

Mental health and the NDIS: A literature review

An examination of the current state of evidence relating to the impact of psychosocial disability on the context of the implementation of the National Disability Insurance Scheme Act 2013.

Commissioned by Mind Australia for the Independent Advisory Council to the National Disability Insurance Agency.

Undertaken by the Centre for Mental Health, Melbourne School of Population and Global Health, Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne.



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1.0 Introduction

1.1 Aim of the literature review

The aim of this literature review is to examine the current state of evidence relating to the impact of psychosocial disability in the context of the implementation of the *National Disability Insurance Scheme Act 2013*. It is intended specifically to assist the work of the Independent Advisory Council to the National Disability Insurance Agency (NDIA), and, more generally, to provide a resource to parties interested in the implementation of the National Disability Insurance Scheme (NDIS) for people who have a disability attributable to mental illness.

The review was commissioned by Mind Australia and undertaken by the Centre for Mental Health within the School of Population and Global Health at the University of Melbourne.

1.2 Background to the review

The NDIS has been designed around the principle of entitlement to support. Such entitlement will ensure that those Australians with disability who meet the criteria for inclusion in the scheme receive the supports they need to participate in the social and economic life of our community. This is a significant shift in emphasis from the previous arrangements, which were predicated on the basis of provision of disability supports through a budgeted amount of funding unrelated to demand. As noted in the Productivity Commission report, this led to a situation where disability support arrangements were ‘inequitable, underfunded, fragmented and inefficient’ and where people with disability had little choice over the supports and services they received, nor certainty about whether they would have access to appropriate supports when needed’ [1] (p. 5).

The principle of entitlement is fundamental to the scheme’s success. The experience of insurance schemes elsewhere suggests that effectiveness may be subject to escalating costs as more people draw on the scheme and/or it is required to fund greater levels of support. In some circumstances, tightening eligibility then becomes a mechanism for managing costs. Whilst the Act sets out the disability requirements for entry into the scheme and identifies the supports that it will fund, its implementation leaves space for interpretation that may impact on who is eligible. This contains the risk that there will be groups of people who will be marginalised or have inequitable access to the scheme. The inclusion of people with disability associated with a psychiatric condition took place relatively late in the process to design the NDIS. Some of the aspects of disability associated with a psychiatric condition are quite different from features of disability associated with physical, sensory and/or learning difficulties, and consequently have not been given the attention they need in the design phase of the scheme. This poses certain problems in the implementation of the NDIS Act. In particular, these relate to the concepts of ‘permanence’ and ‘reasonable and necessary supports’. Related to these definitional issues is a concern about the quantification of the cohort who may be eligible for support under the NDIS.

Further consideration of the application of ‘permanence’ and ‘reasonable and necessary supports’ to the context of impairment associated with a psychiatric condition is required to ensure that the scheme can realise its intention in relation to people with psychosocial disability. These concepts are particularly important in determining who is eligible for the scheme and the supports they will be able to purchase. More specifically, there is a range of contestable issues that require further consideration, including:

- defining notions of ‘permanence’ in relation to the psychiatric condition
- the impact of impaired psychosocial functioning on participation
- the relationship between functioning and what is ‘reasonable and necessary’ support
- the relationship between funded and informal support in the context of the personal experience of psychiatric illness
- the individual’s social status and the impact of structural factors.

This literature review sets out to examine the evidence in relation to these issues.

1.3 Scope and structure of the review

The NDIS Act is explicit about the conditions that need to be met for eligibility into the scheme and what can be funded under it. In the first case, eligibility is based on a notion of permanence of impairment, linked to a capacity to participate in the social and economic life that most Australians enjoy. The Act states that, to meet the disability requirements:+

‘the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:

- (i) communication;*
- (ii) social interaction;*
- (iii) learning;*
- (iv) mobility;*
- (v) self-care;*
- (vi) self-management; and*

the impairment or impairments affect the person’s capacity for social and economic participation; and the person is likely to require support under the National Disability Insurance Scheme for the person’s lifetime.’ [2] (Section 24.1)

The Act also makes accommodation for variation in impairment over an individual’s life course:

‘for the purposes of subsection (1), an impairment or impairments that vary in intensity may be permanent, and the person is likely to require support under the National Disability Insurance Scheme for the person’s lifetime, despite the variation.’ [2] (Section 24.2)

In relation to supports, funding will be provided for:

‘reasonable and necessary supports that help a participant to reach their goals, objectives and aspirations, and to undertake activities to enable the participant’s social and economic participation.’ [3]

The Act does not provide further definition of these terms, and usage varies across other contexts. The review sets out to examine definitions and usage of the terminology relating to ‘permanence’ and to ‘reasonable and necessary’ as they are applied to psychosocial disability attributable to a psychiatric condition (topics 1–3 below). It then goes on to examine a range of key issues that relate to the impact of psychosocial disability within the context of a disability support system (topics 4–8 below).

The literature review addresses eight key topics:

1. The concept of ‘permanent’ impairment and its usage elsewhere, including existing rules set by other schemes and their application in practice (that is, in determining appropriate supports and whether impairment is considered permanent).
2. The likelihood of ‘permanence’ of certain forms of mental illness and the possibility of predicting the long-term course of a particular disorder for a particular individual.
3. The concept of ‘reasonable and necessary’ supports for people with psychosocial disability and how this is used and applied elsewhere.
4. The impact of psychosocial disability arising from mental illness on individuals and the evidence for the nature and extent of psychosocial impairment and its implications in terms of functional impairment.
5. Preferences for support of people with a psychosocial disability arising from mental illness, in relation to the categories of activity in which an individual may experience impaired psychosocial functioning.
6. Common supports used by people with a psychosocial disability arising from mental illness.
7. Gaps between the support preferences of people with a psychosocial disability arising from mental illness and existing services in Australia.
8. The evidence for the effectiveness of different supports, and limitations of that evidence in relation to people’s preferences.

The Act refers to disability ‘attributable to a psychiatric condition’ and notes that the impact of impairment relates to ‘reduced psychosocial functioning’ in one or more of six categories of activity outlined on page 3. For the purposes of this review, the term ‘psychosocial disability’ is used, based on the definition provided by the National Mental Health Consumer and Carer Forum in their document *Unravelling Psychosocial Disability* [4]:

‘Psychosocial disability is the term used to describe the disability experience of people with impairments and participation restrictions related to mental health conditions. These impairments and participation restrictions include loss of or reduced abilities to function, think clearly, experience full physical health and manage social and emotional aspects of their lives.’ (p. 16)

This definition is consistent with that used by Brophy et al [5] in their 2014 study of support preferences with Victorian-based mental health service users. That study was also commissioned by Mind Australia:

‘A mental health issue that affects people’s daily activities such as socialising or interacting with others in a social setting, learning or self-care, or their capacity to fully participate in society.’ (p. 22)

Each section starts with an **introduction** that includes a brief description of the topic and a summary of key points. This is followed by the **findings from the literature** reviewed for that topic area. Each section concludes with a summary that includes a synthesis of the main findings considered in light of the current state of the literature in relation to each topic area, where relevant.

1.4 Method

The review was undertaken in two parts: the first part related to the definitional issues outlined in topics 1–3, and the second to the impact of psychosocial disability and service use outlined in topics 4–8. The methods used for each part are described below.

a) Topics 1–3: ‘permanent impairment’ and ‘reasonable and necessary supports’

In order to discover more about the definitions and usage of ‘permanent impairment’ and ‘reasonable and necessary supports’ related to mental illness, an internet-based search was undertaken to locate policy documents and legislation relevant to Australian Government-funded and other nationwide public health and disability services. Particular attention was paid to documents that described requirements for eligibility for services as it seemed most likely that these would attempt to identify and define client groups. This search was also undertaken in countries with comparable health systems, namely New Zealand, the United Kingdom (UK), the United States (US) and Canada. As the search progressed, it became apparent that an enormous amount of national and local policy and legislation exists relating to the delivery of services to those with disability attributable to mental illness. The scope of the project did not allow for an exhaustive search of these resources and, as such, cannot draw conclusions as to the current state of the definition. Rather, the search aimed to provide some approximation of an understanding of the term ‘permanent impairment’ in Australian and comparable international public health settings.

Where policy documents and legislation were found, these were searched for definitions related to permanent impairment by using the following search terms: ‘mental’, ‘psychiatry’,

‘psychiatric’, ‘permanent’, ‘ongoing’, ‘long-term’, ‘persistent’ and ‘chronic’. Definitions were only included if they made reference to mental illness. While many policy documents and legislation mentioned permanent or persistent mental health impairment, many failed to define these terms.

A similar approach was taken with regard to ‘reasonable and necessary supports’. A targeted literature and policy review was conducted that focussed on NDIS-comparable initiatives in English-speaking countries (those being Australia, New Zealand, US, UK and Canada). The search engines utilised for the purpose of this review were Google scholar and Discovery. Key search terms included either one or a combination of the terms outlined in Appendix A.

b) Topics 4–8: the impact of psychosocial disability

The database Psycinfo was used to search for academic literature related to topics 4–8. This database was also searched for information relating to the course of mental illness described under topics 1–3. The search terms that were used to identify relevant academic literature are provided in Appendix A. These terms were used in various combinations in an attempt to elicit the most relevant literature in each topic area. The search for academic literature was restricted to articles published in English between 1994 and 2014 in peer reviewed journals. The search also focused on literature involving adults aged 18 to 65, excluding literature specifically related to children and older adults (aged over 65 years), although some reference to younger adolescents is made because they form part of a larger sample including young adults. The time and space limitations of this review required a focus on the effects of psychosocial disability related to severe mental illness on three of its common and severe forms only: psychotic disorders (for example, schizophrenia), bipolar disorder and depression.

Following the initial search using the terms provided in Appendix A, abstracts were reviewed to select articles deemed to be most relevant for inclusion in this review. Where there was a vast literature related to the topic, reviews, large-scale studies, longitudinal studies and studies conducted within Australia were selected in an attempt to include the evidence that was strongest and most relevant to the Australian context. Research conducted in countries with more similar health systems and economic situations to Australia, such as the United Kingdom, were also more commonly included than that from less similar contexts, such as India. The literature review also focuses specifically on the effects of psychosocial disability on the individual, excluding those on carers, which comprises its own body of literature.

Following consideration of an early draft of the review, staff from Mind provided additional articles. Reference lists of relevant articles were scanned to identify further relevant literature, and, where the amount of identified literature was limited, search terms taken from relevant articles were used to attempt to identify similar literature. These search terms sometimes included particular authors who had published on the topic or names of particular assessment tools used.

General searching using the Google search engine was also conducted to identify research, statistics and reports released by Government departments and Non-Government Organisations (NGO) providing psychosocial support services that would contain information relevant to these topic areas. Appendix A also includes the names of specific NGOs whose websites were searched for annual reports and other publications to identify relevant information to include in this review.

2.0 The literature review

2.1 Topic one: definitions and usage of 'permanence'

a) Introduction

This section outlines findings of a search for the use of the term 'permanence' in relation to psychosocial disability arising from mental illness as it is used in Australian and international public insurance schemes.

The following summarises key findings from the literature:

- The term 'permanent impairment' or similar is frequently used in Australian and international Government legislation and policy, although it is not always defined.
- There is great variation in the definitions provided for the term 'permanent impairment' and similar terms.
- Despite variations, these definitions include specifications relating to:
 - the presence of a disability/disorder
 - the degree of functional impairment caused by the disability (usually related to an inability to work)
 - the likelihood that the disability and the functional impairment would continue into the future despite appropriate treatment.
- Where the duration of an impairment that is considered 'permanent' is specified, that duration ranges from one to three years across various documents.

b) Findings from the literature

Australia

It is of note that the Productivity Commission report identified the issue of permanence in relation to defining disability but did not draw a specific conclusion in relation to this [1]. The report noted an 'undue emphasis' on a person's current state of functioning at the expense of a more forward-looking assessment of capacity that could take into account the outcomes of early intervention and appropriate and flexible support (p.169). The report notes that all states and territories make some reference to permanence and chronicity where a condition is episodic. Assessment of eligibility would need to cover disability that was 'irreversible' in nature 'even though it may be of a chronic episodic nature' (p.174).

In Australia, documentation of three national public service providers was searched for use of terms relating to 'permanent impairment': Centrelink Australia (provider of Government benefits); transport accident insurers (such as the Transport Accident Commission in Victoria); and Comcare (a Government body that oversees the implementation of Government policy related to the state-based workplace injury insurers). The review also

examined the use of the term in the review of welfare reform by the Commonwealth Government that is currently underway [6].

The *Social Security Act of 1991* [7], which governs eligibility for Centrelink's Disability Support Pension, defines 'permanent impairment' as one that has been diagnosed by a medical practitioner, has been fully treated (where possible) and that is likely to persist for more than two years and cause significant functional improvement that is not expected to improve in the next two years.

Recent figures indicate that 821,738 people out of a total of 23.5 million Australians were claiming the Disability Support Pension (DSP) [6]. Of these, 258,640 people, or 31.1% of the total, recorded a psychiatric or psychological condition as their primary medical condition [8]. This is the largest category of claimants: 26% of claimants recorded a muscular skeletal condition as their primary disability, and 12% a learning or intellectual disability. Moreover, the proportion of people whose primary condition is psychiatric or psychological is increasing: in 2003, this category accounted for 24.7% of DSP claimants, indicating a rise of 6.5% over a ten-year period. For those DSP recipients with a primary 'serious psychiatric condition', this is likely to be their sole medical condition, but for those with a psychological condition (such as depression), they are likely to also have a physical health condition that contributes to their disability [6].

The current review of Australia's welfare system (the 'McClure' review [6]) notes that the definition of permanence currently applied to the DSP is two years, but suggests that this is outmoded and fails to take account of modern advances in working with people with a disability to support their employment capacity (p. 47). The review also calls for better distinction between permanent and temporary incapacity with particular reference to people with psychiatric or psychological conditions (p. 46). It notes that the episodic nature of such conditions may place individuals at a disadvantage within support systems that are designed around notions of permanence that do not take into account changes in the impact of the condition, and calls for 'appropriate interventions and flexible participation requirements to gain and maintain employment' (p. 47). While the report does not offer any advance on the current definition of two years, it suggests that the relationship between permanency of impairment and capacity to work needs review and that a shift in application of 'permanent' is possible, particularly in relation to disability associated with mental illness.

The *Transport Accident Amendment Act of 2013* [9] governs the delivery of services by the Victorian Transport and Accident Commission. The Act describes a 'severe long-term mental disturbance or disorder' as one that has persisted for at least three years and has not responded substantially to effective clinical treatments and has severely impaired functioning.

In contrast to these Acts, Comcare defines 'permanent impairment' in much vaguer terms: 'permanent' is defined as likely to continue indefinitely and includes consideration of the effect of the impairment and the extent to which it may be reasonably capable of being

reduced or removed [10]. Work compensation legislation is set at a State level, and at this level greater specificity relating to duration of a condition to meet the ‘permanence’ criteria may be found. For instance, the Victorian WorkCover Act aligns to the DSP, where ‘permanent’ is taken to be two years.

New Zealand

The accident insurer in New Zealand, the Accident Compensation Corporation, defines ‘permanent impairment’ in the case of mental injury as a loss of function that is well established and unlikely to change substantially in the next year, without further medical treatment [11].

United Kingdom

A search of relevant UK policies and legislation found that, while long-term conditions are often mentioned, no definition of permanent or chronic impairment related to disability (either physical, intellectual or mental or psychiatric) could be found. The searched UK documents include Government Acts that govern the delivery of health and support services such as the *Mental Health Act of 1983*, the *Chronically Sick and Disabled Persons Act of 1970*, the *Health Services and Public Health Act of 1968* and the *Care Act of 2014*. Policy related to assessing eligibility for local government-funded support services was also searched but also failed to identify any use of terms relating to permanent impairment.

United States of America (USA)

The Social Security Administration in the USA, which governs eligibility criteria for access to national health care for people with a low income, defines ‘permanent disability’ as one that prevents someone from both working as they did before or adjusting to other work; that has lasted or is expected to last for at least one year or is expected to result in death [12].

Recent Government Acts that describe access to health care, such as the *Mental Health Parity and Addiction Equity Act of 2008* and the *Affordable Care Act of 2010* mention the term ‘serious and persistent mental health condition’ but do not define it.

Canada

In Canada, access to the Canada Pension Plan requires a disability that is both ‘severe’ and ‘prolonged’. That is, it must regularly stop someone from doing any type of substantially gainful work, is long-term and is of indefinite duration or likely to result in death [13]. A report to the Canadian Federal health department, Health Canada, in 2006 found 16 self-managed care services operating for people with disabilities in Canada [14]. A search of the online documentation of these services failed to find a definition for permanent impairment. Veterans Affairs Canada defines ‘severe and permanent impairment’ as one that results in the veteran requiring supervision or assistance with daily living (including for psychiatric conditions) and defines ‘total and permanent incapacity’ as impairments that are not expected to improve to the point where the veteran will be unable to regain the ability to pursue suitable gainful employment [15].

c) Summary

This search aimed to provide a broad understanding of the use of the term ‘permanent impairment’ within a sample of Australian and international Government health services. Particular attention was paid to documents that describe requirements for eligibility for services as it seemed these would be most likely to define client and disability characteristics.

Many policies and pieces of legislation refer to ‘permanent’, ‘persistent’ or ‘prolonged’ disability related to mental illness, but it was common not to further define these terms. Where permanent impairment in relation to mental illness was defined in Government policy and legislation, this definition was found to vary both locally and internationally. Notwithstanding that, there were some common points. Definitions of ‘permanent impairment’ usually made reference to the presence of a disability/disorder, the degree of functional impairment caused by the disability (usually related to an inability to work) and the likelihood that the disability and the functional impairment would continue into the future. It should be noted that the definitions found were all made in relation to determining access to limited public services and, as such, there was a focus on ‘severe’ disability or impairment when defining permanent impairment. Mild or moderate disabilities and impairments may also be permanent but are assumedly of less concern to Government policy and legislation.

Where permanent impairment was defined, the duration of the disability and functional impairment that is required in order for it to be considered ‘permanent’ varied. In Australia, Centrelink required two years of disability and functional impairment, the Transport Accident Act required three years and Comcare (the Government body overseeing workplace injury insurers) did not require a specific time frame, referring instead to ‘indefinitely’. Internationally, the New Zealand accident insurer referred to a one-year time period. UK policy and legislation did not provide any definition of ‘permanent’. In the US, Government Acts did not define the term, while the US Social Security Administration referred to a one-year time period. In Canada, no specific time frame is mentioned in policy, rather the terms ‘long-term’, ‘indefinite duration’ or ‘not expected to improve’ are used.

Appendix B contains the full definitions of the term ‘permanent’ and other related terms discussed here as stated in the various policy documents and legislation discussed.

2.2 Topic two: the evidence for the long-term course of mental illness

a) Introduction

This section aims to explore the academic literature relating to two main questions:

- Is mental illness ‘permanent’ for some people?
- If so, how can we predict who will recover in the shorter-term and who will not?

To answer these questions, the literature relating to the long-term course of mental illness has been examined to identify factors that provide some predictive power in determining the long-term course of the ill health from its onset. Literature relating to **schizophrenia**, **bipolar disorder** and **depression** is the focus of this section.

The following summarises key findings from the literature:

- Complete recovery from schizophrenia is likely to be relatively rare, probably occurring in approximately 14% of cases.
- The percentage of people diagnosed with bipolar disorder or major depression who experience a single episode followed by no further episodes is probably much higher than for schizophrenia, although recurrence of episodes is still very common.
- Compared with a chronic, unremitting course of illness, a recurrent course comprising periods of illness and remission is far more common.
- People with schizophrenia are consistently shown to have poorer illness course and outcomes than people with other psychotic and non-psychotic disorders, making a diagnosis of schizophrenia a relatively strong predictor of outcomes.
- Earlier age of onset, poorer functioning and more severe symptoms at baseline, early recovery and occurrence of depression symptoms in schizophrenia and bipolar disorder may be among the more supported predictors of illness course and outcomes.

b) Findings from the literature

Schizophrenia

Jaaskelainen et al [16] conducted a systematic review and meta-analysis of combined data from 50 study samples resulting from research examining recovery in schizophrenia in longitudinal, naturalistic research published over several decades. The outcome of this meta-analysis implies that schizophrenia is a disorder from which the minority of people makes a full recovery with no recurrence. However, as the research outlined in the subsequent paragraphs demonstrates, for a large proportion of people with schizophrenia, the course of illness is characterised by fluctuations comprising of periods of illness and remission, rather than a course of severe, continuous symptoms.

Criteria used to determine whether a person has ‘recovered’ from a form of mental illness vary widely across the literature, but Jaaskelainen et al use a fairly stringent definition of recovery in their meta-analysis: that the individual must be both clinically and socially

recovered and that improvements in at least one of the clinical or social outcomes should have persisted for at least two years and symptoms must currently be only mild or significantly better. The median proportion of people with schizophrenia who met these recovery criteria was 13.5%. The mean recovery rate per year for the combined data is 1.4% (that is, over ten years, 14% of people diagnosed with schizophrenia will recover). Calculations based on data from a sub-set of ten studies indicate that recovery estimates for men and women are not statistically different, at 12.9% and 12.1% respectively. Inclusion of studies published over several decades allowed the authors to demonstrate that the rate of recovery has not improved over time.

Most commonly, the long-term **illness course** of symptoms and functioning for people with schizophrenia is described as belonging to one of three main clusters: an initial episode followed by complete recovery (single episode); an episodic course with periods of relapse and remission (episodic/remitting/remission and relapse); and chronic or unremitting course, in which there is no remission from symptoms over the long-term. The percentage of people with schizophrenia whose illness course falls within these three clusters varies widely across studies, perhaps due to: the wide variations in the definitions of remittance, recovery and relapse used; the varying lengths of follow-up studies in which shorter follow-up might fail to identify relapses identified in longer studies; and differing populations from which the study samples are drawn, such as inpatient compared with outpatient treatment populations.

In the literature outlined here, the percentage of people with schizophrenia who experience a **single episode** with no recurrence range from 3% [17] - 59% [18]. However, the latter percentage comes from a three-year study, which might be too short to accurately detect recurrent episodes.

Moller et al [17], in a 15-year follow-up study with 197 participants following their first admission and discharge to an inpatient psychiatric hospital, found that just 3% of participants experienced a single episode followed by full recovery, evidenced by a period of two or more years before follow-up in which both symptoms and functional impairment were mild or better. A higher percentage was identified by Harrow et al [19] who, combining the findings of their 15-year follow-up study of participants following initial hospitalisation for a psychiatric disorder with previous research findings, concluded that ten to 20% of people with schizophrenia will show sustained recovery following an initial episode. Referring only to the presence or absence of psychotic episodes, Harrison et al [20], who followed up patients for between 15 and 25 years, found that 41 to 43% of participants had not experienced a psychotic episode in the two years preceding follow-up; however, other symptoms might have been present. In the much shorter study of Haro et al [18], with a three-year follow-up period, the percentage of participants who had experienced a period of six months or more with only mild symptoms or better and no further hospitalisations was 59%. The relatively short length of this study, however, would prevent the detection of relapses in the longer term.

An **episodic course** of schizophrenia is characterised by periods of moderate or severe symptoms followed by periods of remission, in which symptoms and impairment are mild. Harrison et al (15–25-year follow-up) [20] and Haro et al (three-year follow-up) [18] found that between about nine and 17% of people with schizophrenia in their studies had an episodic course, while Moller et al [17] and Harrow et al [19] (both 15-year follow-up) found 39% and 50% respectively to have an episodic course, again using differing criteria for remission and relapse.

Harrow et al's [19] 15-year follow-up study included participants with schizophrenia and other psychotic disorders such as schizophreniform disorder and affective disorders with psychosis, and other non-psychotic disorders such as personality and eating disorders, and substance abuse. Illustrating the episodic nature of mental illness for many people, at 15-year follow-up, regardless of whether these were followed by relapse, 41% of participants with schizophrenia had experienced at least one period of recovery at some time. In this study, 'recovery' required an absence of major symptoms, adequate functioning and no hospitalisations in that follow-up year. The majority of participants in all other diagnostic groups experienced a period of recovery at some point within the 15 years, including 55% of participants with schizophreniform disorder. For participants with either a nonpsychotic disorder or those with a psychotic disorder other than schizophrenia, 60% who had experienced one period of recovery went on to have three or more periods of recovery.

Estimates of the percentage of people with schizophrenia who will experience an **unremitting, chronic course** of severe symptoms with no periods of remission vary less than those for single episodes and unremitting course. Three of the four longitudinal studies examined here found the percentage of participants with an unremitting course to be between 34 and 57% [17, 18, 20], with one further estimate proposing a range between 25 and 35% [19].

Two additional longitudinal studies characterise the course of schizophrenia in a different way from that outlined above, describing a persistent or fluctuating level of symptom severity over time.

Newman, Bland and Thompson [21] conducted a Canadian study in which the average follow-up period was 29 years from initial hospitalisation for treatment of schizophrenia (conducted from 1963 to 1997). Results of this study led the authors to characterise the course of illness somewhat differently from the three courses mentioned above. They also identified three distinct courses of schizophrenia, but these related more to symptom fluctuations: (1) chaotic course with ongoing severe symptoms; (2) gradual improvement after initial illness; and (3) a relatively stable course over time. It is not clear what percentage of participants' illnesses were characterised by each of these courses, although a stable course was seen as relatively rare. Newman observed little change in symptom scores between the second and third years after admission and the final two years of follow-up, suggesting that overall there was little change in the severity of the illness over the long-

term, supporting the conclusion of Jaaskelainen et al [16] that the yearly recovery rate from schizophrenia is low. Those participants in group one overall spent all of their years after initial admission experiencing either moderate or severe symptoms; group two spent about three-quarters of their years with mild symptoms, and about equal time of the remainder with moderate and severe symptoms; and group three spent most of their follow-up years with moderate symptoms. Across the follow-up period and all groups, 47% of total follow-up time after first inpatient treatment was spent living with a severe level of symptoms, followed by 29% and 25% spent living with moderate and mild symptoms respectively.

In a study involving participants with either bipolar disorder (48%) and/or schizophrenia or schizophreniform disorder (42%) (N = 177) followed up for two years, Green et al [22] plotted the course of the disorder for the study period and identified one additional course to that of Newman et al [21], including two stable and two fluctuating courses. The four recovery trajectories did not vary across diagnoses. The four trajectories were: (1) high-stable, in which recovery was rapid and stable; (2) moderate-high fluctuating, in which initial recovery was moderate but followed by a worsening of the illness and then an improvement; (3) moderate-low fluctuating, in which recovery was poor, then greatly increased, then returned to being relatively poor; and (4) low-stable, in which recovery was poor and remained poor across the study. The number of participants assigned to each group was relatively even. Participants in the low-stable and moderate-low fluctuating clusters had worse lifetime functioning and were less likely to be employed or studying than those in the moderate-high fluctuating and high-stable groups.

It is possible to identify some **predictors of outcome** from the evidence presented in the literature. Consistent across it is the conclusion that people with schizophrenia have poorer illness outcomes and illness course than those with other psychotic disorders such as schizoaffective disorders, and compared with affective disorders such as bipolar disorder and depression. Therefore, diagnosis of schizophrenia is a strong predictor of general illness course and outcomes, although, as shown above, illness course and outcomes do vary across people with schizophrenia.

In Moller et al's study [17], at 15-year follow-up, patients with schizoaffective disorder had lower symptom scores all round than participants with schizophrenia. While people with affective disorders showed higher scores for depressive syndrome, these symptoms declined markedly from admission to discharge and increased again only a little at 15-year follow-up, in contrast to participants with schizophrenia, who showed the greatest presence of paranoid-hallucinatory symptoms at admission, which declined significantly between admission and discharge, but which had again increased at 15-year follow-up, though not to the original level. These observed symptoms at follow-up were largely chronic throughout the 15-year course. Negative symptoms declined less, although still substantially, from admission to discharge but negative symptoms at 15-year follow-up had increased to almost the level seen at admission. Again, these symptoms were largely chronic throughout the 15 years. At the 15-year follow-up point, patients with schizophrenia were shown to have much

greater disability than those with either an affective or schizoaffective disorder, who also showed very similar disability profiles. With few exceptions, those patients with schizophrenia showed greater disability across 14 domains of functioning and the proportions of patients with schizophrenia shown to have severe or very severe impairments (64%) were significantly higher than the two other groups, at 19% for schizoaffective and 5% for affective disorders.

At all-time points in the 15-year study of Harrow et al [19], those with schizophreniform disorder tended to have better outcomes than those with schizophrenia but poorer outcomes than those with any other disorder. Those with psychotic disorders tended to have poorer outcomes than those with nonpsychotic disorders. At two-year follow-up, 10% of patients with schizophrenia were in recovery, and this remained at between 19 and 22% over the 15-year follow-up. The same percentage (19%) of people with schizophrenia was in recovery at 4.5 years as at 10 and 15 years. The authors tracked individual recovery at 10- and 15-year follow-up and found that, of the 11 people in recovery at the ten-year follow-up, seven were still in recovery at 15-year follow-up (64%), while just two participants not in recovery at ten years moved into recovery by 15 years (5%). These results once again suggest a low recovery rate over the long-term. By comparison, from 7.5 years to 15-year follow-ups, 50% or more participants with nonpsychotic disorders were in recovery; this group showed the greatest recovery. Second were those with psychotic disorders other than schizophreniform disorder or schizophrenia, with 37 to 43% in recovery from 4.5-year follow-up onwards. Those with schizophreniform disorder had a 37% or above recovery rate from the 4.5-year time point onwards. There was greater movement from non-recovery to recovery between the ten and 15-year follow-up time points in these groups compared with those with schizophrenia. It is worthy of note that the lowest rate of recovery was seen for all groups at the earliest two-year follow-up and rose sharply for all groups at the 4.5-year follow-up.

Apart from diagnosis, a range of factors has been identified in various studies as predictors of poor outcomes in psychotic disorders; however, indicators of functioning or disability early in the illness course, elapsed length of illness and certain illness characteristics repeat across studies as significant predictors of poor course and outcomes.

Wiersma's 15-year study of social disability in people with schizophrenia [23] found that the best predictor of disability at the 15-year time-point was level of disability measured at the various time-points throughout the study, at baseline, one and two years. The greatest predictive value for outcomes at 15 years was for disability scores at two years. The correlations between scores at these time-points with the disability score at 15-year follow-up were .35, .48 and .55 respectively. In this study, a disability index was calculated using scores from the WHO Disability Assessment Schedule (WHO-DAS) and used in the subsequent data analyses.

Similarly, Haro et al [18] found that the strongest predictor of course at the three-year follow-up was social functioning at baseline, which, in this study, was measured by

determining if the person was living independently, was in paid employment, was socially active and had a romantic partner. Whether the person was in paid employment at entry to the study was the most powerful predictor of course at three-year follow-up, with competitively employed patients having higher likelihood of persistent remission. This may be in part due to the positive effects of competitive employment but is also likely to relate to characteristics of the person and their environment that allow them to maintain employment, such as their own competencies and the presence of strong social support.

Lambert et al [24], in a three-year follow-up study of 392 participants with schizophrenia, also concluded that remission and recovery were predicted in part by functional status at baseline and early improvement (within three months) in functioning and wellbeing, with few participants who did not have good functional level (10%) at baseline going on to achieve good functional outcomes at the final, three-year follow-up (65%).

Tsang et al [25] conducted a review of 62 studies examining predictors of vocational outcomes among people with schizophrenia and also identified that work history was a good predictor of vocational outcomes, as was marital status and education, which could all be considered indices of functioning.

Tsang et al [25] also noted a predictive role of negative symptoms related to vocational outcomes. Harrison et al [20] found the negative depression symptoms of blunted affect, loss of interest and lack of contact with friends to be predictive of poor illness outcomes. Similarly, Peterson et al [26] identified that full recovery was best predicted by fewer negative symptoms, as well adherence to medication, at baseline. Similarly, Moller et al [17] found that the presence of negative symptoms at discharge was predictive of a chronic course of schizophrenia.

Haro et al [18] observed that those participants with a longer duration of illness at entry to the study were less likely to experience any illness remission, while those in this study who were receiving antipsychotic medications for the first time were the most likely to achieve remission. Lambert et al [24] also found that early remission of symptoms and functional impairment and improved subjective wellbeing at three-month follow-up were also predictive of remission and recovery at three-year follow-up.

Perkins et al [27] conducted a meta-analysis of studies that assessed the relationship between the duration of untreated psychosis and the outcomes of first-episode schizophrenia. The authors concluded that a longer period of untreated psychosis before beginning antipsychotic medication relates to poorer symptomatic and functional recovery from the first psychotic episode. However, from the existing literature at that time, they were unable to conclude whether an initial period of untreated psychosis increased the likelihood of further psychotic episodes.

Peterson et al [26], however, observed that having a shorter duration of untreated psychosis at study entry was a strong predictor of having no symptoms at follow-up, with the chance

of remission reducing substantially with each week that psychosis is left untreated. Harrison et al [20] also linked long-term illness outcomes with the early experience of psychosis:

'the strongest predictors [of long-term outcome] were measures of early illness course. Percentage of time spent experiencing psychotic symptoms in the 2 years following onset was the best predictor for all outcome measures: the shorter the percentage of time with psychotic symptoms, the better the long-term and disability scores, as well as the overall course of the illness.' (p. 514)

Bipolar disorder

The way in which terms such as 'relapse', 'remission' and 'recovery' are operationalised varies greatly across studies, as do the duration of follow-up periods. However, some consistency does emerge in describing the most common **course of illness** in bipolar disorder as one in which recovery from an initial episode is most often followed by recurrent episodes [28-31]. Miller et al [29] identified that just 8% of participants never experienced a single month of follow-up without symptoms, while 5% experienced no symptoms after the initial episode, suggesting that those with a single episode followed by complete recovery and those with unremitting symptoms are both in the minority.

Similarly, Salvatore et al's [30] five-year follow-up study with 173 psychiatric inpatients with bipolar I disorder found that 98% of participants at two-year follow-up no longer met DSM-IV criteria for an acute major episode. However, complete absence of symptoms was less common (72%) and return to previous functioning was even more rare (43%). More than half of participants (57%) returned to full syndrome (relapse), had a new episode of depression after initial mania (switch) or had a new episode of either depression or mania (recurrence) within two years of intake.

Similarly, Treuer and Tohen's [31] discussion of the work of Perlis et al (2006) states that this study found that, while 58% of participants recovered from their initial episode within two years, half of these went on to experience recurrent episodes after initial recovery.

Goldberg et al [28] contacted 51 patients hospitalised for bipolar I disorder and 49 for major depression at about 2.5 years and 4.5 years after discharge. In the year preceding the first follow-up, 27% of participants experienced complete remission, while this percentage increased to 41% in the year preceding the second follow-up. Re-hospitalisation rates across the full study period were 45% for participants with bipolar disorder and 41% for those with depression.

Given that research evidence suggests that the course of bipolar disorder typically involves a course of episodes of illness followed by remission, several studies included here provide data on the percentage of total follow-up time people with bipolar disorder spend in any mood episode in contrast to time spent in a 'normal mood' (euthymic). The percentage of time spent in a mood episode in the various studies ranges from 31 to 63% of all follow-up

time [29, 32-35]. These variations might result because some studies include the experience of a subsyndromal level of symptoms in this percentage while others do not, and because of the varying length of follow-up times, from nine months [32] to 20 years [35]. Illustrating the fluctuating nature of bipolar I disorder, Miller et al [29] found that over the study period, 87% of participants spent time at each level of symptoms: none, partial or full. Few participants (8%) never experienced a single month without symptoms and similarly few (5%) had no symptoms after baseline. Taken together, these findings illustrate that, for most people with bipolar disorder, the course of the disorder is fluctuating and a relatively large proportion of time is spent with a subsyndromal level of symptoms or with no symptoms and a milder level of impairment.

Bopp et al [32], tracking the mood of 62 participants with bipolar I or II disorder weekly over an average period of 36 weeks, found that about 37% of total time was spent euthymic (in a normal mood state). Solomon et al [35] followed up 219 participants, who were primarily diagnosed with bipolar disorder, for a median length of 20 years. On average, participants spent 31% of their time with a mood episode (median = 23%). Joffe et al [33] followed up 138 patients with either bipolar I or II disorder for between one and three years from entry into an outpatient program, and found half of participants were euthymic (experiencing normal mood) over the study period, while about 50% of time across all participants was spent with some mood symptoms, although these were most frequently at a low, subsyndromal level. Miller et al [29] traced symptoms monthly for about two years in 61 patients with bipolar I disorder and, similarly to Joffe et al, found the median amount of time spent without symptoms was 59%, while 8% of time was spent being 'fully symptomatic'. Conversely, the majority (72%) experienced at least one month of the total time being fully symptomatic after the baseline episode. In the review of Miklowitz et al [34], Judd et al (2002) are cited as finding that participants with bipolar I disorder have significant symptoms for about 50% of weeks.

Consistently, studies of mood episodes experienced by people with bipolar disorder find that a far higher percentage of time is spent with depressive symptoms compared with mania, including hypomania, or in mood cycling [29-34]. Percentage of time spent with depressive symptoms across studies ranges from 14% [29] to 48% [32], compared with 3% [29] to 7% [32] of time spent with manic symptoms or cycling seen in 9% of follow-up time [32]. Similarly, Judd (2002 in [34]) and Perlis et al (2006 in [31]) estimate the time spent with depressive symptoms is three times and two times, respectively, that spent with mania or mixed episodes. Miller et al [29] also found that it was most common for participants to experience both manic and depressive symptoms across episodes. 18% of participants were classified as experiencing 'rapid cycling' (four or more mood episodes within 12 months) but, overall, there was significant variation in depression scores from month to month within individuals.

Bopp et al [32] also found that those with bipolar I disorder spent more time in depression than did those with bipolar II and, correspondingly, those with bipolar II were euthymic for a significantly greater portion of time than participants with bipolar I. Over the study period,

the level of depressive symptoms varied little for those with bipolar I disorder, whereas those with bipolar II disorder started with a higher level of depression, but this reduced substantially over time. While men initially reported more severe depression symptoms, this reduced to be similar to that of women, who had a more stable level of depression. Conversely, women started the study with a higher level of mania than men, but the gender difference reduced over time.

Salvatore et al [30] also found that depressive symptoms were dominant, with 30% of time spent with depressive symptoms of some type, despite use of antidepressant medication within the sample. Joffe et al [33] similarly found that, across all participants, 41% of time was spent in some level of depressed mood, from subsyndromal (most commonly) to severe depression (least commonly), while just 6% of time was spent in mania. Miller et al [29] found far more time was spent with depressive (mean = 14%) symptoms than with manic symptoms (mean = 3%). Those with bipolar I experienced more time with some manic or hypomanic symptoms compared with those with bipolar II.

Length of episodes has also been discussed in various studies. For example, Miller et al [29], using a sub-sample of 54 participants' data, calculated that the mean time to remission from the index episode was about six months, although ten participants experienced no remission in the first nine months. Solomon et al [35] followed up 219 participants for a median length of 20 years and found that, for the first five mood episodes, one-quarter of participants recovered within five weeks of onset, 50% within 13 weeks and 75% within 38 weeks. Salvatore et al [30] also found that those who had their index mood episode in either a depression or mixed mood state had a worse course than those beginning in mania or psychosis.

In Miller et al's study [29], on average, each participant experienced a mood episode every ten months across the study period; the mean length of these episodes was one month. Conversely, periods of wellness occurred about every seven months and lasted a median of 3.3 months. Solomon et al's [35] participants experienced a mean number of 0.4 episodes per year of follow-up. The mean number of episodes per participant overall was 5.5. Depressive episodes lasted a median duration of 15 weeks, with 75% having recovered within 35 weeks of onset. Cycling episodes lasted a median of three to 14 times longer than episodes of mood elevation or depression and mixed cycling episodes even longer, at four to 20 times longer than single mood episodes. Furthermore, it is far more difficult to recover from an episode of major depression than from an episode of minor depression, mania or hypomania.

Findings from the research cited here as to whether the frequency of episodes increases over time is mixed. Solomon et al [35] studied the first five mood episodes occurring for sub-set of participants and found that the time to recovery from each episode did not vary depending on the number of previous episodes, and that length of episodes was inconsistent, suggesting that episodes did not reliably lengthen over time. Salvatore et al

[30], however, observed acceleration of cycling with successive mood episodes within 30–40% of participants.

The literature also provides evidence for **predictors of outcome** related to the illness. The first of these relates to **age of onset**. There is some evidence to suggest that bipolar disorder that begins in childhood or adolescence tends to follow a worse course than that with onset in adulthood.

The review of Miklowitz et al [34] cites several studies (Axelson et al, 2006; Birmaher et al 2009; Geller et al, 2008) that suggest the onset of bipolar disorder before 18 years of age is associated with more severe course and worse functional impairment compared with those whose bipolar disorder had its onset after 18 years of age. Truer and Tohen [31] also cite several studies suggesting that people with bipolar disorder that begins in childhood or adolescence, rather than adulthood, are at greater risk of poor outcomes, including greater recurrence, more severe symptoms, greater time spent in episodes and poorer functioning. These review findings are also consistent with the work of Suppes et al [36], who found that onset before the age of 17 was related to multiple (20 or more) mood episodes, corrected for age, and more severe course of illness, including greater continuity of symptoms. Early onset was also related to having a family history of bipolar disorder.

Furthermore, Birmaher and Axelson [37] conducted a review of existing literature up to 2006, including eight longitudinal, naturalistic studies, and others examining the characteristics of early onset bipolar disorder. Summing up the research evidence, they concluded that while 70–100% of children and adolescents with bipolar disorder recover from their initial episode, as many as 80% will have recurrences. Furthermore, the course of bipolar with onset at a young age is characterised by frequent switching, with a fluctuating course from subsyndromal to severe symptoms that is more rapid than that seen in adults, making it more difficult to treat. Those young people with low socioeconomic status, earlier onset and longer duration of illness, mixed episodes, psychosis, comorbidities and family history were concluded to have poorer long-term outcomes. The rapid and repeated mood fluctuations seen in early onset bipolar disorder prevent normal psychosocial development; consequently, re-hospitalisations are common, as are psychosis, attempted and completed suicide and overall poor functioning, including academic, social and interpersonal functioning. Furthermore, drug abuse is common, as are conduct and legal difficulties, and service utilisation among young people with bipolar disorder is poor. Naturally, there are also severe negative consequences for the family.

There is some research evidence to suggest that recurrence of mood episodes is linked to **preceding life events** in people with bipolar disorder and might have negative effects on recovery. A model has also been proposed which purports that while early mood episodes in bipolar disorder are triggered by life events, later events become more random. This phenomenon is known as ‘kindling’. However, the research described here suggests that

support for kindling is mixed, and if it does occur, might only occur in a sub-group of people with bipolar disorder.

The review of Alloy et al [38] found negative life events frequently to precede depressive episodes and both negative and positive life events to precede manic episodes. Miklowitz et al [34] also discuss several studies in which it was found that the occurrence of life events related to the recurrence of mood episodes in people with bipolar disorder. These include the findings of Miklowitz and Johnson (2009), who found that life events contributed to relapse and recovery in bipolar disorder; Johnson and Miller (1997) and Johnson et al (2008), who found that negative life events were associated with slower recovery from depression in bipolar disorder and with increases in depression over time; and Johnson (2005), who found that negative life events predicted depressive episodes in both bipolar disorder and depression. Johnson et al (1997 in [39]) also observed that experiencing severe negative life events delayed recovery and might also affect adherence to medication, compounding negative effects.

Wehr et al (1987), Malkoff-Schwartz et al (2000) and Jones et al (2005) (all in [34]) each identified that manic symptoms are often preceded by sleep disruption, such as that associated with childbearing or international travel, and by life events that accelerate engagement with goals. However, some later research suggests this may be related to the broader issue of inconsistent daily and nightly routines, which have also been shown to be more common among people with bipolar disorder.

Since the occurrence of life events is largely unpredictable, and life events may prompt the recurrence of mood episodes in people with bipolar disorder, predicting recurrence at an individual level is difficult. Furthermore, there is also some evidence for the phenomenon known as 'kindling' (Post, 1992 in [40]), in which earlier mood episodes are linked to life events, while later episodes occur more autonomously, without such precedents, as a result of changes in the electrophysiology of the brain following recurrent mood episodes. Bender and Alloy [40] conducted a review of fourteen studies examining the kindling effect in bipolar disorder and found that eight of these observed the effect, including two that only found kindling in only a sub-group of participants. However, four of the higher-quality studies failed to find the kindling effect.

The outcomes of this review led to the conclusion that:

'despite underwhelming evidence in support of the kindling effect in BD [bipolar disorder], it is premature to conclude that the model does not apply.' ([40], p. 393)

Therefore, there is also the possibility that later recurrent episodes might become more unpredictable.

In relation to the effects of the **family environment**, Miklowitz and Johnson (in [34]) found that family impairment contributed to relapse and recovery, and Nolen et al (in [31]) also found that total number of episodes was related to family history of drug abuse, illustrating some effects of the family on recovery from bipolar disorder. Furthermore, also in the Miklowitz review [34], Hooley (2007) found some effect of emotional expression of caregivers (EE) on recovery from bipolar disorder. EE is the term used to describe critical attitudes, hostility or emotional over-involvement of people associated with the person with mental illness. Some studies suggest that adult patients who have familial caregivers with high EE have higher rates of relapse or more severe mood symptoms over a nine-month to two-year period compared with those with low-EE caregivers. Kim and Miklowitz (2004) and Wendel et al (2000) (in [34]) suggest that the impact of EE could be stronger on depressive, compared with manic, symptoms. Miklowitz et al (1988 in [34]) also suggest that the EE effect holds true with adolescents, with more persistent mood symptoms shown in adolescents with high-EE, compared with low-EE, parents.

Several studies identified in this review suggest a unique role for **depressive symptoms** in predicting poorer illness outcomes in bipolar disorder.

Gilbert and Marwaha [41] conducted a systematic review of prospective, long-term follow-up studies (at least 18 months) that included data regarding predictors of employment outcomes in people with bipolar disorder. Three high-quality studies included in this review found that occurrence, and length of, depressive episodes predicted full-time employment or work functioning. Similarly, Coryell et al (1998, in [39]) followed up 113 participants with bipolar disorder for 15 years and found that having persistent depressive symptoms over a two-year period was predictive of poor long-term prognosis. Baca-Garcia et al (2007 in [31]) also found that shorter time to syndromal recovery was predicted partly by lower depression scores at index episode (and shorter initial hospitalisation). Finally, Marneros et al (1991 in [31]) found that prognosis for those whose initial episode was manic was better than for those who first experienced a depressive episode. This is also consistent with the earlier discussed finding of Solomon et al [35], who state that recovery from an episode of major depression in bipolar disorder is more difficult than recovery from mania.

Lack of full remission or the **persistence of residual or subsyndromal symptoms** following a full mood episode might be one predictor of bipolar illness course and outcomes.

Perlis et al (2006 in [31]) found that the persistence of residual symptoms following a full mood episode was predictive of depressive recurrence. In the study of Tohen et al (2006, in [31]), chronic subsyndromal syndromes and the emergence of depressive symptoms were predictive of a shorter time to recurrence, and subsyndromal depression in the first two months of recovery were predictive of depressive relapse. Burdick et al [42] also identified that more severe recent subsyndromal depression was predictive of poor occupational outcome.

There were many **other predictors** noted in other studies of bipolar disorder that were not so commonly cited as those discussed above. These include number of days in the preceding year in which the participant was depressed or anxious which, in the study of Perlis et al (2006 in [31]), was predictive of depressive recurrence. Similarly, Solomon et al [35] found that greater time spent in illness was predictive of recovery, such that every additional year spent in illness with a mood episode resulted in an 8% reduction in the likelihood of recovering from the next mood episode. Suggesting a predictive role of level of functioning, Nolen et al (in [31]) found that number of episodes was predicted by poor occupational functioning, and the review of Truer and Tohen [31] notes two studies in which participants with poorer premorbid functioning had worse outcomes than those with better premorbid functioning.

Burdick et al [42] undertook neurocognitive testing with 33 participants with bipolar I disorder 15 years after an index manic episode. They found that global functioning and social impairment was predicted by measures of scores on the WAIS digit symbol performance measure of processing speed, with greater processing speed predicting better functioning. Greater verbal learning impairment was also a significant predictor of poorer occupational outcomes. The authors also found that increased lifetime of hospitalisations was a significant predictor of poorer occupational outcome. Comparing poor work outcome and good work outcome groups, the former had a three-fold increase in hospitalisations compared with the latter outcome.

Depression

The following section includes various findings of the systematic literature review of Steinert et al [43]. This review included only studies of people with depression assessed by an observer (not self-report) recruited from the community or general practice (not inpatients) and that were naturalistic; that is, in which the researchers did not intervene in any way such that participants received 'usual care' in its various forms. The result of these criteria was the inclusion of 12 study cohorts totalling 4,009 participants followed up for a range of three to 49 years. Various other studies are also described.

Across the studies discussed below, the percentage of participants experiencing just a **single episode** of major depression followed by a full recovery for the duration of the follow-up period ranges from 35 to 60%, suggesting good recovery for a substantial proportion of people experiencing an episode of major depression.

For the six studies reporting on rates of 'stable recovery' included in the review of Steinart et al [43], the percentage of participants who had no further episodes of depression beyond the index episode ranged from 35 to 60%. The mean percentage of participants with stable recovery was 49%. In the two-year study of Viinamaki et al. [44], the proportion of participants who were 'recovered' at final follow-up was about two-thirds; however, this follow-up period may have been too short to detect episodes occurring in further years. Kuehner and Huffziger conducted follow-up assessments with 68 depressed psychiatric inpatients at one, six, 42 and 66 months (5.5 years) after discharge from the inpatient facility. They found that, post-discharge, two-thirds of participants were 'fully remitted' in that they no longer met the criteria for major depression on the Structured Clinical Interview for DSM-IV (SCID-I), and 45% of these had no relapse over the 5.5-year follow-up periods (about 40% overall); 53% of participants were not re-admitted to an inpatient facility over the follow-up time.

Across all of the studies discussed in this section, the percentage of participants experiencing more than one episode of depression ranges from seven to 75%. Excluding the shortest study, of just three years duration, which might be too short to identify **recurrent episodes**, the range is reduced to between 35 and 75%. These findings suggest that a substantial proportion of people experiencing one episode of major depression will go on to experience another episode.

Seven studies in the review of Steinart et al (2014), covering a follow-up span of between three and 23 years, showed that between seven and 65% of participants have a recurring course of depression interspersed with periods of recovery. The mean is 39%. However, these studies also suggest that the longer the period of follow-up, the greater likelihood of detecting recurring episodes of depression, with the shortest study of three years showing just 7% with a recurring course, while the longer studies between six and 49 years showing recurrence rates of 35 to 65%. In the narrative review of Richards [45], the percentages of participants experiencing more than one depressed episode within the various follow-up times are as high as 75%. In the NIMH Collaborative Depression Study (CDS, in [45]), on average participants experienced two more episodes of depression over ten years. The findings also suggested that, with each episode of depression, the likelihood of another is increased, and the time to recurrence is shortened.

Kuehner and Huffziger's [46] 5.5-year follow-up of 68 depressed psychiatric inpatients found that, post-discharge, two-thirds of participants could no longer be diagnosed with major depression nor dysthymia (a more mild, but often longer-lasting form of depression); that is, were in 'full remission'. This percentage increased to 77% at six-month follow-up, after which there was a levelling off of the proportion of participants in full remission (78% at 3.5 years and 72% at 5.5 years). Partial remission was experienced by between 7% (at 42 months) and 21% (at one month) of participants across the 5.5 year period. Note that participants in full or partial remission at any time point are not necessarily the same participants in remission at another time point. Of those with either full or partial remission

of symptoms post-discharge, more than half (55%) experienced at least one recurrence of a depressive episode.

Based on the findings of this review, it appears that the percentage of research participants with major depression who experience a **chronic or unremitting course** of depression over the long-term is smaller than those experiencing a recurrent course or a single episode. Estimates of the percentage of participants experiencing an unremitting course are also relatively narrow, at between six and 17%.

Six studies examining the course of depression over a period ranging from three to seven years in Steinart et al's [43] review showed that the minority of people with depression, between ten and 17%, have a chronic or unremitting course of depression in which there are no periods of recovery. In Kuehner and Huffziger's [46] study, the percentage of participants with 'unremitting' symptoms was fairly stable over time, ranging from 10% at 5.5 years to 15% at 3.5 years. In the review of Richards [45], cited studies similarly report percentages at between six and 15% over various time periods.

Studies of the time course of recovery in major depression reviewed here largely suggest that the majority of **time spent in recovery** occurs in the initial years following onset, after which the rates of recovery greatly slow, making it less likely for a person who does not experience early recovery to go on to recovery later in their illness.

In the study of Kuehner and Huffziger [46], 77% of participants were no longer experiencing depression or dysthymia at six-month follow-up; however, there was little increase in this percentage up to 5.5 years follow-up. Similarly, several studies included in the review of Richards [45] note that the greatest rate of remission or recovery occurs within the first year of the index episode of depression, after which the rate of recovery greatly slows. For example, in the NIMH Collaborative Depression Study (CDS, in [45]), at year one the median recovery rate was 67%, while this slowed to just 9% for each year after. After ten years, 93% had experienced a period of recovery, but the rate of recovery levelled out between five and ten years. Also cited in Richards [45], Wells et al (1992) estimated that 50 to 70% of participants recovered within the first year.

Cronkite et al [47] conducted a 23-year follow-up study that began with 382 depressed participants receiving treatment in the community. This study has several important findings. Firstly, there was a significant, positive correlation ($r = .42$) between depression scores at all of the one-, four-, ten- and 23-year follow-up time points, such that those participants with the highest depression scores early in the study retained the highest level of depression at the end of the study, and vice-versa for those with the lowest level of depression. Secondly, three distinct courses of depression were identified. About 23% of participants had a relatively low depression score at baseline (measured on the Health and Daily Living Form), which reduced rapidly up to the four-year time point and then levelled off, remaining at a relatively low level up to the 23-year follow-up. Half of participants at baseline had a moderate level of depression, which also declined fairly rapidly up to the

four-year follow-up, then levelled off, remaining at a higher level of depression than seen in the low severity group up to the 25-year follow-up. About 28% of participants had a high depression score at baseline, followed by modest reductions in symptoms over the next four years, then continuing declines up to the ten-year follow-up, then a levelling off of symptoms. Therefore, for the low and moderate depression groups, symptoms had declined substantially at the four-year time point and then levelled off, while those with the highest level of symptoms saw a slower decline in symptoms, which levelled off after the ten-year time point.

The review of Steinert et al provides evidence that, for most people experiencing depression, there will be **periods of recovery** in which symptoms remit and functioning improves. Looking at any period of recovery over the follow-up period, across seven studies included in the Steinart et al [43] review, ranging from seven to 23 years of follow-up, between 70 and 85% of participants had a period of recovery at some stage. The mean percentage of participants who experienced at least one episode of recovery was 54%. Between 41 and 89% were remitted or recovered at the final follow-up point.

Three studies included in the review of Steinart et al [43] examined the **length of depressive episodes and the time between them**, although the definitions of what constitutes an 'episode' varied across studies such that estimates of time to recovery ranged from 20 weeks to 20 months. Two studies estimated that the mean amount of time spent in a depressive episode over periods of five and 23 years were 20 months and 41 months respectively. Estimates from three studies regarding the length of time between episodes range from eight months to 3.6 years, with the longest study showing the shortest duration between episodes. Kuehner and Huffziger's [46] 5.5-year follow-up study showed that 15% of total time was spent in a depressed episode, although about 12% of participants spent 50% or more of total weeks in a depressed episode.

The factors measured and identified as significant **predictors of the course of depression** in the studies examined here were many and varied. However, in the review of Steinart et al [43], four studies reported baseline **severity of depression** being predictive of poorer outcomes at follow-up, a finding replicated by Kuehner and Huffziger [46]. Furthermore, two studies included in the Steinart et al [43] review reported the presence of a **comorbid personality disorder** was predictive of poorer outcomes. Both of these findings were also replicated in a two-year follow-up study by Viinamaki et al [44], which included 109 hospital outpatients. In the review of Richards [45], two studies cited note that the presence of residual symptoms, or partial rather than full recovery, related to an increased risk of recurrence.

However, from the variation in findings regarding predictors of the course of depression, Richards [45] concluded:

'It seems that few demographic or clinical factors can be identified with reasonable certainty to predict an individual's likelihood of recurrence. Especially those who have recovered from an index episode and remained well for some time'. (p.1122)

There were several other predictors of depression outcomes cited in single studies found in this review. Kuehner and Huffziger [46] found **unsatisfactory relationships** within the support network to be predictive of all outcomes measured. Time spent in depressive episodes over the 5.5-year period was predicted by earlier age at onset, longer period of depression before entry into the study and scores on the Action Control Scale (which measures state orientation, a tendency toward preoccupation with negative states). Time to recurrence was predicted by number of previous hospitalisations and lack of psychotherapy after discharge. Long-term psychosocial functioning was predicted by number of previous hospitalisations, length of the index depressive episode and state orientation.

In the study of Cronkite et al [47], membership of the three illness course groups was predicted by level of education, number of medical conditions, psychological flexibility and use of avoidance coping. On average, those in the high severity group had less education than the moderate severity group and more medical conditions than those in the other two groups. Those in both the high and moderate severity groups had less psychological flexibility and used more avoidance coping than the low severity group.

c) Summary

The evidence reviewed here, combined with that presented in the following sections in relation to functional impairment arising from mental illness, suggests that, for some people, psychotic disorders, particularly schizophrenia, bipolar disorders, particularly bipolar I disorder, and major depression can persist in the long-term. Therefore, in the sense that symptoms and impairment can persist from the time of onset for many decades, there can be an element of 'permanence' to these disorders. For a proportion of people, evidence of symptoms and functional impairment arising from these and other psychological disorders can still be found at the end-points of decades-long follow-up studies. For people with schizophrenia, those who experience an initial period of illness followed by complete recovery with no further episodes are likely to be in the minority. People who experience an initial episode of major depression or an initial episode in bipolar disorder have a greater likelihood of experiencing no further episodes, although the experience of recurrent episodes is still very common.

Nevertheless, it is also relatively rare to experience a persistent, unremitting long-term course of mental in which there are no periods of remission or recovery, although this course is probably more common for people with schizophrenia than other disorders. Rather, severe mental illness tends to be characterised by a course combining illness

episodes and periods of recovery in which symptoms remit and functioning improves. The length of these recovery periods can be substantial.

Despite some consistency in the identified courses of severe mental illness, the ability to predict what course a particular form of mental illness will take in the long-term, based on factors evident early in the illness course at an individual level, is still limited. While predictors of illness course and outcomes have been identified in the literature, they are many and varied and often have mixed research support in their favour.

One of the most reliable predictors of long-term course and outcomes seems to be a diagnosis of schizophrenia. People diagnosed with schizophrenia consistently demonstrate poorer illness course and outcomes compared with other psychotic and non-psychotic disorders. There are, however, still variations in illness course across people with schizophrenia.

There is also some evidence to suggest that early recovery is predictive of better long-term outcomes across disorders, with the likelihood of recovery declining with a lengthening period of non-recovery. Early symptom severity might also predict later outcomes, with early severity predicting later severity. There also appears to be a predictive role for the experience of depression and negative symptoms within schizophrenia and bipolar disorder, in that recovery from these symptoms may be more difficult than recovery from mania or psychosis. Onset of bipolar disorder in childhood and adolescence has also been linked to poorer illness course and outcomes compared with onset in adulthood.

Research evidence for the predictive value of each of these factors, however, comes from studies that examine predictive models at a group level. Therefore, these factors might have less utility in predicting individual illness outcomes. Finally, it is important to be able to distinguish between fluctuations in symptoms and variations in functioning or relative disability and to understand that these are not dependent variables and do not act consistently across illness types, population groups or for individuals.

2.3 Topic three: use of the terms 'reasonable' and 'necessary'

a) Introduction

The *NDIS Act 2013* makes the following provisions in relation to what is 'reasonable and necessary':

- (a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;
- (b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation;

- (c) the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;
- (d) the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;
- (e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;
- (f) the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:
 - (i) as part of a universal service obligation; or
 - (ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability;
- (g) the support is not prescribed by the National Disability Insurance Scheme rules as a support that will not be funded or provided under the National Disability Insurance Scheme;
- (h) the funding of the support complies with the methods or criteria (if any) prescribed by the National Disability Insurance Scheme rules for deciding the reasonable and necessary supports that will be funded under the National Disability Insurance Scheme [2] (Section 34).

Decisions about what constitutes ‘reasonable’ and ‘necessary’ supports both for individual participants, and under the NDIS scheme more broadly, are therefore central to the operation of the scheme since these determine the types of support services available to meet participants’ goals and needs.

International initiatives aiming to increase the choice and control of people with disabilities over the support services they receive have been implemented in many countries since about the early 1990s [48]. These initiatives have frequently taken the shape of participant or self-directed care programs that involved some form of a personalised budget [14, 49-51]. NDIS-comparable schemes in other countries have differed from the NDIS in certain respects, such as the intended beneficiaries, structure of operation and types of services covered. Yet, many international schemes faced similar design tasks in needing to define the general scope of permissible supports for beneficiaries and in needing to operationalise decisions, criteria and processes around the choice of appropriate support services for individual participants.

The following section summarises findings from a targeted review of NDIS-comparable initiatives in English-speaking countries that focussed on the concepts of ‘reasonable and necessary supports’ for people with psychosocial disability. More specifically, this review was guided by the following two questions:

1. How have other schemes defined ‘reasonable and necessary’ supports for people with psychosocial disability?
2. What rules have other schemes set around these concepts and how are these concepts applied in practice (that is, in determining appropriate supports)?

The types of schemes covered within the scope of the current review include no-fault accident insurance schemes, national health insurance schemes, models of personalised or self-directed health and social care and schemes involving individualised funding or personalised budgets. The schemes examined are listed below:

- New Zealand – Accident Compensation Corporation
- Australia – Victorian Transport Accident Commission, NSW Lifetime Care and Support Scheme
- United Kingdom – self-directed care, personalised budgets, Care Pathways and Packages Project
- United States of America – Cash and Counseling program, Medicare and Medicaid
- Canada – self-managed care, individualised funding.

The following summarises key findings from the literature:

- Relatively few Australian and international public insurance schemes use the terms ‘reasonable’ and ‘necessary’ support or any similar concepts in determining appropriate support services for intended beneficiaries.
- Where the terms ‘reasonable’ and ‘necessary’ are used, they tend to refer to the use of evidence-based treatments and supports with demonstrated efficacy in promoting recovery or rehabilitation for a particular disorder, the cost-effectiveness of that intervention and the delivery of the intervention by an appropriate practitioner for only the time that the intervention has an ongoing benefit.
- There is an increasing move toward the use of personalised budgets aimed at increasing choice and control of people with a disability over the use of benefits to support their rehabilitation and recovery.
- The needs of the individual and resulting payment of benefits are often determined using an assessment of the disorder and resulting impairment and of the individual’s personal needs. Such assessment focuses on the type and severity of the disorder(s) experienced the complexity of the impairment and individual characteristics of the person, such as their aspirations, goals and needs.
- In determining the level of benefit to be received to provide reasonable and necessary supports, a variety of approaches is used, including clustering of disorders

that attract a particular level of payment, placing upper limits on payments made for particular types of services, and use of available historical service use patterns.

b) Findings from the literature

Overall, relatively few of the reviewed schemes explicitly adopt and define the terms ‘reasonable’ and ‘necessary’ care (or similar concepts of equal centrality) in determinations about appropriate support services for intended beneficiaries. Instead, most typically outline the general scope of available support services and a series of steps and decision points in regard to the associated claims and approval procedures.

A notable exception in this respect is the US national health insurance scheme, Medicare, which defines ‘reasonable and necessary’ services in relation to ‘medical necessity’. By statute, Medicare only pays for those medical items and services that are ‘reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member’ [52]. Beyond such statement of medical necessity, however, Medicare policy omits to issue specific regulations and explicit criteria for how these concepts are applied in practice. This in turn has been the subject of considerable scholarly debate and also legal challenges in America, particularly in regard to coverage decisions for new medical technologies [53-55]). According to Neumann [56], ‘necessary’ in the context of Medicare coverage decisions commonly refers to the strength of the available evidence base for specific treatments, whereas ‘reasonableness’ implies some form of moderation or non-excessive use of associated resources.

Three no-fault accident insurance schemes adopt very similar concepts. The New South Wales Lifetime Care and Support Scheme covers payments for the ‘reasonable and necessary treatment, rehabilitation and attendant care services that result from a motor accident injury’ [57]. While the scheme is limited to those who incur severe injuries (those being traumatic brain injury, spinal cord injury, amputations, burns or blindness) in motor accidents, it outlines specific factors that are considered in determinations about what qualifies as ‘reasonable and necessary’ services. Similar to the provisions in the NDIS Act, factors include the benefit to the participant, the appropriateness of the service or request, the appropriateness of the provider, the relationship of the service or request to the injury and cost-effectiveness considerations [57].

New Zealand's Accident Compensation Corporation, a no-fault accident insurance scheme, has adopted similar conceptualisations of 'necessary and appropriate' treatment that also cover mental injury. Under New Zealand's *Accident Compensation Act 2001*, the Corporation is generally liable to pay treatment costs if the treatment is:

'for the purpose of restoring the claimant's health to the maximum extent practicable and

- a) is necessary and appropriate, and of the quality required for that purpose;*
- b) performed only on the number of occasions necessary for that purpose;*
- c) given at a time or place appropriate for that purpose;*
- d) is of a type normally provided by a treatment provider;*
- e) is provided by a treatment provider of a type who is qualified to provide that treatment; and*
- f) has been provided after the Corporation has agreed to the treatment.'* [58]

Moreover, the nature and severity of the injury and the availability and cost of other existing treatment options are typically considered in determinations about necessary and appropriate treatments.

According to the *Victorian Transport Accident Act 1986*, a person is entitled to receive compensation if they sustained a physical or mental injury as a direct result of a transport accident. For individuals entitled to receive such compensation, Victoria's Transport Accident Commission will typically pay the:

'reasonable costs of medical treatment, rehabilitation services, disability services, income assistance, travel and household support services that you may need as a result of your injuries from a transport accident'. [59]

Whether or not a service is reasonable in this context depends, in part, on whether treatment relates to accidental injuries and contributes to recovery and rehabilitation. In principle, the Commission can cover medical treatment expenses for as long as they are necessary, provided that there is evidence of ongoing effectiveness and beneficence.

The nature and scope of entitlements and support services that are generally permissible under a scheme are usually determined during scheme design and anchored within relevant legislation (that is, accident compensation and disability insurance acts) and regulations. On this basis, all reviewed schemes have established structured procedures that govern participant claims processes and support allocations. These procedures follow a common sequence of steps and key decision points in order to determine initial participant eligibility for the scheme and, subsequently, the level and type of appropriate support services covered in individual cases. This section is primarily focussed on models and criteria underpinning the latter type of determination.

Key criteria applied in **determinations about the appropriate level and type of support services** include the type, severity and complexity of the participant's impairment,

participant aspirations, goals and needs and the medical necessity, beneficence or cost of treatment and support services. Underpinning the practical application of such criteria are typically processes of participant impairment and needs assessment and support planning. For example, service budgets in the context of the US Cash and Counseling scheme are generally developed on the basis of participant needs assessments and a person-centred service planning process that can be assisted by counsellors [60].

Resource Allocation Systems (RAS) provide central mechanisms for determining individual funding levels within personalised budgets and self-directed support initiatives in the UK [61, 62]. Traditional RAS models involve a sequence of assessment, care planning, placement and review, which typically resulted in money being allocated for specific services rather than people [63]. Such an approach has generally tended to be more rule-governed, focussed on professional care planning and less transparent for participants. Newer RAS models, by contrast, have been designed to increase transparency and participant choice by clarifying the indicative size of the available budget upfront as a basis for participants to develop their own support plan [63, 64]. Models that assist with predetermining budget allocation levels (for example, based on a combination of statutory assessments and professional judgement) also exist [65].

In a similar vein, the mandated introduction of ‘payment by results’ as a form of case mix funding in the UK mental healthcare system [66] has involved attempts to classify participants according to the level, type and complexity of their mental healthcare and support needs [67]. This has resulted in the development of a *Mental Health Clustering Tool* that incorporates 21 clusters of mental health support needs under the three main groupings of non-psychotic, psychotic and organic [68, 69]. The tool incorporates items from the Health of the Nations Outcomes Scales (HoNOS) and the Summary of Assessment of Risk and Need (SARN). On the basis of routinely collected screening and assessment information, combined with clinical judgement of practitioners, the tool facilitates the rating of participant needs and allocation of participants to specific care clusters. It is noteworthy that the impetus for the clustering approach is not necessarily to determine individual care pathways, but to develop ‘currency units’ that enable an estimation of the typical costs associated with mental healthcare for problems of a certain type, severity and complexity. Such estimation has the potential to both streamline payment of service providers and inform individual budget allocations within self-directed care planning.

Other models to determine individual support budget allocations exist within the Victorian Transport Accident Commission (TAC), where the Transport Accident Act determines upper payment limits for certain types of benefits according to indexed benefits schedules. A medical excess may be borne by participants for certain items. The TAC also provides an individualised funding option for participants with severe injuries that is based on predictable participant needs within a 12-month period. Individualised funding allocations are typically determined on the basis of historical service use patterns (where possible), participant responses to the Life Area Needs Self-Assessment and the level, severity of and

time since the injury. Subsequently, a fixed monthly funding amount is deposited into the participant's bank account that enables them to arrange and manage their own support services.

In the USA, the broad service types that Medicare recipients can receive are generally determined by Congress [52]. Nevertheless, national coverage determinations only exist for a very small subset of medical treatments and technologies and Medicare laws and policies do not explicitly specify all services that are deemed to be 'reasonable and necessary'. In reality, the majority of coverage decisions are therefore based on local determinations made by regional contractors of the Centers for Medicare and Medicaid Services, who process claims on a daily basis and apply clinical judgment and an evidence-based approach in coverage decisions [52].

While all reviewed schemes set certain parameters around the types and levels of support services that are available to participants, the choice of specific support services within this broader set of parameters, particularly in the context of self-directed care programs, is ultimately up to individual participants. Risk enablement and safeguarding have been considered essential aspects to address in the successful implementation of self-directed support and personalised budget programs [50, 61]. Most reviewed schemes incorporate some mechanisms to monitor undue risks for participants. These included a focus on the coverage of evidence-based (and non-experimental) treatments under Medicare, provision of assistance with individual care planning and the explicit documentation within individual service plans of identified risks for participants, as well as back-up plans to mitigate those risks under the Cash and Counseling program [70].

Many key authors involved in the field of self-directed and personalised care have argued that a central challenge in the design and implementation of such schemes is not to overcomplicate procedures for participants in an effort to avoid risks but rather to implement meaningful and necessary safeguards that assist with monitoring presenting risks and enable participants to make informed and supported decisions [61, 63].

c) Summary

This review was limited by the lack of international schemes that are directly comparable to the NDIS. Moreover, none of the identified schemes considered in this review were either specifically or solely designed to cater for the needs of people with psychosocial disabilities. Nevertheless, while often focussed on broader aspects of health and social care, most schemes were inclusive of, and relevant to, people with mental health issues and psychosocial disabilities.

The review of varying definitions and applications of the key concepts of 'reasonable and necessary supports' with similar features to the NDIS indicates that those attempting to arrive at a final definition of these terms are likely to face intrinsic challenges. While schemes designed to cater for the needs of people with impairments in psychosocial functioning can adopt general parameters, criteria and processes to facilitate the definition

and practical application of these concepts, ultimately determinations about what constitutes reasonable and necessary supports have to involve individual-level decisions that can only be resolved on a case-by-case basis. The above review outlines several models and criteria that can be considered in guiding such determinations within the context of the NDIS. As additional guidance, Appendix C outlines those general service types covered by the various schemes discussed in this review.

2.4 Topic four: the impact of psychosocial disability on individuals

a) Introduction

This section outlines how people with psychosocial disability are impacted in their daily lives by the consequences of their mental illness. The literature summarised here illustrates the breadth of disability across the various domains of daily life. In also describing the severity of disability, this section also attempts to quantify in real terms, where the literature is available, how that disability manifests; for example, by quantifying the number of days in which a person was unable to work or unable to complete simple chores within a specified period. The academic literature relating mental illness to functional impairment or disability is vast. Consequently, given the time and space limitations of this review, this section summarises literature only in relation to research participants with psychotic disorders, bipolar disorder and depression. This summary also focuses primarily on reviews, large-scale and longitudinal studies and studies conducted within Australia.

A relatively short section is also included regarding the effects of psychosocial disability on young adults, as they are not well represented in the more general literature.

Table one (on next page) shows the International Classification of Functioning, Disability and Health (ICF) areas that comprise Chapters of Activities and Participation (A&P). The ICF is the international standard classification system of the World Health Organization used to measure health and disability (World Health Organization, 2014). The table aligns each of the chapters to more specific domains or components of A&P. With few exceptions, the literature reviewed in this section suggests that people with psychotic disorders, bipolar disorder and depression experience functional impairment to some degree in all of these areas and components of A&P at some point during their illness, with many of these impairments persisting over the long-term.

Area	Components
Learning and applying knowledge	<ul style="list-style-type: none"> • learning • applying knowledge that is learned • thinking • solving problems • making decisions
General tasks and demands	<ul style="list-style-type: none"> • carrying out single or multiple tasks • organising routines • handling stress
Communication	<ul style="list-style-type: none"> • communicating by language, signs and symbols • receiving and producing messages • carrying on conversations • using communication devices and techniques
Mobility	<p>Changing body position or location or by transferring from one place to another, by:</p> <ul style="list-style-type: none"> • carrying • moving or manipulating objects • walking, running or climbing • using various forms of transportation
Self-care	<ul style="list-style-type: none"> • caring for oneself • washing and drying oneself • caring for one's body and body parts • dressing • eating and drinking • looking after one's health
Domestic life	<ul style="list-style-type: none"> • domestic and everyday actions and tasks • acquiring a place to live • food, clothing and other necessities • household cleaning and repairing • caring for personal and other household objects • assisting others
Interpersonal interactions and relationships	<p>Basic and complex interactions with people (strangers, friends, relatives, family members and lovers) in a contextually and socially appropriate manner.</p>
Major life areas	<ul style="list-style-type: none"> • education • work and employment • economic transactions
Community, social and civic life	<p>Organised social life outside the family, in community, social and civic areas of life.</p>

Table one: ICF Areas of Activity and Participation

Source: ICF Browser Online (<http://apps.who.int/classifications/icfbrowser/>)

The following summarises key findings from the literature:

- Severe mental illness more often than not results in some level of disability.
- Disability or functional impairment can occur in most facets of daily life or domains of functioning, including the ability to work or study, socialise and take care of a home.
- Social and occupational functioning seem to be particularly impaired. As a result, people with severe mental illness are often unemployed, single and socially isolated.
- Functional impairment can be mild to very severe, such that individuals can require some support, or may be completely unable to function without support, in certain areas of life.
- Level of disability varies between people with a form mental illness, but also within the individual, over time, depending, in part, on fluctuations in the severity of symptoms at any particular time and the types of symptoms experienced.
- Resultant psychosocial disability can be persistent and enduring, lasting for decades.
- While functional impairment can decrease if symptoms remit, people with mental illness most often continue to experience some level of functional impairment in a variety of areas, even if their symptoms are no longer seen at a 'clinical' level.
- One of the primary reasons that people with mental illness experience an impaired ability to function in aspects of their everyday lives, even when symptoms of the illness have improved, is because they experience cognitive impairment, such as difficulties in processing and remembering information.
- The effects of psychosocial disability on young adults follow similar patterns to that seen in adults. However, because of their different life stage, these effects are seen in different contexts, for example, in the academic rather than the work context and in relationships with parents and siblings rather than in marital or intimate relationships.

b) Findings from the literature

Statistics reported by the Australian Bureau of Statistics [71] resulting from the 2007 *National Survey of Mental Health and Wellbeing* show that it is common for people who had a mental disorder in the last 12 months to:

- be unemployed: 29% of unemployed people had a mental disorder in the last 12 months, compared with 20% of employed people;
- have been homeless: more than 50% of people who have ever been homeless had a mental disorder in the last 12 months;
- have no friends or no contact with friends: 38% of people with no friends or contact with friends have had a mental disorder in the last 12 months, compared with 20% who had friends or contact with friends;
- have no family members or friends they can rely on: 22 to 25% of people with no friends or family to rely on have had a mental disorder in the last 12 months, compared with 18% who had three or more friends to rely on or confide in;

- be a smoker: current smokers had twice the prevalence of mental disorders in the last 12 months, compared with people who have never smoked;
- be slightly more likely to drink alcohol (21%) every day than to drink no alcohol (18%);
- misuse drugs every day: 63% of those who used drugs on a daily basis had also had a mental disorder in the last month;
- have a 'core-activity limitation' (disability).

These statistics provide an indication of the broad effects that mental illness can have on various areas of daily life, from limiting social contact to increasing risk factors, such as smoking, for poor physical health.

Furthermore, the study of Kavanagh et al [72], in which data from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers from 1998, 2003 and 2009 was used to examine socio-economic disadvantage over time, found that people with any disability experienced increased or persistent disadvantage over the years studied. Experience of multiple forms of disadvantage was also more common among people with a disability, compared with those with no disadvantage. Moreover, across many indicators of disadvantage, the proportion of people living in disadvantage increased as level of disability increased. Summarising the overall effects of this worsening pattern of disadvantage, the authors to conclude:

'The inter-relationships between different domains of disadvantage are likely to impact on the long-term health of people with disabilities' (p. 7).

In addition to the costs of psychosocial disability to the individual's quality of life and to their general health, Hayes et al [73] found that impairment in the ability to carry out activities of daily life for 6,880 people with severe mental illness was a marker of 'increased mortality risk', particularly in younger (15–34 years) and older (above 55 years) people.

Psychotic disorders, particularly schizophrenia, are consistently reported in the literature as being the cause of the most severe and persistent functional impairment relative to other mental disorders. Switjal et al [74] reviewed more than 100 studies published between 2005 and 2010 related to experienced psychosocial difficulties in schizophrenia and concluded that the literature 'illustrates the remarkably broad scope and diversity of psychosocial areas affected in schizophrenia' (p.193).

People with psychotic disorders have been shown to commonly experience overall impaired functioning [75, 76]. Research suggests that functional impairment causes difficulties in diverse areas of life, including in the ICF activity and participation areas of interpersonal interactions and relationships, including intimate relationships and socialising [75-77]; general tasks and demands [75-77]; communication [76]; self-care [75]; domestic life, such as cleaning [75, 76]; major life areas [77], including work [75] and study [76]; and

community, social and civic life [76]. It is less common to experience no disability than it is to have some level of disability associated with the psychotic disorder [23, 75, 76], whereby most people with a psychotic disorder experience moderate to severe disability throughout the course of their illness [23, 75, 76], although the severity of disability is often cyclical, associated with the cycle of illness symptoms [23].

As a result of the range of functional impairments experienced by people with a psychotic disorder, people with a psychotic disorder are frequently unemployed, unmarried and receiving a disability or sickness benefit [75]. Almost one-quarter of participants in the large-scale Australian study *People living with a psychotic illness 2010* [76] reported feeling lonely and isolated, and more than two-thirds said that their illness made it difficult to maintain relationships.

Research suggests that many deficits in functioning across domains relate to the cognitive difficulties experienced with the symptoms of severe mental illness [78], causing deficits in the ICF-classified area of learning and applying knowledge. Consistent with this notion, Switaj et al identified 28 research studies in which difficulties with cognitive functioning were linked to schizophrenia, including the functions of attention, memory and thought [74]. It is worth noting, however, the dearth of attention paid in the mainstream research literature to the degree to which medication side effects contribute to impaired cognitive functioning. Whilst the clinical literature may not acknowledge this, the consumer perspective includes commentary on medication side effects and the impact of side effects of ECT [79-84]. There is also some evidence to suggest that the 'new' medications and treatments are not having the impact on psychosocial outcomes that was anticipated [81].

Impairment in the ability to carry out the tasks of normal life is often significant for people with a psychotic disorder. Guerje et al [75] state that their entire sample of 980 Australians living with a range of psychotic disorders experienced a 'high level of disablement' (p. 643) across 14 domains of functioning, while in the more recent study of Morgan et al [76], half of participants were 'moderately', and 17% 'significantly', disabled. 6% were unable to function independently. Without their normal supports, over the last month, one-third of participants would have been impaired in their ability to care for themselves and 18% unable to complete a simple chore, such as cleaning their room. Over the past year, two-thirds of participants were also severely impaired in their ability to socialise.

Level of disablement resulting from a psychotic disorder, however, is dynamic, relative to the course of active symptoms. Some research indicates that, when symptoms of mental illness are 'active' or more severe, the level of disability also increases [75]. Since different people with the same mental illness experience different patterns of symptoms, they will also experience different patterns and severity of disability. For example, Guerje et al [75] also found that those whose psychotic illness comprised multiple episodes with only partial recovery in between or chronic, persistent symptoms were more at risk of disablement compared with those with single or multiple episodes punctuated by periods of good

recovery. Participants with schizophrenia were also more likely than those with affective psychoses to have deficits in interpersonal relationships, occupational performance and intimate relationships. Wiersma et al [23] studied level of disability over a 15-year period and were able to create five categories to explain the variable course of social disability in participants over time: early improvement in functioning (in the initial years following onset of psychosis) (36%); deteriorating course (29%); prominent all the time (19%); late improvement (in the later years of the 15-year study) (10%); and never a prominent disability (7%).

The table below summarises this evidence, which suggests that between 50 and 60% of people who experience a psychotic disorder will have extended impairment in relation to their psychosocial functioning.

Course of disablement	Likelihood
Early improvement in functioning following onset of psychosis	36%
Deteriorating course	29%
Prominent disablement experienced all the time	19%
Late improvement, after a period of disablement	10%
No disablement	7%

Table two: likelihood and course of disablement (psychotic disorders)

Source: Wiersma et al, 2000

There is also some research to suggest that certain types of symptoms relate to disabilities in varying domains of functioning. For example, Fulford et al [77] showed that the presence of more severe negative and disorganised symptoms related to greater impairment in social and role functioning than other symptom types. Negative symptoms relate to withdrawal, such as social withdrawal and loss of interest in life and its activities, compared with positive symptoms, which are those related to changes in thinking, such as delusions or hallucinations. Disorganised symptoms result from the inability to maintain a train of thought and difficulties in concentration, which can result in disorganised speech, such as use of meaningless words and repetition or moving quickly between topics, and disorganised or unpredictable behaviour. In Fulford et al's study, greater depression and anxiety related to poorer functioning overall, but depression was a better predictor of both global and social functioning than overall negative symptoms.

Psychosocial disability resulting from a psychotic disorder can also persist for long periods of time. Combining indices of disability across seven domains (partner relationship, work role, social withdrawal, household participation, general interests, self-care and social friction) to arrive at one summary index, Wiersma et al [23] identified the following levels of disability at the 15-year time point in participants with schizophrenia: 14% no disability, 26% 'some' disability, 34% 'obvious' disability and 25% 'severe' disability. Across the sample, they identified 14% of participants who needed to be 'continuously cared for' (p. 1,165) over the 15-year study, regardless of the country or mental health care system in which the

participant lived. For the vast majority, however, level of disability showed a substantially fluctuating course, with level of disability in the period following onset of psychosis found to be the strongest predictor of later disability. In sum, for one in seven participants, there was no improvement over the 15-year course; however, for one in three participants, there was considerable improvement over time, such that about 40% of all participants showed little or no disability after 15 years. For the remaining participants, there was still an obvious or severe disability at the end of the 15-year study, suggesting a persistent and severe level of disability for more than half of people with schizophrenia for at least 15 years following onset of the disorder.

The table below summarises this evidence, which suggests that 59% of people who experience a psychotic disorder will have a level of disablement that may require the continuous care.

Level of disability	Likelihood
No disability	14%
Some disability	26%
Obvious disability	34%
Severe disability	25%

Table three: levels of disablement (psychotic disorders)

Source: Wiersma et al 2000

Similarly, Bottlender et al [78] found that 64% of their participants with schizophrenia had a severe to very severe level of social disability 15 years after their initial treatment, compared with 19% and 5% for consumers with schizoaffective and affective disorders respectively.

The overall message from these various study findings seems to be that psychotic disorders follow a highly individualised pattern of symptoms that varies within the individual over time. Consequently, severity and pattern of disability varies across people with psychotic disorders, as well as within the person over time. This cycle of fluctuating functional impairment can also persist for many years.

Studies of functional impairment related to **bipolar disorder** suggest that, compared with people with no psychiatric disorder, people with bipolar disorder can experience overall or global impaired functioning [42, 85, 86], as well as functional impairment in such diverse areas as physical functioning and sleep [85] and in the ICF areas of A&P of learning and applying knowledge [34, 42, 85]; general tasks and demands [85, 87, 88]; communication [36]; mobility [89]; self-care, including medication management [85, 87, 88]; domestic life [85, 87, 88]; interpersonal interactions and relationships in the community [42, 85-87, 89]; major life areas, including work [34, 36, 42, 85-87, 89]; and social and civic life, including leisure and spirituality [85]. Level of impairment varies across the course of the illness and across areas of functioning, ranging from mild to complete disablement in some domains [42, 86]. Goldberg et al (1995) directly compared the functioning of 51 patients hospitalised

for bipolar I disorder and 49 for major depression at about 2.5 years and 4.5 years after discharge. Both participants with bipolar disorder and with depression had moderately impaired functioning, on average, at both follow-up points, although functioning scores were poorer for those with bipolar disorder.

In terms of how these difficulties affect people living with bipolar disorder in their daily lives, Henry et al. [88] demonstrated deficits in the skills of comprehension and planning, finance and communication, transportation, household skills and medication management in people with bipolar disorder. Suppes et al [36] found that more than half of their participants reported being unable to work or being able to work only in sheltered work environments. Judd et al's [86] 15-year longitudinal study found that in three groups with either bipolar I, II or depressive disorder, work functioning was the most impaired domain. Participants had a 'mild impairment' in their ability to work across all months (highest in the bipolar I group), but were completely 'unable to carry out work activities' for between 20% (bipolar II group) and 30% (bipolar I group) of the time. Over the study period, the groups also had 'mild' overall functional impairment and 'fair function to mild overall impairment' in social functioning.

Demonstrating that functional impairments for people with bipolar disorder can persist in the long-term, Burdick, Goldberg and Harrow [42] identified that, 15 years after a hospitalisation related to bipolar disorder, participants still experienced moderate overall functional impairment (mean = 3.7 \pm 2.0 on scale from no impairment (0) to 8 = total disability), impairment in work functioning (mean = 2.4 \pm 1.8 on a scale from 0 = total disability to 4 = excellent functional status) and mild to moderate impairment in social functioning. However, Goldberg et al did show, however, that global functioning improved over time for both groups with bipolar disorder and depression. Just 14% (5/71) of participants with bipolar disorder had poor functioning at both 2.5-year and 4.5-year follow-ups, and close to one-half who had either severe or moderate impairment at first follow-up showed some improvement at the second.

Several studies have also found that even when symptoms of bipolar disorder are 'in remission' or at a sub-clinical level, functional impairment can still persist [42, 86, 89], including in the areas of work and social functioning [42, 89]. Zarate et al. [87] concluded from a review of literature related to functional impairment that 'bipolar disorder, even in clinical remission, appears to be associated with marked reductions in functioning and well-being' (p.313).

Particular types of symptoms might also influence particular aspects of functioning. Depressive symptoms occurring in bipolar disorder have been linked to poorer global functioning [42, 85, 89], work functioning [42, 85, 89], spiritual, cognitive, leisure and social functioning [85]. Kennedy et al. [90], upon reviewing literature from 1980 to the end of 2005, concluded that 'psychosocial and functional impairments appear to be strongly associated with depressive symptoms' (p.29), but that the long-term psychosocial outcome

for people with bipolar disorder tends to be worse than for people with depression alone. Van Rheeahan and Russell [85] also found that participants with current symptoms had significantly worse functioning than those with sub-clinical symptoms.

Explaining why these functional impairments might occur, Burdick et al [42] identified that functional impairments were related to ongoing deficits in attentional processing (relating to the ability to ignore irrelevant, and focus on relevant, information in order to perform cognitive tasks automatically, affecting decision-making, ability to see patterns and do basic arithmetic and many other tasks) and verbal memory (memory for words and verbal information). Similarly, Miklowitz [34], following a review of studies, noted that impairment in ability to work for people with bipolar disorder 'is at least in part attributable to problems with attention, memory, or executive functioning, which are impaired even when patients are clinically stable' (p.505).

Findings regarding disability for people with **depression** follow a similar pattern to those so far outlined for both psychotic disorders and bipolar disorder. The research outlined here suggests that depression has a negative effect on overall functioning [91-95], overall role functioning [92] and physical functioning [93], as well as on the more specific ICF activity and participation domains of: learning and applying knowledge [92]; self-care [92]; domestic life, including management of the home [91, 92]; interpersonal interactions and relationships [91-94]; major life areas, including work [91-94]; and community, social and civic life, particularly social life [91-93]. Level of impairment can vary from moderate to severe [90, 92, 94] and can persist at some level (from mild to very severe) for at least a decade or more from the onset of the depressive disorder [90, 94, 95].

Presence of a clinical level of symptoms and increasing severity of symptoms can result in increased functional impairment [94], but a return to a sub-clinical level of symptoms does not always translate to an immediate [93] or long-term [94] return to pre-morbid or unimpaired levels of functioning. Furthermore, different depressive symptoms can have differential effects on functioning, such that people with a similar level of depression can have differing levels of functional impairment, depending on the type of symptoms experienced [91].

Reported levels of functional impairment range from moderate to severe, with Fried and Nesse [91] reporting the average level of impaired functioning to be 'moderately severe'. Almost one-quarter of their participants had 'significant', more than two-thirds 'severe' and just 8% 'no' functional impairment. Kessler et al. [92], found that almost all participants (97%) were impaired to some degree in carrying out their normal roles during their last depressive episode, particularly in regard to cognitive and social functioning. On average, participants had been totally unable to work or carry out other normal activities on a mean number of 35.2 days in the last year due to their depression. 60% of participants with depression had 'severe or very severe' functional impairment and 19% had 'very severe'. Social functioning was most affected (43% 'severe or very severe' impairment), followed by

household and relationship role functioning (34% 'severe to very severe') and work functioning (28% 'severe or very severe'). Co-morbidity with other disorders, such as anxiety (59%), impulse control (30%) and substance use (24%) disorders was very common, further compounding levels of symptomatology and impairment. Kuehner and Huffziger's (2013) 5.5-year follow-up of 68 depressed psychiatric inpatients found that for the complete group, the level of overall functioning was rated as being lower than 'normal' (mean SOFAS rating ranged from 73 to about 76, with normal functioning indicated by a score of 80 or above) across the complete time period and was stable across all time points, indicating a consistent level of reduced functioning.

Psychosocial disability and adolescents and young adults

Adolescents and young adults are not well represented in the literature so far discussed. The transition from childhood to adulthood is complex and challenging, involving unique life events such as completing one's education and moving into a career, living independently for the first time, developing intimate relationships and developing ties with family and friends [96]. Research suggests that these developmental tasks can be significantly disrupted for those young people experiencing severe emotional disturbance [97]. Despite the different life stage of adolescents and young adults compared with other adults, the general pattern of findings related to psychosocial disability so far discussed is generally replicated in this younger population. These disabilities, however, become evident in the different tasks undertaken at that age. Psychosocial disability is common among those adolescents and young adults at high risk of developing a (or with an existing) form of mental illness and this disability affects many aspects of life. Some level of disability may persist for many years, but may also fluctuate over time.

Puig et al [98] conclude that, compared with a group of healthy matched controls, participants with early onset schizophrenia had 'a generalized pattern of cognitive and real-world functioning abnormalities' (p. 321) similar to that of older adults with schizophrenia. For **young people with a psychotic disorder** or at high risk of developing a psychotic disorder, impaired functioning has been demonstrated in many areas, including physical, emotional and psychosocial wellbeing [99], social functioning [100-102] and occupational functioning [102]. Psychotic disorders among young people are also linked to reduced quality of life for parents and family [99].

Relating to the differential effects on functioning of increasing severity and different types of symptoms, Shim et al [100] found that social difficulties were most related to disorganised and general symptoms. Angell and Test [101] found that increasing positive symptoms over the last six months related to a decline in the number of reciprocal relationships (relationships in which support is given and received to a relatively equal degree over time), a decline in participants' satisfaction with social relationships and an increase in loneliness. They speculated that positive symptoms impair individuals' capacity to offer return support.

Also demonstrating that these impairments can persist over time, Jarbin et al [102] found significant functional impairment ten years after admission to hospital for a psychotic disorder. Those with schizophrenia had the lowest occupational functioning, with half unemployed and not engaged in any daytime activity or activity within a day-care centre. Of those with depression with psychotic features, more than two-thirds were employed at follow-up, and 43% of those with bipolar disorder were employed at follow-up. Similarly, almost 90% of participants with schizophrenia were receiving a disability pension, while two-thirds or more of those with bipolar or major depression were supporting themselves at ten-year follow-up. Participants with schizophrenia also had fewer social contacts, few friends outside organised activities and were less likely to live independently.

Whitney et al [103] identified that adolescents at risk of developing **bipolar disorder** had significant impairment in social reciprocity, particularly social awareness, cognition, communication and motivation. Jansen et al [104] found that presence of either bipolar or depressive disorder in young people (at about 22 years old) was associated with impaired functioning and Goldstein et al [105] also identified mild-to-moderate functional impairment in youth (7–17 years) with bipolar disorder in the areas of interpersonal and work functioning and mild-to-moderate dissatisfaction with current functioning. Janssen et al [104] speculate that impairment for those with bipolar disorder might be the result of impaired neuropsychological performance.

Having current symptoms also increases disability in young people with bipolar disorder [105] and particular symptoms can relate to impaired functioning in specific areas. Goldstein et al [105] found the greatest decline in overall functioning to occur when psychotic symptoms are present. Poorer interpersonal functioning was specifically associated with current psychosis, oppositional defiance disorder and conduct disorder, while work functioning was most affected by current mood symptoms and greater severity of mania. Greater depression, current mood episode and later onset were associated with greater impairment in recreational functioning. Lunsford-Avery et al [106] found that sleep patterns of young people (average of 14 years) with bipolar disorder varied with fluctuations in manic and depressive symptoms, with the participants frequently experiencing disordered sleep patterns and frequent waking during the night. This sleep disturbance, in turn, was associated with impaired academic and social functioning.

Significant overall functional impairment has been reported in young people with **depression** [107, 108], with the domains of social [109-111], academic [109, 110], family [110], occupational and physical functioning [111] among those affected. Verboom et al [109] have also noted differential effects on functioning for girls and boys and Nagar et al [110] also found that whether a parent had a psychiatric illness, their level of education and the child's living arrangements also affected the child's level of functional impairment.

Examining the effects of adolescent depression on functioning later in life, Lewinsohn et al [111] assessed the functioning at age 24 of a large sample of participants who had had a mood disorder in adolescence. While psychopathology in general, and not just depressive disorder, was related to impaired future functioning in various areas, the authors concluded that ‘the effects of adolescent depression appear to cluster in the relatively specific domains of relationship quality and environmental adversity’ (p.360), with the latter referring to the presence of a greater number of daily hassles and major life events for those young adults who had experienced adolescent depression compared with those who had not. Devine et al [112] examined the mood and functioning of young people from an approximate age of 14 until they were about 19 years old and concluded that ‘an adolescent’s level of depressed mood is predictive of his/her adjustment in multiple areas during young adulthood’ (p. 638). Included in these areas of impaired functioning were self-esteem and prosocial competence.

2.5 Topic five: preferences for support

a) Introduction

Literature outlined in the previous section leaves little doubt concerning the existence of broad effects of having a psychosocial disability. Identification of this disability logically leads to the question of what supports are needed by people with mental illness to assist in their daily functioning and, in the longer term, to lead a ‘good life’ [5]. This section outlines the support preferences of people with a psychosocial disability. It is divided into two parts. The first part discusses areas of life in which people with a psychosocial disability indicate they need support. The needs of women with children has been included, given that this group is not well represented in the larger body of research discussed. The second part then outlines findings from the literature in regard to the types of support that people with a psychosocial disability would like to receive.

Studies involving people with a psychosocial disability show a number of commonly indicated areas of life in which they need support. These areas include:

- social life, such as the need for company, family and friends and organised social groups
- improving physical health
- help with money, such as budgeting and finances
- daytime activities, such as work, education and social activities
- getting clear information on their mental illness and its treatment
- accommodation, from finding a place to stay to addressing maintenance issues
- maintaining intimate relationships, including romantic relationships
- activities of daily living, including around meals and looking after their home
- support related to their psychotic symptoms and psychological distress, including help with medications and support or someone to talk to.

- Asking consumers, carers and service providers to rate the support needs of consumers will often result in differing assessments of need.
- Given the power to choose the types of support money can be allocated to, people with a psychosocial disability are willing to allocate funds to address their needs in these areas.
- People with a psychosocial disability frequently state the desire to employ a ‘personal assistant’ or ‘support person’ to help them meet these needs.
- People with a psychosocial disability and their carers also consistently express the need for assistance with planning how to spend an individualised care budget, especially when the person receiving this funding experiences cognitive impairment.
- People with a psychosocial disability have a strong preference for greater housing stability and for the ability to choose their own living arrangements.
- Most often, their preference is to live alone or with housemates that they choose in their own home and not in supported accommodation.
- Living independently has demonstrated positive effects on overall wellbeing, activity and social life.

b) Findings from the literature

The Camberwell Assessment of Need (CAN) [113] measures treatment and **support needs** in 22 domains (see Table four overleaf). Needs can be rated on the CAN by the consumer or a carer or service provider. The CAN is frequently used in studies with people living with mental illness. Results from 11 studies conducted in Australia [114-116], England [117, 118], Israel [119], Spain [120, 121] and several Nordic countries [122-124] that used the CAN to assess the needs of participants with schizophrenia show many similarities in areas of need despite use with different participant groups (for example, inpatients and outpatients, different psychotic disorders) and differing cultures and mental health systems. Table four is a summary of the results of these 11 studies combined. The ‘Consumer’ column shows the total number of participants across all studies who indicated a particular area of need, listing the 22 measured domains of need in order of most frequently indicated to least frequently indicated as an area of need. The same process was reported for carers and service providers, whose sum scores are also shown in Table four. These results illustrate the variation in rating of needs by consumers and others. The agreement between ratings of need by consumers and others varies across studies [117, 118, 122, 125, 126], with some authors noting that case managers [126], staff [122, 125] and parents [122] tend to rate the needs of consumers more highly than do the consumers themselves. Overall, consumers rate most highly as areas of need the areas of psychotic symptoms, company, food, daytime activities and looking after the home.

Given that the studies using the CAN involved varying numbers of participants, and that studies with larger samples might more strongly influence the analysis shown in Table one than smaller samples, we also examined the top 12 ranked domains for each study were examined and made comparisons across the studies. Strong similarities again emerged across studies: in all, the company of others, food, looking after the home, physical health,

psychological distress and psychotic symptoms were ranked consistently among the top 12 areas of need. Daytime activities occurred in the top 12 domains of need in ten of the 11 studies; the need for information about treatment, for intimate relationships and money were in the top 12 in nine of the 11 studies; accommodation in eight; and benefits and transport in seven each.

Consumers			Carers or staff		
Domain of support need	N	%	Domain of support need	N	%
Psychotic symptoms	835	76	Self-care	835	76
Company	599	54	Physical health	599	54
Food	584	53	Self-harm	584	53
Daytime activities	565	51	Food	565	51
Look after home	546	50	Child care	546	50
Psychological distress	522	47	Psychotic symptoms	522	47
Accommodation	467	42	Alcohol	467	42
Information	456	41	Psychological distress	456	41
Money	449	41	Telephone access	449	41
Physical health	419	38	Interrelationships	419	38
Interrelationships	348	32	Information	348	32
Transport	338	31	Daytime activities	338	31
Benefits	309	28	Basic education	309	28
Self-care	239	22	Illicit drugs	239	22
Sexual expression	213	21	Safety to others	213	21
Basic education	212	19	Benefits	212	19
Self-harm	209	19	Company	209	19
Telephone access	119	11	Look after home	119	11
Alcohol	113	10	Money	113	10
Child care	103	9	Sexual expression	103	9
Safety to others	92	8	Transport	92	8
Illicit drugs	91	8	Accommodation	91	8

Table four: endorsed areas of personal support based on the CAN in 11 studies of need in consumers with schizophrenia

Several further studies used the CAN to assess consumer needs but did not report data in a way that allowed inclusion in the analyses above, although these showed similar findings. In a study of 320 consumers from several European countries with psychotic disorders [127], psychotic symptoms were the most common area of need (>90%), followed by accommodation, looking after the home, daytime activities, company of others, physical health, information, psychological distress, intimate relationships and money (about 40% each). Trauer et al [128] used a consumer version of the CAN (the CANSAS-P) with 108 Australian consumers of Neami services, whose most common diagnoses were schizophrenia and mood disorders. The ten most highly rated areas of need in this study were psychological distress, daily activities, psychotic symptoms, sexual expression, company, information, physical health, intimate relationships, accommodation and money, similar to the previously reported studies.

Ochoa et al [121], also using the CAN in a Spanish study with 230 outpatients with schizophrenia, determined that greater symptom severity was related to a higher number of needs, but also that specific symptom types related to particular needs. They found that consumers with more severe negative (for example, emotional withdrawal, lack of spontaneity and flow in conversation), disorganised (for example, difficulty in abstract thinking, disorientation, suspicious thinking) and excited symptoms (for example, poor impulse control, hostility, tension) more commonly required assistance with daily living activities such as looking after the home and self-care. Greater negative symptoms were also related to social needs such as daytime activities and company of others, as well as use of the telephone, education and transport. The latter three were also related to greater disorganised symptoms. The central message of this study is perhaps that individuals attributed the same general diagnosis (schizophrenia) will vary in their level and types of needs, depending on the type and severity of symptoms.

Consistent with 'company' being a common area of need, a survey of 182 consumers and 76 carers who had used SANE Australia's services showed that 72% of respondents said they felt lonely 'often' or 'all the time', with 85% stating that maintaining friendships was harder with mental illness, despite 86% stating that having friendships was integral to recovery [129].

With structured assessments of need, such as the CAN, respondents are restricted to intimating their need in a specified number of domains; therefore, using different tools can identify alternative areas of need. An American study of 385 consumers using a different tool found the greatest areas of need to be: transport; dealing with upsets and crises; talking about problems; finding available services and medical and dental [126]. Case managers rated the overall needs of the consumers more highly, with greatest areas of need rated as: dealing with upsets and crises; talking about problems; issues regarding family, friends and roommates; transportation; managing money; finding available services; managing medication; and daily living skills.

Jansson, Sonnander and Wiesel [130] assessed the support needed by 406 Swedish consumers with a psychotic or personality disorder to carry out ten daily living activities. The most common areas in which consumers needed either some or complete support were: cleaning and washing (41%); interpersonal skills (40%); handling finances (38%); taking medications (34%); buying clothes (31%); preparing a meal (28%); using public transport (31%); buying food (24%); using a telephone (11%); and personal hygiene (10%). Service providers ranked the consumers' needs in a different order, rating most highly: interpersonal skills (60%); taking medications (55%); handling finances (50%); cleaning and washing (46%); buying clothes (40%); buying food (38%); and preparing a meal (38%).

Social functioning was indicated as the greatest area of need in the study of Goossens, van der Klein, Kroon and Achterberg's [131] study of 157 outpatients with bipolar disorder. This included the need for 'standing up for yourself' (22%), coping with quarrels and conflicts (17%), work (14%) and coping with loneliness (13%). About 20% of participants needed assistance with cleaning the house, 14% with management of finances, 12% filling in forms and answering letters and 8% with management of housekeeping money.

Of the 23 participants in an Australian qualitative study by Fossey, Harvey, Mokhtari and Meadows [132] who identified current needs for mental healthcare, most expressed a need for information related to mental illness and its treatment, physical health, lifestyle and occupations. In focus groups with eight Australian participants with multiple admissions to acute care facilities for mental illness, Browne et al [133] found that lack of financial resources had a pervasive impact on the participants' lives and that loneliness and boredom were major problems, as was low self-esteem.

Summarising the findings of various Australian research, the Mental Health Council of Australia [134] concludes that homeless people have a higher prevalence of mental illness than the rest of the population, although exact statistics on rates of homelessness and whether these people are being reached by support services are difficult to determine. Homelessness is especially a problem for young people with mental illness [134].

Reporting on the needs of young people (six to 18 years) recently discharged from an inpatient facility in the United States, Solomon and Evans [135] state that, beyond needs for individual and family therapy, service providers believed that self-help and support groups and advocacy were the most necessary supports for the young person and their families. Vocational services were also rated at a 'moderate' level of need. In addition to counselling and psychotherapy for their child and family therapy, parents and caregivers most frequently wanted after-school activities, self-help and support groups and special summer camps for their child, as well as parent skills training for themselves.

Women with children are not well represented in the studies discussed so far. Since their support needs might differ from people without children, the limited research on the support needs of pregnant women and mothers with mental illness was examined. Using the CAN, Howard et al [136] identified that 22% of women with children in their sample, most

commonly with schizophrenia or affective disorder, had problems with childcare. Comparing women with and without children, those with children were significantly more likely to rate themselves as having difficulty with intimate relationships. They did not vary on any other domain. The other most commonly endorsed areas of need were: transport (70%); psychotic symptoms (65%); psychological distress (41%); daytime activities (39%); physical problems (37%); company (37%); intimate relationships (29%); benefits (32%); accommodation (31%); information (29%) and food (26%).

Using the CAN-Mothers (Can-M) [137], Howard and Hunt [138] identified the most commonly endorsed areas of need for pregnant women or mothers with mental illness as: psychological distress (71%); daytime activities (66%); sleep (57%); information (49%); violence and abuse (43%); general physical health (43%); benefits (40%); company (37%); intimate relationships (37%); accommodation (37%); budgeting (34%); transport (29%); psychotic symptoms (26%); and the practical demands of childcare (26%). Mental healthcare professionals who completed the CAN-M most commonly endorsed the same areas of need, with slightly differing priorities: psychological distress (73%); daytime activities (67%); sleep (50%); violence and abuse (42%); company (39%); general physical health (37%); psychotic symptoms (34%); practical demands of childcare (31%); intimate relationships (30%); and accommodation (24%).

The following part of this section summarises the small number of identified studies that explore the support preferences of people with a psychosocial disability. Some studies related to situations in which people had been given control over their support allocation and investigated how people had used the resources. Other studies asked a hypothetical question about how people would spend their money if they were given control over their own support allocation. Overall, the way participants choose to allocate services is consistent with the areas of need identified in the previous section.

In 2013, Brophy et al [5] interviewed 41 people who had accessed mental health services in the Barwon Region of Victoria to identify the supports they would access, given the power to choose, to support them to have a 'good life'. When asked to first set goals for their good life, overall the participants chose as their top five goals: health (physical and mental) (68%); economic (stability, opportunities to improve their income) (61%); social connection (59%); housing (stability, safety and independence) (34%); and personal relationships (32%). These priority areas match closely the areas of need identified in the previous section. Table five (see next page) summarises the preferred supports of the participants to achieve these goals. Responses also referred to preferences for certain medical (for example, doctors and medication) and psychosocial treatments (for example, psychologist) but, for the purpose of this review, these have been excluded such that only 'supports' are included here. In this study, a 'support person' emerged as a commonly desired form of support and participants went on to identify the characteristics of an ideal support worker: respectful and compassionate; good knowledge of the mental health system; understanding the impact of

mental illness and psychosocial disability; able to perform multiple roles; and good communication skills.

The stated preference for help to reconnect with family and friends identified in Brophy et al’s research highlights the omission of family or family life from other standardised approaches to assessing need (for example, CAN; see page 46 of this review). The current study indicates that family and family life is an important area of need or aspiration that is often overlooked because it is assumed to be covered in other life domains.

The table below summarises the findings from this study.

Goal	Preferred supports
Health	Peer support
	Financial support to subsidise health care
	Group-based activities
	Personal carer
	Prevention strategies
Economic	Training and skills development (for example, budgeting, skills for employment)
	Employment assistance (for example, to help source and maintain employment)
	Financial support and stability
Social connection	Peer support and support groups
	Help to access recreational activities
	Direct assistance from a support person: home-visiting and help with domestic tasks
	Drop-in centres
	Financial support for community and sporting activities
	Help to reconnect with family, friends, and community
Housing	Financial advice and assistance (mortgage or rent assistance, maintenance and housekeeping)
	Moving and relocating
	A housing worker
	Housing that can be a home
Personal relationships (intimate and family)	Funding to help achieve intimate relationships (for example, transport and activity/recreation costs)
	Family relationships supports: information for family members, direct support for family members, reducing reliance on family members, financial support to connect with family members (for example, family counselling, transport and activity costs)

Table five: preferred supports to achieve top five life goals

Source: Brophy et al [5]

This preference for a support person is also a key finding of Davidson et al's [83] in-depth interviews with eight American consumers. Participants in this study clearly described a preference for mental healthcare that provided both relief from symptoms and enabled them to rebuild a 'normal life'. Given the choice of how to spend their 'mental healthcare dollars', after care of neglected basic needs such as food and transport, participants most wanted a support person who could 'accompany and perhaps guide them in participating in normal activities' (p. 108). Participants varied in their suggestions of who that person might be, from a friend or family member to a paid professional, but they agreed on that person's functions: reassurance, companionship, someone to talk to and who will listen and someone to 'hold your hand or show you how to do things until you become comfortable doing these things by yourself' (p. 108). A similar Australian study by Browne et al (2008) had consistent findings, with all participants expressing the need for someone 'who understands' to assist their recovery.

In a paper discussing the advantages and disadvantages of direct payments (DPs) to individuals with a disability to purchase their own care in the United Kingdom, Spandler [139] states that within the broader disability context:

'recipients frequently use the money to employ their own personal assistants (PAs)... although people may choose to meet their demands in a variety of ways, employing and directing PAs has always been at the heart of demands for DPs' (p. 189).

Supporting this proposition, an English interview study with 14 people with a disability, including three with 'mental health problems' (p. 922), discussed the participants' experience of having been offered, or having recently received, 'Individual Budgets' (IBs) to purchase their own care [140]. The study found that participants':

'first priority was generally personal assistance, through directly employed personal assistants, agency staff or paying family/informal carers' (p. 924).

Transport to facilitate greater community involvement and respite care were among the other areas identified as top priorities for care spending (for all people interviewed and not just those with a psychosocial disability). Those participants whose conditions were fluctuating also felt reassured that flexible spending allowed them to allocate their support resources over the year, such that support would be available to them as needed, rather than feeling that their level of care had to be consistent, regardless of actual need. The participants also appreciated the ability to 'think outside the box' about what they could purchase to suit their needs outside the traditional boundaries of care, to be able to maintain consistency in their careers, the ability to 'employ' family or friends and to hire different people for different tasks. Importantly, they also identified the importance of having professional support during assessment and support planning, to have an advocate during this process if they experienced cognitive difficulties and that advocacy or brokerage services be free of charge.

In 1989, a small New York-based trial took place that allocated consumers vouchers that allowed them, in conjunction with a case manager, to purchase services to support their individualised service plans, to attend to emergency needs or to pool vouchers with others to develop new services [141]. Data for the first three months of the program showed that consumers spent most of their service plan funding on housing or respite (>40%), personal needs (>15%), medical and dental care (>10%) and furnishings (about 10%). Emergency funding was primarily spent on temporary housing (>20%), clothing (>20%), food (>20%), personal needs (>10%) and transportation (about 10%). It is not clear whether these were the most commonly used, or simply the most expensive, services. Pooled funding was used for 29 new support programs; eleven focused on self-help, such as an advocacy centre, and ten on leisure and social activities, such as a drop-in centre. These were allocated more than 50% of the pooled vouchers, illustrating the importance of such services to the consumers. Six programs were vocational and one educational. The author concluded that case management should be a 'freestanding reimbursable service' in its own right and that such voucher programs need to be based on the consumers' individualised service plan.

Staff of an American program providing flexible and personalised community support for mental health consumers to live well in the community monitored how time was spent with consumers over a three-year period [142]. This monitoring identified that 17% of contacts with consumers were for social and recreational purposes, although these took up about 31% of their work time. Supporting activities of daily living made up about 14% of contacts (12% of time in year one), vocational contacts ranged from 10% to 17% from year one to year three, between 3% and 5% of contacts related to family, between 1% and 4% to living arrangements and less than 1% to physical health. It was also identified that, over time, fewer hours were spent in one-to-one support and psychotherapy, with simultaneous increases in time spent in vocational contacts, indicating a response to the consumers' changing needs over time.

The Victorian Mental Illness Awareness Council (VMIAC), in consultation with consumers, developed a guide titled *What consumers want from mental health community support services*. The central tenet of the listed preferences is that the needs and preferences of the consumer and their 'total personhood' be central to support service planning and delivery. In particular, consumers express their desire for support to maintain their relationships with others with experience of mental illness and to support their participation in community and education when they are ready.

In relation to the **housing and housing support preferences** of people with mental illness, research evidence shows a clear preference for, and clear benefits of, living independently alone or with housemates chosen by the individual. Housing stability also emerges as a major concern, with housing instability having clear effects on social and community participation and participation in general activity. Browne and Courtney [143] cite a series of studies suggesting that recovery is better when consumers are able to live in accommodation and with living companions that are chosen to suit their preferences and

needs. Summarising the research evidence regarding these housing preferences, Browne, Hemsley and St John [133] state that ‘consumers have a strong preference for normal living situations’ (p.403); that is, to live independently in a home of their own, alone or with a friend or partner and not with other consumers under supervision.

Interviews with 13 Australian participants with schizophrenia living in either a boarding house or their own home [143] confirm these preferences, with the majority of participants wanting their own home and to choose their living companions in order to foster feelings of ‘belonging’ and of being ‘in charge of their lives’ (p. 317) and to gain the positive effects of supportive housemates. Costs of housing often prevented participants from living independently or meant a trade-off between paying rent and buying other essential items, like enough food. Those living in their own home indeed reported more social and general activity. Housing stability was essential to all participants to allow them to build friends and networks, which were often lost with relocation, which in turn improved their mental health and wellbeing. Browne et al [133] also found that housing for people with mental illness was seen as ‘central to building a future’ (p. 406) by providing a solid base from which they could build their recovery, with participants expressing that having to move (sometimes from one type of housing to another) is ‘unsettling’. There was also agreement that having influence on choice of housing was imperative. Browne and Courtney [144] confirmed that living in their own home compared with living in boarding houses related to better overall functioning and more opportunity for social support outcomes for people with schizophrenia. In the study of Freeman et al [116], 60% of interviewed patients currently living in high support settings in New South Wales wanted to live elsewhere, with half saying they would like to live independently and about one-third saying they would like to live alone.

Discussion with 15 Victorians living in supported accommodation [145] identified that, where supported accommodation is required, consumers should be able to choose their supported housing and have opportunities for control over the housing environment; that there should be a balance between those with and without mental those living within the housing unit; and that the housing needs to be stable, and not time-limited.

2.6 Topic six: service access and use

a) Introduction

While the previous section outlined the preferences for support that people with a psychosocial disability would like to access, this section of the review attempts to identify those psychosocial support services that are most commonly used in Australia. Given the breadth of organisations providing psychosocial support services to people with a psychosocial disability in Australia, sector-wide information on use of existing services is difficult to ascertain within the constraints of this review. However, data identified from Government and other services is summarised.

The literature review identified the following:

- Emotional support, services that assist in accessing other support and treatment services and services providing information about mental illness and recovery planning are highly utilised by people living in Australia with a psychotic illness.
- Employment services are also commonly used by people with a psychosocial disability and the demand for these is increasing.
- Housing services are commonly used by younger people with mental illness and the demand for these is also increasing.

b) Findings from the literature

Table six provides a categorisation of support services delivered by community-managed mental health providers and available to people with psychosocial disability and their families. It excludes disability employment services, a Commonwealth-funded service type that also provides specialist support to people with a psychosocial disability. Across Australia, expenditure, excluding disability employment support, on non-clinical mental health services represents about \$500 million of Commonwealth, State and Territory Government expenditure. In 2012–13, these services provided support to 87,800 people across Australia.

Community Mental Health Support Service Type	Service Cluster Description
Non-clinical Residential Service	A residential mental health service is a service established in a community setting that provides specialist support and care for people with mental illness.
Family and Carer Services	Family and carer services are services that provide families and carers of people living with mental illness support, information, educational and skill development opportunities to assist them in fulfilling their caring role while retaining their own health and wellbeing.
Individual Support and Rehabilitation Services	Includes individuals' support and psychosocial rehabilitation that includes functions such as assessment, skill development, coaching/mentoring, counselling and negotiation of relationships. This service type also supports access to community transport, domestic support, community participation and recreational and health management activities.
Group Support and Rehabilitation	Group support activities that aim to improve the quality of life and psychosocial functioning of mental health consumers through the provision of group-based, social, recreational and pre-vocational activities.
Support Facilitation	Provision of complex case management and co-ordination
Group-based Peer Support	Group-based services that share a common interest and are led and self-managed by peer workers.
Individual Peer Support	Individually orientated services that share a common interest, shared lived experiences and mutual learning. These services aim to support and mentor individuals who have similar life experiences and to help people to develop skills and confidence in building their support networks and social relationships. They also assist consumers to develop crisis situations.

Table six: community mental health supports by service type

The importance of psychosocial rehabilitation services to people with mental illness and their carers was illustrated by findings from a survey conducted through SANE Australia [129], which showed that people accessing psychosocial rehabilitation services reported feeling less lonely and were better at managing their illness than people not accessing such services.

The report *People Living with Psychotic Illness 2010* [76] reported that almost one-third of participants had accessed services through non-government organisations over the last year, making use of services such as group rehabilitation programs (22%) and individual supports.

Table six was created using data from this report and illustrates the types of one-on-one supports used by participants. In addition to individual counselling or emotional support (69%), information about mental illness (44%) and recovery planning information (41%), participants most commonly received one-on-one help with accessing other community

services (45%) or other mental health services (37%). More than two-thirds of participants had also worked with a case manager in the last year. Through the Personal Helpers and Mentors Services (PHaMs, described below), 12% of participants had personal helpers who assisted them with their daily activities (64% of those using PHaMs), referrals to services (49%), going with them to appointments (45%) and acting as their advocate (45%).

Type of one-one-one support	Proportion of participants (%)
Counselling or emotional support	69
Help to access other community services	45
Information about mental illness	44
Information on recovery planning	41
Support to link with mental health services	37
Home help	32
Free or cheap meals	32
Help to access education	27
Accommodation or help to find accommodation	25
Vocational training/employment skills/experience	23
Help to find or keep a job or volunteer work	22
Financial assistance/material aid or help to access financial assistance/material aid	19

Table seven: proportion of participants in the study of people living with a psychotic illness 2010 using different types of one-on-one support services

Source of data: Morgan et al [76]

The Australian Institute of Health and Welfare (AIHW) [146], reporting on the use of **government-funded support services** in 2010–11, state that over 87,200 people experiencing a psychosocial disability accessed non-residential support services in that year across Australia. These services included accommodation and community support, community access, employment and respite services. Employment services were the most frequently accessed. The most common profile of service users was male, aged 25–54 years, living alone in a private residence in a major city and receiving a disability support pension. Access of these services had increased at a rate of 15% per year over the previous five years, illustrating the strong demand for such services.

Regarding residential services, including residential facilities, hostels and group homes, 3,900 people with a psychosocial disability had accessed these services in 2010–11 [146]. Users of these facilities tended to be older than those accessing non-residential facilities (35–64 years), but with otherwise similar demographics. Each year for the last five years, the percentage of people living in these facilities with a psychosocial disability had also increased by 2%.

AIHW [146] also report on the use of specialist homelessness services (SHS) by people with a mental health issue, stating that this group made up almost one-quarter of SHS clients in

2011–12 (over 40,000 service users). In contrast to residential facilities, the highest use was among the very young, with those aged 18–24 years accessing the most SHS services, followed by 15 – 17-year-olds. SHS service users were more likely to be female. Service users of SHS experiencing a mental health issue were also more likely to be Aboriginal or Torres Strait Islander.

Homelessness among those users of SHS with a mental health issue is very common, with close to half (45%) having been homeless in the last year [146]. The main reasons for seeking help from SHS for people with a mental health issue were: domestic and family violence (16%); housing crises (14%); and financial difficulties (11%). Despite the nature of SHS, users of the service were most commonly provided with general assistance, rather than housing/accommodation support (71%), and SHS users most commonly received services for either 45 days or over 180 days (one-quarter of users each) [146].

Personal Helpers and Mentors (PHaMs) is a national Government-funded scheme that uses a strengths-based approach to provide long-term holistic support to people with mental illness [146]. In 2012–13, over 15,000 people accessed PHaMs [147], often provided through non-government organisations. Common functional impairments experienced by those accessing PHaMs at the time of entry related to: ‘learning, applying knowledge and general demands’; ‘social and community activities’; ‘interpersonal relationships’; ‘education’; ‘communication’; ‘domestic activities’; ‘self-care’ and ‘transportation and mobility’ [146]. The popularity of this scheme is in keeping with consumer preferences for a ‘support person’ reported in the previous section.

In 2012–13, over 34,000 carers also accessed Government-funded carer support via **Mental health respite: Carer support** (MHRCS), and almost 60,000 families were engaged in community activities. Almost 10,000 individuals received personal support, via the Family Mental Health Support Service (FMHSS).

2.7 Topic seven: gaps in existing services

a) Introduction

Following on from the previous section, in which psychosocial support services most commonly used within Australia were identified, this section summarises the available literature regarding gaps in existing services for people with a psychosocial disability. As with the previous section, the limitations of this review restrict this examination to published academic literature and government reports on the subject. Furthermore, given the difficulties inherent in collecting data from people with a psychosocial disability who do not access any mental health services, research evidence on the unmet needs of people with a psychosocial disability comes largely from information gathered from people who access some mental health services. Therefore, information on what gaps in psychosocial support services might exist tells us more about how to reduce the gaps for people already accessing some services, rather than informing us of the gaps that cause people to not access any

support services at all. However, there is some Australian literature available that reports on the assessment of unmet needs in people with a severe mental disorder and this literature is summarised here.

A summary of key findings from the literature is presented below:

- There are common unmet needs identified across Australian studies of people with a psychosocial disability. These include the need for:
 - clear information on mental health conditions, and available treatments and supports
 - greater involvement in social and leisure occupations and in work
 - support with psychological distress and psychotic symptoms, including managing medications
 - improving physical health
 - suitable and stable housing that suits the person's preferences.
- While service gaps might be partly responsible for these unmet needs, cost of services and barriers to identifying suitable existing services might also prevent people with a psychosocial disability from accessing existing support services.

b) Findings from the literature

Slade, Leese, Cahill, Thornicroft and Kuipers [148], in a study of 73 London-based adult mental health service users, found that having unmet needs strongly influences participants' quality of life. Consequently, reducing participants' unmet needs improves their reported quality of life. These findings echo those of an earlier study [149].

The Australian Bureau of Statistics [71] has reported data from the *2007 National Survey of Mental Health and Wellbeing* on whether people with a mental disorder who accessed mental health services had their service needs met. Almost 30% reported greater need for information, more than 20% had not had their need for skills training met, and almost 20% needed greater social intervention. For those who did not use mental health services, unmet need was lower, at around 5% for information and social intervention and fewer for skills training. Results of the survey also indicate that social intervention and skills training needs were the least-likely type of service need to be fully met, with just 25% indicating a need for social intervention reporting that their needs had been met [150]. A study of the earlier findings of the *1997 National Survey of Mental Health and Wellbeing* [151] found that people with anxiety problems were particularly likely to have unmet needs.

Almost one-third (31%) of participants in the Australian *National Survey of Psychotic Illness* [76] identified an unmet need for a support service such as help with housing, finances, employment, legal and practical assistance. About one-quarter (23%) had unmet physical needs in relation to their health; and about 5% had unmet socialising and leisure needs. When asked why they had not accessed services to meet their overall needs (which included treatment needs), the most commonly cited reasons were lack of availability (38%), cost

(31%), not knowing how to access the service or who to ask about them (20%) and long waiting times (10%). In looking to the future, participants predicted that major challenges in the next year other than the symptoms of their mental illness were likely to be related to financial matters (43%), loneliness and social isolation (37%), lack of employment (35%), poor physical health (27%) and lack of stable or suitable housing (18%).

Of the 23 participants in an Australian study by Fossey et al. [132] who identified current needs for mental health care, most expressed a need for information related to mental illness and its treatment, physical health, lifestyle and occupations; this need was often unmet. The greatest barrier perceived by participants as preventing adequate information being received was poor communication with doctors and mental health professionals. All participants stated they needed assistance in developing skills to conduct work, leisure and home activities, but these needs were most often completely or partially unmet. Needs related to work-related skills included interview skills, job training and ongoing job support, but these were all seen as unmet. Keeping busy was seen as central to maintaining mental health, but many participants reported few activities and frequent boredom. Many participants also expressed the need for practical help with financial issues such as budgeting, debt management and home maintenance. Perceived barriers to having these needs met related to not being able to articulate their needs, not knowing how to access help and embarrassment about asking for help. Many participants also wanted help with housing issues such as improving their housing situation, taking care of their home or moving to another home. Financial difficulties often posed a barrier to accessing practical help.

Chopra and Herrman [152] investigated the unmet needs of 18 former long-stay patients from a community care unit in Melbourne eight years after admission. Five key areas of unmet need among the participants were identified. Promotion of independence was one area of unmet need, including an ongoing lack of participation in meaningful activities and a lack of vocational rehabilitation. Participants lacked stability in accommodation, resulting largely from movement between residential settings and a subsequent lack of belonging to any one community. This instability also contributed to poor consistency of care. Participants also lacked stable social networks, particularly related to their families, and all of these circumstances contributed to the participants feeling a profound sense of loss.

Four Australian studies were identified that used the Camberwell Assessment of Need to assess mental health consumers' unmet support needs [114-116, 128]. One of these studies [115] examined the needs of participants with three different diagnoses separately (schizophrenia, affective disorders and other disorders) but no systematic differences in unmet needs appeared across these groups. For example, relationships appeared as the greatest unmet need across the three groups. Summing together the percentage of participants with an unmet need in the 22 measured domains across the four studies shows that the highest levels of unmet need are for relationships, psychological distress, company, daytime activities, psychotic symptoms, information, self-harm, illicit drug use, money and

physical health. However, there are two notable differences to this pattern across studies. From the three groups in the study of Cleary et al. [115] who were recruited from a Sydney inpatient facility, between 13% and 47% ranked their needs related to self-harm as being largely unmet, while 9% or less of participants in the three remaining studies rated their self-harm needs as unmet. Conversely, in the studies of Trauer et al [128], Issadakis and Teesson [114] and Freeman et al. [116], physical health needs were rated as being unmet by 22%, 28% and 14% of participants respectively, while 12% or less of the participants in the three groups of the Cleary et al [115] study rated their physical health needs as unmet. These differences might arise from the different settings from which participants were recruited.

Examining the top 12 ranked unmet needs for each group separately, psychological distress and interrelationships appeared in the top six unmet needs for all groups; daytime activities were in the top eight unmet needs for all groups; company was in the top seven unmet needs for five of the six groups, but was either the number one or two in four of the groups; money and psychotic symptoms ranked in the top 12 unmet needs in all groups; information was ranked nine or above for five groups; and illicit drugs in the top 11 for four groups.

Two of the Australian studies of unmet needs using the CAN also asked a clinician or carer to report on the consumer's unmet needs [114, 115]. In both studies, the carer or staff member was more likely to rate consumers' needs as being unmet, and there was generally low agreement on ratings between the consumer and the other respondent. The needs most frequently rated by carers as unmet were psychological distress, company, daytime activities, money and interrelationships [115]; and by staff members [114], daytime activities, company, interrelationships, psychotic symptoms and psychological distress. Therefore, despite low agreement in these studies, overall the needs ranked most highly as unmet were similar between consumers and others completing the CAN.

Freeman, Malone and Hunt [116] interviewed 159 patients across New South Wales (NSW) living in high support settings for consumers with mental illness and found that consumers had experienced a great deal of housing instability, with almost half having lived on the streets or in crisis accommodation at some point because they were unable to find more appropriate housing. Close to 60% expressed a wish to live elsewhere (outside their current supported accommodation). Despite one-half saying they would like to live independently and about one-third saying they would like to live alone, a survey of the NSW accommodation services showed that only about half offered their consumers a choice of housing options, although most encouraged consumers to find alternative accommodation when their needs changed.

In 2012, Neami reported that in the last 18 months there had been a significant waitlist for access to the PHaMs program in three states [153]. While increased funding for this service had occurred as a result of this demand, it illustrates both the demand for that service and that the demand may outweigh supply in some areas of Australia. In their 2012/13 Annual Report [154], Neami also reported on the unmet needs of service users, measured using the

CANSAS [113]. Company (42%), daytime activities (40%), physical health (35%), psychological distress (34%) and intimate relationships (32%) were the top five areas of unmet need. These findings are consistent with findings from the academic literature, summarised above.

Islam [155] interviewed 35 young British adults (aged 18–25 years) with mental health problems and found that, in terms of gaps in the existing services they received, the young participants recognised the burden placed on their families by their mental illness and proposed that families needed support to lessen this pressure. They also reported difficulties with employment, but that this was rarely discussed in the community supports that they received. Rather, they stated that visits from case managers or coordinators focused almost solely on monitoring health and compliance with medication, with little discussion of employment, housing, the possibility of earning an income or future planning in general. On being asked to describe ideal services for young people, the participants frequently noted that these services needed to be uniquely for young people, but also family-friendly and focused on social inclusion. Given that this is a British Study, however, care should be taken in generalising the findings to an Australian context, with similar studies required involving young Australians involved with the mental health system.

2.8 Topic eight: evidence for the effectiveness of different supports

a) Introduction

This section provides a summary of the evidence for the effectiveness of a selected number of psychosocial support intervention types. Given the breadth of possible interventions that it would be possible to include, we have chosen to focus on five types of intervention for which there are relatively recently published reviews that synthesise the findings of a significant body of work assessing the effectiveness of that intervention. These intervention types also aim to address some of the major needs identified by people with severe mental illness that have been outlined in the previous sections (that is, the need for stable and suitable housing, greater social interaction and improved social skills, assistance with the activities of everyday life and employment). Given the strong preference expressed for an individual support person as a means of improving quality of life in research cited earlier in this review, personalised support has been included as a category. Psychoeducation for families has been included because of its application to Tier Two of the NDIS.

The types of intervention included in this section are:

- employment support
- housing
- peer support/peer services
- skill building
- personalised support
- psycho-education for families.

This section draws on the findings of narrative and systematic reviews, meta-reviews and meta-analyses related to the effectiveness of these various types of psychosocial support interventions. Because of the paucity of this type of evidence in relation to peer support, a wider literature has been used in relation to this intervention.

A summary of key findings from the literature is presented below:

- This section summarises evidence for the effectiveness of supported employment, permanent supportive housing, peer support services, skill building and personalised support as types of psychosocial support interventions.
- Authors of the reviews outlined here consistently note the need for research designs of higher quality to make stronger conclusions on the effectiveness of psychosocial support interventions, as the number of high-quality studies is currently limited. This lack of quality studies consequently limits the conclusions that can be drawn in this area.
- Results of reviews of the effectiveness of the four types of psychosocial support included suggest that the strength of evidence for:
 - supported employment services in assisting people to gain competitive employment is strong
 - skills training effects on a range of outcomes is strong
 - supportive housing is moderate
 - the effects of personalised support services on satisfaction with services and illness acuity is moderate, while evidence for effects on functioning is weak
 - peer support is mixed and is particularly limited by the minimal number of high-quality studies. Where positive effects are shown, they relate to reductions in use of inpatient services, improved relationships with providers and engagement with care, empowerment, hopefulness, activation and recovery. However, one review concluded that the positive effects achieved do not go beyond those achieved by support from a professional and another showed no positive effect on hospitalisations, symptoms or service satisfaction.
- The effectiveness of these types of psychosocial supports is often measured using direct outcomes such as rates of homelessness and placement in competitive employment and the effects on functional outcomes and wellbeing is less clear.

b) Findings from the literature

Marshall et al [140] conducted a review of 12 systematic reviews and 17 randomised controlled trials (RCTs) assessing the effects of **supported employment programs** for people with mental illness with or without a concurrent substance use disorder. Supported employment in this review refers to a direct service that has multiple components, which is designed to ‘help adults with mental disorders or co-occurring mental and substance use disorders choose, acquire, and maintain competitive employment’ (p.16). Competitive employment is that in which the employment setting is integrated within the community and the consumer holds the position directly, rather than the position being held by the agency [140].

The authors concluded that there was a ‘high’ level of evidence for the effectiveness of supported employment in assisting people with mental illness to attain competitive employment. In this context, a ‘high’ rating means that the authors have confidence in the outcomes, which are based on ‘three or more RCTs with adequate designs or two RCTs plus two quasi-experimental studies with adequate designs’ (p.18). There was insufficient evidence to conclude that supported employment had a positive effect on other ‘non-vocational’ outcomes, although the results of four RCTs suggest that competitive employment compared with no employment could be related to improvement over time in other outcomes such as quality of life and social functioning.

In a 2008 review [139] of the findings of nine RCTs and four studies examining the effectiveness of converting day treatment services to supported employment, Bond similarly concluded that 40% to 60% of people with severe mental illness were able to obtain competitive employment when enrolled in supported employment programs, compared with about 20% who were not enrolled. However, positive non-vocational effects are only observed when employment is maintained for a period of time. Bond also reviewed the evidence for seven principles of supported employment and concluded that there is strong support for the following principles:

- (1) Services must focus on competitive employment.
- (2) The only eligibility criteria for receiving supported employment services should be consumer willingness, and not any other measure of job readiness.
- (3) Job placement should be rapid, occurring as soon as the consumer expresses their readiness for employment and should not be preceded by a long period of assessment, training or counselling, consistent with principles two and three.
- (4) Supported employment needs to be integrated with the broader mental health treatment team.
- (5) Job placements must be based on consumer preferences, strengths and experience and not any other judgement in regard to suitability for particular employment.

Bond [139] also concludes that ‘sheltered employment’, in which people with a disability work together in a contained worksite; day treatment with a non-vocational focus; and

other non-competitive approaches to employment, might in fact interfere with the goal of competitive employment. Furthermore, positive effects of general treatment strategies such as psychotherapy do not generalise to competitive employment. Only strategies that directly assist the consumer to find and keep competitive employment will have positive vocational outcomes. There is also some evidence to suggest that only sustained competitive employment has positive effects on non-vocational outcomes such as improved quality of life, as concluded by Marshall et al [140].

In the review of Bond and Campbell [156] **supported housing** is defined as ‘an approach in which consumers rent or lease independent, affordable housing that is integrated into the community (i.e. separate from the mental health service agency with no live-in staff)’ (p. 37). People living in supported housing still have access to crisis services from staff [156] and flexible home support as needed [157]. Reviewing five previous reviews regarding the effects of supportive housing, Bond and Campbell tentatively conclude that compared to ‘usual services’, supportive housing is an evidence-based practice, despite some problems with the methods used to assess outcomes.

Two reviews published this year (2014) [136, 144] review the research evidence from 1995 to 2012 for ‘permanent’ supportive housing: supported housing that assists people with mental illness and substance use disorders to secure long-term ‘affordable, independent housing’ ([136] p.288); and ‘recovery housing’: short-term housing that is most often accessed following inpatient or residential treatment [144]. The two reviews concluded that the strength of the evidence for recovery housing and permanent supportive housing was ‘moderate’, taking into account the quality of the research and the strength of outcomes. Rog et al [136] found that permanent supportive housing reduces homelessness, emergency room visits and hospitalisation, while increasing housing tenure. No functional outcomes were reported. Reif et al [144] found that recovery housing is related to positive outcomes regarding substance abuse, incarceration, employment and psychiatric symptoms, but no other functional outcomes. Both reviews reported methodological limitations in the research reviewed.

The Mental Health Council of Australia [134] outlines three Australian examples of good practice in supported housing which follow some key principles: that consumers have choice in their housing, an unrestricted length of stay, the unconditional option to stay in the housing, various options available to support their changing level of need, and services available to ensure housing is not lost if hospitalised. The first example is the Housing and Accommodation Support Initiative (HASI) operating in NSW. HASI offers six different levels of support dependent on the tenants’ needs, and provides housing and housing support that is also linked with psychosocial rehabilitation services. The service operates within a partnership between Government departments and the NGO sector. Other similar programs operate in Victoria (Housing and Accommodation Support Program), Queensland (Project 300), South Australia (Returning Home) and Western Australia (Independent Living Program).

The second example is the Neami Community Housing Program mentioned earlier in this report. Most tenants live alone and fewer with a maximum of one other person. Rent is charged at a greatly reduced rate, and while services are offered, tenants do not have to engage in treatment or support services to maintain their tenancy. Client-directed support is offered in which a case worker encourages the tenant to create goals and then assists the tenant to create a stepped plan for achieving those goals [134].

The On Track Community Programs, Alternative Outreach Program operating in NSW is the third example. On Track is based on a partnership with private property owners and investors willing to lease their properties at a reduced rate. The On Track team manages all aspects of the tenancy and provides intensive case management as needed. After successful tenancy of one year to 18 months, case management can be gradually withdrawn.

Chinman et al [158] reviewed the research evidence from 1995 to 2012 regarding the effectiveness of **peer support/ peer services** and concluded that the strength of evidence is 'moderate', using the same rating system as the reviews included in the previous paragraph [136, 144]. A 'peer' is defined by Chinman et al as 'a person in recovery' (p. 430). The goals of peer support are described as assisting the person with mental illness and/or substance use disorder in developing coping and problem-solving strategies for self-management; drawing on experience and empathy to promote 'hope, insights and skills'; fostering engagement in treatment and supports; and establishing a 'satisfying lifestyle' (p. 430). Chinman et al divided the types of peer support studies reviewed into three types. 'Peers added to traditional services' describes the addition of a peer to existing services such as assertive community treatment. 'Peers delivering structured curricula' involves a peer delivering a specified curriculum to the consumer aimed at promoting self-management, and 'peers in existing clinical roles' refers to working in a role such as a case manager in a way that is informed by their own lived experience of a mental illness. There is stronger evidence for the former two types of peer support, while support for the latter was mixed. Results of the review suggest that the utilisation of peers can reduce use of inpatient services and improve relationships with providers; engagement with care; and levels of empowerment, hopefulness and consumer activation.

Another recent systematic review and meta-analysis of 18 RCTs of non-residential peer support interventions examined the effectiveness of mutual peer support, peer support services and peer delivered mental health services [142]. Overall, the authors concluded that there is little current evidence for the effects of peer support for people with severe mental illness. Specifically, the results of this review indicate there is little or no evidence that peer support is associated with positive effects on hospitalisation, overall symptoms or satisfaction with services; although there was some evidence that peer support was associated with positive effects on hope, recovery and empowerment at the time of intervention and after. However, these findings were inconsistent. Reporting on the quality of studies reviewed, the authors state that the outcomes of the peer support interventions

are incompletely reported and there is a high risk of bias. Therefore, higher quality trials are needed to draw definitive conclusions about the effects of peer support.

An earlier Cochrane review of the effects of services provided by a peer or ‘consumer provider’ [145] included only randomised controlled trials that compared either provision of a particular service by a professional compared with the same service delivered by a peer, or which compared services with or without peer provided services as an adjunct. Results of this review suggest that the results of these RCTs are equivocal. That is, the outcomes from peer provided services are no better or worse than services provided by a professional.

Authors of these reviews consistently state the difficulties in drawing strong conclusions from the current research assessing the effects of peer support services owing to the limited number of high quality studies in the area. While this current state of evidence is lamentable, the growing interest in the value of peer support services for people with severe mental illness both in Australia and internationally suggests that this evidence base is likely to grow rapidly in the coming years [159]. Furthermore, it is important to note that this review has also only discussed published reviews of the peer support literature, including reviews of RCTs and a Cochrane review. Such reviews are likely to exclude qualitative consumer based research that may capture the personal benefits of peer support not captured by other methodologies.

Skill building can refer to a variety of approaches aimed at developing skills to better address difficulties arising from a severe mental illness. In the 2014 review of Lyman et al [84], the authors review studies of four components of skill building: social skills training, social cognitive training, cognitive remediation, and cognitive behavioural therapies with coping skills for psychoses as their focus. Social skills training, including life skills training, involves the development of skills to deal with everyday social situations and daily living skills. Social cognitive training assists in the development of the ability to accurately interpret and respond to social interactions. Cognitive remediation aims at developing memory and attention in order to promote psychosocial skills and thinking, and cognitive behavioural approaches aim to promote self-management of the symptoms of the mental illness. The results of this review of more than 100 studies of various skill building interventions led the authors to conclude that the level of evidence for the effects of skills building overall is ‘high’ [84]. However, there was lesser support for life skills training alone and cognitive-behavioural approaches. Overall, compared with control conditions, the review found evidence for the positive effects of skill building on cognitive functioning, including attention and memory; social and daily living skills, and associated functioning in the community; and illness management and consequent reductions in symptoms and relapses.

Furthermore, Lyman et al [84] conclude that components of skills training are best delivered within integrated approaches that are:

‘based on an individual’s constellation of skills, challenges, and motivations... continuously adjusting the services mix on the basis of an individual’s progress and needs has the best chance of achieving outcomes and being cost-effective in practice. (p.737)

Gibson et al [160] examined the last 20 years of research evidence regarding the effects of occupational therapy interventions on recovery for people with severe mental illness. From their review, they conclude that evidence for the effects of social skills training is ‘moderate to strong’. However, consistent with the findings of Lyman et al [84], the level of evidence for training in daily life skills is ‘moderate’, as is the evidence for combining skills training for daily living activities, work and social participation with neurocognitive training. Studies of the effects of social skills training variously demonstrated a range of positive effects from specific skills such as assertiveness to broader skills such as role functioning, social and leisure activities and wellbeing. In some cases, symptom reduction was also observed.

In relation to **personalised support**, the ‘support preferences’ section of this review notes that people with mental illness involved in qualitative research on the topic consistently note their preference for a ‘support person’ to provide support, assistance and interaction as a means of fostering a better quality of life. In 2012, Siskind et al [161] published a review of 15 studies that assessed the effects of personalised support on outcomes for people with a severe and persistent mental illness. A definition of ‘personalised support’ was adopted for this study that captures the provision of one-on-one, non-clinical support by a person who does not necessarily have clinical training. For the purpose of the review, the support provided by such a support person was divided into living skills, community access, emotional support and advocacy. The studies reviewed were deemed to have weak to moderate quality designs, as is the case in a number of other reviews discussed so far. However, the review of existing evidence led the authors to conclude that overall there is moderate evidence to suggest that personalised support services can promote patient satisfaction with services and reduce illness acuity (hospitalisations, forensic contact and symptom severity). They also concluded that there is a ‘weak’ level of evidence that personalised support can improve personal functioning, such as interpersonal interactions, problem solving and living skills.

The provision of psychoeducation for individuals with mental illness and their families has come to be viewed as an evidence-based practice for the treatment of schizophrenia [162-164]. As a result, **family psychoeducation** is frequently recommended in treatment guidelines such as those of the Royal Australian and New Zealand College of Psychiatrists for the treatment of schizophrenia [165].

Based on recommendations regarding the length and conduct of family psychoeducation issued by the Schizophrenia Patient Outcomes Research Team (PORT) [166], the RANZCP state that:

Family psychoeducation is a program delivered for at least nine months, in which the person with schizophrenia and family members are helped by clinicians to learn communication and problem-solving skills to solve the many challenges that accompany schizophrenia. (p. 29)

Also defining family psychoeducation, Rummel-Kluge and Kissling [167] state that family psychoeducation is information delivered to the person with mental illness and their family in a structured and didactic way that focuses on the illness and its treatment, and associated emotional aspects. The aim of family psychoeducation is to promote coping among the family in relation to the mental illness of their family member [167, 168].

While research has evaluated a broad range of outcomes of family psychoeducation, with some mixed results, the most consistently reported positive effect of family psychoeducation is a substantially reduced relapse rate for people with schizophrenia and schizoaffective disorders in comparison with individuals whose families do not undertake psychoeducation [162, 168]. Despite variations in the content and delivery of psychoeducation programs and definitions of 'relapse', McFarlane et al [169] cite eight previous reviews stating that the effect of family psychoeducation on relapse and rehospitalisation rates is 'large and significant'. They also report a 'remarkable consistency of effects on relapse rates, with minimum reductions of about 50% of the control groups' rates' (p. 231), and that these differences increase over time. Lincoln et al [168] conducted a meta-analysis using data from 18 randomised controlled trials comparing psychoeducation to standard care or other non-specific interventions and published between 1982 and 2005. At post-intervention, they found a medium effect size for relapse and rehospitalisation, which persisted with a small significant effect size up to 12 months follow-up. However, in contrast with the comments of McFarlane et al [169], no significant effects remained beyond the 12-month follow-up. Lincoln et al also determined that only those psychoeducation programs that involved the family, with or without the person with schizophrenia present, were capable of producing significant effects on relapse and rehospitalisation.

While Lincoln et al [168] found no positive effects of psychoeducation on symptoms, functioning, and medication adherence, positive effects of psychoeducation on some of these and other outcomes have been reported in various reviews, though with less consistency than for relapse and rehospitalisation. Other positive outcomes reported include improvements in the functioning of the individual with the mental illness, such as increased social functioning [163] and work functioning [170]; occupational outcomes such as increased employment rates [162] and increased work tenure [170]; and positive outcomes for the family, such as decreased family burden and improved wellbeing [162, 170].

Because of great variation between studies in the constituents of family psychoeducation programs delivered and the delivery models used [163, 164, 168], the essential or 'active' elements of such family psychoeducation programs that lead to positive outcomes have not yet been clearly identified. As Dixon et al [163] state the 'Minimum ingredients are still not clear' (p. 905). However, PORT recommend that family psychoeducation for schizophrenia take place over a minimum of nine months, include families (and/or other carers) with both low and high EE, and should not be based on the premise that family dysfunction is the aetiology of schizophrenia [166]. Beyond these general recommendations, some studies have tried to isolate active components of family psychoeducation, with some inconsistent findings. For example, Schooler et al (1997), as discussed in Murray-Swank and Dixon [162], found no additional effect on relapse and rehospitalisation rates over two years for the inclusion of in-home education, problem solving, and communications skills training in addition to basic education and monthly support groups for families of people with schizophrenia. This is in contrast to the statement of McFarlane et al [169] that problem solving, coping skills training, expanded social support and communications skills are all necessary to produce long-term robust outcomes for families from family psychoeducation.

Despite the complexities of research regarding the efficacy of family psychoeducation, it remains consistently endorsed as an evidence-based practice in relation to the treatment of schizophrenia, particularly. There is also emerging evidence that family psychoeducation can produce benefits in relation to other mental illnesses [163], especially bipolar disorder [162, 163].

c) Summary

Overall, these reviews assessing the effectiveness of psychosocial support interventions for people with severe mental illness and/or a substance abuse disorder suggest that supported employment [139, 140] and skill building [84, 160] have the strongest level of evidence in their favour. Supportive housing [136, 144, 156] has 'moderate' strength evidence to support its effectiveness, while personalised support has 'weak' evidence in support of its effectiveness [161]. Two of three reviews relating to peer support included here conclude that there is no evidence overall for the effectiveness of peer support, while the third concludes that the evidence for peer support is 'moderate' [145]. The latter had broader inclusion criteria for the studies included while the former two reviews included only RCTs. Given that RCTs are considered to provide the strongest quality of evidence, it is tempting to therefore conclude that the evidence for peer support is minimal.

It is also important to note that effectiveness for some of these interventions, particularly supported employment and housing, tend to be measured by direct outcomes such as whether consumers gain competitive employment and consumer rates of homelessness. More distal outcomes such as improved functioning and wellbeing are less frequently measured, and therefore there is less evidence on which to base conclusions in this regard. Furthermore, lesser strength evidence is not always the result of equivocal or negative study findings, but can also be the result of weak study design that results in positive study

outcomes, such that reviewers can only make tentative conclusions based on the strength of evidence at that time. The quality of studies assessing the effects of personalised support, for example, was rated as 'weak' [161].

Notwithstanding, supported employment services that specifically promote competitive employment among people with severe mental illness and/or a substance use disorder consistently show that these services are successful in promoting attainment of competitive employment [139, 140]. It is less clear whether tenure is maintained once employment is gained, and there is some research evidence to suggest that functional and psychosocial gains are only made if a job is maintained in the longer term. Skill building has also been deemed as an evidence-based practice, specifically social skills training, social cognitive training and cognitive remediation [84, 160]. There is lesser support, however, for the effectiveness of life skills training alone and cognitive behavioural approaches to illness management, which can also be grouped under the 'skills building' intervention type. There is some evidence that supportive housing can reduce homelessness and hospital contacts [136, 144, 156]. Evidence for the positive effects of peer support [145, 158] are mixed, although positive findings relate peer support to improved service engagement, hope and motivation among people with mental illness and/or a substance use disorder. There is also a moderate level of evidence that personalised support services can promote satisfaction with services and reduce illness acuity; although, the evidence for the effects of personalised supports on functioning is currently weak [161].

In relation to peer support and peer services, the findings presented shaped by the chosen approach in this review to selecting studies from narrative and systematic reviews, meta-reviews and meta-analyses. This has resulted in the identification of a limited number of quality studies regarding the effects of peer support on outcomes for people with mental illness or substance use disorder. When the search is widened to include literature from individual studies, it is possible to identify more evidence for effectiveness of intervention and for consumer satisfaction. Notably Chinman et al [158] and Pitt et al [145] both concluded that the 'weak to moderate' quality of evidence in relation to peer support calls for more studies with stronger methodologies in order to better understand the effects of peer support on outcomes for people with a mental illness.

3.0 Conclusions from the literature review

A key issue confronting effective implementation of the NDIS relates to the definition and determination of **'permanence'** of disability associated with mental health issues. The review considered the evidence in relation to illness course and prediction of return of functioning vs impairment, and how the notion of 'permanence' has been treated in similar schemes. It noted that various schemes deal with the issue of 'permanence' of disability as a criterion for compensation or support in very different ways. There is, however, typically a requirement that a condition is likely to persist for a duration of between one and three years and to cause such a level of disability as to prevent the person from being able to work in gainful employment. In other words, in the majority of the schemes examined, the notion of permanence was linked to capacity to undertake paid employment, for the purposes of access to income and other support. The judgment of the disability and its likely persistence tends to be made using a standard battery of tests, in some cases, and/or the opinions of appropriate experts.

Using such criteria, the findings from the academic literature discussed in the later sections of this review suggest that much of the disability arising from mental illness could meet such 'permanence' criteria. The negative effects of mental illness are, for a large proportion of people, ongoing and pervasive. However, what makes the assessment of 'permanence' most difficult is the fluctuating or remitting nature of the course of mental illness. The literature suggests that the experience of a consistent level of unremitting symptoms and high-level functional impairment among people living with schizophrenia, bipolar disorder or depression is relatively rare. Rather, people with such disorders are more likely to experience periods of illness interspersed with periods of remission or recovery. For example, some research suggests that for people with bipolar I disorder, time spent experiencing a mood episode compared with time spent experiencing 'normal' mood is about equal when measured over the long-term, though a cycle of movement between normal and depressed or elevated mood may persist for many years. Furthermore, some mood episodes may be triggered by uncontrollable life events, both positive and negative, which are impossible to predict. Therefore, mental illness is most often not 'permanent' in the sense that it that its effects are not consistent over time, though the pattern of impairment and functioning can persist for many years.

Our ability to predict the long-term course of mental illness is fairly limited. The best predictors of the long-term course of a particular form of mental illness are likely to be the diagnosis itself, with people with schizophrenia tending to experience worse outcomes than people with other disorders, and characteristics of the illness occurring in the early stages. For example, some research suggests that level of symptoms and functional impairment that have occurred in the past are the best predictors of course in the future. High levels of disablement and symptom severity experienced at onset and early in the course of the illness may best predict later higher level disablement and severity. However, the outcomes are likely to be mitigated by many other factors such as access to quality treatment and

supports. Recovery from most disorders also tends to drop off over time, such that if a person does not recover from an episode of mental illness within the early years following onset, the likelihood that they will recover is likely to be greatly decreased. It is also likely that people who experienced onset of their mental illness during childhood or adolescence also experience a more severe illness course and poorer outcomes in the long-term.

All of the research findings examined here point to a fluctuating illness course that is highly individualised and difficult to predict; this makes determining what are the '**reasonable and necessary**' supports needed to improve a person's quality of life a complex task. Also, what support is needed in times of illness also differs from what is needed in times of wellness. Perhaps this is why public insurance schemes tend not to use a specified narrow and specific definition to determine what is 'reasonable and necessary' to support a person with a psychosocial disability arising from mental illness. In a number of cases of international public insurance schemes, the solution to such complexity has been to arrive at a decision regarding a reasonable funding amount that is then used at the discretion of the person, who, with support as necessary, is able to determine what is most 'reasonable and necessary' for the improvement of their own wellbeing.

In considering the **impact of psychosocial disability**, the research points to the individualised nature of the experience. People who have been diagnosed with the same disorder can experience vastly different severity and types of disability. However, research evidence shows that people with severe mental illness are most often affected to some degree in all areas of their daily lives, experiencing difficulties in social and occupational functioning, maintaining a home and completing the tasks of daily living. It is likely that part of the reason for these difficulties relates to impairments in cognitive functions like memory and information processing that makes carrying out common daily tasks difficult or impossible. Many people with a psychosocial disability also experience homelessness and housing instability, and homelessness is particularly common for younger people with a mental illness. People with schizophrenia seem to be the most severely disabled. There is also research to suggest that over time, those with a disability, including people with a psychosocial disability, experience increasing disadvantage and multiple sources of disadvantage, which has long-term deleterious effects on their health.

Disability can also persist for many years, despite receding symptoms. Psychosocial disability can fluctuate over time within the one individual, such that the level and type of support needed to engage in life's activities varies over time. Consistent with the breadth of difficulties experienced by people with a mental illness, research identifies **common areas of life** in which people with a psychosocial disability require **support**. These areas include socialising, and developing and maintaining intimate relationships; improving physical health; getting support with psychotic symptoms and feelings of distress; getting clear information about mental illness and treatments; money; keeping busy with daytime activities including education and work; accommodation and maintaining a home; and activities of daily life like preparing meals.

Not surprisingly, Australian services that assist people with a psychosocial disability to meet these needs are highly utilised. Many people with a psychosocial disability, however, also report having unmet support needs. Their needs might be unmet because no suitable services exist or because the services they are using do not fully meet their needs. Alternatively, the needs of people with mental illness also go unmet because they cannot afford to access services to meet them or because they do not know how to find out about existing services and how to access them. Needs relating to getting clear information about the mental illness, getting more involved socially and with education or work, getting support to deal with psychotic symptoms and psychological distress, improving health, and gaining suitable housing seem especially likely to be unmet.

Given a personal budget or the opportunity to choose support services to meet their individual needs, people with a psychosocial disability frequently state that once they meet their basic unmet needs, such as getting enough food and using transport, their preference is for spending their funding to support these areas of unmet need, such as engaging in more leisure and social activities, and improving their physical health. To assist them in meeting their needs, having an individual support person is one commonly preferred type of support for people with a severe mental illness. UK-based research regarding individual care funding for people with a disability also emphasises the importance of having available professional support to assist people with a disability and possibly their carers to make a care plan that guides the spending of their personalised funding. This is particularly important if the person with a psychosocial disability experiences cognitive impairment, as is frequently the case.

There is a limited amount of high quality research that has studied the outcomes of formal interventions to support people with psychosocial disability and very little research that studies the effects of these interventions on functional outcomes and wellbeing. The strongest evidence is for the ability of supported employment services to facilitate people with psychosocial disability to gain competitive employment and for certain types of skills training to improve functioning in various domains. There is also some evidence to suggest that supportive housing can reduce homelessness and hospitalisations, and that personalised support services can have positive effects on service satisfaction and some illness outcomes. There is also less, though some, evidence that personalised support has positive effects on functioning. Finally, the evidence for the effects of peer support is mixed, with few quality studies available, as defined by the specific criteria applied to the literature in this review. However, with growing interest in the value of peer support services in improving consumer experience of mental health services and outcomes, this evidence base is likely to rapidly grow in the coming years.

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Appendix A: search terms and NGO websites searched

Note: the use of * after the root of a word returns matches with any word beginning with that root. For example, schiz* will return matches with schizophrenia, schizophrenic, schizophreniform, schizotypal, schizoaffective etc.

General terms	General terms continued...
Australia*	schiz*
bipolar	service**
chronic*	support*
course	support need
depress*	unmet
difficulties	want
disability	Assessments
effect*	Adolescent longitudinal interval follow-up evaluation
function*	Adult needs and strength assessment tool
functional impairment	Camberwell Assessment of Need
help	Complete Needs Assessment
impact*	MARISTAN scale of needs
independence	Needs for Care Assessment
independent living	Support Intensity Scale
individual* support	Authors
life satisfaction	Hunt
long-term/long term	Malone
mental*	Slade
meta-analysis	Trauer
need*	
outcome*	Terms used in review of 'reasonable and necessary'
permanen*	accident compensation
personal*	cash and counselling
predict*	disability insurance
prefer*	Medicaid
psycho*	Medicare
psychosocial disability	necessary
psychiatr*	personalised budget
psychiatric disability	reasonable
quality of life	self-directed care
review	self-managed care
satisfaction	social insurance

Non-Government Organisation (NGO) websites searched for service use

- Aftercare
- Anglicare
- ARAFMI
- Australian Community Support Organisation (ACSO)
- Break thru people solutions
- Care Connect
- Centacare
- cohealth
- EACH
- ERMHA
- Life without Barriers
- Mind Australia
- Mental Illness Fellowship of Australia, national and in all states and territories
- National Mental Consumer and Carer forum
- Schizophrenia Fellowship of NSW
- Mental Health Carers Tasmania
- NEAMI national
- Peninsula support service
- SNAP Gippsland
- St Luke's Anglicare
- Uniting Care Australia
- VicServ

Appendix B: definitions of ‘permanent’ in relation to permanent impairment

Australia

Centrelink Australia: eligibility for Disability Support Pension

You may receive Disability Support Pension if you:

- are aged between 16 years of age and Age Pension age
- meet the residence requirements
- meet the income and assets tests for your situation

and

- are permanently blind, or
- are assessed as having a physical, intellectual or psychiatric impairment and
- are unable to work, or be retrained for work, for 15 hours or more per week at or above the relevant minimum wage within the next two years because of your impairment and have actively participated in a Program of Support

Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination 2011

Social Security Act 1991

(4) For the purposes of paragraph 6(3)(a) a condition is **permanent** if:

- (a) the condition has been fully diagnosed by an appropriately qualified medical practitioner; and
- (b) the condition has been fully treated; and

Note: For **fully diagnosed** and **fully treated** see subsection 6(5).

- (c) the condition has been fully stabilised; and *Note:* For **stabilised** see subsection 6(6).

Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination 2011

- (d) the condition is more likely than not, in light of available evidence, to persist for more than 2 years.

Fully Stabilised

(6) For the purposes of paragraph 6(4)(c) and subsection 11(4) a condition is fully stabilised if:

- (a) either the person has undertaken reasonable treatment for the condition and any further reasonable treatment is unlikely to result in significant functional improvement to a level enabling the person to undertake work in the next two years; or
- (b) the person has not undertaken reasonable treatment for the condition and:
 - (i) significant functional improvement to a level enabling the person to undertake work in the next two years is not expected to result, even if the person undertakes reasonable treatment; or
 - (ii) there is a medical or other compelling reason for the person not to undertake reasonable treatment.

Transport Accident Amendment Act 2013, No. 71 of 2013 (Australia)

Amendments relating to serious injury applications. After section 93(17) of the Principal Act

"(17A) For the purposes of paragraph (c) of the definition of serious injury, a person has a severe long-term mental or severe long-term behavioural disturbance or disorder if that person, for a continuous period of at least 3 years—

- (a) has a recognised mental illness or disorder (other than abnormal illness behaviour) as a result of a transport accident; and
- (b) displays symptoms and consequent disability that have not responded, or have substantially failed to respond, to known effective clinical treatments provided by a registered mental health professional who is registered under the Health Practitioner Regulation National Law to practice (other than as a student); and
- (c) has severely impaired function with symptoms causing clinically significant distress and severe impairment in relationships and social and vocational functioning."

(6) For the purposes of assessing the degree of psychiatric impairment the A.M.A Guides apply, subject to any regulations made for the purposes of this section, as if for Chapter 14 there were substituted the guidelines entitled "The Guide to the Evaluation of Psychiatric Impairment for Clinicians".

- (6A) The guidelines referred to in subsections (2C) and (6)
 - (a) must be published by the Commission in the Government Gazette;
 - (b) have effect on the day after the day on which the guidelines are published in the Government Gazette;
 - (c) may be amended, varied or substituted by a subsequent edition of the guidelines published by the Commission in the Government Gazette.

(7) In this section **A.M.A Guides** means the American Medical Association's Guides to the Evaluation of Permanent Impairment (Fourth Edition) (other than Chapter 15) as modified by this Act.

Guide to the assessment of the degree of permanent impairment Edition 2.1 (2011) (Australia).

Australian Government Comcare. (Comcare implements government policies related to WorkCover) There is a table within this document that has criteria for assessing per cent of impairment (which is drawn from the American Medical Association's *Guides to the Evaluation of Permanent Impairment* 5th edition 2001).

Permanent impairment is described as:

3. PERMANENT IMPAIRMENT

Compensation is only payable for impairments which are permanent. Under subsection 4(1) of the SRC Act 'permanent' means 'likely to continue indefinitely'. Subsection 24(2) of the SRC Act provides that for the purposes of determining whether an impairment is permanent, the following matters shall be considered:

- (a) the duration of the impairment
- (b) the likelihood of improvement in the employee's condition
- (c) whether the employee has undertaken all reasonable rehabilitative treatment for the impairment
- (d) any other relevant matters.

Thus, a loss, loss of the use, damage, or malfunction, will be permanent if it is likely, in some degree, to continue indefinitely. For this purpose, regard shall be had to any medical opinion concerning the nature and effect (including possible effect) of the impairment, and the extent, if any, to which it may reasonably be capable of being reduced or removed.

Guidelines for evaluation of permanent impairment. First Edition. Department of Justice and Attorney-General. Queensland Workers' compensation Scheme. November 2013.

The first edition of the Guide is based on the American Medical Association's *Guides to the Evaluation of Permanent Impairment, Fifth Edition* (AMA5 Guides).

Permanent impairment

11.8 A psychiatric disorder is permanent if in your clinical opinion, it is likely to continue indefinitely. Regard should be given to:

- the duration of impairment;
- the likelihood of improvement in the injured workers' condition;
- whether the injured worker has undertaken reasonable rehabilitative treatment;
- any other relevant matters.

The American Medical Association's Guides to the Evaluation of Permanent Impairment. Sixth Edition. 2008.

'The *Guides Sixth* is the latest standard in medical impairment rating, emphasizing the fundamental skills physicians need to evaluate and communicate patient impairments. Determine a grade within an impairment class using functionally based histories, physical findings and broadly accepted objective clinical test results.'

The Queensland Workers' compensation scheme claims that 'However extensive work by eminent Australian medical specialists representing all Australian Medical Colleges has gone into reviewing the AMA Guides to ensure they are aligned with clinical practice in Australia' (a quick search on Discovery revealed this to be true).

***NSW Lifetime Care and Support Scheme* (equivalent to TAC in VIC)**

Couldn't find anything on mental health.

New Zealand

The ACC User Handbook to the AMA "Guides to the Evaluation of Permanent Impairment" 4th Edition. (2002). Accident Compensation Corporation (ACC). New Zealand

They define permanent impairment in the case of 'mental injury' (a clinically significant behavioural, cognitive, or psychological dysfunction) as:

"A loss, loss of use, or derangement of any body part, organ system, or organ function, that is well established and unlikely to change substantially in the next year, with or without further medical treatment."

UK

Their version of the NDIS is run by local authorities (perhaps akin to local councils? Or Medicare Locals).

– **In Control**

Looked through this website – led me to the following info:

Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England 2010. Department of Health. February 2010.

No mention in this document of a definition of permanent or chronic mental illness. Some mention of the needs of those with fluctuating or long-term conditions. The document referred to Mental Health Act, 1983; Chronically Sick and Disabled Persons Act 1970, and the Health Services and Public Health Act, 1968. None of which made reference to permanent or chronic impairment.

Putting people first. A shared vision and commitment to the transformation of Adult Social Care.

No mention of permanent or chronic impairment

Also looked at **Fair Access to Care Services (FACS): prioritising eligibility for care and support**. A government publication which one Local authority said they used to assess eligibility. No definitions of permanent or long-term disability. That document referenced the **Care Act 2014** which also did not define permanent or long-term disability.

Many of these UK documents talk about long-term or ongoing support, but do not define.

Care pathways and packages projects.

Couldn't see anything there about assessing or defining permanent or chronic mental illness / disability.

USA

Looked at **Mental Health Parity and Addiction Equity Acts, 2008. Affordable Care Act 2010**. The affordable care act does mention serious and persistent mental health condition – but no definition.

<http://longtermcare.gov/medicare-medicaid-more/>

Medicare provides only short term care. Medicaid (for low income people) provides long-term care for those with a permanent disability as defined by the Social Security Administration (www.socialsecurity.gov):

The definition of disability under Social Security is different than other programs. Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability. "Disability" under Social Security is based on your inability to work. We consider you disabled under Social Security rules if:

- You cannot do work that you did before;
- We decide that you cannot adjust to other work because of your medical condition(s); and
- Your disability has lasted or is expected to last for at least one year or to result in death.

This is a strict definition of disability. Social Security program rules assume that working families have access to other resources to provide support during periods of short-term disabilities, including

workers' compensation, insurance, savings and investments.'

Then there is another insurance longtermcare.gov that provides long-term care (presumably for those with Medicare). Cannot see definitions there.

Canada

<http://www.servicecanada.gc.ca/eng/services/pensions/cpp/disability/definition.shtml>

To qualify for a disability benefit under the Canada Pension Plan (CPP), a disability must be both "severe" and "prolonged", and it must prevent you from being able to work at any job on a regular basis.

- **Severe** means that you have a mental or physical disability that regularly stops you from doing any type of substantially gainful work.
- **Prolonged** means that your disability is long-term and of indefinite duration or is likely to result in death.

Both the "severe" and "prolonged" criteria must be met simultaneously at the time of application. There is no common definition of "disability" in Canada. Even if you qualify for a disability benefit under other government programs or from private insurers, you may not necessarily qualify for a CPP disability benefit.

Self-Managed Care Programs in Canada: A Report to Health Canada. June 2006. Spalding, K., Watkins, J.R., Williams, A.P. http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2006-self-auto/2006-self-auto-eng.pdf

A report to Health Canada in 2006 found 16 self-managed care services operating in Canada: Veterans Independence Program, Choice for support in independent living, Vela microboard Association, Alberta Self-Managed Care Program, Alberta Individualised Funding Program, Saskatchewan's Individualised Funding Program, In the company of friends (Manitoba) etc.

Veteran's affairs Canada:

<http://www.veterans.gc.ca/eng/services/transition/rehabilitation/permanent-impairment-allowance>

Severe and permanent impairment

This term is used to identify that the Veteran requires supervision or assistance with daily living and has conditions such as an amputation, loss of vision or hearing or speech, or psychiatric condition.

Total and permanent incapacity

This term is used to indicate that the Veteran's health issue(s) and impairment(s) are not expected to improve to the point where they will regain the ability to pursue suitable gainful employment.

Appendix C: overview of General Service Types Covered by Selected Schemes

Scheme	Main Service Types covered	Services excluded
US Medicare	<p>Medicare services covered include:</p> <ul style="list-style-type: none"> • Inpatient hospital care (incl. critical access hospitals and skilled nursing facilities) • Hospice care and home health care • Doctors' services and outpatient care • Physical and occupational therapy services • Prescription drug coverage <p><i>(Note. Most Medicare services apart from inpatient hospital care require participants to pay a monthly premium.)</i></p>	<p>Medicare does not cover:</p> <ul style="list-style-type: none"> • Long-term care (also called custodial care) • Personal care • Most dental care • Eye examinations related to prescribing glasses • Dentures • Cosmetic surgery • Acupuncture • Hearing aids and exams for fitting them • Routine foot care
US Medicaid	<p>Mandatory benefits provided by States include:</p> <ul style="list-style-type: none"> • Inpatient hospital services • Outpatient hospital services • EPSDT: Early and Periodic Screening, Diagnostic, and Treatment Services • Nursing Facility Services • Home health services • Physician services • Rural health clinic services • Federally qualified health centre services • Laboratory and X-ray services • Family planning services • Nurse Midwife services • Certified Paediatric and Family Nurse Practitioner services • Freestanding Birth Centre services (when licensed or otherwise recognized by the state) • Transportation to medical care • Tobacco cessation counselling for pregnant 	No explicit exclusions specified.

Scheme	Main Service Types covered	Services excluded
	<p>women <i>(Note. In addition, States can provide a range of optional benefits)</i></p>	
<p>Cash & Counseling (US)</p>	<p>Personal assistance services, including:</p> <ul style="list-style-type: none"> • Personal care services • Home and community-based services • Items that increase the individual's independence or substitutes (such as a microwave oven or an accessibility ramp) • Support broker and consultant • Financial management services 	<p>No explicit exclusions specified.</p>
<p>Victorian TAC</p>	<p>Treatment</p> <ul style="list-style-type: none"> • Ambulance services • Hospital services • Medical services • Pharmacy items • Therapy services • Dental services • Nursing services • Rehabilitation and disability services • Equipment <p>Support</p> <ul style="list-style-type: none"> • Damaged medical aids • Equipment • Home services support • Child care • Independent living • Modifications to your home • Modifications to your vehicle 	<p>The TAC cannot pay for</p> <ul style="list-style-type: none"> • Treatment or services unrelated to your accident • Treatment for a medical condition or injury that you have before your transport accident, or that is not a direct result of your transport accident • Treatment or services that have no clear benefit to you • Treatment or services provided outside of Australia • Treatment that is received by the injured person from a person who is not appropriately registered, qualified or authorised to provide the service • An outstanding account for treatment or a service you received more than two years ago • Alternative therapy treatment, such as massage, unless provided by a registered health

Scheme	Main Service Types covered	Services excluded
		<p>care professional</p> <ul style="list-style-type: none"> • Travel costs unrelated to your TAC claim
NSW Lifetime Care and Support Scheme	<p>Treatment, rehabilitation and care services, including:</p> <ul style="list-style-type: none"> • Medical treatment and pharmaceuticals • Dental treatment • Rehabilitation • Ambulance transportation • Respite care • Attendant care services • Domestic assistance • Aids and appliances • Artificial members (limbs), eyes and teeth • Educational and vocational training • Home and transport modification • Workplace and educational facility modifications • Other kinds of treatment, care support or services prescribed by the regulations 	<p>Services and items that the Authority cannot pay for include:</p> <ul style="list-style-type: none"> • Services for injuries or medical conditions you had before the motor accident, unless there is evidence they have been made worse by the accident • Accommodation costs (for example, rent or bond for rental properties) • General household items such as standard furniture, clothes, shoes, textbooks, school fees, linen, household appliances, storage and white goods • Purchase of houses or cars • Treatment, rehabilitation, medical services, equipment or medications not related to your injury from the motor accident (for example, general doctor's visits) • Items that were lost or damaged in the motor accident • Loss of wages or other weekly benefits • Assistance to keep your business open, such as paying for temporary staff to do your job • Extra expenses you might incur in hospital or rehabilitation, such as additional food, laundry, newspapers, magazines or TV hire • Treatment, rehabilitation and care or any other services for members of your family • Transport costs other than to approved treatment and rehabilitation services.
New Zealand	Treatment and rehabilitation:	Explicit exclusions mostly relate to the

Scheme	Main Service Types covered	Services excluded
<p>Accident Compensation Corporation</p>	<ul style="list-style-type: none"> • acute treatment • public health acute services • elective surgery • pharmaceuticals • imaging • home-based care • rehabilitation • transport • compensation for lost earnings • lump sum compensation • modifications (housing/ vehicles) • accidental death benefits. 	<p>types of injuries (e.g., pre-existing) rather than the services not covered.</p>
<p>Individualised funding, Personal budgets, Self-directed care, Self-managed care</p>	<p>These schemes typically outline very broad parameters in relation to the types of support or service areas covered, which differ between schemes but commonly include the following (Blackman, 2007):</p> <ul style="list-style-type: none"> • Health and safety • Education and employment, • Personal autonomy or independence (e.g., self-employment) • Community connecting or inclusion, involvement in family and wider community life (including relationships, recreation and leisure, hobbies, unpaid and paid work, skills training/coaching and volunteering) • Personal care supports • Residential • Home living –food preparation –housekeeping • Professional support, behavioural support, and medical support. • Those things important to self-esteem and social inclusion. 	<p>No explicit exclusions specified.</p>