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Foreword

Wellways Australia has a vision for society’s future, in which people experiencing mental ill health and psychosocial disability, their families and friends, are understood, accepted and have the same life opportunities as other citizens. Our advocacy vision is of inclusive communities that celebrate diversity and highlight the strength that diversity brings, challenging traditional prejudices and the exclusion they foster, while replacing marginalisation with expressions of welcome. The pathway towards this vision involves challenging and redressing social and systemic barriers, such as stigma, discrimination and exclusion - which currently have profound negative consequences on all aspects of the lives of people who experience mental ill health and their families.

Wellways Australia was established in 1978 by families who were impacted by the effects of serious mental health challenges in a time when there were few services or supports. They formed a united voice and collectively advocated to governments for much needed services. The advocacy values that motivated the establishment of Wellways, four decades ago, remain central to our vision and the work we do today.

Wellways services have been researched and designed to equip participants and families to pursue fulfilling and meaningful lives of their own choosing. For Wellways, the provision of recovery-oriented services is achievable, and the outcomes measurable. Yet we recognise that beyond our services there are social barriers, shored up by stigma, discrimination and exclusion, which prevent or limit life opportunities for people with mental health problems and their families. Full participation in community is a human right. Yet often the people we work with are unable to attain this right. Therefore, recovery and advocacy underpin all of our work and are, in fact, our two very clear ‘reasons for being’.

The appointment of Consumer and Carer Consultants for Advocacy and Leadership, illustrate Wellways’ strong commitment to social, systemic, local and personal justice. Our community engagement strategy highlights the voices and experiences of those impacted by mental health challenges, and supports advocacy leadership within communities where we have a service presence.

Herein we share with you our vision and commitment to influence the mental health system for the better.

Cassy Nunan and Rachael Lovelock
Consultants Consumer and Carer Advocacy and Leadership
Introduction

Wellways’ Advocacy Mission

To advocate for the needs and issues related to mental health recovery and social inclusion, that people including consumers, families, staff, advocacy members and community members care about the most and will make the greatest difference.

What is Advocacy?

**Advocacy** is an assertive form of communication or activity that promotes, protects and defends the rights of people who experience disadvantage, or are at risk of being disadvantaged. People who are at the greatest disadvantage are those who have disabilities or serious illness, or are discriminated against based on cultural differences, sexuality, age, race, religion and gender. Advocacy ultimately defends human rights. Human rights include: the right to have adequate housing, employment, financial stability, community belonging and to access health and support services. For advocacy to be effective, change is required, including changed attitudes, systems and structures that reinforce discrimination, disadvantage and disempowerment.

Mental health advocacy

The Australian Government Department of Health publication, ‘The Kit: a guide to the advocacy we choose to do,’ offers the following definition of mental health advocacy.

> **Advocacy in mental health is not so much about people representing other people, but about people representing themselves. It is also about consumers representing consumers and carers representing carers.**

One of the aims of advocacy for people experiencing mental ill health and their families, is exposure to options and choice so that they can retain as much control as possible over their lives and achieve the outcomes they want. Another aim relates to systemic and social change and is best driven by multiple groups with a vested interest (‘consumers’, ‘carers’, allies, communities) that promotes social inclusion. ‘Advocacy can … right wrongs, change the balance of power, address injustice, improve mental health services and alter attitudes and values.’ Footnote.

The scope of Wellways advocacy plan is broad and multi-dimensional, encompassing activities to be undertaken by and with consumers, carers, staff and communities, which promote and support human rights and citizenship.
The plan includes all advocacy activity that occurs across Wellways programs – for example Community Education, Brainwaves radio program, Foundation Training, the Bruce Woodcock lecture and so on. Specific pieces of social/community and systemic advocacy work will be undertaken by the Advocacy Team.

The Historical Context

Human Rights Movements

In recent history, mental health advocacy achieved great success in the context of other human rights campaigns. Following the Second World War, international concerns about peace and human rights issues gained prominence. These in part influenced the establishment of the United Nations and resulted in the development of international agreements such as the United Nations Commission on Human Rights and the Universal Declaration of Human Rights (Wikipedia). From the 1950s through to the 1970s, groups of people experiencing inequality and human rights deprivations formulated social movements and utilised the strength of numbers to protest about these injustices. These included the African American Rights movement, Women’s Liberation and Gay Rights movements, and the Psychiatric Consumer Survivor movement. During this period, the issues raised by social movements resulted in significant social and systemic reform.

The Anti-psychiatry and Consumer Survivor Movements

In the early 1950s, seminal thinkers from disparate fields and countries – sociologist Michel Foucault from France, American psychiatrist and academic Thomas Szasz, Scottish psychiatrist, R.D. Laing, and Italian psychiatrist and neurologist Franco Basaglia (Rissmiller & Rissmiller, 2006) heralded what came to be known as the ‘anti-psychiatry’ movement. The anti-psychiatry movement raised international awareness about the use of inhumane approaches to treat people diagnosed with serious mental illnesses. Practices included the use of metrazol, a chemical that induced convulsions and resulted in spinal fractures for 42% of patients. It also resulted in poisoning or death from shock (Foerschner, 2010, p. 7). The frontal lobotomy was a procedure that removed a section of the brain that was believed to be diseased. Twenty-five percent of patients died as a result of this procedure (Foerschner, p. 4). Throughout the 1950s the views of the antipsychiatry movement achieved widespread exposure and the public became more informed about the cruelty and harmfulness of many practices. In the 1960s the ‘consumer survivor’ movement gained traction as a lived experience, social justice cause. Outcomes from the anti-psychiatry and early consumer survivor movement include reduction in the use of ECT and eventually the eradication of chemically induced convulsions and lobotomy surgery (Rissmiller and Rissmiller, 2006).
The Australian Consumer Movement

CAPIC (Citizens Against Psychiatric Injustices and Coercion), a radical collective of ‘survivors’, was one of the earliest advocacy bodies in Australia. It was established in Victoria in the early 1970s and was known to stage protests such as stealing ECT equipment from psychiatric hospitals and liberating people from institutions (The Kit, 2006). In the late 1970s, ARAFEMI in NSW and the Schizophrenia Fellowship of Victoria (now Wellways) were established by families of people with mental health challenges – initially to provide mutual support opportunities. Both organisations advocated to governments about the need for support and rehabilitation services in the community, and succeeded. VMIAC (Victorian Mental Illness Awareness Council) was funded in 1982, and was the first Australian consumer peak advocacy organisation. It continues to receive government funding to provide individual, group and systemic advocacy and also conducts consumer-led research.

Australian Mental Health Services and Human Rights

In Australia, as recently as 40 years ago, most people diagnosed with serious mental health issues spent much of their lives receiving treatment within the confines of psychiatric institutions. After the Second World War, governments all over the world began to scrutinise the financial viability of institutions, and conceptualise systems that would allow the antiquated asylum system to be dismantled.

De-institutionalisation became widespread in Australia during the 1980s, and ‘90s (Gooding, 2016, p.33). The majority of patients were relocated to live in the community, mostly with family who struggled with the burden of cost and responsibility (Burdekin, 1993).

In 1993, The Burdekin Report revealed that the newly implemented system was failing people. The report claimed that in all Australian states and territories the rights of people with mental illness to access inpatient care in safe, therapeutic environments was frequently ignored or abused and that inadequacy of community care services was a disgrace (Equal Opportunity Commission, 1993). Of most concern was the widespread violation of human rights, which resulted in social exclusion and impoverished existences. Further, families found themselves being the sole providers of support to their loved ones, which reduced their capacities to generate income, and created distress and social isolation.

Twelve years later the “Not for Service Report” (2005), was released. This review of Australian mental health services found that after 12 years of mental health reform any person seeking mental health care faced the risk of his or her basic needs being ignored, trivialised or neglected. Adverse health, social and economic effects of Australia’s inept mental health care system largely fell on those with mental health
issues and their families and carers, notably the most vulnerable people in the community (p. 14).

In the 2010s, government policy and legislation, directions in mental health service provision, and funding reforms continue create a context of flux. With the introduction of the NDIS people experiencing mental health challenges and their carers face a new era of service reform, and reductions in state allocated mental health funding. And, as in the past, human rights issues, such as employment, income support and community inclusion, remain an ongoing challenge.

**Social change Movements and Recovery**

**Social Change Movements**

In implementing our advocacy strategy, we have much to learn from social change movements and human rights theory. As indicated above, social change movements play an essential role in effecting change for groups that experience health and social inequity (Brown et al., 2004). Health change movements are defined as informal networks that mobilise around shared beliefs and experiences of inequality, and collectively seek to change ‘medical policy and politics, belief systems, research and practice’ that inadvertently or actively exclude full societal participation. These include an array of ‘formal and informal organisations, supporters, networks of co-operation and media’ (2004, p. 51). Embodied health movements have sought to ‘introduce the biological body to social movements’, especially with regard to the embodied, or lived experience (2004, p. 50).

Advocacy-oriented social movements work within systems to influence change – rather than taking a direct disruptive approach. Whereas activist-oriented groups engage in direct action, challenge current scientific and medical paradigms, and work largely outside dominant systems (2004, p. 53). Wellways situates itself as an advocacy-oriented social change organisation. An advocacy-oriented approach can only succeed by facilitating receptive environments and respectful alliances within communities, and by promoting ‘multi-level dialogue’, critical thinking and partnerships. Socially inclusive communities are those that actively embrace humanitarian values, such as acceptance, awareness, equity and inclusion. Therefore social inclusion advocacy is by necessity collaborative, and must promote and demonstrate these values in action.
Advocacy and Recovery

The CHIME model provides evidence that recovery is only possible when people’s lives are influenced by **Connectedness, Hope, Identity, Meaning and Empowerment**. It’s essential that mental health advocacy also aligns with CHIME practice values and approaches. Empowerment can only occur when advocacy actively involves, or preferably, is led by those who have directly experienced injustices and inadequate services and have intrinsic knowledge of what changes must be made. Recovery and inclusion can only be achieved when ‘consumers’ and ‘carers’ are connected and active within community, can envisage with hope the life they wish to lead, are empowered by choice to make decisions about what affects them, and can be active agents in the change they wish to see.

By not working in this way, there is a risk of imposing professional or global frameworks and practices and reinforcing social inequalities in communities.

Campbell and Burgess (2012) insist that individuals and communities must be regarded as ‘experts in their own right, as crucial partners in dialogue,’ rather than ‘simply assistants in implementing an externally posed agenda’.

Campbell and Burgess also emphasise the need to pay attention to the ‘role of poverty, social inequalities and injustices as the causes of mental ill health’, rather than just consequences of mental health problems. With this in mind, social drivers and social contexts can be given due attention, rather than placing all the emphasis on scaling up psychiatric and psychological services (2012, p. 381).

**Wellways practice models and frameworks**

Wellways is committed to providing quality services that promote recovery and advocacy for the people we work with, and their communities. These services are informed by current best practice and quality frameworks, and evaluative feedback. Wellways’ Community Recovery model guides how we promote and support community recovery with individuals and families, and foster natural supports and other connections within communities of choice.

*In undertaking mental health advocacy, it’s essential to develop an understanding of the needs and interests of people affected by inequality and disadvantage, and to collaboratively assist them to generate a vision for change. As employees and volunteers of a service provider – and as community members – we can be allies to these needs by promoting multi-level dialogue, offering partnership, resources, knowledge, linkages and support.*

The Well Together document, prepared by Mark S. Salzer and Richard C. Baron, from the Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities (Philadelphia, PA, USA), also informs our recovery practice and advocacy work. The research behind Well Together insists that ‘inclusive communities – ones in which everyone has the opportunity to lead meaningful and satisfying lives – require a fundamental reframing of the ways in which we all relate to one another’ (Salzer, 2016). Well Together asserts that, for recovery to be truly possible, then communities must actively include all members. This is because communities offer access to all aspects of health and economic participation. Therefore community participation is the most fundamental of human rights.

**Stigma and Social Exclusion**

Wellways recognises that recovery oriented practice and advocacy approaches must remain cognisant of the ways that stigma, discrimination and social exclusion pose barriers that prevent people with mental health conditions, and their families, from fully participating in community life. Wellways’ participants and carers claim that negative stereotypes and myths affect all aspects of their lives.

International literature reports that misinformed attitudes result in barriers to participation, which in turn lead to economic hardship and seriously limit opportunities for people to have meaningful lives (Corrigan, 2005). Internalised stigma also prevents people from accessing mental health services. By necessity, advocacy and recovery practice must actively address stigma and its impacts.

Our community education work follows Patrick Corrigan’s strategies for preventing stigma:

**Contact:** People who regularly interact with persons who struggle with mental illness will be less likely to stigmatize

**Education:** Members of society who know more about mental illness are less likely to endorse shameful myths and unjust behaviours

**Protest:** Discriminatory behaviours may decrease when important segments of society clearly state ‘these actions are not acceptable.’
Identifying Advocacy Issues

Stakeholder Perspectives

Wellways derives authentic advocacy perspectives from people who have lived experiences of mental health challenges, families, workers and others – all of these voices influence and guide our advocacy strategy. Perspectives and experiences are derived from:

- The lived experience of participants in our programs, including family members and carers,
- The knowledge, experience and views of staff, particularly peer workers,
- The views and experiences of our advocacy members,
- Knowledge and expertise of sector partners, peak bodies and advocacy organisations,
- Views expressed by community members.

Wellways Consultation Processes

The organisation has structures and processes in place to consult, research, analyse, reflect upon and act upon experiences and perspectives.

The forums we draw on comprise the following:

- The Consumer and Carer Sub-committee to the Board,
- Consumer and Carer Participation Committee (organisation-wide),
- Regular ‘Experience of Service’ survey,
- Regular advocacy member surveys,
- Regular participant consultations,
- Community engagement workshops,
- Consultations undertaken by the Consultant, Consumer and Carer Participation,
- Collaboration and information-sharing with other agencies and peak bodies,
- Consultation with government departments.

Our advocacy work is influenced by:

- The findings and evaluations of our services and programs,
- Evidence of Australian and international leading practice,
- Consultations and dialogues at the systemic level, with governments, policy makers, peak bodies, sectoral partners and other stakeholders.

The resulting evidence from these sources informs our advocacy activities.
Prevalent Advocacy Concerns

In March 2016, consultations undertaken mostly by peer workers, with Wellways participants, and families/carers in Victoria, Tasmania, New South Wales and the ACT, informed us of the issues that are of most concern. Matters raised in these consultations informed Wellway’s ‘Call to Action’ for the 2016 federal election campaign. The concerns expressed are reflected in research and are known to cause widespread impacts on health, financial viability and participation.

The Big Issues for Participants

Study, Training and Employment

- People with mental health challenges experience significant interruptions to study, training and employment,
- There is widespread discrimination in relation to getting work and housing.

*Participant: I have been discriminated against when applying for work. There needs to be more education and awareness out in the community.*

- While wanting to work they are under-employed and on a low income.

Having a Suitable Home

- People who have mental health challenges are more likely than any other group to experience homelessness and housing problems,
- There is widespread stigma discrimination in relation to accessing adequate housing,
- Housing is often substandard and in unfavourable areas.

*Participant: There’s too much competition in country areas, and not much that I can afford…it’s so stressful…informing real estate agencies that I’m on the pension puts me at a disadvantage. I’m living with my sister and her family, which is a huge imposition.*

Inadequate Service Responses

- People with mental health problems often receive services that don’t have a recovery focus, and this results in reduced chances of having the life participants choose,
- Participants often experience the removal of choice and control,
- Stigma within services is widespread,
- People with mental health challenges are less likely to receive adequate treatment for physical health problems.
The Big Issues for Families/Carers

Lack of Support, Service System Information and Knowledge about Recovery

- Carers do not have enough support to manage the challenges they face on their own journey, or assistance to understand the mental health system and how to best support their loved one,
- They are not supported to understand what recovery means, and that it is possible.

*Worker: Many partners/carers ...have pushed their needs aside. Resentment is common, broken and strained relationships are due to lack of support...need more education on strategies for understanding mental illness and how to maintain a relationship.*

Poverty, Relationship and Housing challenges

- The expectations and demands of being a carer often result in interruptions to career and financial hardship,
- Financial issues mean that the person who has mental health issues needs to live with the family/carer, and this puts pressures on relationships and can lead to overcrowding in homes.

*Worker: Impact on carers’ mental health is high...strained relationships, some fear for the safety of their family members and are hyper-vigilant which adds to their stress and puts further stress on their relationships with the care recipient and other members of the family.*

Carers are also burdened by stigma and many find themselves alienated from friends, family and community.

*Carer: I was unable to work due to the stress and demands of being a carer. I had no support from family – they turned their backs on me. I felt very alone and lost under the weight of what was happening.*

The Big Issues Shared by Participants and Carers in Regards to the NDIS

- For families/carers and people struggling with mental health problems, housing issues, inability to work, low income, discrimination, stigma, social exclusion, and lack of support to carry on with life, are human rights issues. These issues need to be addressed within the functional areas of the NDIS,
- Uncertainty about the NDIS providing necessary services for people affected by mental health challenges.
Participant: I’ve had no experience of the NDIS as yet and not much awareness of it, how it functions, what it offers... There’s still a lot of confusion. There are still questions as to whether or not this covers people with mental illness.

- There are concerns that families/carers will be excluded from the pre-planning and assessment processes,
- Will families/carers be provided with support services?

Advocacy as Core Business

The above challenges represent the most widespread and insidious experiences of insufficient service provision and injustice encountered by those who access our services. These issues have been observed by staff and are also recognised in research. However, these issues are not definitive or exhaustive. Advocacy is a core responsibility of all Wellways staff. But, how does Wellways’ Advocacy Framework guide staff in responding the advocacy needs of participants, and in particular, the prevalent concerns expressed in 2016?

Advocacy is typically undertaken in four main ways: self-advocacy, individual advocacy, social/community advocacy and systems advocacy.

Self-advocacy – is when a person uses their own skills and knowledge to pursue an issue that is related to their own needs and rights.

Mental health workers can support participants to improve self-advocacy skills, knowledge and confidence. Wellways programs, such as Building a Future and My Recovery, also assist with the development of self-advocacy skills.

Individual advocacy – this is when a person is supported by another person or organisation to achieve an outcome that is based on their rights and needs.

Workers can assist participants with many of these matters through individual advocacy, by supporting them to meet their needs and deal with challenges. Workers can also facilitate contact with external bodies (eg. Housing and employment services, local employers, training organisations, Centrelink), and or specific advocacy organisations (eg. an Independent Mental Health Advocate).
Social/community advocacy – this approach focuses on challenging and changing social structures and community attitudes that result in exclusion and injustice.

Systems advocacy – this is a form of advocacy that operates at the level of government or system inadequacies, such as policy and legislation, and the delivery of health and community services.

Community Engagement Strategy and Action Plan

The Advocacy Team is responsible for implementing the Community Engagement Strategy and coordinating whole of organisation approaches. The Community Engagement Strategy guides how we engage with communities within regions where Wellways has a service presence, and commit time and resources to developing the capacities of communities to work on advocacy projects. Social and systemic advocacy issues will be the central focus of Wellways’ Community Engagement Strategy.

Advocacy Capacity Building and Support within Regions

One of the core tasks of the Advocacy Team will be to work within regions to build advocacy knowledge and capacities, and assist with the development of projects.
This will involve bringing together partners, community stakeholders and leaders, as well as people whose lives have been effected by experiences of disadvantage, discrimination and exclusion.

Advocacy Team Actions

1. Consumer, carer and regional staff and community capacity building
   - Capacity building with regional staff and identification of staff who can provide ongoing local support to advocacy projects,
   - Provision of workshops in regions to build allegiances, knowledge about advocacy, capacity to undertake advocacy leadership and/or participation,
   - Assistance in formulating local advocacy initiatives,
   - Invitations extended to community leaders, stakeholders, service agencies, government representatives and officials etc., to partner in identified local advocacy projects,
   - Provision of Wellways’ Advocacy Kit and support via advocacy team, regional staff and Wellways’ Participation Consultant.

2. Capturing and linking local interests and advocacy activities through Wellways’
   - Community education program,
   - Foundation training,
   - Family and consumer education program alumni,
   - UMI workshops,
   - Helpline,
   - Brainwaves,
   - Advocacy membership.

3. Capturing data about advocacy issues and activities to formulate and inform
   - Policy positioning documents,
   - Government relations platforms,
   - Sectoral best practice.

4. Circulating data about advocacy issues and activities with other sectoral bodies
   - Peak bodies,
   - Social issues advocacy organisations,
   - Mental Health Consumer and Carer Dialogues,
   - Representative organisations.

Allies and Spheres of Influence

Government: Policy, funding, regulations and standards

- Federal government,
- State governments,
- Local governments.
Peak/leading bodies: directions, standards, representation, specialist interests

- NMHC, MHA, CMHA, professional bodies,
- Consumer and carer peaks and bodies (NMHCCF, VMIAC, Flourish, Tandem, etc).

Mental health community sector: delivery of mental health treatment, support and services

- clinical,
- Sub-acute,
- Community mental health,
- Mutual support and self-help services,
- Residential services,
- Disability services,
- Specialist services,
- Related community services (eg housing, AOD, sexual assault).

People who use the services of the sector

- Consumers,
- Carers and natural supports,
- Peer workers.

General community: leaders and stakeholders

- Local government service workers,
- Service clubs,
- Churches,
- CALD groups,
- Aboriginal organisations,
- Schools,
- Police,
- Media,
- Others identified locally.

**Advocacy Products**

Advocacy Framework
Advocacy Action Plan
Community Engagement Advocacy Workshop
Advocacy Toolkit
Position Papers
Consultation Reports
Call to Action documents
Marketing tools

Wellways Desired Advocacy Outcomes

Wellways advocacy strategy will undertake and support activities that work towards the following desired outcomes.

Community outcomes
- Broad enhanced understanding of key issues around mental health, resulting in stigma reduction,
- Inclusion, in all aspects of community life, for people with mental health challenges and their families,
- Improved health and social conditions across the community,
- Economically robust and diverse community,
- Policy and legislation is reformed in key areas,
- Government investment is expanded in priority agenda areas.

Consumer and Carer outcomes
- Participation and leadership in advocacy activities with enhancement of skills and confidence,
- Heightened empowerment, meaning and hope,
- Robust participation in employment, community and social activities,
- Respected and valued as equal citizens.

Wellways outcomes
- Raised awareness of Wellways reputation for its strengths and values,
- Increased workforce capacity in regards to community development and social inclusion knowledge and skills,
- Staff, members, participants, carers, volunteers, donors and board mobilised, around issues that matter, our vision and mission. Provides greater meaning and value to work.

Community-centred advocacy is key to Wellways’ advocacy plan. Wellways’ Advocacy Team will work closely with regions where we have a service presence, to assist the development of local advocacy and community inclusion projects – to influence and improve service provision, to reduce stigma/discrimination and promote equitable access to resources, and social inclusion.
Measurable Outcomes

Advocacy Membership
The advocacy team have a mandate to increase the numbers of advocacy members to upward of 500 and to generate ongoing involvement of members in all campaigns. Currently in 2016 there are 215 members. Membership activity can be tracked through the ThankQ data management system. Outcomes will be reported against the following measures:

- Growth of membership,
- Members responding to surveys, calls to action and other internally generated campaigns,
- Members involved in community engagement workshops,
- Sustained engagement with regional advocacy activities,
- Members involvement in social and other media
- Increased numbers of staff joining as members and becoming personally involved in advocacy.

Community Engagement Strategy
Success of the community engagement strategy will depend on a range of variables, such as:

- Capacities, resources and synergies between individuals involved in workshops,
- Staff resourcing and support in regions,
- Wellways regional relationships with external stakeholders.

Measures of success:

- Advocacy activities generated by attendance at community workshops,
- Establishment of regional consumer and carer advisory groups to advocacy,
- Progression of community advocacy plans and activity,
- Increased advocacy membership within regional areas,
- Increased social and other media about mental health matters in regions,
- Surveys with workshop attendees that report a sense of increased community inclusion and awareness about mental health issues, reduced stigma and discrimination etc.,
- Surveys with people affected by mental health issues who attend workshops indicating heightened skills, confidence, community participation, and/or access to Wellways services.

Wellways program indicators

- Increased uptake in regions of Wellways programs such as community education and training, the Brainwaves model, peer-led education programs and Helpline,
• Former program participants becoming involved in advocacy activities.

Advocacy Team Reporting Outputs

• Dashboard reporting of activities and measurables as above,
• Responses to systemic issues utilising various forms of media, including:
  - electronic (web updates, blogs, facebook, twitter, enews)
  - print (journal articles, newspaper, conference presentations),
  - aural (radio, Brainwaves),
  - and visual media (videos, photography).
• Demonstrated engagements with membership in expressing need and views about systemic issues,
• High profile meetings
• Representation at the level of peak bodies, committees and consultations.
References


