A review of the PRIMHD social outcome indicators

Suggested improvements to the collection and use of national social outcome data.

Final Report

23 December 2016

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Report written on behalf of Platform Trust & the National Mental Health KPI Programme

INTENDED AUDIENCE

The intended audience for this report is the sponsors of the National Mental Health Key Performance Indicator Programme.

ACKNOWLEDGEMENTS

This document has been developed with input from the advisory group for this project. The members are as follows:

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Professor Rex Billington	School of Public Health & Psychosocial Studies, AUT	Subjective and objective outcome measurement and research
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1. INTRODUCTION

1.1 Background

The national NGO Benchmarking Club was formed in 2014 under the auspices of the New Zealand mental health KPI programme. The purpose of the NGO Club was to provide a forum whereby NGOs could make performance comparisons between themselves, explore variations in practice, learn from one another and implement service improvements. Over the course of 2015, the participating NGOs developed seven core KPIs that they considered were relevant and meaningful to mental health NGOs for national benchmarking purposes.

Two of the seven core KPIs match two of the social outcome indicators (SOIs) that the Ministry of Health subsequently introduced into the national Programme for the Integration of Mental Health Data (PRIMHD) from 1 July 2016 (ie, accommodation and employment status).

A review of the collection and use of these two SOIs by selected NGOs in the Northern Region of New Zealand was carried out by Platform Trust (2015). This review found that whilst the process of data collection by NGOs was considered to be good, the actual use of the social outcome indicators was considered to be only fair. Although NGOs were collecting and reporting this data, it was clear that they considered this data to be primarily a contractual requirement and were not utilising the information to either drive service improvements or to add value to the service user experience.

The review also found that whilst the SOI data was considered to be of some value at a commissioning and policy level, the same data was considered to be of 'little value' to frontline staff and of 'no value' to service users. The final recommendations from the review included the need to define some more granular categories for each of the SOIs in order to help increase their utility at a local level.

On the basis of these recommendations, the NGO Benchmarking Club communicated to the Sponsors of the KPI programme that it was a priority for them to increase the value of the collection and use of SOI data. The national mental health KPI programme subsequently commissioned Platform Trust to undertake a further review of the social outcome indicators currently collected in the Programme for the Integration of Mental Health Data (PRIMHD) with a view to increasing their utility.

This report summarises the findings of that review and recommends some ways to improve both the collection and the use of these indicators at local, regional and national levels.

1.2 Scope

The scope of the project was primarily focused on the following three social outcome indicators that were introduced into PRIMHD on 1 July 2016:

- employment
- accommodation and
- education / training.

The review also considered other social outcome indicators (both objective and subjective) where there was strong evidence that other life domains are (a) essential to a person's wellbeing and sense of social inclusion, (b) can be measured, and (c) the data can be used to understand change in a person's health status and inform improvements to service delivery.

1.3 Benefits

The terms of reference for this review outlined the anticipated benefits including:

- Greater consistency and 'sense making' from the SOIs and the potential for the refined set of data to be included in other KPI benchmarking forums.
- Increased ability to make best use of SOIs to drive collective service improvement initiatives.
- Consensus on how to measure and understand 'change' using these SOIs.
- An understanding of whether 'targets' can be applied to these SOIs and, if targets are a possibility, determining the value of these targets to different stakeholder groups.
- An opportunity to concentrate workforce development initiatives on the collection and utilisation of SOI data as part of the trend towards outcomes orientated purchasing of services.
- Increased understanding across the mental health and addiction (MH&A) sector about how to maximise the utility of this information at a:
    - service user level
    - individual service provider level
    - commissioning level and
    - aggregated population level.

1.4 Method

This review used a number of different methods to address the key objectives for the project. Data sources included:

- A literature review.
- A limited review of relevant New Zealand national household surveys.
- Analysis of APQ6 data from Pathways.

- Brief survey of NGO and DHB service providers.
- Interviews with key informants.
- Input from an expert advisory group, which met formally on two occasions and also provided feedback via email review.

The first stage was based on a scan of the literature and involved reviewing a mixture of peer-reviewed articles (some of which were sourced by Te Pou), web-based documents and the grey literature that was identified through a process of 'snowballing', or the pursuit of references of the references identified during the course of the review. This process relied on the use of some key words such as 'mental health outcome measures', 'mental health outcome indicators', 'objective and subjective measures of wellbeing', 'social inclusion', 'social outcome indicators', 'population health' and 'social determinants of health' with an emphasis on employment, housing and education indicators.

Whilst the project wasn't tasked with making an assessment of the veracity of different measures of social outcome a number of formal questionnaires or outcome tools that included questions on topical subjects such as housing, education and employment were also considered. These included the Activity & Participation Questionnaire (APQ6), the Living in the Community Questionnaire (LCQ) and the New Zealand version of the short form World Health Organisation's Quality of Life measure (WHOQoL- BREF).

In addition, the review considered relevant questions that are included in some of New Zealand's national household surveys, including the Household Labour Force Survey (HLFS) and the New Zealand General Social Survey (NZGSS). Much of the supporting material relating to the area of employment, volunteer work and housing was gleaned from these two national surveys and can be found in the following document - (Statistics New Zealand, 2016) *Household surveys programme 2016–20: Responding to New Zealand's information needs*.

The second stage of the review relied on information that was obtained directly from mental health and addiction service providers as follows:

a) Te Pou undertook an analysis of 2,328 collections of Pathways APQ6 (Activity and Participation Questionnaire) data with specific attention on the '*number of hours worked*' to determine if there were some meaningful sub-categories of hours that could be mapped back to the three broad PRIMHD employment categories.

b) In addition, six of the nine mental health NGOs participants in the national mental health NGO Benchmarking Club and fifteen of the twenty District Health Boards completed a brief survey that asked how each organisation was currently collecting and using the PRIMHD social outcome data. At the same time, they were also asked about their utilisation of formal outcome instruments. A summary of the outcome

measures that were reported via this survey is presented as appendix one to this report.

The third stage of the review involved meeting with the National Association of Mental Health Servicers Consumer Advisors (NAMHSCA), the DHB PRIMHD Information Co-ordinators and four NGO service user advisors to test the preliminary findings from the review and, more specifically, to test the appetite for the establishment of a national item bank.

1.4.1 Limitations

The review was undertaken within time and budget constraints which limited the extent to which many of the issues could be investigated. Other limitations included the following:

- PRIMHD social outcome indicators have only been mandatory since 1 July 2016, so sector understanding about the collection and use of this data is still evolving at this stage.
- A very small sample of service user advisors and NGOs - not representative of the wider MH&A sector.
- Limited engagement with other key stakeholders in the wider MH&A sector.
- Limited review of formal outcome instruments/tools.
- Limited information relating to the measurement of change over time.
- Limited information on targets.

2. THE CORE CONSTRUCT

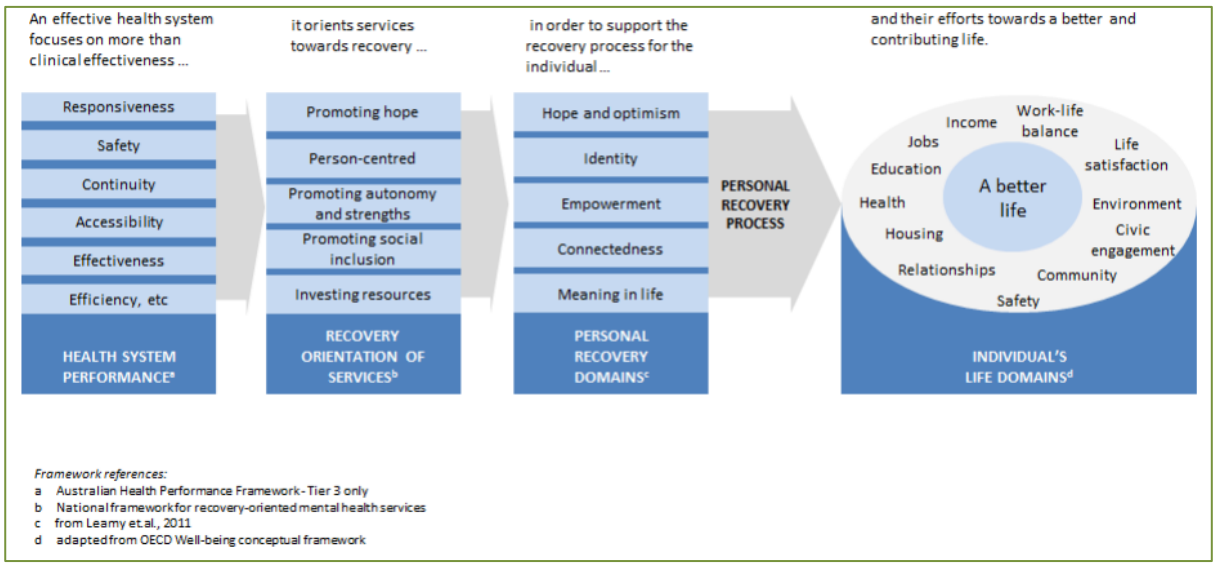
2.1 What is it that we are attempting to measure?

Rising to the Challenge (Ministry of Health, 2012) outlines a vision for a mentally healthy New Zealand that requires a whole-of-government response that encompasses the many issues that impact on health and wellbeing, such as income, housing, education and employment. Specifically the Plan is interested in making measurable improvements in mental health and wellbeing, physical health and social inclusion.

Developing data collections and indicators to support mental health and addiction reform is a complex task. The concepts of recovery, life purpose, wellbeing and quality of life all overlap, further complicating the task. In addition to the collection of service activity data, the Ministry of Health has incorporated three social outcome measures (housing, employment and education/training) into the national data collection - the Programme for the Integration of Mental Health Data (PRIMHD). However, there is an element of confusion in the MH&A sector about the rationale for these indicators. This review suggests that these social outcome indicators best suit a social inclusion agenda as expressed in *Rising to the Challenge* (2012) and have developed this report on that basis.

In the process of reaching this conclusion, the project looked at the Commonwealth of Australia's (2015) framework for measuring recovery. This framework (see figure 1) manages to tell a story about how the idiosyncratic nature of a person's recovery combines with health system performance (eg, access, continuity of care, etc.) and the recovery orientation of services to contribute towards a better life. It includes life domains that have a claim to be considered as universal – that is, relevant to people living in all societies (Durand, 2015).

Figure 1: Proposed framework for measuring recovery in specialist mental health services



Source: Commonwealth of Australia (2015) *Measuring recovery in Australian specialised mental health services: A status report.*

2.2 Social inclusion

In recent years, the concept of social inclusion/exclusion has emerged in discussions about social disadvantage and social cohesion. Social inclusion and social exclusion can be viewed as two ends of a single dimension (Hayes et al, 2008). Social exclusion negatively impacts on people's ability to get well and stay well, to enjoy their lives and to function in their local communities. A socially inclusive society is more than simply the inverse of social exclusion and involves equity of opportunities and outcomes with regard to labour market participation and income, education and training, as well as access to social benefits, health services and good housing (Spoonley et al, 2005).

The New Zealand Mental Health Commission's Occasional Paper (2009) offers some insights into those aspects of life that various stakeholders considered to be more important from the perspective of a socially inclusive society. These domains were reflected, to some extent, by Statistics NZ (2011b) in their work on social cohesion. Wilson, Jenkin & Campain (2011) included this report in a limited review of the literature on indicators of social inclusion. The results of that review are summarised in table 1. It should be noted that, in many instances, these domains encompass a range of areas or sub domains that are not shown in this table.

Table 1: Sub-domains of social inclusion

Saunders et al (2007)	Social cohesion (Statistics NZ, 2011)	Australian Social Inclusion Board vision (www.socialinclusion.gov.au)	EU based Australian Social Inclusion Board headline indicators (Australian Social Inclusion Board, 2010)	4th National Mental Health Plan – social inclusion indicators (Commonwealth of Australia, 2009)
Economic exclusion	Employment	Employment	Access to job market	Participation in employment
			Poverty and low income	
	Knowledge and skills	Participating in education and training		Participation in employment
Disengagement	Relationships Civil participation	Voluntary work	Limited social supports and networks Effect of local neighbourhood	Community participation
		Family/caring roles		
		Coping with crisis		
		Connecting with people		
		Voice heard		
	Safety			
	Cultural identity			
	Leisure and recreation			
Service exclusion		Access services		
	Health		Health	
	Standard of living			Living in stable housing
	Transport			

Source: Wilson, E.; Jenkin, E. & Campain, R. (2011). *Outcome Measurement of Community Based Mental Health Services in Western Australia: Literature and Concept Summary.* Melbourne: Inclusion Matters.

2.3 Developing indicators of social inclusion

Despite the emerging interest in social inclusion/exclusion, there are very few studies in the field of mental health that directly measure it (Wilson et al., 2011, p17).

The indicators for the housing and employment domains were developed on the basis that key stakeholders wanted to see the contribution of services towards achieving a better life for service users. In addition, they wanted to be in a position to make direct comparisons between the outcomes for MH&A service users and the general population. In other words, measuring service user participation in the labour market and then comparing it with everyone else's participation in the labour market would provide an indication of the relative economic activity (and associated wellbeing) of MH&A service users in New Zealand. This approach to the measurement of disparities has the advantage of being able to utilise existing indicators such as those that form part of the national household surveys conducted by Statistics NZ.

The disadvantage of this approach is these supposedly objective indicators may appear irrelevant to service users and providers. This is particularly the case, where data is aggregated for policy, funding and planning purposes. The challenge is to measure outcomes in a way that is both aggregable and meaningful.

With this challenge in mind, Slade (2010) recommended an outcome strategy that encompasses both objective quality of life indicators (eg, housing, employment, etc) as well as service user's progress towards their own personal goals. Some of the other challenges are covered in the following section.

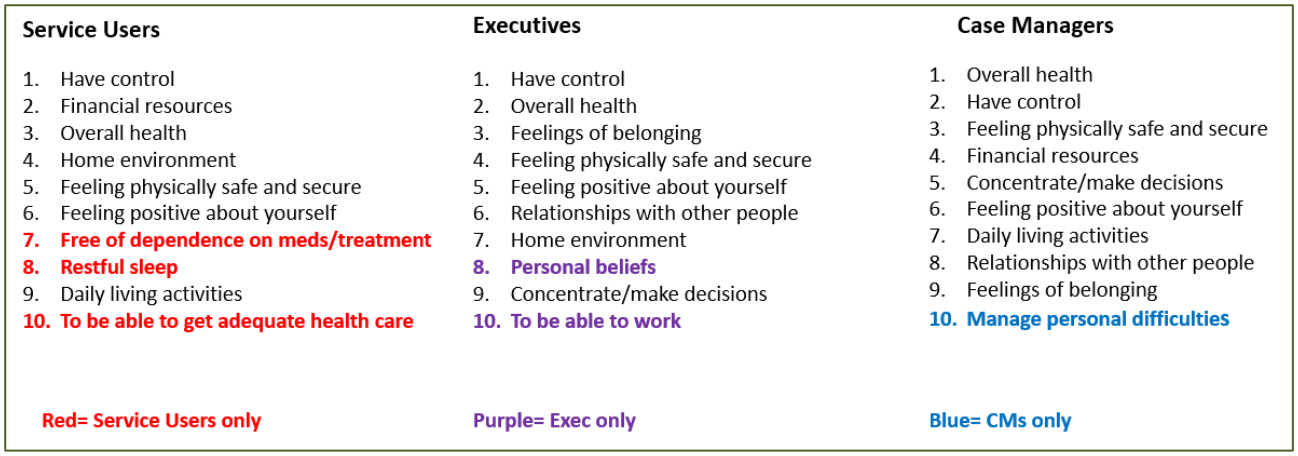
2.4 Challenges

The dimensions that are measured matter

When it comes to measuring outcomes, some life dimensions are considered to be more important than others, reflecting the relative priorities of different sub-groups. For example, a small unpublished pilot study undertaken in New Zealand by the mental health NGO WHOQOL collaborative has shown that service users attach varying levels of importance to different aspects of life, as measured by the WHOQOL-BREF (NZ version) .

As shown in figure 2, the top ten items of the WHOQOL-BREF (out of a total of 31 items) in this pilot study were both selected and then ranked very differently by service users compared to groups of executives and front-line staff/case managers.

Figure 2: Findings – Top ten: What's Important



Source: Presentation at AMHOIC Conference 2015. Results from unpublished pilot study by the Mental Health NGO WHOQOL collaborative.

Value judgements

Slade (2010) argues that the primary advantage of 'objective' indicators is that they are based on social norms and so avoid illness-related expectations. Their main disadvantage is that they impose social roles on people who may not want to conform to them. Some people are able to get on very well in life without a job, a partner or friends. Attempting to impose social roles on these people has the potential to be oppressive.

However, it is not possible to measure outcomes without making some kind of value judgement as all outcomes are inherently value-based. Slade maintains that measuring outcomes that are biased towards citizenship might be slightly less oppressive than measuring outcomes that are of a purely clinical nature.

Subjective and objective measures

Individuals are also more likely to compare themselves to others in their local community and to then compare themselves to slightly better-off people or places, not to national norms (personal communication with Rex Billington). This is why someone's employment status has been found to be a weaker predictor of subjective wellbeing in those countries that have higher unemployment rates.

The field of subjective wellbeing (SWB) measurement is a topic in its own right, but it is noted that how people think and feel about different aspects of their life is as important to consider (if not more important) as those things that government defines as being 'a good life'. For this reason, a number of NGOs are using the WHOQOL-BREF (NZ version), which is a tool developed by the World Health Organisation for people to self-assess their quality of life.

Personal agency

The concept of personal agency plays an important role in this area of outcome measurement. It cannot be assumed that every indicator is appropriate for every individual

as a measure of social inclusion. For example, a service user may be unemployed, have low educational attainment but prefer a vocational route (eg, traineeship, apprenticeship) to employment. A personal recovery orientation would give primacy to the goals that matter to the individual and which contribute to their sense of personal identity.

Quantitative and qualitative information

The literature on the indicators associated with social inclusion is critical of the reliance on highly quantitative material. There is a tendency to measure social inclusion/exclusion in a quantitative manner without understanding some of the qualitative elements at both local and national levels.

Neoliberalism

The following excerpt is a critique of the outcome assessment tools called the *Recovery Star* from a political standpoint. This has prompted the creation of the 'UnRecovery Star' by the mental health survivor group called *Recovery in the Bin*.

> "The Recovery Star continues an onslaught of neoliberalism in mental health, in which people are to be made individually responsible for difficulties which would be better thought of as originating in society. Through this lens, the holism of the Recovery Star becomes a complete colonisation of a person with a set of ideas that appear to be liberating but in fact absolve the powerful from the need to acknowledge and address inequalities of all kinds. For example, widening the conversation to include work and financial skills might seem welcome because loss of role, loss of meaningful activity and financial worries are very significant drivers of distress. However, in so doing, we may be failing to notice with the service-user that they live in an unjust society in which finding one's way and having access to decent housing, meaningful roles, security, having protected rights and simply being allowed to be different seem to be increasingly the domain of the privileged".

Retrieved from https://criticalmhnursing.org/2015/10/19/the-recovery-star-meets-the-unrecovery-star/

Micro and macro level data

One of the greatest challenges in the development of key performance indicators is to develop indicators that are meaningful for service users and their families, while also meeting the needs of service providers, funders and policy makers.

A related challenge concerns high level aggregated data compared with micro-level information. If social inclusion is context-dependent, then the reliability of the measures and their impact are greater at the local or micro-level. Whilst it is possible to obtain value and

consistent meaning at both micro and macro-levels, it is difficult to do this well, as has already been demonstrated in the Northern Region (Platform Trust, 2015).

Data collection protocol supporting data collection

Many sector representatives complained about the frequency of SOI data collection by multiple teams/organisations, with the added complication that there is the potential for disagreement relating to the accuracy of the duplicated data. Ideally, MH&A services should operate as 'one-system' and apply the data collection protocol accordingly, thereby avoiding the risk of unnecessary and annoying duplicate data collection.

The lack of a data collection protocol has also been noted by Te Pou and is addressed in their *Guide to Supplementary Consumer Records including Social Outcome Indicators* (2016). The Guide recommends that the SOI data should be collected at the following transition points - referral start and end/discharge, when there is a change in the service user's circumstances and/or every 3-months, in accordance with best clinical practice. The minimum requirement for data collection is once per year.

All comments that were made about the data protocol during the course of this review have been referred to Te Pou. No recommendations relating to this area are included in this report.

Domain specific issues

There were a number of suggestions about possible improvements to the three PRIMHD indicators, which are covered in detail in sections 3 to 6 of this report.

3. EMPLOYMENT

3.1 Introduction

Work can be an important mechanism for enhancing wellbeing, and for some people it is a central part of their recovery (Duncan & Peterson, 2007). Conversely, long term unemployment is seen as a key cause of poverty and social exclusion. An article by Brown, Woolf & Smith (2012) on the determinants of life satisfaction in New Zealand noted the negative relationship between unemployment and life satisfaction as being one of the strongest findings in the international literature on wellbeing economics.

Globally, people with mental illness have significantly lower rates of employment than the rest of the population, and periods of economic recession are related to worse mental health in the general population, especially amongst men (Katikireddi et al, 2012). The differences between the general population, people with psychological issues (based on the Disability survey (Statistics New Zealand, 2013)) and people in contact with specialist mental health services in New Zealand are reflected in figure 3.

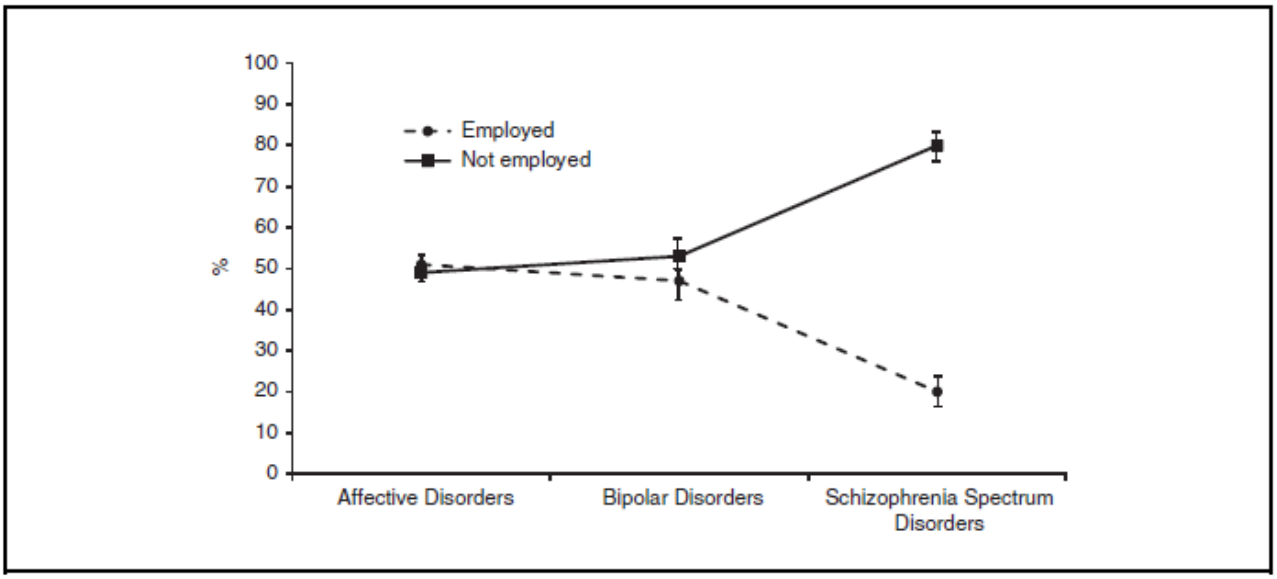
Figure 3: Labour force participation across different sub-groups of the New Zealand population

Source: Lockett et al. (2016). *Employment – getting evidence into policy and practice.* TheMHS 2016 presentation.

Jonsdottir & Waghorn's (2015) review of international epidemiological and observational studies found that there is a negative relationship between employment rates and the severity of psychiatric illness. Figure 4 on the following page shows the overall mean labour force activity for included studies for each major category of mental illness. They found a

gradient of increasing raw proportions employed from the most severe disorder category (psychosis) to the least severe (affective disorders).

Figure 4: Employment status by diagnostic category showing 95 percent confidence intervals.



Source: Jonsdottir & Waghorn (2015, p18) Psychiatric disorders and labour force activity.

The capability to find employment is critical for wellbeing, but the quality of the work also matters. Marmot (2010) has emphasised the risks of getting people off government benefits and into low-paid, insecure and health-damaging work. In addition, the income from employment on its own might not be a reliable indicator of economic wellbeing because people with the same income level, at a point in time, may have quite different living standards. The availability of other resources (eg, savings, assets, informal economy, assistance from friends, family and support agencies) coupled with the needs of the household, will influence whether or not someone's income is sufficient to meet their everyday needs (Layte et al, 2001).

Families in New Zealand that reported that they had insufficient income tended to have the following characteristics – they received a government benefit, had unpredictable income, rented their home and juggled expenses. These families were particularly susceptible to a number of negative 'life shocks' such as illness, redundancy or relationship separation and found it hard to cope with any unexpected expenditure such as medical bills, car repairs and funeral costs (Quigley and Watts, 2015).

3.2 PRIMHD employment status categories

The following table lists the data elements and the applicable code sets that are used when recording a service user's employment status in PRIMHD. The aim of this review is to consider how to add value to the three main categories outlined below.

Table 2: PRIMHD employment categories

Code	Description	Code Valid From	Code Valid To	Used for/Comment
1	In Paid employment >=30 hrs a week	01-07-2014	30-06-2020	Full time
2	In Paid employment for 1 to less than 30 hrs a week	01-07-2014	30-06-2020	Part time
3	Not in Paid Employment – less than 1 hour per week	01-07-2014	30-06-2020	

Source: Health Information Standards Organisation (Revised January 2016) *PRIMHD Code Set Standard HISO 10023.3:2015* (pp 55-56).

3.3 Household Labour Force Survey

3.3.1 Description

The Household Labour Force Survey (HLFS) is a continuous national survey of households that aims to produce statistics relating to the employed, unemployed and those not in the labour force. The survey also collects demographic information such as age, gender, locality, and ethnicity to provide estimates for different population groups.

Since 1985, the HLFS has provided quarterly measures of:

- the number of employed and unemployed people in New Zealand
- the number of people who are not in the labour force
- hours worked
- occupations and industries people work in
- duration of unemployment
- steps people take to find work
- steps people take to find more work hours and
- the number of people in formal study

3.3.2 Redevelopment of the HLFS

Following a major redevelopment, a new version of the HLFS went into the field in April 2016. One strand of the redevelopment was to add new primary content to the survey, including some topics that might be of interest to the MH&A sector such as:

- employment relationships (whether people are in permanent or temporary jobs and what types of temporary jobs)

- length of job tenure
- additional hours of work wanted
- whether people have more than one job

In addition to this primary content, Statistics NZ is also planning to add a number of shorter supplementary topics to the main questionnaire on a rotating or ad hoc basis. Table 3 shows the proposed schedule for these supplementary topics up to 2020. Please note that Statistics NZ has signalled that both the scheduling and the content of this programme are subject to possible revision due to resourcing issues or changing information needs.

Table 3: Planned supplementary and rotating content for Household Labour Force Survey 2016–20

Survey content	Quarter																			
	2016				2017				2018				2019				2020			
	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
HLFS	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Supplements																				
Income		■				■				■				■				■		
Childcare							■													
Working Life												■								
Education and Training															■					
Rotating topics																				
Disability						■				■				■				■		
Work-related health				■																
Volunteer work						■								■						
Employment transitions									■											
Redundancies										■										
Skill-related underemployment																				■
Types of self-employment																			■	

Source: Statistics New Zealand (2016) Household surveys programme 2016–20: Responding to New Zealand's information needs.

3.3.3 Considerations for the mental health & addiction sector

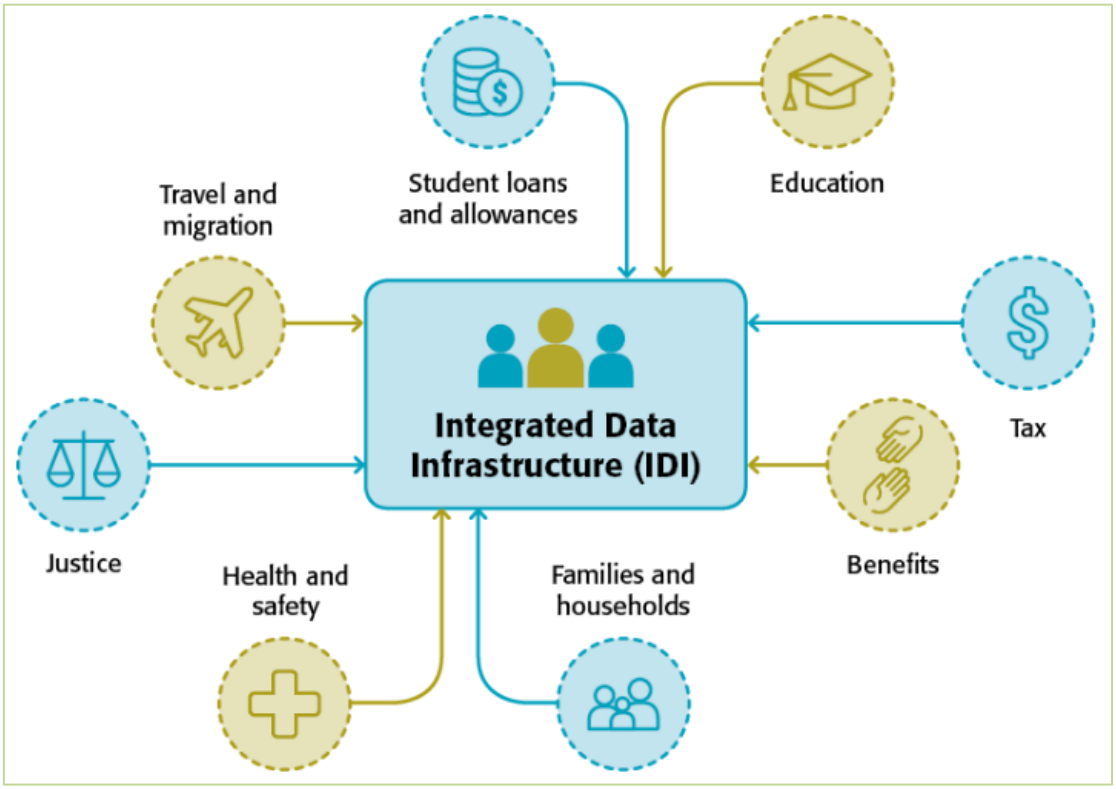
Disability topic

Whilst it will be very useful to produce estimates of labour market characteristics disaggregated by disability status, the tool that Statistics NZ are intending to use (ie, the Washington Group Short Set on Functioning) will not specifically identify people with experience of mental health and addiction problems. The six questions in the tool are all focused on functional impairment and not the type of disability. It is noted that the questions that relate to mental health are still under development and are excluded from the initial Washington Group Short Set.

In New Zealand there is no national survey which enables us to accurately understand labour force participation rates by health condition or by disability (Lockett et al., 2016 submitted, under review). However the work of Jonsdottir & Waghorn (2015) and Morgan et al. (2016) would indicate that labour force participation rates are significantly lower, especially when severity of disorder is taken into consideration.

The Integrated Data Infrastructure (IDI), which is governed by Statistics NZ, is a potential source of information about national labour force participation rates for MH&A service users as it contains a large amount of microdata about people and households, including census information, PRIMHD data, benefits and tax information (see figure 5). Potentially this data could be linked for research, policy and evaluation purposes to give greater insights into the inequities that are experienced by people who have mental health and addiction problems.

Figure 5: Overview of data available in the IDI.



Source: Statistics NZ (2016). Retrieved from http://www.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure.aspx

Implications:

- Despite government's intention to identify and reduce the gap in social and economic outcomes between disabled and non-disabled people, the proposed changes to the HLFS survey will not help to make visible the economic disadvantages that are experienced by people with mental health and/or addiction problems.
- Provisions to help service users leave the roll of welfare beneficiaries will require a greater level of system flexibility with regard to benefit entitlements and ongoing access to support services.

- On a more positive note, the HLSF does highlight specific questions which could be used to supplement the PRIMHD social outcome indicators in order to provide more meaningful information at the local level. These questions are highlighted throughout this report alongside questions that have been gleaned from other formal questionnaires.

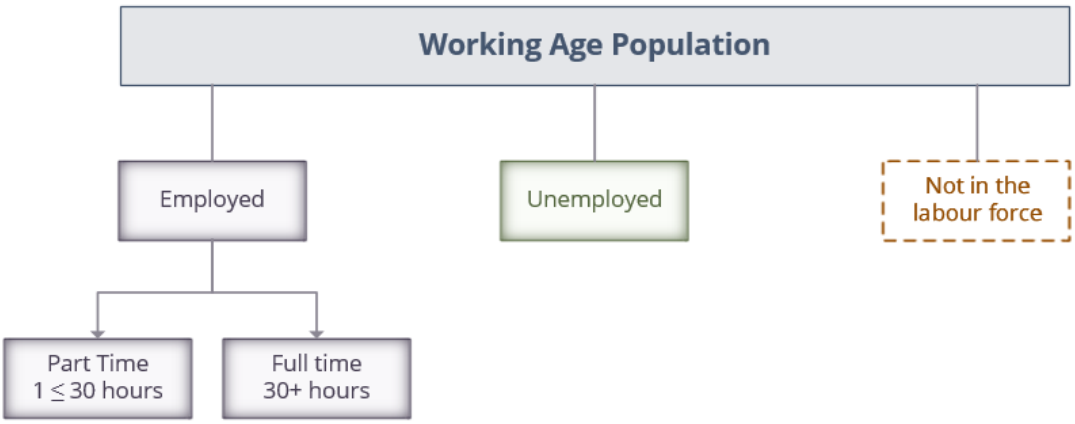
Recommendations:

- Ministry of Health to work with Statistics NZ to develop some standard annual reports using the Integrated Data Infrastructure (including labour force participation rates), which would help to support the national social inclusion agenda for MH&A service users.

Labour Force Status

The labour force status classifies the population (aged 15 years and over) into three mutually exclusive groups, based on their economic activity in **the week prior to the interview**. The three groups are: employed, unemployed, and not in the labour force (see figure 6). The priority rules and definitions for grouping the population into these three groups conform closely to the international standard definitions specified by the International Labour Organisation (ILO).

Figure 6: NZ Labour Force Classification based on Statistics NZ categories



Implications:

- It is not clear if this information is being collected from all service users in the working age population (ie, people aged 15 – 64 years of age) or if information is also being collected from people who are outside this age bracket.
- It will be important to stratify this information based on age, gender and ethnicity to highlight areas of inequity that would benefit from targeted social investment.
- Currently, there are people who are not in the *'paid labour force'* who are being counted as 'unemployed' in PRIMHD because there are only three options for reporting into PRIMHD - unemployed, part-time or full-time.

- It is important to have consistent reference periods when assessing someone's employment status. It is noted that the PRIMHD specialists have recently agreed to implement the same reference period as that used in the HFLS – ie, the average number of hours one week prior to the date of the interview. This is also consistent practice with a number of other outcome measures such as the LCQ and the APQ6.

Recommendations:

- Ministry of Health to clarify the scope of data collection with regard to 'employment' so that it is clear that it applies to everyone in the working age population.
- Ministry of Health to include a caveat to the above rule which enables providers to record the employment status of someone over the age of 65 years who is in some form of paid employment.
- Ministry of Health to include two new categories in PRIMHD (ie, 'not in the labour force' and 'employment status unidentifiable') so as not to artificially inflate the number of people who are counted as being 'unemployed'.

Full-time / part-time status of the employed

Employed individuals are classified as being in full-time employment if they usually work a total of 30 hours or more per week in all jobs. Part-time employment is defined as usually working less than 30 hours per week in all jobs. It is important to note that the NZ Disability Survey (Statistics New Zealand, 2013) found that part-time employment was particularly common amongst those people with psychiatric/psychological impairment. These definitions of part-time and full-time employment have been adopted by PRIMHD to enable national comparisons to be made with the HLFS. What is not clear is who is counted as being employed (eg, does this category include women who are on maternity leave, people who are in receipt of ACC compensation, etc?).

Implications:

- Service providers have different interpretations of who is considered to be 'employed' and these differences contribute to the collection of poor quality data.
- The evidence suggests that the cut-off point for eligibility for welfare payments (15 hours) and health entitlements (eg, community services card) act as a powerful disincentive for service users to obtain and then sustain competitive employment. Despite the implementation of various employment initiatives under Work & Income NZ (eg, *Sustainable Employment Trials*), it is not surprising to see service users clustered towards the lower end of the part-time labour force.

Recommendations:

- Te Pou to continue working with MH&A sector representatives and the Ministry of Health to regularly update the Guide to PRIMHD Supplementary Consumer Record Requirements (Te Pou o Te Whakaaro Nui, 2016) in order to provide clear definitions

and a consistent methodology for the collection and use of the social outcome data that is recorded in PRIMHD.

- As much as possible, the PRIMHD Standards that have been developed by the Health Information Standards Organisation (2016) and Te Pou's *Guide*, should reflect the national standard definitions that have already been developed by Statistics New Zealand.
- The MH&A sector continues to participate in the Ministry of Social Development's *Health and Disability Long-term Work Programme* (2014), which includes a provision for reviewing all government financial incentives/disincentives for disabled people and people with health conditions to work.

Number of hours employed people actually work per week

The HLFS collects information on the number of hours a respondent actually worked in the reference period, as well as the number of hours they usually work per week. This information is used by Statistics NZ to analyse changes in employment characteristics over time. The standard output for use in Statistics NZ publications are outlined in table 4.

Table 4: Standard output for use in tables published by Statistics NZ

Part-time hours per week	Full-time hours per week
1 - 4 hours worked	30 - 34 hours worked
5 – 9 hours worked	35 – 39 hours worked
10 – 14 hours worked	40 - 44 hours worked
15 – 19 hours worked	45 – 49 hours worked
20 – 24 hours worked	50 – 54 hours worked
25 – 29 hours worked	55 – 59 hours worked

By asking for more granular information about the average number of hours worked, service providers will be able to show incremental changes over time. For example, at the moment any increase or decrease in the number of part-time hours worked is treated as if there is 'no change' because it occurs within a very broad range (ie, 1 to 30 hours). However, that small increase/decrease in hours may be very significant, especially from the perspective of the individual service user, and so it needs to be tracked in some way – at the local level only.

Implications:

- The Pathways APQ6 data (see section 3.5) indicates that 52 percent of service users work less than 10 hours per week, so even very small changes in the '*number of hours worked*' are important to measure, particularly at the lower end of the scale.
- The 'number of hours worked' is not currently collected in PRIMHD. However, this level of detail might be useful for providers to collect at the local level in order to track changes in employment status over time.

- The standard 5-hour time blocks used by Statistics NZ would appear to offer good information for the purposes of analysis at the local level.

Recommendations:

- Service providers that are not using the APQ6 should consider collecting the '*average number of hours worked in the past week*' as a supplementary data item.
- Service providers to assign the average number of hours worked in the past week to a 5-hour time-block to enable change over time to be more easily tracked and benchmarked at the local level.
- Funders and providers to review how the change in '*employment status at the point of exit from services*' and the change in the '*number of hours worked*' over time help to inform one another.

Wanting a job

The evidence from the literature indicates that 70 to 90 percent of service users would like a job (Grove, 1999; Secker et al., 2001; Statistics NZ Disability Survey, 2013). In addition, the evidence from Pathways analysis of their APQ6 data suggests that 50 percent of service users who wanted employment also wanted help from a service provider to obtain it. These figures contrast sharply with the number of service users who are actually in any form of paid employment.

Implication:

- Service users have one of the lowest rates of employment. At the same time they have one of the highest '*want to work*' rates (Lockett, 2016). This indicates that providers need to be more proactive in working with service users to help identify their interest in employment and to act accordingly; ie, link them with a high intensity, high-fidelity supported employment service.

Recommendations:

- Providers to routinely ask service users if they would like a job and, if the answer is 'yes', follow-up with a question asking if they would like some help to obtain one.
- Providers to ensure that people who have the highest levels of labour force disadvantage have access to high intensity evidence-based supported employment services as a matter of priority.
- The Ministry of Health, the Ministry of Social Development and all DHB funders ensure that high intensity, high fidelity, evidence-based employment services are available to service users in every DHB locality.

Relevant question from HLFS

- *"Would you like to work?"*

Relevant question from APQ6

- *"Are you interested in increasing your level of participation in employment?"*

Preference for working more or less hours, and under-employment

Information is collected by the HLFS for all employed individuals who usually work less than 50 hours per week about their preference to work more hours, availability to do so, how many hours they would like to work, and methods used to get more hours.

Implication:

- Some form of paid employment does not necessarily mean that people are not open to considering an increase (or a decrease) in the number of hours that they regularly work.

Recommendation:

- Service providers need to proactively engage service users in a discussion about their paid work to help determine if (a) they would like to make any changes and (b) if they need support to make any changes.

Relevant questions from NZGSS (2014)

- *"Would you like to work more hours?"*
- *"What is the main reason you work fewer hours than that?"*

Adequacy of income

Quigley and Watts (2015) have researched the perceptions of income adequacy of low income families in New Zealand. While many people on a low income reported that their income met their everyday needs, many of these people also reported that there were times when it was 'not enough'. Those families that reported that they did not have enough income tended to receive a government benefit, have unpredictable income, rent their home and juggle expenses. In order to make ends meet, some people were going without food, heating, developing the skills and interests of their children, going on holiday and participating in social occasions.

Implication:

- In addition to absolute income, how income is managed, what expectations are held, the predictability of income and expenses, and the presence of support all influence people's judgements of income adequacy.
- It is important to note that most service users will report that they need more income.

3.4 Activity and participation questionnaire (APQ6)

3.4.1 Background

The Activity and participation questionnaire (APQ6) is a simple measure of vocational and educational activity and social participation which occurred **in the past week.** It was designed for use in community mental health settings (Stewart et al., 2010) and was included as a discretionary component in the New South Wales Mental Health and Outcome Assessment Tool (MH-OAT) collection. The APQ6 was used as the starting point for the development of the *Living in the Community Questionnaire* (LCQ) – a new consumer self-report measure that has been designed to measure social inclusion outcomes in Australia.

In the course of developing the LCQ, a number of New South Wales services were asked about their perception of the APQ6. They noted that it was simple to use, easy to understand and was not a burden in terms of data collection. However, some respondents indicated that reliably calculating the number of hours spent on various activities was often a challenge for service users.

3.4.2 Description

The APQ6 involves six questions about the amount of time spent in work and other social activities. The six questions are answered with a tick-box option and a space to indicate how many hours people did in the past week.

Activity and participation questionnaire (APQ6)

1. *Last week did you have a full-time or part-time job of any kind? How many hours?*
2. *In the last four weeks were you actively looking for work?*
3. *Last week did you do any of the following types of unpaid work? How many hours?*
4. *Are you currently taking any course of study? How many hours per week?*
5. *In the last week have you participated in any of these activities? (Followed by a list of social activities). How many hours?*
6. *How do you currently feel about your level of activity? What can we do to help you with this?*

Pathways is using the questionnaire to encourage meaningful conversations about how well people are doing and what actions that staff can take to support people to achieve their goals. A presentation by Wild Bamboo at the Australasian Mental Health Outcomes & Information Conference in 2015 indicated that at least three other mental health services in New Zealand have also chosen to implement this instrument.

Implications:

- If a service user has completed an APQ6, the service provider can use this data to populate the PRIMHD categories relating to employment and education.
- The service user's response to the question about the '*number of hours worked*' could easily be mapped to the proposed 5-hour time bands.

- The questions about (a) 'actively looking for employment', (b) 'interested in increasing employment' and (c) 'would like help with increasing employment and education' are all considered useful as supplementary questions at the local level.
- The reference period is the past week.

Recommendations:

- Te Pou and several NGO service providers to consider testing the APQ6 with a view to assessing its sensitivity to aggregate team and organisational change.
- In lieu of being involved in implementing and testing the APQ6, NGO service providers to collect some supplementary information to enable small changes in a service users employment status to be made more visible at the local level.
- Given that the burden of data collection needs to be carefully weighed against the possible benefits, it is recommended that service providers choose what (if any) supplementary questions might be of particular relevance to them. The decision to collect additional data will depend on the aspirations of individual service users, the focus of service delivery, the robustness of the organisation's information infrastructure as well as staff capacity and capability in this area.

An example of some possible supplementary questions (and their source) relating to the area of employment are given below in table 5 below. A more complete list of questions is included as appendix two.

Table 5: Example of optional supplementary employment-related questions

PRIMHD	Optional supplementary questions	Source
Unemployed	• Would you like to work?	NZ HLFS
	• In the last four weeks, were you actively looking for paid work?	APQ6
	• What are the most useful things we can do to help you with this?	APQ6
Part-time	• Average number of hours worked in the past week?	APQ6
	• Would you like to work more (or less) hours?	NZGSS & APQ6
	• What are the most useful things we can do to help you with this?	APQ6
Full-time	• Average number of hours worked in the past week?	APQ6
	• Would you like to work more (or less) hours?	NZGSS & APQ6

3.5 Te Pou analysis of Pathways APQ6 data

Te Pou undertook an analysis of Pathways APQ6 (Activity and Participation Questionnaire) data, focusing specifically on the responses to the *number of hours worked.* The aim was to explore the use of 5-hour and 10-hour time bands to inform a discussion about the possible disaggregation of the current broad employment status categories into more useful sub-categories.

The intention was to ascertain if more meaningful information for service users, funders and service providers about changes in employment status and, at the same time, offer ways for providers to effectively map this disaggregated data to the three broad employment status categories used by PRIMHD.

3.5.1 Preliminary findings

The analysis involved the most recent two years of data (July 2014 to June 2016). Please note that the analysis of the entire dataset from 2011 onwards showed almost exactly the same percentages.

Table 6: Frequency of 'hours worked' (APQ6 data)

Category	Number of collections	Percentage of all collections
Not working	1,991	86%
Working – under 10 hours	175	8%
Working – 10-19 hours	90	4%
Working – 20-29 hours	36	2%
Working – 30+ hours	36	2%
Total	**2,328**	**100%**

The 'number of hours worked' was further broken down to give more useful sub-categories for analysis purposes. The new categories could still be mapped to the existing PRIMHD definition of 'part time' (defined as being in paid employment from 1 to less than 30 hours per week).

Please note that an individual service user could potentially be counted more than once in the given time period.

Table 7: 'Hours worked' grouped into a combination of 5 and 10 hour blocks (APQ6 data)

Number of hours worked, 5 and 10 hour blocks	Number of collections	Percentage of those working	Notes
Under 5 hours	102	30%	An *under 10 hours* category would describe 52% of worked hours data
5-9 hours	73	22%	
10-19 hours	90	27%	
20-29 hours	36	11%	
30+ hours*	36	11%	
Total	**337**	**100%**	

* Maps to existing PRIMHD definition of 'full time'

This information was further disaggregated into 5 hour blocks, as per the following table.

Table 8: Hours worked grouped into 5 hour blocks (APQ6 data)

Number of hours worked, day equivalents	Number of collections	Percentage of those working	Notes
1-4 hours	102	30.3%	
5-9 hours	73	21.7%	
10-14 hours	52	15.4%	
15-19 hours	38	11.3%	Note the drop off at the 15 hour threshold
20-24 hours	28	8.3%	
25-29 hours	8	2.4%	
30+ hours*	36	10.7%	
Total	**337**	**100%**	

*Maps to existing PRIMHD definition of 'full time'

This analysis confirmed that the 5-hour time blocks were preferable to the 10-hour time blocks, principally because most service users were clustered beneath the 15-hour threshold. This is the point at which people's welfare entitlements start to be negatively affected by their paid work.

3.5.2 Analysis of change over time

Analysis of change over time was not possible using this data set as it was stripped of all unique identifiers (eg NHIs) for privacy reasons. In addition, Te Pou was of the view that before any analysis of this nature could take place, some decisions would need to be made as to how change would be demonstrated at a team or organisational level.

In terms of reporting, Te Pou also recommended that consideration be given to the following:

Recommendations:

- Providers to monitor both increases and decreases in the number of paid work hours over time.
- Te Pou to continue analysing APQ6 data to further explore questions that are of interest to the MH&A sector (eg, results by different NGO service types).

4. VOLUNTEER WORK

4.1 Introduction

People volunteer for an endless variety of reasons. Many people want to gain experience, acquire new skills, meet new people, or expand their network of contacts as a way of obtaining a new job or starting a career. Others just want to give something back to their local community, help a friend or promote a worthwhile activity.

A number of stakeholders in the MH&A thought that voluntary work should be collected alongside data about a service user's employment status. In some instances, District Health Board funders had already included 'voluntary work' in their service provider contract reporting requirements, mainly because they wanted to recognise the contribution of unpaid work to the enhancement of an individual's wellbeing as well as the role that it plays in the building of strong communities and civil society.

However, whilst unpaid work does have an economic aspect to it, there are good reasons to separate voluntary work from paid employment, not the least being the issue of poverty. There is a wealth of local and international data on the damaging educational, health, social and economic impacts of poverty, particularly on children (Boston & Chapple, 2014). For the reasons outlined in the previous chapter, the MH&A sector has a strong interest in collecting information that will help shed light on income disparities for MH&A service users. It becomes difficult for stakeholders to advocate for change in this area if employment-related data includes people who are either not in the labour market or who are in voluntary work.

Recommendation:

- All stakeholders to separate 'voluntary work' from any reporting related to 'employment' in PRIMHD. This includes the sub-category 'unemployed'.

4.2 Unpaid work - Health Labour Force Survey

It is noted that the volunteer work topic has been proposed for inclusion in the HLFS during 2017. It will include questions on people's participation in unpaid work for other individuals, households or organisations over a four-week period. It will ask whether people did such work, the number of hours worked, the type of work, and the type of organisation or setting in which it was performed. The information will allow more frequent estimation of the economic value of unpaid work and will help Statistics NZ to provide a more complete picture of the volume and type of productive unpaid work carried out in New Zealand and the characteristics of the volunteer workforce.

5. HOUSING

5.1 Introduction

Housing fulfils a physical need for shelter and provides social functions of individual respite and the basis for family life. Access to safe, adequate and affordable housing are well recognised as core indicators of personal and communal wellbeing, and overcrowded or inadequate housing has been linked to negative health and social outcomes.

Peace and Kell (2001) noted that housing difficulties, homelessness and transience were significant problems for MH&A service users. They identified three issues that emerged from interviews with both provider and service user groups:

- the unaffordability of suitable housing relative to income,
- problems relating to benefit income and benefit debt (also an affordability issue) and;
- discrimination in finding and retaining housing.

These three issues can be classified as barriers in the sense that they are beyond the scope of mental health and addiction service provision to remedy on their own. However, given that there is a negative relationship between poor-quality housing and MH&A problems, it is important that key stakeholders in the MH&A sector (a) understand the living situation of service users and (b) work with other agencies to influence change in this area.

5.2 PRIMHD accommodation categories

Table 9: PRIMHD accommodation categories

Code	Description	Code Valid From	Code Valid To	Used for/Comment
1	Independent	01-07-2014	30-06-2020	
2	Supported	01-07-2014	30-06-2020	Accommodation financially supported either partly or fully by the funder
3	Homeless	01-07-2014	30-06-2020	

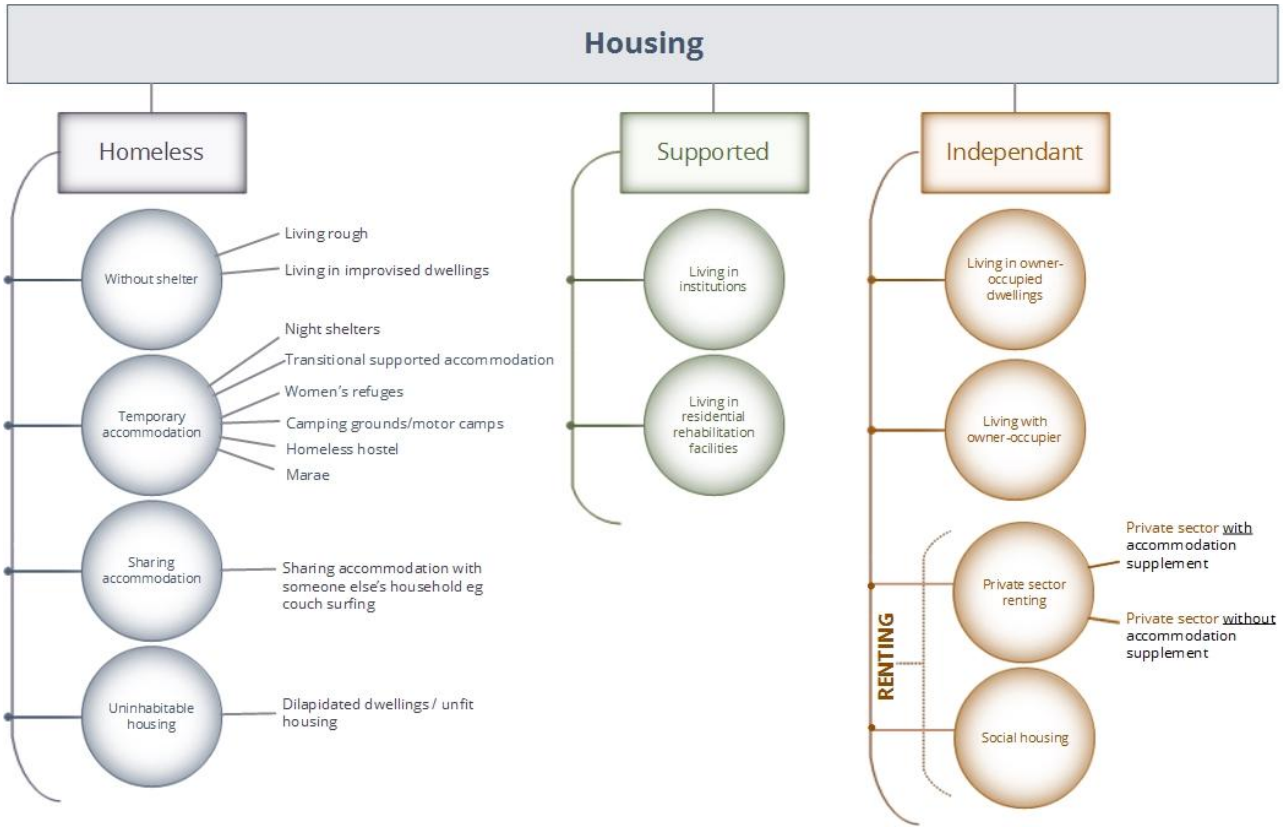
Source: Health Information Standards Organisation (Revised January 2016) PRIMHD Code Set Standard HISO 10023.3:2015 (pp 55-56).

Definitions

A number of service providers reported that front-line staff were experiencing problems classifying the wide range of living situations to fit the PRIMHD categories. It was noted that a couple of DHBs had developed their own drop-down lists to make it easy for staff to make the

right selection. In the interests of obtaining good quality data, the reviewer has developed the classification system in figure 7 for further discussion with the MH&A sector. It includes the many different types of living situations that Statistics NZ (2009) define as homelessness, including any housing which would not normally be considered as being suitable for habitation.

Figure 7: Different types of living situations classified under PRIMHD housing categories



5.3 NZ General Social Survey

5.3.1 Description

The New Zealand General Social Survey 2014 (NZGSS) is New Zealand's official national multidimensional survey of well-being. The survey is biennial, aligned with international measures, and was first administered in 2008. Face-to-face interviews are conducted with over 8,000 randomly selected people aged 15 years and over, living in private dwellings throughout New Zealand.

The primary content of the NZGSS includes information that spans ten core aspects of wellbeing, including housing.

5.4 The quality of housing

The proposed Housing and Physical Environment supplement in the NZGSS will augment the current questions to do with '*major problems with your house*' and will collect information on people's housing and their natural and built environment in relation to their broader well-being outcomes. The objectives and content of the supplement are currently under development and will be in the field in 2018.

Questions from NZGSS (2014) that are relevant to housing quality.

- *"How would you describe the condition of your house or flat?"*
- *"Does your house or flat have no problem, a minor problem or a major problem with dampness or mould?"*
- *"In winter, is your house or flat colder than you would like?"*

Question from Living in the Community Questionnaire (Australian Mental Health Outcomes and Classification Network, 2015).

- *How would you rate your current living situation overall (thinking about cost, location, security and space)?*

In the 2012 NZGSS survey, 33.4 percent of participants reported a major problem with the quality of their housing. The survey also recorded a large difference between people renting their accommodation (49.8 percent reported a major problem) and those living in their own home (25.4 percent). This suggests that home ownership is valuable for wellbeing. However, as the Salvation Army report highlights, the rate of home ownership has steadily fallen since 1991 from 74 percent to 64 percent in 2015.

Implications:

- In the present environment, there is a very real risk that service users will be unable to afford to own their own home because of a combination of rising house prices, low income and increased expenditure on the basics such as food and power. In addition they are likely to be paying higher rent for poor quality accommodation.

Recommendation:

- Service providers to collect information about the quality of housing for use at the local level.

5.5 Housing affordability

Both the cross-party report into *Ending Homelessness* (2016) and the Salvation Army's report on *Homeless Baby Boomers* (2015) have highlighted the inequities that exist with regard to

affordable housing. Access is further complicated by the inadequacies of the current Accommodation Supplement, which has not been adjusted since 2007.

Implication:

- The level of accommodation assistance that is provided by the government is insufficient to meet the housing needs of service users who have low to modest incomes.

Recommendation:

- Service providers to monitor different types of 'independent rental accommodation' in order to capture information about the uptake of the accommodation supplement by service users.

5.6 Overcrowding

In New Zealand, crowding is measured by the Canadian National Occupancy Standard (Goodyear et al, 2012) which essentially defines it as a situation whereby one or more additional bedrooms are required to meet the sleeping needs of the household.

Gray's (2001) summary of the literature on the effects of household crowding concluded by saying that the debate about the relationship between crowding and health is long standing and inconclusive. She thought that the complexity of relationships makes it too difficult to separate the effects of crowding from confounding variables such as the physical condition and type of housing, socio-economic factors and lifestyle choices. Issues of measurement and other methodological difficulties also limit the ability to establish causality.

In New Zealand, Baker et al (2003) also state that while it is widely assumed that crowding represents a threat to mental health, the evidence base for this is less than for the physical effects of crowding. Peace & Kell (2001) found that MH&A service providers did consider that overcrowding was an issue for some Pacific service users more than other groups, but this opinion raises the question of how crowding is defined, particularly with regard to cultural norms.

The complexity of the issues put the issue of household crowding well beyond the scope of MH&A service providers and, for that reason, no questions relating to overcrowding have been recommended in this report. That said, it is recognised that overcrowding is still an issue for some families and that front-line staff do have a role in supporting people who express an interest in changing their living circumstances.

6. EDUCATION

6.1 PRIMHD education and training status

Table 10: PRIMHD education and training categories.

Code	Description	Code Valid From	Code Valid To	Used for/Comment
1	Yes	01-07-2014	30-06-2020	The service user is currently participating in training or education provided by and NZQA registered, recognised or accredited education organisation
2	No	01-07-2014	30-06-2020	The service user is not currently participating in training or education provided by and NZQA registered, recognised or accredited education organisation

Source: Health Information Standards Organisation (Revised January 2016) *PRIMHD Code Set Standard HISO 10023.3:2015* (pp 55-56).

6.2 Overview

Education is one of the strongest indicators of social status (Fiske & Markus, 2012) and it is also one of the key determinants of success in adult life (Boston, 2013). Given that there is a strong social gradient in health (Michael Marmot, 2006), it is not surprising that there appears to be a positive education effect associated with health, with the more highly educated tending to report better health and lower mortality rates than their less educated counterparts (Marmot et al, 1997).

Despite this positive correlation between education and health, this particular indicator had a mixed reception by service user advisors, many of whom questioned its utility, plus a few who were completely unsupportive of it. That said, there was some level of support with regard to its relevance and applicability for youth, specifically those youth who are at risk from becoming completely disengaged from employment, education or training, otherwise known as NEET.

Pacheco (2015) maintains that the rising level of New Zealand youth who are NEET is concerning at both the local and national level, with youth exclusion, disengagement, and overall under-utilisation in the labour market associated with serious personal, economic and social costs.

There is a multitude of empirical evidence suggesting that young people out of employment or education are likely to have a lifetime of poorer outcomes in terms of future unemployment, lower future wages, and reduced happiness and health. There is also evidence in New Zealand of path dependence, with indications that youth who experience a long-term spell of NEET (at least five months) will experience much poorer outcomes than their non-NEET peers after two years; and that the outcomes are particularly poor for individuals who leave school between the age of 15 and 17 years (Pacheco, 2015).

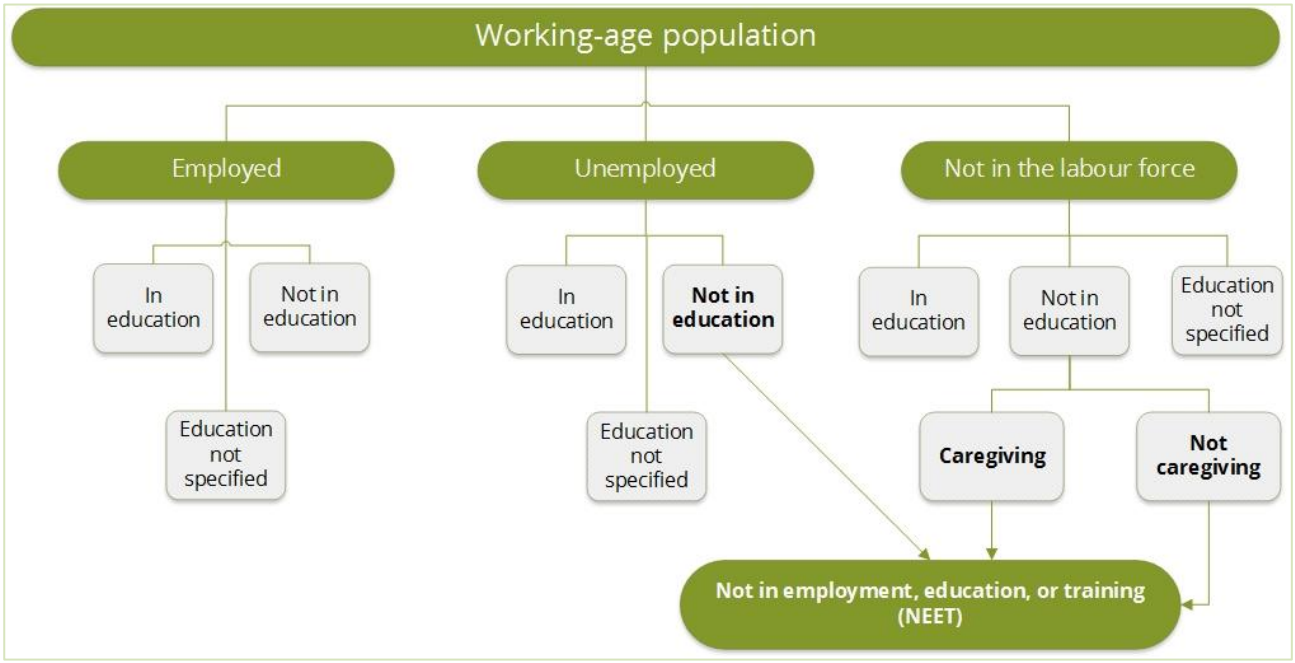
6.3 Refocus on youth who are NEET

Implication:
The development of policies and interventions to mitigate child poverty and to increase opportunities for youth to engage in education or training will have significant economic, health and social benefits.

Recommendation:

- Refocus the education and training indicator on youth aged 15-26 years.
- NEET, as a measure, has an internationally understood definition that is based on an established concept. If the Ministry of Health wants to continue collecting this type of information, it might consider adopting the official measure as described by Statistics NZ (2011a) (see figure 8 below).

Figure 8: Who counts as NEET using the official measure from the HLFS.



Source: Statistics New Zealand (2011a). Introducing the youth not in employment, education, or training indicator. Wellington: Statistics New Zealand.

7. DISCUSSION POINTS

7.1 Person-directed planning

The message from service user advisors was that providers need to rely less on formalised outcome measures and personal plans and focus instead on supporting people to articulate their goals, dreams and aspirations. They were of the opinion that a good relationship built on trust and empathy was more likely to produce the information that a staff member needed in order to complete the SOI information in PRIMHD, rather than relying on a form.

This approach is in accordance with person-directed planning as a mechanism to facilitate social inclusion and is well documented in Connie Lyle O'Brien and John O'Brien's (2000) article: "*Origins of Person-Centred Planning - A community of practice approach*".

7.2 Personalised outcome measures

A recurring question in outcome assessment is how to measure the unique set of strengths and difficulties that are specific to the individual and their circumstances. One of the responses has been the development of an individualised, service user/consumer-generated outcome measure (CGOM).

Despite the growing popularity of and use of CGOMs, they have been viewed with some scepticism, mainly because of the lack of psychometric data for these types of measures, including empirical evidence about their validity (Elliott et al., 2016). However, whilst they are not an evidence based assessment tool, the focus on the individual is very appealing.

7.3 Development of a national item pool/bank

An item bank incorporates a collection of questions that have been organised and catalogued in a similar way to books in a library, including calibrated data on their measurement characteristics. The questions in the item bank would have good validity (ie, testing what is intended to be tested), good reliability, precision and be sensitive to change.

The main advantage of an item bank is its flexibility. In theory it enables people to have access to a wide range of well documented and tested questions from other tools, covering a wide variety of situations. Service users could design their own CGOM based on their personal goals and aspirations. The advantage for providers is that they could have the results related back to some larger reference framework that enabled them to interpret the scores.
The establishment of a national item bank for MH&A services in New Zealand is not a simple task and would require a research team with the necessary expertise to undertake the psychometric calibration of all of the questions. If such research project ever got off the

ground, it is recommended that NGOs be supported to reach agreement on a few standard questions that all service providers could incorporate into their routine assessment process. This core set of questions would enable comparisons to be more easily made between similar services. In many respects, this was one of the objectives that led to the development of the PRIMHD social outcome indicators.

In the absence of the necessary funding for a research project, the first step is to develop an item pool (not an item bank) that includes some candidate questions which have not been psychometrically tested, but which all stakeholders agree might be useful at the local level. A list of some candidate questions can be found in appendix two to this report.

Recommendations:

- The MH&A sector develops a list of optional questions that service providers can choose to use at the local level.
- Establish a central repository (eg, Te Pou) for some candidate questions as part of the process for developing an item pool.
- Consider whether or not it is worthwhile to pursue research funding to calibrate these (and other) questions so that they can be used to support the development of service user/consumer generated outcome measures (CGOMs).

7.4 Cultural assessment

It has been suggested that some optional questions be included in the item pool that support a good assessment, particularly from a cultural point of view. The following five questions are specific to Māori and form part of Te Kupenga (Statistics New Zealand, 2014b).

- How important is involvement in Māori culture to you?
- Have you visited your ancestral marae in the last year?
- Are you able to speak some te reo Māori?
- Have you had face-to-face contact with whānau living in another household in the last month?
- How important is spirituality to you?

These questions are an example of questions that are in existing survey instruments, which could be included in the item pool for local use.

7.5 Target-setting

One of the objectives of this review was to establish whether or not targets could be applied to these SOIs and, if this was a possibility, to determine the value of these targets to different stakeholder groups.

Social inclusion is inherently multi-dimensional, which is why different countries have adopted a set of indicators to help capture the domains that they consider to be fundamental to a socially inclusive society. Whilst these broad domains are critical for the development of public policy, they are unlikely to provide specific measures of the effectiveness of MH&A services because MH&A services are only a small contributor to social issues at both individual and population levels.

Given the problems with attributing change, specific targets are not recommended for the three PRIMHD SOIs. However, this does not preclude them from being used as part of a quality improvement programme. For example, the national NGO Benchmarking Forum offers opportunities for the best-performing organisations to share their achievements in each domain so that other NGOs might learn about what processes and practices work well in different settings and lift their own performance accordingly.

In the spirit of an open learning system, NGOs could set themselves the target of closing the gap based on the best three performing NGOs. Such a criterion could be seen, not as a ranking exercise, but as an application of peer review. This does not mean that the three top performers could rest on their laurels, as they would still need to strive for top performance across all of the SOIs (not just one) and then remain (within a certain range) at the already achieved level or continue to improve further.

Some distinctions might need to be made between different service types to enable fair comparisons to be made between organisations, but the NGO Benchmarking Club has already started this process by making a distinction between mobile community support services, residential services and respite services for benchmarking purposes, which offers a good platform for further work.

The final comment about target-setting is that it is essentially a political act. To fulfil its potential within a social inclusion agenda, it must embody a firm commitment by all parties (ie, service providers, funders and the Ministry of Health) to substantially improve the position of all service users over a specified time-frame. It is not considered ethical practice to collect this information without making this commitment. This view was supported by service user advisors who made it clear that whilst some individual service users might be reluctant to share personal information that they considered to be irrelevant to their own journey of recovery, they might do so if they thought that the information would be used to advocate for social change that benefited the wider group.

7.6 Other national data sources

As previously mentioned, the Integrated Data Infrastructure (IDI) is a potential source of information about a number of different policy issues related to MH&A, including housing, employment and education/training. Rather than having a number of different agencies asking for the same information, from the same group of citizens, albeit in slightly different

ways, there is an opportunity to consider how different national data collections (including PRIMHD) relate to one another. At a national policy level, there may be opportunities to utilise the data that is contained in the IDI to better inform the Ministry of Health's MH&A work programme as well as supporting government's cross-sector activity under *Better Public Services*.

7.7 Workforce development

Trauer & Coombs (2010) have highlighted the difficulties with implementing routine outcome measurement into mental health and addiction services. They pointed out that there are numerous challenges that beset the uptake and use of outcome data including philosophical and practical issues about what should be measured, the application of routine measures, concerns about the quantification of the human condition, questions about the utility of the information, variable ability amongst staff to accurately interpret the information and an underdeveloped information infrastructure. However, perhaps the biggest challenge of them all is the shift towards routine outcome measurement, which gives primacy to the perspective of service users.

In the midst of these seemingly insurmountable difficulties, one thing is certain – the move towards evidence-based practice, based on good quality data, is inexorable. Government's current interest in integrating administrative datasets to help drive social investment decisions only serves to underline this trend. It is now up to all key stakeholders in the MH&A sector to determine how well prepared they are to participate in this new environment.

7.8 Relevance to children and older persons

It is noted that the three social outcome indicators are heavily weighted towards adult MH&A service users. One reviewer requested that some consideration be given to the development of social outcome indicators that were more relevant for children and older persons.

8. SUMMARY OF RECOMMENDATIONS

The following table summarises all of the recommendations that have been made throughout this report.

Recommendation	Section
Ministry of Health to work with Statistics NZ to develop some standard annual reports using the Integrated Data Infrastructure (including labour force participation rates), which would help to support the national social inclusion agenda for MH&A service users.	3.3.3 Disability topic
Ministry of Health to clarify the scope of data collection with regard to 'employment' so that it is clear that it applies to everyone in the working age population.	3.3.3 Labour force status
Ministry of Health to include a caveat to the above rule which enables providers to record the employment status of someone over the age of 65 years who is in some form of paid employment.	3.3.3 Labour force status
Ministry of Health to include two new categories in PRIMHD (ie, 'not in the labour force' and 'employment status unidentifiable') so as not to artificially inflate the number of people who are counted as being 'unemployed'.	3.3.3 Labour force status
Te Pou to continue working with MH&A sector representatives and the Ministry of Health to regularly update the Guide to PRIMHD Supplementary Consumer Record Requirements (Te Pou, 2016) in order to provide clear definitions and a consistent methodology for the collection and use of the social outcome data that is recorded in PRIMHD.	3.3.3 Full-time / part-time status of the employed
As much as is possible, the PRIMHD Standards that have been developed by the Health Information Standards Organisation (2015) and Te Pou's Guide, should reflect the national standard definitions that have already been developed by Statistics New Zealand.	3.3.3 Full-time / part-time status of the employed
The MH&A sector continues to participate in the Ministry of Social Development's *Health and Disability Long-term Work Programme* (2014), which includes a provision for reviewing all government financial incentives/disincentives for disabled people and people with health conditions to work.	3.3.3 Full-time / part-time status of the employed
Service providers that are not using the APQ6 should consider collecting the '*average number of hours worked in the past week*' as a supplementary data item for use at the local level.	3.3.3 Number of hours employed people actually work per week
Service providers to assign the *average number of hours worked in the past week* to a 5-hour time-block to enable change over time to be more easily tracked and benchmarked at the local level.	3.3.3 Number of hours employed people actually work per week
Funders and providers to review how the change in '*employment status at the point of exit from services*' and the change in the '*average number of hours worked*' help to inform one another.	3.3.3 Number of hours employed people actually work per week

Recommendation	Section
Providers to routinely ask service users if they would like a job and, if the answer is 'yes', follow-up with a question asking if they would like some help to obtain one.	3.3.3 Wanting a job
Providers to ensure that people who have the highest levels of labour force disadvantage have access to high intensity evidence-based supported employment services as a matter of priority.	3.3.3 Wanting a job
The Ministry of Health, the Ministry of Social Development and all DHB funders ensure that high intensity, high fidelity, evidence-based employment services are available to service users in every DHB locality.	3.3.3 Wanting a job
Service providers need to proactively engage service users in a discussion about their paid work to help determine if (a) they would like to make any changes and (b) if they need support to make any changes.	3.3.3 Preference for working more or less hours, and under-employment
Te Pou and several NGO service providers to consider testing the APQ6 with a view to assessing its sensitivity to aggregate team and organisational change.	3.4.2 Activity and participation questionnaire (APQ6)
In lieu of being involved in implementing and testing the APQ6, NGO service providers to collect some supplementary information to enable small changes in a service users employment status to be made more visible at the local level.	3.4.2 Activity and participation questionnaire (APQ6)
Given that the burden of data collection needs to be carefully weighed against the possible benefits, it is recommended that service providers choose what (if any) supplementary questions might be of particular relevance to them. The decision to collect additional data will depend on the aspirations of individual service users, the focus of service delivery, the robustness of the organisation's information infrastructure as well as staff capacity and capability in this area.	3.4.2 Activity and participation questionnaire (APQ6)
Providers to monitor both increases and decreases in the number of paid work hours over time.	3.5.2 Analysis of change
Te Pou to continue analysing APQ6 data to further explore questions that are of interest to the MH&A sector (eg, results by different NGO service types).	3.5.2 Analysis of change
All stakeholders to separate 'voluntary work' from any reporting related to 'employment' in PRIMHD. This includes the sub-category 'unemployed'.	4.1 Volunteer work
Service providers to collect information about the quality of housing for use at the local level.	5.4 The quality of housing
Service providers to monitor different types of 'independent rental accommodation' in order to capture information about the uptake of the accommodation supplement by service users.	5.5 Housing affordability
Refocus the education and training indicator on youth aged 15-26 years.	6.3 Education

Recommendation	Section
NEET, as a measure, has an internationally understood definition that is based on an established concept. If the Ministry of Health wants to continue collecting this type of information, it might consider adopting the official measure as described by Statistics NZ (2011a)	6.3 Education
The MH&A sector develops a list of optional questions that service providers can choose to use at the local level.	7.3 A national item pool/bank
Establish a central repository (eg, Te Pou) for some candidate questions as part of the process for developing an item pool.	7.3 A national item pool/bank
Consider whether or not it is worthwhile to pursue research funding to calibrate these (and other) questions so that they can be used to support the development of service user/consumer generated outcome measures (CGOMs).	7.3 A national item pool/bank

APPENDIX 1 – RESULTS FROM DHB & NGO PROVIDER SURVEY

DHB responses = *11* NGO responses = *3*

DISORDERS AND SYMPTOMS	DHB (# of mentions)	NGO (# of mentions)
EDI (for eating disorders)	1	-
Alcohol & Drug Outcome Measure (ADOM)	7	3
Behaviour & Symptom Identification Scale (Basis-32)	1	-
Health of the Nation Outcome Scale (HoNOS suite)	11	-
Kessler Psychological Distress Scale (K10)	1	1
Mental Health Screening Form III (MHSF III)	1	-

CHILD AND ADOLESCENT DEVELOPMENT	DHB (# of mentions)	NGO (# of mentions)
Connors Comprehensive Behaviour Rating Scales	1	-
Substance & Choices Scale (SACS)	1	-
Behaviour Rating Inventory of Executive Functioning (Brief-SP)	1	-
Strengths & Difficulties Questionnaire (SDQ)	2	-

COGNITIVE ABILITIES	DHB (# of mentions)	NGO (# of mentions)
Peabody Picture Vocabulary Test (PPVT 4)	1	-
Stanford-Binet Intelligence Scales (SB5)	1	-
Wechsler Adult Intelligence Scale (WAIS)	1	-
Wechsler Intelligence Scale for Children (WISC)	2	-

SERVICE DELIVERY AND STRATEGY	DHB (# of mentions)	NGO (# of mentions)
Social Impact Measurement for Local Economies	1	-
Session Rating Scale (SRS)	-	1
Outcome Rating Scale (ORS)	-	1
Knowing the People Planning (KPP)	2	-
Marama Consumer Experience Real-Time Feedback	1	1
Consumer Satisfaction Survey	1	

QUALITY OF LIFE	DHB (# of mentions)	NGO (# of mentions)
WHO Quality of Life - Brief Form (WHOQOL-BREF)	-	1
Activity & Participation (APQ6)	1	1

OTHER TOOLS – these were reported but are not outcome tools	DHB (# of mentions)	NGO (# of mentions)
Assessment Data Manager	1	-

APPENDIX 2 – OPTIONAL SUPPLEMENTARY QUESTIONS

The table below includes some optional supplementary questions for possible inclusion in a national item pool. It offers examples of questions that some NGO providers are already asking at the local level. Whilst the focus of this report is on the social outcomes that are of interest to PRIMHD (ie, employment, housing and education/training), an item pool could potentially be expanded to include a wide range of well researched questions that service users and providers could select from.

However, it should be noted that such a development is not a simple task and should, therefore, be subject to some further debate.

Optional supplementary questions (in no particular order)	Adapted from source
Employment	
Last week did you have a full-time or part-time job of any kind?	APQ6
What was the average number of hours that you worked in the past week?	HLFS & APQ6
Would you like to work more (or less) hours?	NZGSS & APQ6
In the last four weeks, were you actively looking for paid work?	APQ6
What are the most useful things that we can do to help you with this?	APQ6
Voluntary work	
In the last week, how much time did you spend doing voluntary or unpaid work through an organisation or group?	LCQ
Would you like to do more or less voluntary work?	LCQ
Housing	
How would you describe the condition of your house or flat?	NZGSS
Does your house or flat have a problem with dampness or mould?	NZGSS
In winter, is your flat/house colder than you would like?	NZGSS
How would you rate your current living situation overall (thinking about cost, location, security and space)?	LCQ
Education	
Are you currently undertaking any course of study?	APQ6
Are you currently enrolled in any of the following courses of study? (Selection)	LCQ

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