possible and the application is as streamlined as possible. As it currently stands the burden experienced by people receiving income support increases as their ability to cope with system requirements decreases.

Gathering information in this area is particularly challenging given the length of time people spend in income support systems and the variations in systems across the country. The information that can be collected retrospectively in a survey related to transition between systems is limited, forcing the changes seen in the surveys applied in this project. To learn more about the impact of transitions between specific income support systems, other methods are required. There are two pieces of work that we know of (currently unpublished) that will shed further light on the experience of transition between income support systems. The first is the Pillar Two project of the Collaborative Partnership, examining the role of a transition specialist to support exit from workers' compensation (referred to above). This project examines the outcomes of a single transition point and utilises survey and interview data to examine whether a formal support reduces some of the barriers described by interviewees in the current project. The second study is a data linkage study examining the change to workers' compensation legislation in NSW, and will utilise administrative data to describe outcomes for people leaving long term workers' compensation benefits. The findings of both of these projects are expected to be available in 2022 and are likely to add to what is known about this challenging topic of transition between income support systems.

ADDRESSING PROJECT AIMS

The Cross Sector Report identified ten income support systems available to those whose temporary or permanent injury or illness impacted their ability to work. Initially the “pathways” that people took were described as a “cascade” of income support systems, primarily based on eligibility rules for each system related to the mechanism of injury and geographic location. The survey and interview data suggest that individual circumstances, beyond those described in the Cross Sector Report, have a large influence on people’s experience of income support systems. Based on these findings, pathways that people take and the way individuals move around the systems may be better described using a pinball analogy, where people may bounce, rebound and utilise multiple systems simultaneously (that is, have more than one ball in play). Movements or transitions between systems may arise by formal guidance, informal guidance or sometimes chance rather than an expected and smooth linear process. The structure of income support systems can, and has been, represented well in a systems dynamics model that shows how systems impact each other. However, experiences of people within the systems and the reasons why people move between systems were not described as a predictable cascade. Movement or transitions were described in the logics of people’s lives, what opportunities present and what makes sense for them, rather than system rules and eligibility.

Synthesis of the three project components is provided under each project aim to better understand how this project contributes to the understanding of how people move between systems. Where possible the incidences of movement, key pathways and significant drivers of transition between income support systems have been described, usually referencing information in other sections of this report. This section also provides recommendations for policy makers and system designers of future approaches that may drive improved outcomes for people ill or injured and unable to work.

1. QUANTIFY THE MOVEMENT OF PEOPLE BETWEEN THE TEN MAJOR BENEFIT AND INCOME SUPPORT SYSTEMS OPERATING IN AUSTRALIA DURING ONE FINANCIAL YEAR.

To attempt to quantify the movement of people between income support systems in Australia the agreed methodology utilised a survey and in-depth interviews of people with lived experiences. The unreliability of data collected this way means we are unable to quantify the volume of movement of people between systems with confidence. This is a result of recall bias/failure (being unable to accurately recall all previous events) and the long time periods involved when utilising multiple systems. From the interviews we found that individuals find it hard to track and describe temporal aspects of their journey, and that movement between systems can take years. While focus on a single financial year can provide information on people exiting one system and entering another, it provides less insight into the reasons behind movement between systems. During interviews people would articulate movement by working backwards in time and in terms of significant events where they could pinpoint when things happened, and could describe the outcomes at that point in time when prompted. Even after simplifying the survey format it was evident that individuals found it difficult to describe their experiences in a sequential fashion. This was clear in the free text components where some individuals would try to narrate their response to articulate their reasoning for choosing a particular reply. To confidently quantify the movement of people between systems, administrative data linkage

approaches are likely required. However, we are not aware of any attempts to cover up to ten income support systems via data linkage, given the practical difficulties of linking data across just two systems (e.g. worker's compensation to social security).

Taking the aforementioned into consideration, following are some of the key findings from the survey:

The most commonly used income support system was Centrelink, with most respondents arriving directly from paid employment. Both the survey and interviews described a range of complex circumstances that impacted the person's experience of what was previously thought to be a simple income support "pathway".

Of participants completing Survey 1, nearly 20% said they accessed multiple income support systems at the same time. The most common systems concurrently engaged were workers compensation with income protection, income protection and paid employment and workers' compensation and employment. This may be a reflection of the flexibility within income protection and workers' compensation systems to adjust levels of benefits based on other sources of income.

Outside of paid employment it was most common to engage with a single system, usually Centrelink. Of those that reported using more than one system, the most common combination was Centrelink and superannuation withdrawals, and moving from workers' compensation to life insurance was most common without involving Centrelink.

Across each of the systems, paid employment was the most common income source prior to engaging with the system. Each system had small proportions of respondents indicating various sources of income in the month prior, reflecting the many and varied pathways people experienced through these systems.

It must be noted that the information provided in this report reflects the recruitment methods applied. We purposefully aimed to recruit people in "downstream" systems as they were identified as being more likely to have interacted with multiple systems. To this end recruitment was successful, but the proportions of people interacting with each system should be considered an indication only, and further work is required to reliably quantify transitions across each system.

2(A). TO IDENTIFY AND UNDERSTAND THE KEY PATHWAYS AND SIGNIFICANT DRIVERS OF MOVEMENT BETWEEN SYSTEMS

At commencement of the project, the notion of pathways seemed an appropriate way to describe passage through the income support systems, guided by a stepwise logic such as 'finishing work then applying for system X, then apply for system Y'. However, a different language may better describe what happens in reality from participants' perspectives. People applied an opportunistic type of logic, whereby the need to get money resulted in a very pragmatic approach. When an opportunity presents or someone is made aware of another option, they then try to access it.

Many respondents reported initially believing that their situation was short term and they just needed to recover and then they could go back to work. As such, the concept of planning for the future was not a consideration. People started with the first system they came across and then, when that was financially exhausted, they began to look for an

alternative source of income – i.e., there was no ‘planning’. It appears that movement may also be based on social factors such as the cost of health care, the individual’s specific needs and their family and economic situation. The opportunistic approaches may also be based on the resources (financial, knowledge and social) available at the time. The ability to navigate the steps required diminish over time, as the longer a person has been injured or disabled, the less capacity they have for the administrative requirements imposed by income support systems. Interviewees indicated there was often a requirement to relocate interstate (for social, lifestyle or financial reasons) and sometimes several times over their journey, bringing additional challenges. As such they had to renegotiate some processes in a new location (e.g. connecting with a new GP or Centrelink office). Such individual level variations that come into play are hard to capture when mapping movement between systems.

In summary, there is a disconnect between how schemes are envisaged to operate and the experience of people within them. While scheme managers may understand and determine clear criteria for eligibility and transition between income support systems, the black and white nature of eligibility can clash with the human experience. Modelling readily represents how the system functions as a whole, but further information is needed to understand the specific drivers of movement between individual systems.

2(B). TO IDENTIFY AND UNDERSTAND THE HEALTH, ECONOMIC AND SOCIAL OUTCOMES FOR PEOPLE TRANSITIONING BETWEEN SYSTEMS, INCLUDING PEOPLE ACCESSING MULTIPLE SYSTEMS CONCURRENTLY

Items in the survey did not directly measure health, economic or social outcomes for participants. However, it is possible to draw inferences about these outcomes from a range of questions asked in the survey. Data collected was able to capture and describe respondents’ levels of financial distress, with more than half of respondents disagreeing that they had enough income to cover their essential living costs. Just 20% of respondents agreed that they were capable of paid work, and less than one quarter agreed that they would get or keep a job in the future (Table A1.22). These represent poor economic outcomes.

Indications are that health outcomes after transition are also poor. Only 40% agreed that they could get the healthcare they needed (Table A1.22), and nearly half rated their current health as poor (Table A1.23).

It should be noted that these responses reflect people’s state at the time of survey completion, rather than at points of transition between systems. A longitudinal survey design would overcome issues of recall and shed light on outcomes immediately before and soon after transition.

The data collected showed that transition processes are arduous and stressful. By design these transitions are supposed to be a filter for eligibility and possibly prevent people accessing the system if not eligible. Understanding the resources (financial, knowledge and social) required to enable transition between these systems is important. Many of the transitions people described were reactive, that is they had very little agency and power in them. This exacerbated the economic hardship that many were facing. Applying for the DSP or NDIS funding appeared to be the only proactive choices, where people were aiming to achieve a better outcome. Those who were successful did describe a more

positive experience compared to those who were not, however multiple attempts were required, and each application draws down further on limited resources.

2(C). TO IDENTIFY AND UNDERSTAND THE FACTORS AND CHARACTERISTICS THAT INFLUENCE HEALTH AND WORK OUTCOMES FOR INDIVIDUALS TRANSITIONING BETWEEN SYSTEMS INCLUDING THE SIGNIFICANT BARRIERS TO WORK PARTICIPATION;

From the survey and interview data two in five people indicated that they attempted to return to work, and three out of ten of these people attempted multiple times. More than half of the return to work attempts were in part time or casual roles. Many wanted to get back into the workforce, but their health prevented them from doing so, leaving very few opportunities to improve their situation. Initiatives that build employers' confidence around disability (e.g. Employ My Ability) may improve the experience of returning to the workforce.

There appears to be limited understanding of how systems operate together. Systems seem to operate independently between themselves. There is not a clear system overview, even among experts in particular income support systems, and very little planning as to how to assist individuals to identify where their best outcome is likely to be. It appears to be left to opportunity and that person's own ingenuity at times as to where someone may end up.

2(D). TO IDENTIFY AND UNDERSTAND CHANGES TO INCOME AND IMPACT ON IMMEDIATE FAMILY RELATIONSHIPS AS PEOPLE MOVE BETWEEN SYSTEMS;

The interviews and surveys identified changes to family relationships where individuals relied heavily on a partner or a family member for social and financial support. There were situations whereby individuals had previously been two independent people in a relationship and then suddenly were completely reliant on their partner. In one example, the complete financial reliance on their partner made leaving an abusive relationship even more difficult in the absence of additional supports.

There is an aspect of the NDIS that is aimed at alleviating some of the pressures on relationships as part of disability support. Individuals in relationships talked of having to decide if it was financially beneficial for a partner to give up a carer role to return to work, leaving the ill or injured person potentially without a carer support person.

As such we have some evidence from the interviews of the impacts on immediate family relationships. Some commented that Centrelink deemed them to be in a relationship (financially) even though the relationship had not matured to that point. The data captured in the project did not suggest family relationships are a careful consideration in any of the systems, with the possible exception of the NDIS.

2(E). TO IDENTIFY AND UNDERSTAND CHANGES TO HEALTHCARE AND WELFARE USE AS PEOPLE MOVE BETWEEN SYSTEMS;

The survey data indicated people had a limited ability to meet living and health care costs. Over half of respondents disagreed that they had enough income to pay essential living

costs (Table A1.22). One in four indicated they were unable to access the healthcare they needed.

A recurrent challenge discussed by the interview respondents was the time and energy necessary for the administrative requirements, both initially moving into and staying within income support systems. Of particular note was how this burden was felt by those who were unwell at the time or who were still coming to terms with their situation, diagnosis or illness. People with complex conditions described how there was often a requirement to pay for testing or private specialists, which was often reported as unattainable and exacerbated financial stress. There was often confusion when transitioning between income support systems regarding which income support system was covering certain incomes or payments during the transition period.

2(F). TO IDENTIFY AND UNDERSTAND THE ECONOMIC IMPACT TO AUSTRALIA OF PEOPLE TRANSITIONING BETWEEN SYSTEMS INCLUDING PRODUCTIVITY LOSSES

Experiences shared by interview respondents related to the inevitable conclusion of being unable to fulfil work requirements and reluctantly finishing paid employment. Three quarters who reported receiving Centrelink payments indicated they were previously in paid employment one month prior. For the vast majority, their health prevented them from being able to work, despite several attempts to return to paid work. More than half of the survey respondents experienced a period of no income, many for more than a year, and had to rely on support networks to assist or simply “went without”. One third indicated that a waiting or ‘qualifying’ period was the reason for no income.

The system dynamics model developed through the project is a good basis to determine the economic impact of system transitions, and its overall structure has been validated by an expert group. Applying specific scenarios and assumptions, the model can be used to more comprehensively address this project aim. The project team can provide specific training on how to do so, and will be available in the future to provide further support with modelling as required.

2(G). IDENTIFY AND UNDERSTAND THE LIKELY IMPACT OF THE CORONAVIRUS PANDEMIC ON THE MOVEMENT, EXPERIENCE AND OUTCOMES FOR PEOPLE ACCESSING THE VARIOUS SYSTEMS.

The reported impacts of the pandemic were related to accessing health care and being unable to attend in person at Centrelink rather than limiting opportunities to work. Most respondents were longer-term recipients of income support, and as such had not become ill/impacted due to the pandemic.

People interviewed who were currently receiving their income from Centrelink described receiving an increase in payments during the pandemic. Even so, these respondents described a preference to be receiving DSP payments rather than the temporarily higher Jobseeker benefit, as they viewed DSP as a better life option.

The system dynamics model provides a basis to explore scenarios related to the pandemic. For example, any income support policy that was being considered, or changes in population growth as a consequence of the pandemic, can be input into the model to

estimate what potential outcomes or implications of policy changes may be on the performance of the total system

We welcome the opportunity to work with the partners to maximise the use of the model and how it can be used to further address a number of these aims.

3. TO DEVELOP BASELINE DATA FOR FUTURE USE, AND OUTCOME INDICATORS INCLUDING MEASURES FOR WORK PARTICIPATION

The project was commenced with the expectation that movement through income support systems would align with eligibility criteria and identify common routes, or “pathways”, through income support. The intention was then to identify information that could be used to identify with each pathway, such as personal characteristics, work and health outcomes, and indicators of return to work. Given that individual circumstances have a much larger influence on the experience of income support systems than can be described by scheme eligibility and system rules alone, it was not possible to develop baseline data and outcome indicators using the survey and interview methods employed in the project.

The developed model represents the best known baseline data for future use as a starting point to address this aim. Alternative collection methods are required if new information is required due to the limitations of retrospective data. Possible methods include prospective data (e.g. longitudinal cohort) or a data linkage study that would further address similar research aims.

4. TO MAKE RECOMMENDATIONS (FOR POLICY MAKERS AND SYSTEM DESIGNERS) THAT WILL INFORM FUTURE APPROACHES TO DRIVE IMPROVED OUTCOMES FOR PEOPLE WITH HEALTH OR DISABILITY.

Based on the information gathered in this project, the research team make the following recommendations:

1. Make use of the co-designed system dynamics model to investigate the impact of future policy settings and initiatives

The model provides a platform for policy experimentation to determine whether an approach to improve outcomes may be beneficial or otherwise. For example, the model could be used to demonstrate how a universal basic income approach could affect the costs and friction associated with transitions between systems. While the model could demonstrate the overall cost impacts, the findings of this study could be used to estimate the expected impact on the experience of people within the systems. A/Prof Thompson will continue to be available to support use and experimentation with the model in this way.

2. Develop an overarching strategy to investigate the issue of system transitions further

The methods applied in this study were retrospective and relied on individuals to accurately recall events over many years involving a large number of different income support systems. While this leads to some limitations in the reliability of the data gathered, it is apparent that the lived experience of transition differs to the “cascade” of systems described in the Cross Sector Report. To better understand the impact of transitions between systems, two approaches are proposed: data linkage and prospective cohort

studies. Both of these approaches can be challenging to implement, particularly across the multiple income support systems in place.

A clear understanding of transitions between ten income support systems is unlikely to be achieved in a single study. Therefore a strategy should be developed to identify the most efficient methods to gather appropriate information for key transitions. Part of this strategy should identify studies already underway that address specific types of transition (for example, we are aware of two studies focused on transition out of workers' compensation involving the Healthy Working Lives Research Group). Such a strategy should prioritise the types of transition where currently little information exists, and aim to establish the feasibility of data linkage or prospective cohort study methods to progress understanding.

3. Provide income support education as early as possible when health impacts the ability to work

In this study the majority of people were in paid work the month prior to receiving income support. During the interviews, people described an expectation that their inability to work would be temporary. It is at this initial point of work disability that it may be best to provide information regarding the income support systems that exist and what the requirements for each system are. Such information should also be made available to those who end employment involuntarily, do not have leave entitlements or are on short term contracts and may finish employment very abruptly.

One of the challenges identified in this study is the highly personalised nature of the circumstances surrounding requiring income support, and how these have a large influence on the outcomes in terms of travelling through the systems. A technical approach could be to develop a chat bot-style function that allows people to ask questions and be provided guidance in response. An example of an organisation that has used this type of technology is the Victorian Equal Opportunity and Human Rights Commission sexual harassment support and response tool (<https://www.humanrights.vic.gov.au/resources/respond-to-sexual-harassment/>). The implementation of this trial chat bot has demonstrated that it is possible to achieve a personalised response, even in a sensitive environment.

One education-based solution could be to pool efforts to create a cross-organisational resource that enables people, particularly early in the early stages of work disability, to gather information on what might happen should they continue to be unable to work. A generic port of call could be especially useful since people do not necessarily make distinctions between the services and the supports that the schemes do. The technology could enable people to access information relevant to their specific circumstances at a time of their choosing, and could be promoted to people through various channels including employers (e.g. when an episode of sick leave is recorded) and medical professionals (e.g. General Practitioners).

Such a development would need careful consideration of who would take the lead, where the resources would reside and ownership of the content. The data gathered in this project suggest this information would be best provided before engaging with Centrelink, as Centrelink benefits tended to be an "end point" for many, and a last resort. Guidance is required as quickly as possible once health impacts a person's ability to work.

4. Improve support for employers so they are better able to support people to stay at and return to work

Regardless of the income system encountered, the majority enter the system from paid work. There is an opportunity to strengthen support provided to employers so that they are better able to retain and return people to work. Initiatives, such as “Employ My Ability”, are likely to improve the confidence of employers around workers with temporary or ongoing work limitations. There is an opportunity to extend such support to employment services currently offered within systems of income support. In this study, participants described a general desire to return to work, but limitations in their capacity. They also described being proposed work roles that were clearly beyond their current capabilities. A greater understanding of work ability would also appear to benefit employment services designed to support those with temporary or ongoing work limitations.

5. Identify approaches to system entry that ease transition and determine how to adapt such approaches across systems

Interview participants identified the need for greater transparency and visibility of available resources. Easy to follow checklists of how to apply, and processes that allow people to readily check the progress of their application would be one way to achieve this. Enabling the transfer of information between systems, such as medical diagnoses and specialist reports, would facilitate transition and reduce the burden placed on the individual to meet the specific requirements of each system. Combining these two approaches would allow applicants to readily identify the paperwork requirements they had already met from previous engagement with income support, and clearly indicate what further documentation may be required to successfully transition to another system of income support. Enabling the preparation of documentation ahead of time (for example when transitioning from workers’ compensation to Centrelink benefits) may also reduce the length of time that people experience zero income. Most of these approaches require cross-system collaboration to identify areas where system administration can be streamlined.

6. Extend case management capabilities within income support systems

Study participants described a lack of guidance regarding options outside of the system they were currently engaged in. It may be possible to increase the knowledge base of case managers, or select groups of case managers, within each system with a more holistic view of the various systems of income support and how they operate. An alternative to extending the current case manager role within systems would be to introduce “system case managers” who operate “across” systems. Such people would require training in the eligibility requirements and application processes of multiple systems of income support. Specific Allied Health professionals, such as social workers, may be in an ideal position to fulfil such a role with specific training. Consideration is required related to who would identify and employ people in this role, and how appropriate referrals would be identified and made. Regardless, an approach involving enhanced case management may guide people to access appropriate services across the various systems available to them.

APPENDIX 1 – SURVEY TABLES

TABLE A1.1: DEMOGRAPHIC CHARACTERISTICS

	Survey 1	Survey 2	Combined
Number of Participants	n=260	n=447	n=707
Age			
18 to 24 years	9 (3.5%)	24 (5.4%)	33 (4.7%)
25 to 34 years	19 (7.3%)	59 (13.2%)	78 (11%)
35 to 44 years	52 (20%)	80 (17.9%)	132 (18.7%)
45 to 54 years	86 (33.1%)	112 (25.1%)	198 (28%)
55 to 65 years	86 (33.1%)	151 (33.8%)	237 (33.5%)
Over 65 years	8 (3.1%)	21 (4.7%)	29 (4.1%)
Gender			
Male	80 (30.8%)	166 (37.1%)	246 (34.8%)
Female	176 (67.7%)	271 (60.6%)	447 (63.2%)
Non-Binary	0 (0%)	9 (2%)	9 (1.3%)
Prefer not to say	4 (1.5%)	1 (0.2%)	5 (0.7%)
Highest Level of Education			
Primary school or less	2 (0.8%)	2 (0.4%)	4 (0.6%)
High school (not completed)	41 (15.8%)	61 (13.6%)	102 (14.4%)
High school (completed)	26 (10%)	54 (12%)	80 (11.3%)
TAFE / Trade Certificate	61 (23.5%)	140 (31.3%)	201 (28.4%)
Diploma	51 (19.6%)	66 (14.8%)	117 (16.5%)
University - undergraduate degree (completed)	46 (17.7%)	73 (16.3%)	119 (16.8%)
University - postgraduate degree (completed)	30 (11.5%)	35 (7.8%)	65 (9.2%)
Other	3 (1.4%)	16 (3.6%)	19 (2.7%)
State			
ACT	1 (0.4%)	12 (2.7%)	13 (1.8%)
Queensland	49 (18.8%)	108 (24.2%)	157 (22.2%)
New South Wales	91 (35%)	98 (21.9%)	189 (26.7%)
Northern Territory	0 (0%)	3 (0.7%)	3 (0.4%)
South Australia	22 (8.5%)	39 (8.7%)	61 (8.6%)
Tasmania	4 (1.5%)	18 (4%)	22 (3.1%)
Victoria	67 (25.8%)	117 (26.2%)	184 (26%)
Western Australia	26 (10%)	52 (11.6%)	78 (11%)
Living arrangements			
Partner/spouse and no dependent children	69 (26.5%)	-	-
Partner/spouse and dependent children	49 (18.8%)	-	-
I live by myself	59 (22.7%)	-	-
Single parent with dependent children	31 (11.9%)	-	-
I live with other family members	32 (12.3%)	-	-
I live with people who are not family members	13 (5%)	-	-
Prefer not to say	7 (2.7%)	-	-
Number dependent children (n=80)			
1	29 (36.3%)	-	-
2	41 (51.2%)	-	-
3	6 (7.5%)	-	-
4	4 (5%)	-	-

TABLE A1.2: DEMOGRAPHICS OF SURVEY COMPLETERS CURRENTLY RECEIVING CENTRELINK BENEFITS AND CENTRELINK DSP, JOBSEEKER AND YOUTH ALLOWANCE RECIPIENTS WITH AN ASSESSED WORK CAPACITY

	Survey 2	DSS Data
Currently receiving Centrelink benefits	n=454	n=900,138
Benefit type		
Disability Support Pension	317 (69.8%)	55.5%
Newstart/JobSeeker	88 (19.4%)	42.7%
Sickness Allowance	8 (1.8%)	
Youth Allowance	5 (1.1%)	1.8%
Other	31 (6.8%)	
Age	n=409	
18 to 24 years	22 (5.4%)	6.8% ¹
25 to 34 years	48 (11.7%)	13.4%
35 to 44 years	71 (17.4%)	15.0%
45 to 54 years	105 (25.7%)	24.0%
55 to 64 years	143 (35.0%)	33.4%
Over 65 years	20 (4.9%)	7.4%
Gender		
Male	145 (35.5%)	48.9%
Female	254 (56.7%)	51.1%
Non-Binary	9 (2.2%)	
Prefer not to say	<5 (<1.0%)	
Reported education		
Below high school equivalent	49 (12.0%)	<0.1%
High school equivalent or higher	344 (84.1%)	74.6%
Unknown/other	16 (3.9%)	25.4%
State		
ACT	9 (2.2%)	1.0%
Queensland	102 (24.9%)	22.2%
New South Wales	95 (23.2%)	31.3%
Northern Territory	<5 (<1.0%)	1.1%
South Australia	36 (8.8%)	8.8%
Tasmania	18 (4.4%)	3.4%
Victoria	102 (24.9%)	24.1%
Western Australia	46 (11.2%)	7.9%

1. Comparison age range in DSS data is 16-24

TABLE A1.3: DEMOGRAPHIC INFORMATION FOR RESPONDENTS FROM AWARE SUPER RECRUITMENT STRATEGY

	Aware Super respondents	Other survey respondents
Age	n=86	n=621
18 to 24 years	0	33 (5.3%)
25 to 34 years	5 (5.8%)	73 (11.8%)
35 to 44 years	13 (15.1%)	119 (19.2%)
45 to 54 years	36 (41.9%)	162 (26.1%)
55 to 64 years	31 (36.0%)	206 (33.2%)
Over 65 years	<5	28 (4.5%)
Gender		
Male	41 (47.7%)	205 (33.0%)
Female	44 (51.2%)	403 (64.9%)
Non-Binary	0	9 (1.4%)
Prefer not to say	<5	<5
Highest Level of Education		
Primary school or less	<5	<5
High school (not completed)	<5	98 (15.8%)
High school (completed)	<5	76 (12.2%)
TAFE / Trade Certificate	10 (11.6%)	191 (30.8%)
Diploma	25 (29.1%)	92 (14.8%)
University - undergraduate degree (completed)	22 (25.6%)	97 (15.6%)
University - postgraduate degree (completed)	18 (20.9%)	47 (7.6%)
Other	<5	17 (2.4%)
State		
ACT	<5	12 (1.9%)
Queensland	6 (7.0%)	151 (24.3%)
New South Wales	45 (52.3%)	144 (24.2%)
Northern Territory	0	<5
South Australia	0	61 (9.8%)
Tasmania	<5	21 (3.4%)
Victoria	31 (36.0%)	153 (24.6%)
Western Australia	<5	76 (12.2%)
Living arrangements		n=174
Partner/spouse and no dependent children	34 (39.5%)	35 (20.1%)
Partner/spouse and dependent children	31 (36.0%)	18 (10.3%)
I live by myself	11 (12.8%)	48 (27.6%)
Single parent with dependent children	6 (7.0%)	25 (14.4%)
I live with other family members	<5	28 (16.1%)
I live with people who are not family members	0	13 (7.5%)
Number dependent children	n=37	n=43
1	10 (27.0%)	19 (44.2%)
2	22 (59.5%)	19 (44.2%)
3	<5	<5
4	<5	<5
Financial distress (1-10)		
Median score (Range)	6 (1-10)	8 (1-10)

TABLE A1.4: INCOME SUPPORT SYSTEMS USED AT ANY TIME

	Survey 1	Survey 2	Combined
Income supports used	n=260	n=530	n=790
Employment (including Jobkeeper)	129 (49.6%)	N/A	129 (16.3%)
Centrelink	178 (68.5%)	501 (94.5%)	679 (85.9%)
Superannuation withdrawals	64 (24.6%)	162 (30.6%)	226 (28.6%)
Workers' compensation	70 (26.9%)	98 (18.5%)	168 (21.3%)
Life insurance (e.g. Income protection & TPD)	98 (37.7%)	46 (8.7%)	144 (18.2%)
Motor Vehicle Accident Insurance	13 (5%)	34 (6.4%)	47 (5.9%)
DVA	3 (1.2%)	5 (0.9%)	8 (1.0%)
Personal investment	28 (10.7%)	-	-
Family member or other source	77 (29.6%)	-	-
Paid sick leave	97 (38.2%)	-	-
Accessed multiple systems at same time	n=246	-	
Yes	44 (17.9%)	-	
Systems accessed at same time	n=44	-	
Employment/Sick leave	25 (56.8%)	-	
Workers comp	21 (47.7%)	-	
MVA	2 (4.5%)	-	
Life insurance IP	29 (65.9%)	-	
Life insurance TPD	8 (18.2%)	-	
Super withdrawals	12 (27.3%)	-	
Centrelink	17 (38.6%)	-	
Number of systems accessed at same time			
2	22 (50.0%)	-	
3	17 (38.6%)	-	
4	3 (6.8%)	-	

TABLE A1.5: USE OF MULTIPLE SYSTEMS AT ANY TIME

	Combined surveys
	n=790
Number of systems accessed at any time	
1	434 (54.9%)
2	237 (30.0%)
3	93 (11.8%)
4	20 (2.5%)
5	1 (0.1%)
1 system	n=434
Centrelink	367 (84.6%)
Super	5 (1.2%)
Workers Compensation	29 (6.7%)
Life Insurance	30 (6.5%)
MVA	3 (0.6%)
DVA	0
2 systems	n=237
Centrelink + super	115 (48.5%)
Centrelink + workers' compensation	45 (19.0%)
Centrelink + life insurance	29 (12.2%)
Centrelink + MVA	15 (6.3%)
Centrelink + DVA	3 (1.3%)
Super + life insurance	6 (2.5%)
Workers' compensation + life insurance	21 (8.9%)
Workers' compensation + MVA	1 (0.4%)
Life insurance + MVA	2 (0.8%)
3 systems	n=93
Centrelink + super + workers' comp	33 (35.5%)
Centrelink + super + life insurance	26 (28.0%)
Centrelink + super + MVA	10 (10.8%)
Centrelink + super + DVA	3 (3.2%)
Centrelink + workers' comp + life insurance	10 (10.8%)
Centrelink + workers' comp + MVA	2 (2.2%)
Super + workers' comp + life insurance	7 (7.5%)
Super + workers' comp + MVA	1 (1.1%)
Workers' comp + life insurance + MVA	1 (1.1%)
4 systems	n=20
Centrelink + super + workers' comp + life	8 (40.0%)
Centrelink + super + workers' comp + MVA	8 (40.0%)
Centrelink + super + life + MVA	2 (10.0%)
Centrelink + super + life + DVA	1 (5.0%)
Centrelink + workers' comp + DVA + MVA	1 (5.0%)

TABLE A1.6: REPORTED INCOME SOURCE FOR THE MONTH PRIOR TO ENGAGING WITH EACH SYSTEM

	Centrelink	Workers' Compensation	MVA	Life insurance (TPD)	Life insurance (IP)	Super withdrawals
	n=596	n=146	n=45	n=47	n=87	n=207
Paid work (including leave entitlements)	455 (76.4%)	137 (93.8%)	29 (64.4%)	19 (40.4%)	66 (75.9%)	114 (50.4%)
Centrelink		10 (6.8%)	14 (31.1%)	11 (23.4%)	8 (9.2%)	116 (51.3%)
Workers' compensation	35 (5.9%)		3 (6.7%)	5 (10.6%)	10 (11.5%)	11 (4.9%)
MVA compensation	7 (1.2%)	1 (0.7%)		0	0	1 (0.4%)
Life insurance (IP or TPD)	30 (5.0%)	4 (2.7%)	2 (4.4%)	7 (14.9%)	0	14 (6.2%)
DVA/Part DVA pension	2 (1.3%)		1 (2.2%)	0	0	4 (1.8%)
Superannuation withdrawals	46 (7.7%)	2 (1.4%)	0	2 (4.3%)	2 (2.3%)	
Other	0	2 (1.4%)	3 (6.7%)	0	1 (1.1%)	13 (5.7%)

TABLE A1.7: PERIODS OF NO INCOME ACROSS SURVEYS

	Survey 1	Survey 2	Combined
	n=255	n=524	n=779
Period of no income	137 (53.7%)	267 (51.0%)	404 (51.9%)
Main reason for no income	n=137	n=267	n=404
I had to wait before I could apply or receive benefits	48 (35.0%)	81 (31.4%)	129 (32.7%)
I couldn't find work	2 (1.5%)	45 (17.4%)	47 (11.9%)
My partner was working/didn't need income	8 (5.8%)	23 (8.9%)	32 (8.1%)
I was unable to work because of my health	53 (38.7%)	-	53 (13.4%)
Other	26 (19%)	109 (42.2%)	134 (33.9%)
Duration of period of no income (months)	Mean 7.36 Median 4.0 Range 0-24	Mean 15.8 Range 0-240	
Paying for things without an income			
Used personal savings	86 (62.8%)	-	
Used credit card/personal loan	49 (35.8%)	-	
Relied on family member	60 (43.8%)	-	
Sold assets	43 (31.4%)	-	
Had a lump sum to get through	20 (14.6%)	-	
Went without	75 (54.7%)	-	
Other	15 (10.9%)	-	

TABLE A1.8: MAIN REASON FOR MOVING TO EACH INCOME SUPPORT SYSTEM

	Centrelink	Workers' Compensation	MVA	Life insurance (TPD)	Life insurance (IP)	Early Super withdrawals
	n=590	n=146	n=45	n=46	n=85	n=152
Unable to work due to health	364 (61.7%)	87 (59.6%)	27 (60.0%)	18 (39.1%)	54 (63.5%)	23 (15.1%)
Left paid work	31 (5.3%)	4 (2.7%)	0	3 (6.5%)	0	17 (11.2%)
Reached time limit of benefits	19 (3.2%)	0	1 (2.2%)	1 (2.2%)	6 (7.1%)	8 (5.3%)
Became eligible	59 (10.0%)	40 (27.4%)	5 (11.1%)	17 (37%)	14 (16.5%)	21 (13.8%)
Other income used up	14 (2.4%)	0	0	1 (2.2%)	5 (5.9%)	18 (11.8%)
Family situation changed	37 (6.3%)	0	0	0	0	6 (3.9%)
Chose to move	2 (0.3%)	0	0	0	0	13 (8.6%)
No longer eligible	6 (1.0%)	3 (2.1%)	1 (2.2%)	3 (6.5%)	2 (2.4%)	0
Benefits more than elsewhere	3 (0.5%)	0	1 (2.2%)	0	0	0
Other	55 (9.3%)	12 (8.2%)	10 (22.2%)	3 (6.5%)	4 (4.7%)	0
Financial hardship	0	0	0	0	0	7 (4.6%)

TABLE A1.9: RESPONSES TO NDIS QUESTIONS

	Survey 1	Survey 2	Combined
NDIS questions	n=256	n=166	
Applied for services through NDIS	37 (14.2%)	148 (33.1%)	185 (26.3%)
In the process of applying	24 (9.2%)	18 (4.0%)	42 (6.0%)
Application successful	21 (56.8%)	94 (56.6%)	115 (56.7%)
Still pending	-	21 (12.7%)	21 (10.3%)
Time taken for NDIS to make decision (months)	Mean 6.6 Median 4.0 Range 0-24	Mean 7.5 Range 0-96	
Income source at time of NDIS application		n=166	
Centrelink		146 (88.0%)	
Workers' compensation		4 (2.4%)	
MVA		3 (1.8%)	
Life insurance		2 (1.2%)	
Superannuation payment		5 (3.0%)	
Family member		17 (10.2%)	
Paid work (any type)		25 (15.1%)	
Savings		1 (0.6%)	
Employment a goal in NDIS plan	12/37 (32.4%)		
Type of support (Multiple could be selected)	n=2	N=150	
Employment support	2/37 (5.4%)	11 (7.3%)	
Employment skill building	1/37 (2.7%)		
Resume writing	1/37 (2.7%)		
Connecting with employment provider	1/37 (2.7%)		
Supports in work (e.g. workplace modifications)	1/37 (2.7%)		
Carer/support at home	-	41 (27.3%)	
Therapies/exercise	-	41 (27.3%)	
Transport/community participation	-	26 (17.3%)	
Domestic help (e.g. cleaning/gardening)	-	38 (25.3%)	
Counselling/Psychology	-	16 (10.7%)	
Aids/equipment/supplies	-	31 (20.7%)	
Financial help (reference to DSP or finances)	-	15 (10.0%)	
Home modifications	-	5 (3.3%)	
Other	-	23 (15.3%)	
Used NDIS support to gain employment	2 (5.4%)	32 (19.6%)	34 (17%)
NDIS employment support received		n=29	
Found work to match capability		5 (17.2%)	
Provided support to keep current work		3 (10.3%)	
Assistance with transport		4 (13.8%)	
Provided support worker		5 (17.2%)	
Provided training/preparation/qualification		7 (24.1%)	
Other		3 (10.3%)	

TABLE A1.10: RETURN TO WORK ATTEMPTS FOR 680 SURVEY RESPONDENTS

	Survey 1	Survey 2	Combined
RTW	n=228	n=452	n=680
RTW at any time	54 (23.7%)	224 (49.6%)	278 (40.9%)
How many times RTW	n=54	n=224	n=278
1	21 (38.9%)	34 (15.2%)	55 (19.8%)
2	7 (13%)	50 (22.3%)	57 (20.5%)
3 - 5	20 (37.0%)	65 (29%)	85 (30.6%)
6-10	5 (9.3%)	22 (9.8%)	27 (9.7%)
Don't know/can't remember	-	13 (5.8%)	-
More than 1 but can't recall	-	5 (2.2%)	-
Capacity of work			
Full time work	12 (22.2%)	47 (21.1%)	59 (21.2%)
Part time work	27 (50%)	114 (51.1%)	141 (50.7%)
Casual	15 (27.8%)	128 (57.4%)	143 (51.4%)
Other	N/A	11 (4.9%)	-

TABLE A1.11: SUPPORTS USED WHEN MOVING TO INCOME SUPPORT SYSTEMS

Supports used	To MVA	To WC	To IP	To TPD	To super withdrawals	To Centrelink
	n=13	n=56	n=76	n=25	n=56	n=157
Family member	3 (23.1%)	14 (25%)	29 (38.2%)	7 (28%)	15 (26.8%)	50 (31.8%)
Lawyer	6 (46.2%)	14 (25%)	5 (6.6%)	9 (36%)	4 (7.1%)	9 (5.7%)
Case manager	1 (7.7%)	14 (25%)	10 (13.2%)	3 (12%)	2 (3.6%)	8 (5.1%)
Friend	0 (0%)	12 (21.4%)	9 (11.8%)	3 (12%)	7 (12.5%)	23 (14.6%)
NDIS officer	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1.8%)	1 (0.5%)
Employer	2 (15.4%)	16 (28.6%)	10 (13.2%)	0 (0%)	0 (0%)	3 (1.9%)
C'link website	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	62 (39.5%)
Other	1 (7.7%)	6 (10.7%)	13 (17.1%)	4 (16%)	13 (23.2%)	17 (10.8%)
No one / Not applicable / don't know	3 (23.1%)	11 (19.6%)	20 (26.3%)	8 (32%)	22 (39.3%)	50 (31.8%)
Most helpful support						
Family member	1 (7.7%)	9 (16.1%)	28 (37.3%)	5 (20%)	12 (21.4%)	36 (22.9%)
Lawyer	6 (46.2%)	8 (14.3%)	3 (4%)	8 (32%)	4 (7.1%)	6 (3.8%)
Case manager	1 (7.7%)	8 (14.3%)	5 (6.7%)	0 (0%)	0 (0%)	5 (3.2%)
Friend	0 (0%)	5 (8.9%)	2 (2.7%)	0 (0%)	6 (10.7%)	12 (7.6%)
NDIS officer	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Employer	1 (7.7%)	11 (19.6%)	6 (8%)	0 (0%)	0 (0%)	0 (0%)
C'link website	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	36 (22.9%)
Other	1 (7.7%)	4 (7.1%)	11 (14.7%)	4 (16%)	12 (21.4%)	12 (7.6%)
No one / Not applicable / don't know	0 (0%)	11 (19.6%)	20 (26.7%)	8 (32%)	22 (39.3%)	50 (31.8%)

TABLE A1.12: CENTRELINK INCOME SUPPORT TABLE

	Survey 1	Survey 2	Combined
	n=254	n=530	n=784
Accessed Centrelink at any time	162 (63.8%)	501 (94.5%)	663 (84.6%)
Benefits accessed	n=162	n=501	n=663
Jobseeker/Newstart	148 (91.3%)	340 (70.7%)	488 (75.9%)
Disability Support Pension	49 (30.2%)	363 (75.3%)	411 (63.9%)
Youth allowance	14 (8.6%)	55 (11.4%)	69 (10.7%)
Sickness allowance	17 (10.5%)	82 (17%)	99 (15.4%)
Other Centrelink payment	28 (17.3%)	42 (8.7%)	72 (11.2%)
Jobkeeper	8 (4.9%)	2 (0.4%)	8 (4.9%)
No Centrelink payment	N/A	5 (1%)	5 (1%)
Income month prior to Centrelink	n=158	n=438	n=596
Paid employment (including sick/annual leave)	125 (79.1%)	330 (75.3%)	455 (76.4%)
Workers' compensation	11 (7%)	24 (5.5%)	35 (5.9%)
Motor Vehicle Accident Insurance compensation	2 (1.3%)	5 (1.1%)	7 (1.2%)
Life insurance (e.g. Income protection & TPD)	14 (8.9%)	16 (3.7%)	30 (5.0%)
DVA/Part DVA pension	2 (1.3%)	1 (0.2%)	2 (1.3%)
Superannuation withdrawals	12 (7.6%)	34 (7.8%)	46 (7.7%)
Main reason for moving to Centrelink	n=156	n=434	n=590
I was unable to work because of my health	92 (59%)	272 (62.7%)	364 (61.7%)
I left paid employment	6 (3.8%)	25 (5.8%)	31 (5.3%)
I had reached the time limit of benefits	10 (6.4%)	9 (2.1%)	19 (3.2%)
I became eligible for Centrelink	13 (8.3%)	46 (10.6%)	59 (10.0%)
My other income sources were used up	6 (3.8%)	8 (1.8%)	14 (2.4%)
My family situation changed	12 (7.7%)	25 (4.8%)	37 (6.3%)
I chose to make the move	2 (1.3%)	0 (0%)	2 (0.3%)
No longer eligible for my previous income	N/A	6 (1.4%)	6 (1.0%)
Centrelink benefits more than elsewhere	N/A	3 (0.7%)	3 (0.5%)
Other	15 (9.6%)	40 (9.2%)	55 (9.3%)
Family situation changed since getting income from Centrelink (n=24)			
Separated from partner	13 (54.2%)	-	-
Children no longer dependent	4 (16.7%)	-	-
Had more children	3 (12.5%)	-	-
Other	10 (41.7%)	-	-

TABLE A1.13: SUPERANNUATION INCOME SUPPORT TABLE

	Survey 1	Survey 2	Combined
	n=260	n=530	n=790
Accessed superannuation at any time	64 (24.6%)	162 (30.6%)	226 (28.6%)
Timing of super withdrawal		n=151	
Before 2020	-	98 (64.9%)	
After 2020	-	53 (35.1%)	
Accessed super due to health impacts	-	27 (50.9%)	
Lost job due to COVID	-	12 (22.6%)	
Other reason	-	13 (24.5%)	
Income month prior to Super	n=57	n=150	n=207
Paid employment (including sick leave)	24 (42.1%)	90 (60%)	114 (50.4%)
Workers' compensation	3 (5.3%)	8 (5.3%)	11 (4.9%)
Motor Vehicle Accident Insurance compensation	1 (1.8%)	0 (0%)	1 (0.4%)
Life insurance (total)	9 (15.8%)	5 (3.3%)	14 (6.2%)
Social security (Centrelink)	20 (35%)	96 (64%)	116 (51.3%)
DVA	0 (0%)	4 (2.7%)	4 (1.8%)
Other	0 (0%)	13 (8.7%)	13 (5.7%)
Reason withdrew Super	n=54	n=98	n=152
I was unable to work because of my health	23 (42.6%)	0 (0%)	23 (15.1%)
I left paid employment	3 (5.6%)	14 (14.3%)	17 (11.2%)
I had reached the time limit of benefits	7 (13%)	1 (1.0%)	8 (5.3%)
No longer eligible for previous form of income	1 (1.9%)	4 (4.1%)	5 (3.3%)
I became eligible to access my Super	5 (9.3%)	16 (16.3%)	21 (13.8%)
My other income sources were used up	6 (11.1%)	12 (12.2%)	18 (11.8%)
My family situation changed	1 (1.9%)	5 (5.1%)	6 (3.9%)
I chose to make the move	1 (1.9%)	12 (12.2%)	13 (8.6%)
Financial hardship	N/A	7 (7.1%)	7 (4.6%)
Other	7 (13%)	27 (27.6%)	34 (22.4%)
Time to receive super (months)		Mean 4.5 Range 0-84	

TABLE A1.14: WORKERS COMPENSATION INCOME SUPPORT TABLE

	Survey 1	Survey 2	Combined
	n=260	n=530	n=790
Accessed Workers' Compensation at any time	70 (26.9%)	98 (18.5%)	168 (21.3%)
Workers' Compensation jurisdiction	n=56	n=90	n=146
ACT	0 (0%)	1 (1.1%)	1 (0.7%)
NSW	32 (57.7%)	18 (20%)	50 (34.2%)
QLD	0 (0%)	19 (21.1%)	19 (13%)
SA	8 (14.3%)	7 (7.8%)	15 (10.3%)
TASMANIA	0 (0%)	2 (2.2%)	2 (1.4%)
VIC	12 (21.4%)	28 (31.1%)	40 (27.4%)
WA	4 (7.1%)	12 (13.3%)	16 (11%)
Comcare (national)	N/A	3 (3.3%)	3 (2.1%)
Income month prior to Workers' Compensation	n=56	n=90	n=146
Paid employment (including sick leave)	50 (89.2%)	87 (96.9%)	137 (93.8%)
Motor Vehicle Accident Insurance compensation	1 (1.8%)	0 (0%)	1 (0.7%)
Life insurance (total)	3 (5.4%)	1 (1.1%)	4 (2.7%)
Super withdrawals	0 (0%)	2 (2.2%)	2 (1.4%)
Social security (Centrelink)	2 (3.6%)	8 (8.9%)	10 (6.8%)
Other	0 (0%)	2 (2.2%)	2 (1.4%)
Reason applied to Workers' Compensation	n=56	n=90	n=146
No longer eligible for previous form of income	1 (1.8%)	2 (2.2%)	3 (2.1%)
I became eligible for Workers' Compensation	3 (5.4%)	37 (41.1%)	40 (27.4%)
I left paid employment/ ran out of leave	2 (3.6%)	2 (2.2%)	4 (2.7%)
I was unable to work because of my health	47 (83.9%)	40 (44.4%)	87 (59.6%)
Other	3 (1.2%)	9 (10%)	12 (8.2%)

TABLE A1.15: LIFE INSURANCE INCOME SUPPORT TABLE

	Survey 1	Survey 2	Combined
	n=260	n=447	n=707
Accessed life insurance at any time	98 (37.7%)	46 (8.7%)	144 (18.2%)
Type of life insurance	n=98	n=45	n=143
TPD	29 (11.4%)	21 (46.7%)	50 (35.0%)
Income protection	85 (33.5%)	10 (22.2%)	95 (66.4%)
Life insurance as part of superannuation	-	10 (22.2%)	10 (7.0%)
Other	0	8 (17.8%)	8 (5.6%)
Type of income from life insurance through super		n=10	
Ongoing or regular payments	-	4 (40%)	
One off payment or lump sum	-	5 (50%)	
Other	-	1 (10%)	
Reason applied to life insurance through super			
Left paid employment	-	2 (20%)	
Reached time limit of benefits	-	1 (10%)	
Became eligible	-	3 (30%)	
Other income sources used up	-	2 (20%)	
Other	-	2 (20%)	
Time to receive payment (months)		Mean 5.8 Range 0-21	
Income month prior to life insurance through super			
Paid employment	-	5 (50%)	
Sick leave/annual leave	-	5 (50%)	
DVA	-	1 (10%)	
Centrelink	-	1 (10%)	
Family member	-	1 (10%)	

TABLE A1.16: INCOME PROTECTION INCOME SUPPORT TABLE

	Survey 1	Survey 2	Combined
	n=77	n=10	n=87
Income month prior to IP			
Paid employment (including sick/annual leave)	58 (75.3%)	8 (80%)	66 (75.9%)
Workers' compensation	10 (13%)	0 (0%)	10 (11.5%)
Superannuation withdrawals	2 (2.6%)	0 (0%)	2 (2.3%)
Social security (Centrelink)	7 (9.1%)	1 (10%)	8 (9.2%)
No payment	N/A	1 (10%)	1 (1.1%)
Reason applied to IP	n=75	n=10	n=85
Reached the time limit of benefits	6 (8%)	0 (0%)	6 (7.1%)
No longer eligible for previous form of income	2 (2.7%)	0 (0%)	2 (2.4%)
Became eligible for Income protection benefits	8 (10.7%)	6 (60%)	14 (16.5%)
My other income sources were used up	4 (5.3%)	1 (10%)	5 (5.9%)
I was unable to work because of my health	54 (72%)	0 (0%)	54 (63.5%)
Other	1 (1.3%)	3 (30%)	4 (4.7%)
Time to receive payment (months)		Mean 8.5 Range 0-36	

TABLE A1.17: TPD INCOME SUPPORT TABLE

	Survey 1	Survey 2	Combined
Income month prior to TPD	n=25	n=22	n=47
Paid employment (including sick/annual leave)	9 (36%)	10 (45.5%)	19 (40.4%)
No income	0 (0%)	2 (9.1%)	2 (4.3%)
Workers' compensation	3 (12%)	2 (9.1%)	5 (10.6%)
Life insurance policy	5 (20%)	2 (9.1%)	7 (14.9%)
Superannuation withdrawals	2 (8%)	0 (0%)	2 (4.3%)
Social security (Centrelink)	6 (24%)	5 (22.7%)	11 (23.4%)
DVA	0 (0%)	1 (4.8%)	1 (2.2%)
Reason applied to TPD	n=25	n=21	n=46
Reached the time limit of benefits	1 (4%)	0 (0%)	1 (2.2%)
No longer eligible for previous form of income	2 (8%)	1 (4.8%)	3 (6.5%)
Became eligible TPD insurance	4 (16%)	13 (61.9%)	17 (37%)
I was unable to work because of my health	18 (72%)	N/A	18 (39.1%)
My other income sources were used up	N/A	1 (4.8%)	1 (2.2%)
I left paid employment	N/A	3 (14.3%)	3 (6.5%)
Other	N/A	3 (14.3%)	3 (6.5%)
Time to receive payment (months)		Mean 11.2 Range 0-60	

TABLE A1.18: MVA INCOME SUPPORT TABLE

	Survey 1	Survey 2	Combined
	n=260	n=530	n=707
Accessed MVA income support at any time	13 (5.0%)	34 (6.4%)	47 (5.9%)
MVA Jurisdiction	n=13	n=32	n=45
ACT (MAII)	0 (0%)	2 (6.3%)	2 (4.4%)
NSW (Green Slip)	3 (23.1%)	3 (9.4%)	6 (13.3%)
QLD (MAIC)	2 (15.4%)	7 (21.9%)	9 (20%)
SA	2 (15.4%)	5 (15.6%)	7 (15.6%)
Tasmania (MAIB)	0 (0%)	4 (12.5%)	4 (8.9%)
VIC (TAC)	4 (30.8%)	8 (25%)	12 (26.7%)
WA (ICWA)	2 (15.4%)	3 (9.4%)	5 (11.1%)
Type of compensation received			
Lump sum	6 (46.2%)	-	
Statutory benefit	2 (15.4%)	-	
At-fault driver's CTP	3 (23.1%)	-	
Don't know/can't remember	2 (15.4%)	-	
Income month prior to MVA			
Paid employment (including sick/annual leave)	8 (61.5%)	21 (65.7%)	29 (64.4%)
DVA	1 (7.7%)	0 (0%)	1 (2.2%)
Social security (Centrelink)	3 (23.1%)	11 (34.4%)	14 (31.1%)
Workers' compensation	0 (0%)	3 (9.4%)	3 (6.7%)
Life insurance policy	0 (0%)	2 (6.3%)	2 (4.4%)
Other	0 (0%)	3 (9.4%)	3 (6.7%)
Reason applied to MVA	n=13	n=32	n=45
Reached the time limit of benefits	1 (7.7%)	0 (0%)	1 (2.2%)
Became eligible for MVA Insurance benefits	5 (38.5%)	0 (0%)	5 (11.1%)
I was unable to work because of my health	6 (46.2%)	21 (65.5%)	27 (60.0%)
No longer eligible for my previous income	0 (0%)	1 (3.1%)	1 (2.2%)
MVA was more than receiving elsewhere	0 (0%)	1 (3.1%)	1 (2.2%)
Other	1 (7.7%)	9 (28.1%)	10 (22.2%)

TABLE A1.19: SICK LEAVE INFORMATION TABLE

	Survey 1 n = 84	Survey 2 n=460	Combined n=544
Amount of sick leave provided by employer			
None	-	153 (33.3%)	153 (28.12%)
1 week or less	10 (11.9%)	46 (10%)	56 (10.3%)
Between 1 and 2 weeks	22 (26.2%)	127 (27.6%)	149 (27.4%)
More than 2 weeks	38 (45.2%)	60 (13%)	98 (18%)
Don't know/can't remember	14 (16.7%)	74 (16.1%)	88 (16.2%)
Ran out of sick leave	63 (75%)	190 (41.1%)	253 (46.6%)
Length of sickness when ran out of sick leave	n=63		
Up to 1 week	3 (4.8%)	-	
Up to 2 weeks	9 (14.3%)	-	
Up to 3 weeks	1 (1.6%)	-	
Up to 4 weeks	3 (4.8%)	-	
More than 1 month	47 (74.6%)	-	
After running out of sick leave	n=63	n=190	n=253
Went back to work	4 (6.3%)	30 (15.8%)	34 (13.4%)
Used annual leave	18 (28.6%)	48 (25.3%)	66 (26.1%)
Lost my job	10 (15.9%)	18 (9.5%)	28 (11.5%)
Used leave without pay	21 (33.3%)	70 (36.8%)	91 (36%)
Applied for workers compensation	-	3 (1.6%)	N/A
Something else	10 (15.9%)	21 (11.1%)	31 (12.3%)

TABLE A1.20: LUMP SUM PAYMENT INFORMATION

	Survey 1 n=260	Survey 2 n=458	Combined n=718
Lump sum received at any time	71 (27.3%)	84 (18.3%)	154 (21.6%)
System providing lump sum	n=71	n=84	n=154
Workers compensation	28 (40%)	50 (60.2%)	78 (51%)
MVA	19 (27.1%)	18 (21.7%)	37 (24%)
Life insurance (e.g. Income protection & TPD)	28 (40%)	15 (18.1%)	43 (28%)
Payout from superannuation policy	23 (32.9%)	4 (4.8%)	27 (17.5%)
DVA	0 (0%)	1 (0.2%)	1 (0.6%)
Other	4 (5.6%)	7 (8.5%)	11 (7.1%)
Victims of crime compensation	2 (2.8%)	2 (2.4%)	4 (2.6%)
Trauma insurance	-	1 (1.2%)	1 (0.6%)
Time to receive lump sum payment (months)			
Workers compensation	-	Mean 17.3 Range 2-240	
MVA	-	Mean 22.8 Range 0-84	
Life insurance (e.g. Income protection & TPD)	-	Mean 9.1 Range 1-36	
Payout from superannuation policy	-	Mean 7.7 Range 6-9	
Victims of crime compensation	-	Mean 3.5 Range 2-5	

TABLE A1.21 CURRENT INCOME BY SYSTEM

	Centrelink	Workers' Comp	MVA	Life Insurance	Early Super withdrawals	DVA	Paid work (current job)	Other
Current income source (n=454)	427 (94.1%)	15 (3.2%)	3 (0.6%)	2 (0.4%)	20 (4.3%)	4 (0.9%)	216 (46.6%)	13 (2.8%)
Duration of current income source								
One off	0	0	0	1 (50.0%)	6 (30.0%)	0	0	0
Less than 1 year	44 (10.5%)	11 (73.3%)	1 (33.3%)	0	2 (10%)	1 (25%)	53 (25.9%)	7 (24.1%)
Between 1 and 2 years	66 (15.7%)	4 (26.7%)	2 (66.7%)	1 (50.0%)	6 (30.0%)	0	42 (20.5%)	6 (20.7%)
Between 3 and 4 years	49 (11.6%)	0	0	0	1 (5.0%)	1 (25.0%)	33 (16.1%)	3 (10.3%)
More than 5 years	248 (58.9%)	0	0	0	4 (20.0%)	2 (50.0%)	73 (35.6%)	10 (34.5%)
Don't know/can't remember	14 (3.3%)	0	0	0	1 (5.0%)	0	4 (2.0%)	2 (6.9%)

TABLE A1.22 LEVEL OF AGREEMENT WITH SURVEY STATEMENTS

Level of agreement (n=260)	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A
I have enough income to pay my essential living costs	22 (8.5%)	66 (25.4%)	32 (12.3%)	66 (25.4%)	72 (27.7%)	2 (0.8%)
I can get the healthcare that I need	24 (9.2%)	76 (29.2%)	44 (16.9%)	63 (24.2%)	50 (19.2%)	3 (1.2%)
I have a safe place to live	76 (29.2%)	130 (50.0%)	29 (11.2%)	15 (5.8%)	8 (3.1%)	2 (0.8%)
My family relationships are strong	62 (23.8%)	84 (32.3%)	50 (19.2%)	42 (16.2%)	16 (6.2%)	6 (2.3%)
I am capable of paid work	11 (4.2%)	40 (15.2%)	32 (12.3%)	54 (20.8%)	116 (44.6%)	7 (2.7%)
I will get/keep a job in the future	21 (8.1%)	43 (16.5%)	56 (21.5%)	41 (15.8%)	84 (32.3%)	15 (5.8%)
I make a valuable contribution to society	40 (15.4%)	70 (26.9%)	76 (29.2%)	37 (14.2%)	27 (10.4%)	10 (3.8%)

TABLE A1.23 CURRENT CIRCUMSTANCES

	Survey 1
Health today	n=260
Excellent	2 (0.8%)
Very Good	16 (6.2%)
Good	28 (10.8%)
Fair	85 (32.7%)
Poor	124 (47.7%)
Prefer not to say	5 (1.9%)
Covering costs of healthcare	
Public health system	185 (71.2%)
NDIS	17 (6.5%)
Private Health insurance	93 (35.8%)
Out of own pocket	129 (49.6%)
Other	40 (15.4%)
When paying out of own pocket how much do you typically pay (n=129)	
Full amount	17 (13.2%)
Reduced amount (e.g. gap fee)	25 (19.4%)
Both (depending on the health care service)	87 (67.4%)
Chosen not to seek medical care because couldn't afford it	
	182 (70.0%)
Current take home income*	Mean \$1441.39
Per week	Mean \$827 Median \$500 Range \$2,250
Per fortnight	Mean \$1,019 Median \$800 Range \$3,500
Per month	Mean \$3,886 Median \$4,500 Range \$4,788
Per year	Mean \$50,836 Median \$50,000 Range \$150,000

* Respondents could select to answer in weekly, fortnightly, monthly or yearly category.

APPENDIX 2 – INTERVIEW ANALYSIS

TABLE A2.1: SUMMARY OF THEMES IDENTIFIED FROM THE INTERVIEWS

Main theme 1 - Transition or progression between systems			
Themes	Definition	Subthemes	Example of quotes
Challenges	Challenges faced for specific income support systems (whilst progression through or transitioning between different income support systems) and broad challenges of people's journeys through systems encountered	<p>Employer</p> <ul style="list-style-type: none"> • Lack of employer support initially • Difficulties fulfilling work requirements • Physical and psychological burden • Difficulties being able to attend medical appointments • Difficulties coming to terms with the decisions • Reluctantly finishing paid employment • Unable to continue in their position due to employer ultimatums <p>Centrelink</p> <ul style="list-style-type: none"> • Uncertainty about how to commence • Lack of guidance • Paperwork and language • Misplacement/"lost" forms • lack of communication • Having to attend in-person <p>Life Insurance</p> <ul style="list-style-type: none"> • Coming to terms with situation • Paperwork • Lack of communication <p>Workers compensation</p> <ul style="list-style-type: none"> • Lack of employer support • Lack of insurer support • Paperwork <p>DVA</p>	<p>"I was taking unpaid time off work to go to medical appointments, but there was still the expectation that I would make up the hours"</p> <p>"So, I was really struggling in the new role and eventually they said look this isn't working, we're going to have to let you go"</p> <p>"that was kind of basically what I did until I couldn't anymore.... it got to a point where I just couldn't do it anymore and just had to quit"</p> <p>"was reluctant to finish working 'cause I did enjoy what I did"</p> <p>"when you first start it you don't know...all of the steps that they want you to go through.....they don't tell you any of this stuff"</p> <p>"when we were applying, it was bouncing around Centrelink, all over the place, trying to find someone that could give us.....the right form because it's not obvious on – anywhere, um, what the form is"</p> <p>"Centrelink is not actually to help you. You go in there with a question and they will send you to a computer bank along a wall...Nobody will talk you through the system"</p> <p>"it's an overwhelming amount of paperwork, even for someone who's healthy.... the idea that you've somehow got to navigate it when you're not healthy, like this is impossible"</p> <p>"their exact wording was, I can't coach you on what to say on your application. I said, I'm not asking you to coach me, I'm just asking you to tell me what information you require"</p>

		<ul style="list-style-type: none"> • Lack of communication • Confusion over payments during transition process <p>Other</p> <ul style="list-style-type: none"> • Unaware of what was available or entitlements • Implications for other areas of life 	<p>"I had to do that all by myself, and they were actually quite angry about me making a claim....Got mocked, I actually got mocked at the staff meet- at a staff meeting in front of other staff members about it"</p> <p>"I actually stumbled across my income protection that was attached to my super"</p>
Impacts	Impacts of progression through income support systems (Health, economic and social impacts)	<ul style="list-style-type: none"> • Difficulties obtaining a diagnosis • Limited/no employer entitlements • RTW to assist with financial burdens • Financial implications • Support networks (formal & informal) 	"I might have had a much better health outcome, but the reason ... wasn't lack of information, it was lack of money...I was on Newstart....I would say most of the problems that have led to inadequate health outcomes for me or suboptimal outcomes for me have been to do with not having the money to see doctors, rather than not having the information"
Changes	Changes due to challenges of progressing through income support systems	<ul style="list-style-type: none"> • Changes to health care • Changes to income • Changes to immediate family relationships 	"we weren't really at that stage in our relationship for him to take on that financial responsibility for me. Um, very difficult thing to broach um with somebody that, you know, you're in a kind of new relationship with [laughs], all of a sudden, the government deems that, you know, you're responsible for me"
Influences	Influences of progression through systems on health and work outcomes	<ul style="list-style-type: none"> • Factors and characteristics that influence health and work outcomes • Implications from delays in applications • Desire to keep working 	"If I had have applied for the pension when I first got diagnosed, it would have been fine. But I wanted to keep working, but apparently cos they've tightened up the criteria for everything um it made it harder. I wanted to keep working. I wanted to prove that I could keep working until I couldn't"
Perspectives of others	Reflections on how other people would experience the same systems.	Concern for others who may be less equipped to deal with the challenges.	"how does a person...that...hasn't graduated high school coping with that stuff? Or English as a second language or you've just got so many medical things that, you know, your brain's not functioning or your body's not functioning or you're under heavy medication?"
Decision making	Key drivers of decisions that were made along the way	<p>Consequences:</p> <ul style="list-style-type: none"> • Illness • Disability • Injury • Treatments • Paperwork • Application process • Temporary thinking (this is a temporary situation) 	<p>[Newstart to DSP] "that's what pushed me to go towards the disability pension and my friend said the exact same thing It was just the sheer amount of boxes you had to tick to get your payments"</p> <p>"For the amount of paperwork they wanted... all too difficult, basically... I think that's pretty much how it's designed...instead of spending my energy doing that and chasing that process it was much better for me to just focus on trying to get better and get back to full-time work"</p>
Positive supports	Support networks that had a positive impact	<ul style="list-style-type: none"> • Formal supports <ul style="list-style-type: none"> ○ Centrelink ○ Employer ○ Charities/advocates ○ Local minister of parliament ○ Legal representation 	<p>"Went through a disability advocate, that's when they actually got their claim approved"</p> <p>"Cancer Council, they provide a, financial advice service free of charge for cancer sufferers...they advocated...did absolutely everything for me. They were amazing. I'm not sure that I would have been able to achieve that myself."</p>

		<ul style="list-style-type: none"> ○ GP/mental health services ○ Disability programs/life coaching • Informal supports <ul style="list-style-type: none"> ○ Family/friends/work colleagues ○ Social media groups/publications 	<p>"I never thought, in a million years....I'd ever join a Facebook support group, but they're really good".</p>
Covid impacts	Implications of Covid-19 on health and employment	<ul style="list-style-type: none"> • Financial (lack of work) • Health (limits accessing medical teams) • Feeling forgotten 	<p>"from a disability standpoint we've been completely forgotten about really during the, during the COVID pandemic.... like literally the most vulnerable during a pandemic has just gone, yeah hey, guys? What about what's over here? So, yeah, the disability, like, community has literally just been forgotten about during this whole thing"</p>
Interactions with NDIS	Descriptions of interactions with NDIS.	<ul style="list-style-type: none"> • Complex application / confusing <ul style="list-style-type: none"> ○ Gave up • Not approved diagnosis (therefore no support) • Added pressure for family to assist • Unfavourable inactions (rude) • Goal-based system very "demeaning" • Not appropriate for progressive illnesses 	<p>"NDIS would make a huge difference if we could have somebody come and clean the house because it also puts an immense pressure on my partner, he needs to do everything"</p> <p>"I found it even more complex than Centrelink. I didn't get past the point of the access request I think I tried, two or three different applications just wording it differently and I just went, oh I'll just organise a cleaner myself...just some of the people I spoke to were so rude".</p>
Future plans	Descriptions of what the future holds or plans for the future.	<ul style="list-style-type: none"> • Difficulty planning • Uncertainty about the future <ul style="list-style-type: none"> ○ Financially ○ Health • Desire to return to work (if feasible) 	<p>"all I'm doing right now is just killing time until I die to be perfectly honest"</p> <p>it's like a Russian roulette of symptoms with my disease..... looking forward to the future....it kind of makes me a bit depressed so I try and just take one day at a time and live with the symptoms that I've got..... it's hard to make plans</p>
Main theme 2 - Experiences within systems			
Themes	Definition	Subthemes	Quotes
Negative experiences	Negative experiences with the different income support systems encountered	<p>Centrelink</p> <ul style="list-style-type: none"> • Community care service provider • Job providers <ul style="list-style-type: none"> ○ Lack of empathy ○ Difficult to converse with ○ Lack of understanding/Inflexible ○ Sceptical/ disbelieving ○ Lack of training <p>DVA</p>	<p>"uncontrolled hand movement and hand tremor is literally what's stopping them from being able to do paperwork"</p> <p>"I remember being in the Centrelink office... with a wheelie walker crying and – someone at the Centrelink office actually told me something along the lines of...I was a faker"</p> <p>"job providers, I felt so unequal.... there was a lack of equity. Very pushy... sort of very focused on getting you into a job and getting their bonus.... they're working</p>

		<ul style="list-style-type: none"> • Outdated procedures Employer <ul style="list-style-type: none"> • Unsupportive Life insurance <ul style="list-style-type: none"> • Lack of communication Medical practitioner <ul style="list-style-type: none"> • Disbelieving/unsupportive NDIS <ul style="list-style-type: none"> • Paperwork/tick boxes • Goal-based system/ demeaning • Difficult process/condescending Workers Compensation <ul style="list-style-type: none"> • IME interactions • Financial-Gap fee for specialist • No effort to make a connection Consequences of negative experiences <ul style="list-style-type: none"> • Financial implications • Family taking on carer roles 	<p>for themselves to get their own bonus I can honestly say the experience I had with the job provider was nothing but negative"</p> <p>"There is a saying amongst all of the ex-military people that DVA is deny then delay until death because as soon as someone dies, DVAs claims are all stopped. They just delay and delay as long as possible all claims"</p> <p>"DVA, they wrote a procedure back 15 - 20 years ago, they don't update it, medical knowledge changes, but if it falls outside an SOP, then they deny it".</p> <p>"dealing with the insurance company was the most stressful part of the whole cancer experience"</p> <p>"I have called the NDIS ... and I was told point blank no it's not an approved diagnosis.... if there's no box to tick and if I ring them and they say, it's not on my list, how can I apply for it?</p> <p>"I had a doctor at a chronic pain clinic kind of scoff at me and go oh you're not really disabled compared to my patients who are amputees, they're the ones who are really disabled"</p>
Positive experiences	Positive experiences with the different income support systems encountered.	<ul style="list-style-type: none"> • Centrelink <ul style="list-style-type: none"> ○ Job search provider ○ Mental counselling • NDIS <ul style="list-style-type: none"> ○ "Me Well" representative ○ Funding for core supports • DVA <ul style="list-style-type: none"> ○ SOP's ○ Advocate • Employer • Life insurance • Superannuation <ul style="list-style-type: none"> ○ Withdrawals (post 2020) ○ Insurance through Superannuation • Workers Compensation claim 	<p>"TPD – they, they were happy to accept everything no questions asked"</p> <p>"to get my income protection that didn't take actually long at all"</p> <p>"my employer has stood by me....it's a small business...said you work as little as you want as much as you want. If you can't work at all, that's okay"</p> <p>"One of my workplaces was supportive. The only reason I had to leave that one was because I didn't make enough money.</p> <p>"I put a claim into WorkCover, and that was accepted immediately"</p>

		Consequences of positive experiences <ul style="list-style-type: none"> Financial implications Sense of support/security/improved mental health 	“my TPD paid out and I built a house, so I don’t have to pay rent” “it made a massive difference to have 70 per cent of my income...it meant that we didn’t have the same hit on our lifestyle that we would’ve otherwise”
Feeling or emotions (expressed by interviewees)			
	Definition	Subthemes	Quotes
Feelings or Emotions	Emotional responses to transitioning within and between systems of support throughout their journey	<ul style="list-style-type: none"> Ableism Degrading Distress Fear Frustration Overwhelming Reluctancy Stigmatised strain Stress Struggling Stunned Terrifying Traumatic Worry or frightened 	“it just adds that level of stress that you really don’t need at what’s a super stressful time” “I think the most challenging aspect was the fear that they were going to deny me the DSP” “when I got on the disability pension I didn't have to go to the job provider....Like I felt like I've been left alone...it was my very first thought.... and I started crying 'cause I thought, thank god....it was great to have that more money 'cause now I can see my specialists and I've got more money for medication... I wasn't able to get all those extra medications when I was on Newstart so it's not just the money but it's the money to provide for your medical needs.”
Analogies (made by interviewees)			
	Definition	Subthemes	Quotes
Analogy	<p>Descriptions respondents used to describe their journeys whilst interacting with the systems and transition or progression between systems</p> <p>Respondents used analogies to describe many aspects of their journeys, from the application processes, completing the paperwork, navigating the systems etc.</p>	<ul style="list-style-type: none"> Barriers Bouncing around Curtain closes Disbelief Fit the same box Hoops Kept in the dark Like pulling teeth Maze Minefield Mountain Nightmare 	“it’s like a maze and then it’s snakes and ladders and it’s like the rules change halfway through, you think you’re kind of doing it and then it’s like, aha, but you didn’t do that, though, did you? No, sorry, begin again, and the clock starts again” “just like bounced between Youth Allowance and Newstart” “like some kind of dolphin; jump through all these hoops” “in a world of jumping through burning hoops, expected to apply for any job not just a part-time job, but any job” “It was a bit of a nightmare” “applying for the disability support pension was an absolute nightmare....I was in tears, it was so hard, it was incredibly hard”

		<ul style="list-style-type: none"> • Pick my battles • Spanner in the works • Stick their head in the sand • Trapped 	
Recommendations (made by interviewees)			
	Definition	Subthemes	Quote
Suggestions (Advice)	Suggestions for how to improve the experience of others.	<ul style="list-style-type: none"> • Things that could be done better (Suggestions of ways of improving people's experiences as they navigate different income support systemss) • Lessons learnt (Information or experience gained that could be/was beneficial in assisting with income support systems) 	<p>"I think that there's a lot of false economy at a lot of stages in the process. So, um making it harder for people to access worker's compensation or the DSP makes it harder for people to get medical treatment which might let them go back to the workforce or stay in the workforce"</p> <p>(income protection) "so it was a lifesaver and it was purely by chance and I tell everybody that I know to make sure if you don't have it, start putting – like, attach it to your super plan because it was it was an absolute lifesaver"</p>