Ensuring effective care, support and treatment:
Approaches that support recovery, including early intervention

Lachlan, South Australia

The difficulty with having a mental illness is sometimes you don’t even know you’re sick. When I was first admitted to hospital, I didn’t understand the extent of my symptoms. I was experiencing a psychotic episode, and was diagnosed with Schizoaffective Disorder.

Even now I’m still not sure if it’s really what I suffer with, but I take the medication anyway. I know the drugs are not harming me; maybe I don’t want to admit to myself that they help me get through.

I had to tackle my mental health issues and found a local activity program. When I started I felt alone, misunderstood and confused. I forced myself to come every day. Soon I realised it was part of my routine and something I look forward to.

I now know it has a positive effect. All participants attend the program as part of their recovery journeys. We share our experiences with illness, symptoms and medication and support each other. This reminds me that I am not alone, that others have experienced similar things. I now support others which has increased my self-esteem and confidence.

I began to look towards the future and set recovery goals. Seeing my goals and achievements written down gave me confidence and hope. I was very surprised at the number of good things in my life.

My self-esteem and confidence has skyrocketed. I’m now living independently, which has been a massive step in my recovery. I’ve also reconnected with my church and my lacrosse club. This has been so important as I’m once again involved with a sport that I love. I have been accepted by the members of my former club and encouraged to join in with club community events and to take up playing again.

I now know it’s important to have goals and plans for the future and to work hard to achieve them. I’m very proud of myself and how far I’ve come in my journey.

Watch Lachlan’s video at www.mentalhealthcommission.gov.au
The ability to lead a contributing life is everyone’s right, whether or not they experience mental health difficulties. Access to timely recovery-oriented support, both at the emergence of illness and throughout life, is vital if we are to uphold this right for those who do live with mental illness and those close to them.

We asked people in our National Contributing Life Project pilot surveys what helped and what hindered them in living a contributing life.

The three most important things that have emerged from the early findings are:
1. relationships and connections
2. stigma and discrimination
3. a sense of personal control, including having enough money

What’s important in having a meaningful life?
“Feeling like I am making a difference and achieving something good”
“Having a purpose and a healthy self-identity”
“Being valued by others”
“Having friends and the belief that there is more opportunity to have more friends in the future”

The Commission supports the definition offered in the recently released National Framework for Recovery-Oriented Mental Health Services that recovery entails:
‘...being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues.’

Recovery and a contributing life are inter-twined – you may have recovery goals in place but poor physical and mental health, job redundancy or eviction from your home all hinder progress towards those aspirations.

Therefore the Commission believes that incorporation of a whole-of-life perspective into any recovery approach is essential, as is intervening as early as possible.

Getting help early when things are going wrong is vital.

We know that 75 per cent of all cases of mental illness will occur by the time Australians reach 25 years old. When you’re young, the onset of mental illness disrupts every facet of your life – school, family, social life and job prospects – and your future potential.

This chapter takes a wide perspective on recovery, in its broadest meaning and the opportunities it brings for a contributing life for all people. It spotlights two effective means of support, care and treatment:

1. We look at early intervention and what this promises for our young people, in particular through integrating clinical support with other life needs
2. We look at how the lived experience and expertise of peer workers can offer hope in supporting the recovery of others.
We know that life and circumstances can put barriers in the way of a contributing life. Being able to live a contributing life is not just about having mental health-related recovery goals in place, but can also be about having something meaningful to do and connecting with people.

These goals are unlikely to be achieved by a person who is experiencing poor physical health, has just lost their job, or who has been evicted from their home.

Since 2009, the adoption of recovery approaches by mental health services and community organisations has been a priority for action under the National Mental Health Plan. We know that every state and territory has the concept of recovery embedded in their strategies or service plans.

The 2013 National Framework for Recovery-Oriented Mental Health Services highlights three characteristics for every service. Such a service:

- recognises and embraces the possibilities for recovery and wellbeing created by the inherent strength and capacity of all people experiencing mental health issues
- maximises self-determination and self-management of mental health and wellbeing, and
- assists families to understand the challenges and opportunities arising from their family member’s experiences and recovery processes and how they can assist in their recovery while also helping them with their own needs.

Early intervention is a term mostly used in the context of working with children and young people. This is logical, because this is the period when illness often begins to emerge and where interventions can be especially effective at mitigating the direct impacts of symptoms, and avoid later difficulties.

Early intervention can involve connecting with people as they start their families, throughout pregnancy, and in early childhood. The first few years of a young person’s life are crucial in setting the scene for the rest of their life. A child who lacks stimulation or who is exposed to chronic stress can find it extremely difficult to overcome a tough start.

We know that successive governments at a national and state level are investing more in early intervention approaches for young people. Nationally we are seeing a range of early intervention services: headspace centres and e-headspace, early psychosis intervention services, online supports and games such as ReachOut.com, Bite Back and SPARX, and initiatives targeting schools and universities, such as the Schools Early Action Program in Victoria and Batyr.

We know that there is a great need for earlier intervention for people of all ages who are experiencing mental health difficulties for the first time or who have recently experienced a worsening of their mental health issues. We know there are serious consequences of not intervening early – these are most notably seen when a crisis occurs and potential economic, accommodation and employment impacts for that person are highly likely.

There are many clues that our support services across health and housing sectors are all too often reactive and crisis-driven rather than focused on intervening early.
Ensuring effective care, support and treatment

Early findings from our Contributing Life Project give some evidence of a current lack of emphasis on early intervention. These give us a small insight into the detrimental impact this can have on people’s everyday lives. The second answer below also shows that early intervention can simply mean thinking ahead and providing follow-up, so that further crises could be prevented.

What could have been done to improve the support you received?

“Not having to go to the general emergency department… If I am not able to be in hospital, then give me an adequate alternative and validate the fact that I have come to the emergency department out of desperation – not because I want attention.”

“Maybe a mentor or a support person who can come into the hospital/system and give more 1:1 support… little supported outings – not just thrown back out there after a long stay, bag in hand and an appt. with psychiatrist 2 weeks away.”

Rates of mental health-related Emergency Department (ED) attendances by those experiencing a mental health crises have not improved over recent years. Levels marginally shifted in the five years to 2010-2011, when there were an estimated 243,444 ED attendances by people with a mental health-related primary diagnosis. This finding reflects gaps in the system of supports accessible to people in the community, and in the ability of services to reach out to, or follow up, those who are vulnerable.

During the four years to 2010-2011, the numbers of people who accessed accommodation services due to being homeless or at risk of homelessness because of a mental health problem grew by five per cent each year. Again, this is not heading in the direction in which we wish to see change.

We are told that Australia is lagging behind other countries in its recognition and employment of peer workers. The evidence suggests that the peer workforce offer a number of benefits, including reducing the rate of hospital admissions for the people with whom they work. In the USA, peer workers are certified professionals, and the Centre for Medicare and Medicaid Services recognises peer support providers as a distinct provider type, and considers this an evidence-based model of care.
Spotlight issue
Early intervention for young people

While early intervention is important at all stages of life, the Commission recognises how vital it is that services are available to support young people at the onset of mental health difficulties.

We know that more than half of those in the general population who are experiencing mental health problems are reluctant to seek help, and this is even higher among young people, especially males.45

Some studies have reported that delays in seeking treatment for first episode psychosis have been found to range from an average of one to two years.133,134 Such delays are unacceptable, because we know that people living with untreated mental illnesses can have a delayed response to treatment commenced at a later stage, which in turn impacts on their ability to lead a contributing life.135

We know that for young people, the first point of contact in a crisis will not necessarily be either with mental health or targeted early intervention services.136

The Young People in Custody Health Survey, conducted in New South Wales in 2009, found that 87 percent of young people in the juvenile justice system were found to have at least one psychological disorder.137 Youth homeless services and helplines such as Kids Helpline report that 48 percent of contacts by young people experiencing homelessness accessing this service also experienced suicidal thoughts or self-harm.138

The responsibility to intervene to help young people does not lie within the spectrum of health services alone but is the responsibility of all sectors.

Early intervention for those aged 12 to 25 years can mean avoiding massive upheaval during these formative years, which can have lifelong impacts. Studies show that the deterioration in the life chances of people with psychosis does not come just from their disturbing symptoms, but broader psychosocial disruption: educational interruptions, loss of relationships, and stigma and identity struggles affecting personal development.139 For example, workforce participation is particularly low among people experiencing mental illness, as is average household income in adulthood compared to the general population.139,141

There is some clinical debate about at which age or point in time that medical treatment should be offered to young people with mental health problems.142-144

Ongoing research and evaluation of early intervention services for young people are crucial.

The National Survey of Young Australians showed that a high number of youth (37 per cent) and Aboriginal and Torres Strait Islanders youth (26 per cent) accessed the internet for advice.145

Internet self-help programs for young people are a growing area of interest, with a number of online self-help resources for young people currently available. We know from a 2012 cross-sectional study by ReachOut.com of 3,682 young people under 25, that after going online, young people who had high or very high levels of psychological distress are more likely to seek help (refer Figure 5). They said they would go to a mental health professional (41 per cent), a friend (40 per cent) and a medical doctor (29 per cent).146

This reinforces that early intervention services need to be designed in collaboration with young people, and regularly seek their feedback.

Figure 5: Where young people experiencing high or very high psychological distress are more likely to go for help

<table>
<thead>
<tr>
<th>Who help was sought from</th>
<th>per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>headspace centre</td>
<td>30</td>
</tr>
<tr>
<td>Online discussion forum</td>
<td>25</td>
</tr>
<tr>
<td>Phone hotline (e.g. Kids Helpline)</td>
<td>20</td>
</tr>
<tr>
<td>Therapist, counsellor, mental health professional</td>
<td>15</td>
</tr>
<tr>
<td>Medical doctor</td>
<td>15</td>
</tr>
<tr>
<td>Teacher</td>
<td>10</td>
</tr>
<tr>
<td>Parent</td>
<td>10</td>
</tr>
<tr>
<td>Girlfriend/boyfriend/partner</td>
<td>10</td>
</tr>
<tr>
<td>A friend</td>
<td>10</td>
</tr>
<tr>
<td>A family member</td>
<td>10</td>
</tr>
</tbody>
</table>

Getting support for your daughter

What it means for Cecilia, Victoria

I came to Australia from Chile in 2000 with my two daughters. When my oldest daughter had her first schizoaffective episode at 16 years, I decided to take her to a youth centre. I could speak only a little bit of English, so it was very difficult to explain what was wrong. The staff recognised she was unwell and helped us straight away. Shortly after she was hospitalised for a while.

I quit my job in order to take care of her. Her illness pushed me to learn English and pursue further study, so that I could understand her mental illness. My daughter came to classes with me because she was fearful of being alone.

My caring role affects my personal relationships because people don’t understand my daughter’s illness, and why I have to leave suddenly in order to help her. In addition, the relationship with my younger daughter has been affected. Even though she understands her sister has a mental illness, she resents that I can’t spend more time with her.

I still worry about my oldest daughter. I never know when her symptoms will reappear. She is doing well and managing her medication, seeing a psychiatrist and a psychologist, and she is aware that she must manage her illness in order to live the life she wants to live (like any chronic illness). She lives independently with her partner. We catch up on a daily basis and she calls me any time she feels she needs it. We are a team.

I cannot explain the emotions I felt caring for my daughter when she was unwell. I don’t know how I did it. But good things can happen. It pushed me to learn and develop as a person. When a door is closed, a window is opened.

Watch Cecilia’s video at www.mentalhealthcommission.gov.au
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What the evidence shows is good practice

Good practice models of recovery and early intervention reflect the World Health Organization’s view that policy and practice should not be solely concerned with mental disorders but also recognise and address the broader issues that promote mental health.147

The Commission has therefore looked to good practice across different settings.

We believe that good practice incorporates the direct involvement of people living with a mental health difficulty and their support people. The supports offered must be sufficiently flexible, not only to meet the specific needs of a range of groups, but also to respond to the changing needs of individuals as they move along their recovery journey.148

Achieving this requires close collaboration of government and non-government supports in a range of areas. It requires the development of integrated models of care that address the full range of factors affecting mental health and wellbeing – such as education, employment and housing. It must also be evidence-based and outcomes-driven.149

The Commission is aware of a number of approaches in Australia which demonstrate a pro-active, early intervention approach to supporting recovery journeys for adults. These also demonstrate collaboration between public, private and not-for-profit agencies, and between education and employment providers, housing, health services, and organisations working for social engagement.

One example is the ‘Platform 70’ Project, a joint initiative of Bridge Housing, Neami National and St Vincent’s Hospital Sydney to deliver housing, mental health and health services to 70 people ‘sleeping rough’ in the City of Sydney. In March 2013, it was reported that a number of participants had started further education, had begun to address their substance use problems, commenced work and re-engaged with their families.150

In the UK, New Horizons strategy (2009) and No health without mental health: A cross government mental health outcomes strategy for people of all ages have generated a philosophy and practice of joint working between government departments and between government and non-government organisations in that country.151

In the US state of Texas, mental health services are being integrated within a broad public health and early intervention approach incorporating housing, employment, technology, justice and child and adolescent services, among others. This initiative is being implemented in steps, beginning with demonstration projects which are evaluated to provide ongoing learning and measurement of benefits.152

In Australia, headspace is based on a collaborative approach to early intervention in youth mental health. Funding has just been committed for a new National Centre for Excellence in Youth Mental Health to discover and translate new evidence-based treatments, and develop and support a new workforce for expanding frontline services and maximising outcomes.7

The World Health Organization recommends a ‘whole of school’ approach to early intervention, based on evidence that this is more effective than topic-based interventions within the curriculum.147

Co-ordination and communication between schools, families and services are essential to a whole-of-life early intervention approach. Often parents or teachers can be the catalysts for accessing timely support. An example of such an approach is the Got It! initiative in New South Wales.153 This targets children in middle childhood who are experiencing behavioural problems, working to keep them in school.

“I think there should be some more mental health services available for young people over 18 who I still consider to be children. Also there needs to be more education in schools, especially earlier on”11
In focus: Peer work

The Commission feels strongly that the peer workforce must:
- be an essential component, not an ‘add on’ to any support team, with equal status to their team colleagues
- be remunerated appropriately at a level commensurate with their skills and training – a good and willing volunteer is just that, not a peer worker
- be supported and sustained into and in the role with high-quality, ongoing training and supervision
- be supported by national competencies and standards, and
- have a clear career trajectory.

Mental health peer workers are in paid roles that require them to bring expertise to their position based on their lived experience of mental illness, either personally or as a family member or supporter.

Peer work can take many forms; from giving hope and modelling recovery to contributing to the recovery of people and their families, by providing social support, advocacy, and one-to-one mentoring. Approaches are flexible and peer workers can address aspirations and personal goals, rather than focusing on medical treatment. Family peer workers play a crucial role in offering others support and advice to navigate through the mental health system and advocate for change.

Evidence on the major benefits of the peer workforce to mental health outcomes and recovery has developed rapidly in the last decade, with some seeing their employment as “one of the single most effective ways to develop and sustain a culture that stays focused on recovery practices.”

They can influence and change service culture and practice, and bridge gaps between supports provided by other professionals. The benefits of having a peer workforce include reduced social isolation, increased service access for substance use and health difficulties, improvements in social functioning, enhanced empathy and acceptance, reduced stigma and an increased feeling of hope.

Peer workers can bring about positive change in the culture and recovery focus of the organisation in which they work; for example, with colleagues becoming more aware of the language they use. Evidence suggests that peer workers can also help to reduce the use of seclusion and restraint.

The peer workforce can provide a meaningful career option for some people living with mental health difficulties. The available research evidence indicates that peer workers perform at least as well as other staff in areas such as reducing hospitalisation rates, accessing hard-to-reach clients and reducing levels of substance use. While the benefits of peer work have long been recognised in the addiction field, the peer workforce is now the most rapidly growing workforce in the mental health sector in Australia, with many working in the non-government sector (see Figure 6).

Recent research undertaken by Health Workforce Australia included a small-scale survey of 305 people who identified as peer workers. Of this sample, 18 per cent worked casually, 29 per cent full-time and 53 per cent part-time. About half of the sample worked for non-government organisations, while 17 per cent worked in public hospitals, 11 per cent in a Commonwealth-funded mental health service or program and ten per cent in a state or territory funded public mental health service or program.

Figure 6: Mental health peer workers by service type

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public hospital</td>
<td>17.0%</td>
</tr>
<tr>
<td>Private hospital</td>
<td>1.0%</td>
</tr>
<tr>
<td>Private mental health service/program</td>
<td>3.0%</td>
</tr>
<tr>
<td>Aboriginal community controlled health organisation/service</td>
<td>0.3%</td>
</tr>
<tr>
<td>Commonwealth-funded mental health service/program</td>
<td>11.0%</td>
</tr>
<tr>
<td>State or territory funded public mental health service/program</td>
<td>10.0%</td>
</tr>
<tr>
<td>Non-government organisation</td>
<td>51.0%</td>
</tr>
</tbody>
</table>

Source: Health Workforce Australia 2013 (Unpublished)
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In focus: Peer work continued...

Figure 7: Consumer and carer peer workers as a proportion of the direct care mental health workforce

As peer workers can be employed under various titles and awards, further research is needed before we can have a complete picture of the numbers and characteristics of the Australian peer workforce. Although these professionals have been employed in some Australian states for many years, the actual numbers of full-time positions in public health services remains very small and has increased very little over time (Figure 7). In practice, many are employed for just a few hours a week, and misunderstandings about the role and value of peer work still prevail.

The endorsement of the Certificate IV in Mental Health Peer Work by the National Skills Standards Council provides a solid foundation on which to expand the peer workforce across all domains of a contributing life. The Commission is sponsoring Community Mental Health Australia to undertake the Peer Work Qualification Development Project to develop training and assessment resources for both the consumer and carer peer worker streams.

The study by Health Workforce Australia gives us more information about the profession. We now need to build upon the evidence and this momentum with some real action. The Commission calls upon all governments to together develop a National Mental Health Peer Workforce Development Framework and include peer work approaches as a key performance indicator for service contracts and programs.

We also endorse the call for a national target for peer workers in mental health-related support services. This target aims for 50 per cent of services employing peer workers in four years and 100 per cent in ten years. These actions will help to improve outcomes, and employment rates of people with mental illness and their families and supporters.

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Using lived experience to help others

What it means for Judi, Western Australia

I gave birth to my son in 1984 and became overwhelmed and anxious in the most debilitating way. These feelings were not something I had ever dealt with. I was a professional, successful woman.

I knew I was not coping as a mother and trying to find answers for how I felt led me nowhere. I felt even more convinced that I had good reason to keep my feelings veiled. My son was aged just 4 weeks when I decided to go back to work. I knew the decision was a sacrifice that had changed me to the core and the trauma was deep and resonated for many years to come.

Eleven years later, I had another child. The self-blame started on her delivery. I met a nurse at a sleep clinic who told me I was not alone. She really cared that I was finding being a mother so difficult. This empathy changed my outlook. I felt validated and hopeful.

At a local peer-led support group at the hospital, I talked about my experience with postnatal depression and anxiety. This helped me heal and I started to recognise my own resilience.

One year later I was facilitating the support group as a volunteer and had started a psychology degree and a psychotherapeutic qualification.

I became a volunteer with a Post Natal Depression organisation and eventually became Vice President three years later.

In 2010 I developed and delivered a program called Making Sense of Motherhood. I continue to co-ordinate and facilitate this course, designed to support and enhance the relationship between a mother and baby.

The program and the marketing material have been sensitively developed to encourage women to speak up and seek help. They contain information that I would have found most useful had it been available during my time of need. A woman who calls or is referred to the service, speaks directly to me.

My life has been changed by my lived experience. Every single aspect of my work draws on the experiences I had throughout my journey. I believe peer health workers and peer mental health workers have the skills to support ourselves and others through their own resilience and recovery.

Watch Judi’s video at www.mentalhealthcommission.gov.au
What we don’t know

Where we need more evidence and to shine a light

There is a lot we don’t know. We don’t know about equity of access to early intervention approaches, or whether we’re reaching those most in need of early intervention.

We do know there are priority areas that we need to shine a light on.

While early intervention is intuitively important within a recovery approach, the actual evidence base for its effectiveness with children and young people in Australia is very limited, and based mainly on research assessing the impacts of early interventions for psychotic disorders. In general, evaluations of early intervention approaches have only generated data on short-term outcomes, and there is a pressing need to monitor their longer-term impacts on mental health and wellbeing.

We also know little about the relative effectiveness of different forms of intervention. We don’t know enough about the impacts of whole-of-school programs in Australia – we need to better understand why some schools have not adopted KidsMatter or MindMatters to help reduce the risk of mental health difficulties in the school community.

So far, the evaluations of early intervention programs are in their infancy and have focused mainly on implementation processes and activity. With significant new investments in this area, we need to take evaluation seriously. We need adequate outcome baseline measures and to track improvements to mental health over time.

We need to continue to investigate the ways in which new types of interventions – online and mobile therapies, blogs and virtual communities, games and applications – are being used in practice by people across the age-range and ensure they are effective in supporting a recovery-based approach.

We don’t know much about help-seeking behaviour for mental health problems by young people and adults from CALD backgrounds. The Commission has heard that both CALD communities and Aboriginal and Torres Strait Islander youth continue to have a very high level of unmet needs and in the first instance will often seek help from a family member or community leader, rather than mainstream health services. The widespread use of universal approaches to mental health literacy may mean that groups known to be at high risk of mental health difficulties are not being effectively supported.

We need to consider our early intervention approaches for adults, at all ages and stages. Best practice models should support the person within their community and avoid further deterioration and the subsequent need for acute or crisis care. We need to know why people are not receiving the right treatment the first time they ask for help.

Families, friends and support people play a key role in supporting a person on their journey to recovery. This can come at a cost, with relationships becoming strained, financial stress and many supporters’ own mental health deteriorating. We don’t know enough about what families and support people need to recover from what can sometimes be a frustrating and exhausting experience of caring for a loved one and navigating their way through a maze to reach mental health supports.
Where the Commission is looking for continuous improvement

We know early intervention is a must for young people and should be a right for all people. This means acting at the earliest sign of a problem and the earliest days of an illness.

Promoting and enabling recovery is the responsibility of schools, workplaces and communities as well as mental health services. We welcome further action in this area and recognise progress has begun.

We need to better understand why only some Australian schools have adopted universal school programs, and how to support educators to extend their uptake. We also look to further development into their impacts.

It is crucial that we continually re-evaluate and refine Australia’s approach to early intervention in the light of emerging findings about successful practice.

Early intervention and recovery are not new ideas. The Commission is aware that translation of these models into practice still has a long way to go.

Initiatives that take into account all of the needs of a person, including their mental and physical health, are good investments.

We look for the systematic evaluation of early intervention programs – we need to know if they are making a real difference. We need continuous improvement in the quality of information on their outcomes and reach. Equally, we need to hear about the experiences and views of people and their supporters who are using early intervention services. The Commission calls for such evaluation to be adequately resourced, and also to examine barriers to implementation.

We know something of the type and amount of intervention that is required to prevent the onset of mental health problems in young people. This is a rapidly expanding area of research and the Commission welcomes increased expertise in this field.

There are areas where further gains in mental health and wellbeing can be achieved, particularly among young Aboriginal and Torres Strait Islander peoples, people from CALD backgrounds, people in regional and remote areas and those experiencing socio-economic disadvantage. The Commission is looking for further research to show what works for these groups and their families and what the barriers are to seeking support.

We know early intervention is a must for young people and should be a right for all people. This means acting at the earliest sign of a problem and the earliest days of an illness.