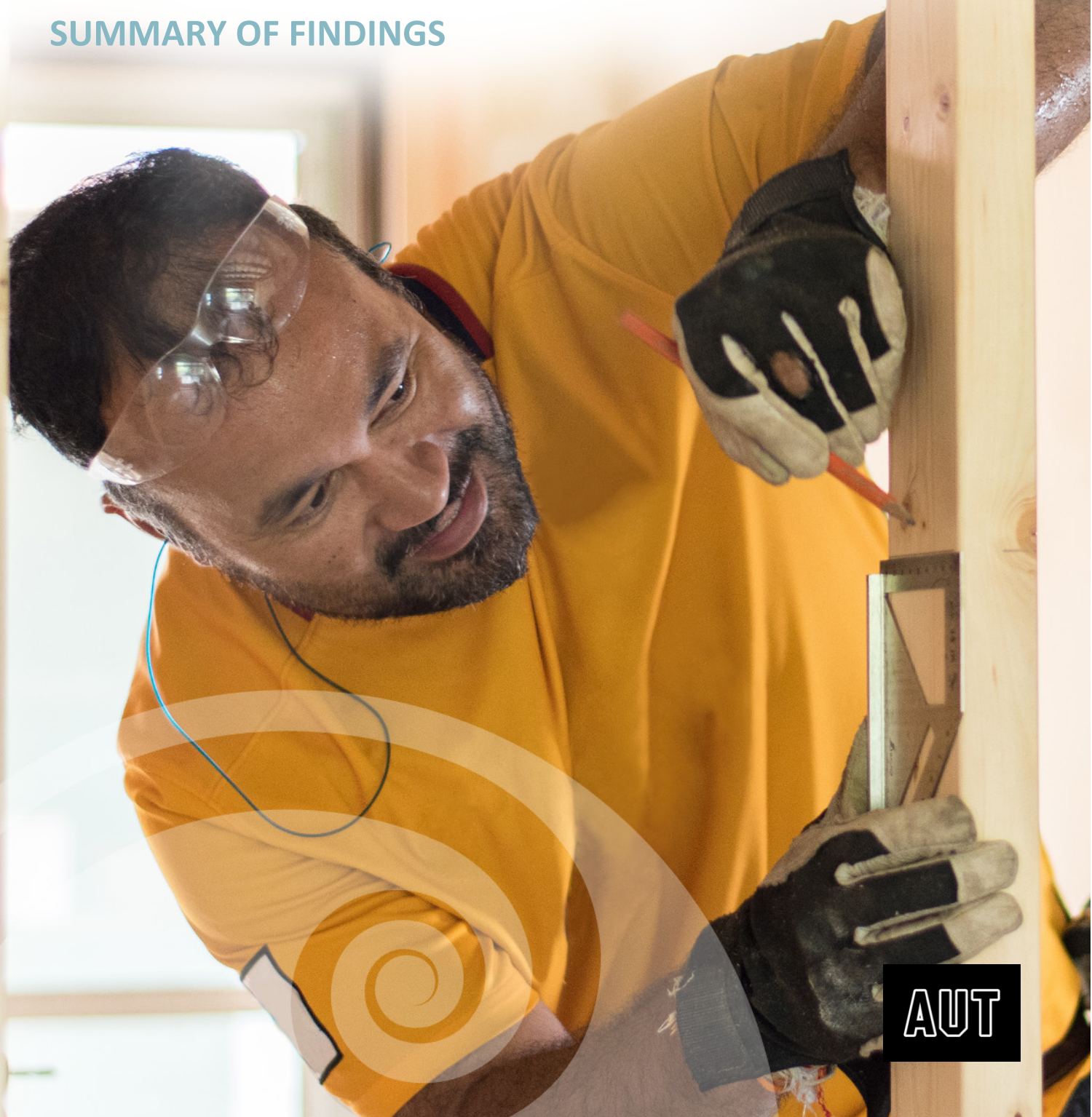




**AUT CENTRE FOR
PERSON CENTRED RESEARCH**

Support for gaining paid work for
people living with a long-term
condition: Systematic literature review

SUMMARY OF FINDINGS



AUT



Research led by AUT's Centre for Person Centred Research. Funded by New Zealand Ministry of Social Development & Health Research Council partnership grant number 18/804

Key implications from this report

- People living with long-term conditions find gaining work and sustaining that work difficult due to attitudes, discrimination and unmet need for non-standard or flexible work arrangements. Because of these difficulties, networking and relationship-based job searches are reported to be a more successful strategy for finding work than relying on advertisements or job centres.
- Strategies focused on developing positive work (and employment) experiences of people living with long-term conditions are crucial. Experiences (positive and negative) can shape and shift expectations for employers, people living with long-term conditions, families and health practitioners about what is appropriate and possible.
- The Individual Placement and Support approach is the intervention with the strongest evidence for effectiveness for people with a mental health diagnosis. This is a well-described, principle-based approach, and it aligns with findings from qualitative research with people living with various long-term conditions. The principles focus on integration of employment specialists with treatment teams, personalised job search including networking approaches, financial advice and work incentives planning and ongoing support once working, as appropriate to each situation.
- As it is implemented, the Individual Placement and Support approach should be further developed within the Aotearoa New Zealand context, in particular incorporating and building from Māori values and perspectives.
- Research to trial the application of Individual Placement and Support principles or similar approaches for people living with other long-term conditions (beyond mental health conditions) is justified given overall findings and stakeholder feedback.
- Innovation is needed to develop Indigenous-led approaches to support gaining and maintaining paid work in the context of living with long-term conditions.



Project team

The team for this project combined expertise and experience across many domains. The principal investigator (Fadyl) is PhD qualified in vocational rehabilitation and an experienced researcher in rehabilitation and disability. She has published across a range of international peer-reviewed journals on the topic of vocational rehabilitation and teaches vocational rehabilitation at postgraduate level. The author group are comprised of senior researchers with both methodological and topic expertise. The project collaborators are leaders their respective service areas, and the stakeholder reference groups were grounded in everyday practice and experience.

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Summary overview of project and findings

For detailed findings with references, please see the full report submitted to the Health Research Council and Ministry of Social Development, April 2020.

Background to the project

In many societies including Aotearoa New Zealand, paid work is the main form of income for a vast majority of people. It is associated with health benefits derived from the social acceptance and sense of contribution that work offers, and is uniquely valued as a form of occupation. However, work can become increasingly difficult to obtain and maintain when people have disruptions affecting work-ability if they do not get the right support at the right time. **People living with health conditions and/or experiencing disability often have difficulty accessing paid work** due to a number of complex factors. Across the developed world, research has investigated what issues people face and what is effective to support people who live with long-term conditions to gain and maintain paid work. This project was a **series of systematic literature reviews** to gain an overview of the high-quality research that has been conducted in this area. The findings can inform policy and service development in Aotearoa New Zealand, as well as further research.

Systematic review design

A systematic review is designed to provide a comprehensive summary of current evidence on a specific question. This involves an extensive and methodical search of literature, and an evaluation of the quality of each included study. Conclusions are based on combined research findings, including an assessment of the strength of the evidence given the available research.

In this project, we investigated the following research questions:

1. What do robust intervention studies show is effective in helping people who are currently unemployed and experiencing long-term conditions and/or disability gain paid work and sustain new paid work? (see [definition](#) of long-term condition below)
2. What do in-depth qualitative studies suggest may be important for implementation of employment support services for these populations?

The design of the project employed **six rigorous systematic reviews** conducted over 18 months that together create a broad picture of the research on this topic. Furthermore, at three key stages in the process, we consulted with four **stakeholder reference groups** who assisted the research team on our approach to searching literature, relevance and applicability of findings to the local context, and key research gaps. The particular stakeholder reference groups were selected to span diverse experiences across different types of long-term conditions, and were made up of people with lived experience of long-term conditions and people involved in services and advocacy. We had one **Māori stakeholder reference group** and three **condition-specific stakeholder reference groups** (mental health, amputation and progressive neurological conditions). Each stakeholder reference group provided feedback on the overall project and the specific reviews with most relevance to their expertise and experience. The figure below shows the overall design of the project. While reviews 2-4 were originally conceptualised as 'updates' from the most recent existing systematic review, there were no systematic reviews specific to the populations that we focused on, so these reviews covered the last 15 years of published research.

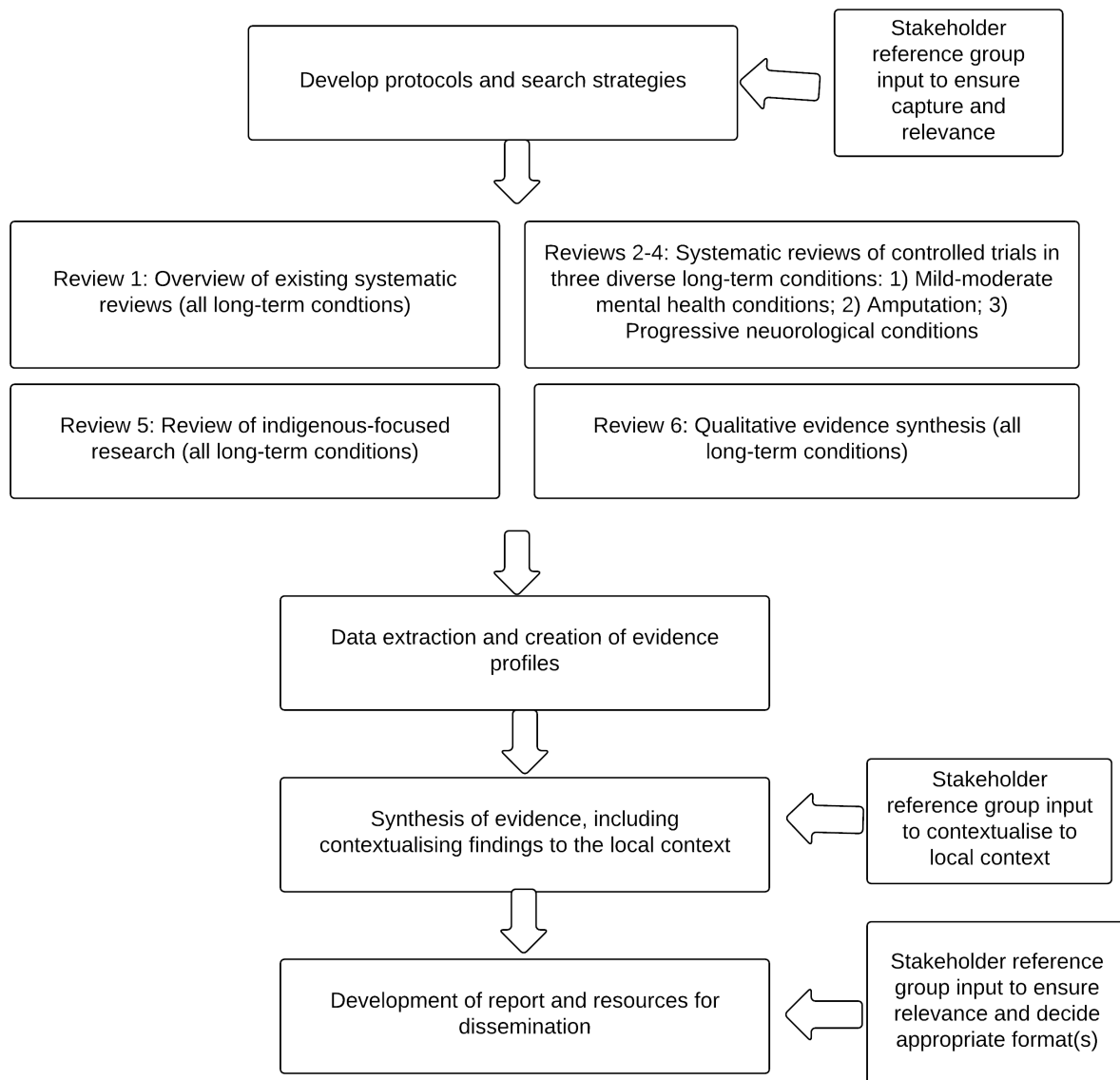


Figure 1: Design of the project

Findings: Overview of systematic reviews across long-term conditions

Our overview of systematic reviews assessed findings from all previously published systematic reviews which have examined the effectiveness of interventions to support people experiencing any long-term condition and/or disability gain paid work. We found 20 existing systematic reviews that fitted the scope set out in our protocol. Of these, 10 were focused on severe/serious mental illness. The systematic review which was the highest quality of these 10 reviews was also the most recent (Suijkerbuijk et al, Cochrane Database, published in 2017). In this review, a large number of studies were considered, allowing comparisons to be made across different intervention types. The review authors concluded that the **strongest clinical trial evidence** was in favour of **Individual Placement and Support (IPS)** as an approach to help people living with a diagnosis of severe mental illness gain and maintain employment. This conclusion was based on international evidence drawn from studies in many different settings. Our mental health stakeholder reference group included people who are **already practicing IPS in Aotearoa New Zealand**, and feedback from them was that it is feasible to implement IPS successfully, as it is a well described intervention with clear guidelines for implementation that can be tailored to local contexts. The Māori stakeholder reference group were



positive about the IPS approach. To ensure resonance for Māori they advised a shift in language away from 'individual' towards **'personalised' and increased involvement of whānau**.

The other long-term conditions that were the focus of existing systematic reviews were **acquired brain injury, multiple sclerosis, autistic spectrum disorder and spinal cord injury**. These had much less conclusive findings. In general, while there are **many interventions being used in practice for people with these conditions, few of these strategies have been tested in robust intervention studies**. There were few trials found, and those that were identified provided only very low quality evidence for effectiveness of the vocational interventions tested because of problems with study design and/or an insufficient number of participants to detect group differences (making it difficult to say if an intervention is effective or not). Authors of these reviews also noted poor reporting in regard to the interventions themselves – with a **lack of detail of what was involved and how to implement**. The best conclusions we can draw about what works in these populations currently are based on observational studies (where available), qualitative research (see qualitative review findings) and practice expertise.

Findings: Systematic review focusing on Indigenous peoples and services

In this review we specifically searched for research that addressed Indigenous peoples' access to and engagement with employment support. **Very few intervention studies have looked at what works to increase access to paid work for Indigenous peoples living with long-term conditions**. There were two included studies – one randomised controlled trial and one qualitative study, both focused on vocational rehabilitation interventions for Navajo people. Both studies included Indigenous researchers. Both, however, were guided by a Western framework regarding provision of employment support and vocational rehabilitation. The trial found no difference in outcome between two different employment interventions delivered alongside culturally-informed treatment for people with drug dependence, but the trial processes were not well reported. The qualitative study found that **trusting relationships** with service providers and inclusion of Navajo **cultural teachings as part of these services** were important to successful outcomes for Navajo people who experience disability.

The Māori stakeholder reference group emphasised that a key issue is that both paid work and support to obtain it are predominantly **conceptualised according to Western society and values**. The group discussed the **rights of Māori to equitable outcomes** (for gaining employment when living with a long-term condition) and to **lead or participate in the development of solutions**. They also recognised the phenomenon of intersectionality, where the combination of ethnicity and 'ability' or illness can have a cumulative impact which further disadvantages Indigenous people with long-term conditions looking for paid work. To honour Te Tiriti o Waitangi and in particular tino rangatiratanga, the Māori stakeholder reference groups strongly encouraged the research team to look beyond current employment interventions. In searching the broader literature, we identified literature focusing on Indigenous livelihoods and food sovereignty as interventions to promote wellbeing. These Indigenous-led initiatives are in a development phase. However, we suggest this may be a fruitful avenue for future research, exploring **innovative, Māori-led approaches to address economic and health inequities**. These sorts of approaches provide examples of going **beyond the concept of 'employment'** when considering the need for people (including those who live with long-term conditions) to have **access to legal, safe livelihoods**.



Findings: Condition-specific systematic reviews

We undertook a search of controlled trials for work and employment support interventions in three specific conditions: amputation, mild to moderate mental health conditions and progressive neurological conditions (e.g. multiple sclerosis, Parkinson's disease). Despite a comprehensive search strategy, the studies we found all focused on mild-moderate mental health conditions. We found no controlled trials of vocational rehabilitation or employment support interventions for people living with amputation or progressive neurological conditions. Most of the clinical trial research for these groups has focused on surgical or drug treatment. The lack of focus on employment or work interventions is a major gap in intervention studies. For these two populations, the best conclusions we can draw currently about what works to support paid work is based on observational studies (where available), qualitative research (see qualitative evidence synthesis findings) and practice expertise.

For people living with **mild-moderate mental health conditions**, we found 12 studies that were within scope, including 2714 participants. These studies were conducted in the USA (5) Sweden (2), Norway (2), Netherlands (1), Denmark (1) and Canada (1). Four of the studies from the USA were focused specifically on veterans with post-traumatic stress disorder.

Seven of the 12 studies identified investigated **approaches based on Individual Placement and Support, modified for different settings** and for people with less severe diagnoses. Findings of the individual studies were mixed, but most had sample sizes that were insufficient to reliably detect group differences. In response to this limitation we conducted a meta-analysis – a statistical method for combining the results of several similar studies. The **meta-analysis** estimated that there was a significant intervention effect for Individual Placement and Support approaches in this population, **with more people who had received IPS in competitive employment at follow-up compared to control groups**. In future research, it will be important to **further explore implementation needs** regarding delivery of IPS in various other settings beyond specialist mental health treatment. However, it is perhaps unsurprising given this intervention has already shown good results for people receiving specialist mental health treatment (see Overview findings above), that it shows effectiveness when modified for people who are experiencing mild-moderate mental health issues.

Two of the 12 studies focused on **cognitive behavioural therapy** as pre-vocational training for people with mild-moderate mental health conditions. The results of these studies were mixed and **more high-quality research is needed to develop conclusions** regarding effectiveness of this type of intervention. A meta-analysis was inappropriate in this instance, as the interventions in the two studies differed in content and approach. The remaining three included studies were focused on three different interventions, were designed for very specific population groups, and were assessed as having high risk of bias.

Feedback from all the stakeholder reference groups was that mild-moderate mental health conditions are a significant issue for many people living with long-term conditions (i.e. not just people who live with a 'mental health' condition as their primary or sole condition). This is due to the experience of managing a long-term condition itself and negotiating additional societal barriers. Stakeholder reference groups were **keen to support testing of interventions that employ IPS principles (adapted as appropriate), especially for people living with conditions where stigma, discrimination and/or uncertainty around abilities are issues**. They were also keen to explore other interventions that might be less intensive but of particular relevance to people living with long-term conditions – see findings from the qualitative evidence synthesis. As noted above, **Māori involvement in developments for Aotearoa is crucial**.



Findings: Qualitative evidence synthesis

While clinical trial research can show what interventions have been tested and what has been shown to be effective, **much of the information we need about how to design interventions that work for people comes from qualitative research**, which focuses on experiences and socio-cultural context. Given the significant overlap in experiences across various long-term conditions, we conducted a thematic synthesis across all long-term conditions, combining results and noting differences for specific conditions where appropriate. These are detailed in the full report. Here we provide a summary of findings.

The first topic we synthesised was **social, cultural and biographical factors affecting opportunities for paid work for people living with a long-term condition**. Our systematic review found 27 studies that primarily addressed this topic. These originated from a wide range of countries, with the largest number (10) from Canada. Studies addressing this topic included policy analysis and data from a wider range of stakeholders (e.g. employers, case managers, service providers) in addition to people with lived experience of a long-term condition.

The second topic was **the experiences of people living with long-term conditions with regard to gaining paid work and maintaining that work once gained**. Our systematic review found 35 separate studies that primarily addressed this topic. These originated from 12 countries, and a third were from the USA.

The third topic was **the experiences of vocational rehabilitation and employment support services for people living with long-term conditions**. Our systematic review found 21 studies that primarily addressed this topic. These studies were conducted in a range of Western industrialised countries, but most from the USA and Sweden.

Across the three topics, the various issues reported in the findings were interrelated. For example many of the **wider socio-cultural issues were also evident in the experiences of individuals seeking work**. There was considerable overlap between the principles that underpin the Individual Placement and Support approach and the qualitative evidence across various long-term conditions regarding the issues people experience and what they find helpful. The **qualitative evidence synthesis can provide a more nuanced understanding** of what it is about this approach that makes it successful. Across these topics the following came through as salient issues:

Accessing work

- **Going outside of the traditional job advertisement and recruitment processes** carried huge opportunities for supporting people into work. Networking was reported as a key strategy for gaining employment. Personalising job matches and creating opportunities in collaboration with employers also played an important role. Linked to this, **perceived work-ability can be influenced by having more flexible structures**.
- Having access to **real-world skill-building opportunities** that were not perpetual work-readiness programmes were also key – such as internships, mentoring, and supported employment.
- There is a need to focus on **opportunities that are possible now**, rather than waiting for people to be ‘stable’ or assessed as ‘ready’ while at the same time **acknowledging that accommodations / adjustments may be needed**. The reality of living with a long-term condition is that it does affect what is possible for people. With the right support, the person living with the condition will be able to assess what is realistic for them.
- The person who is seeking work is constantly influenced in their relationships with others. **Messages from health and social care professionals** about what is expected have considerable



influence, and the prior experiences of everybody in the person's interpersonal networks will have an **effect on what people think is realistic or even possible**.

- Lack of money for job-seeking basics such as transportation and interview attire, along with **fear of financial hardship** coming off benefits were real barriers to seeking paid work. There is a need for active consideration of the way in which benefits systems are managed. This may include consideration of explicit measures to **safeguard people who want to try work, and clear and accurate advice on entitlements and abatement**.

Creating 'successful' experiences for all stakeholders

- There was a clear message about the importance of **support to get appropriate workplace supports and adjustments**. At the time when people are beginning work, they are often managing a fragile situation of coping with new work. Appropriate supports increases the possibility of successful maintenance at this stage, and in doing so enables good experiences for the stakeholders involved (workers, employers, health professionals, whānau and families, etc). Good experiences can result in more opportunities and shifts of attitudes in the future.
- **Negotiating disclosure was an major issue**, given that in the current time there is a dominant perception that people living with long-term conditions cannot work. Once again, there is a role here for advocacy and support. Findings indicated that **disclosure is important** for a range of reasons, but perhaps it should be conceptualised in a less dichotomous way (i.e. to disclose or not). The language of 'disability disclosure' could detract from **considering other ways of managing information sharing**. Examples from the literature included workplace cultures of sharing relevant information about accommodation needs and promoting interdependent workplaces.
- It is actually having **people with long-term conditions visibly in paid work and coping with appropriate accommodations** that will help change attitudes and challenge discriminatory practices. **Positive experiences for all stakeholders feed through into more opportunities and openness to possibilities**.
- There were reports of people tolerating poor working conditions or having **strategies for coping with work that compromised other parts of their lives**. These are particularly important to think about in terms of advocacy and support. Support services need to be aware of the ways people cope and **support them to make informed decisions about how to manage**, including considering possibilities such as further negotiation within the workplace (perhaps through an advocate). In the longer term having more visibility of people working with long-term conditions may help to mitigate some of these issues (as above).

Other funding and policy considerations

- Findings highlighted that **service providers are often forced to do what they are rewarded for** – be that funding or acknowledgement or both. For a funder, it is important to **periodically analyse** what is being (sometimes inadvertently) rewarded and checking that it is **consistent with the intent of the system**, and **in line with current evidence** about what achieves the outcomes sought.



Overall conclusions

- With the exception of mental health conditions, there is very limited evidence on the effectiveness of interventions that aim to support people living with long-term conditions to gain paid work. However, high-quality qualitative evidence provides detailed insights into what works and what support is needed.
- Evidence from clinical trials shows that Individual Placement and Support results in improved employment outcomes for people living with a diagnosis of severe mental illness when compared to other employment approaches or general psychiatric care. The evidence for this approach is the highest quality evidence for any vocational intervention for any population of people with disabilities or chronic health conditions.
- There is emerging evidence for effectiveness of Individual Placement and Support to improve employment outcomes for people living with mild to moderate mental health conditions. This is encouraging because people with other long-term conditions commonly experience symptoms consistent with mild to moderate mental health conditions as well.
- As they are implemented, services should be further developed within the Aotearoa New Zealand context, in particular, building from and incorporating Māori values and perspectives.
- Support needs to be flexible enough to incorporate ups and downs, explicitly address disclosure and discrimination, help negotiate the risks of changing or coming off benefits, and provide opportunities for successes for all stakeholders (employers, people with conditions, significant others). Qualitative research supports the principles that characterise the Individual Placement and Support approach. In addition, it highlights the importance of social support from other people both within and outside the workplace.
- Formal health care and social support systems can either enhance or undermine good services. Attention needs to be paid to the unintended effects of funding models and service structures – for example, when the activities and outcomes that services are effectively rewarded for undermines what they are set up to achieve. This includes funding, collaboration and messages about work-ability from service providers.
- Innovation is needed to develop Indigenous-led approaches to support gaining and maintaining paid work in the context of living with long-term conditions. These may differ from approaches conceptualised according to Western values and concepts.