



NSW Consumer Advisory Group – Mental Health Inc.
ABN 82 549 537 349

18 September 2014

Select Committee on Health
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Sir/Madam,

Re: Submission to the Senate Inquiry into Health Policy, Administration and Expenditure

NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) is the independent, state-wide peak organisation for people with a lived experience of mental illness (consumers). We work with consumers to achieve and support systemic change. NSW CAG's vision is for all people with a lived experience of mental illness to participate as valued citizens in the communities they choose.

NSW CAG is pleased to provide input into the Inquiry into Health Policy, Administration and Expenditure by the Senate Select Committee on Health. Our submission focuses on and makes recommendations in relation to, consumers' healthcare access and experiences. These issues are relevant to items b, f and g in the terms of reference for this Inquiry.

We thank you for considering our submission and we look forward to opportunities to further inform the inquiry process. Should you wish to discuss any aspect of our submission, I can be contacted on _____ or _____

Yours sincerely,

Dr Peri O'Shea
Chief Executive Officer



NSW Consumer Advisory Group – Mental Health Inc.

***Submission to the Senate Select
Committee on Health:***

Health policy, administration and expenditure

18 September 2014

This submission was compiled on behalf of NSW CAG by:

Karina Ko, Policy Officer

Acknowledgements

NSW CAG would like to thank the individual participants who generously shared with us their experiences and insights.

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NSW Consumer Advisory Group - Mental Health Inc.

NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) is the independent, state-wide peak organisation for people with a lived experience of mental illness (consumers). We work with consumers to achieve and support systemic change.

NSW CAG’s vision is for all people with a lived experience of mental illness to participate as valued citizens in the communities they choose. Participation is a fundamental human right as enshrined in Article 25 of the *International Covenant on Civil and Political Rights* (ICCPR). We work from the premise that the participation of consumers results in more effective public policy and facilitates individual recovery.

Our work is guided by six principles:

- Being person centred and empowering consumers in the interests of consumers;
- Adopting a recovery approach to building positive futures;
- Promoting positive images and reducing stigma and discrimination;
- Enhancing best practice and building understanding of effective approaches to consumer participation;
- Capacity building of our organisation, consumers and services; and
- Promoting professionalism and continuous improvement in our ways of working.

NSW CAG is an independent non-government organisation that receives core and project funding from the Mental Health Commission of NSW.

Introduction

NSW Consumer Advisory Group - Mental Health Inc. (NSW CAG) welcomes the opportunity to provide feedback to the Select Committee on Health's inquiry into health policy, administration and expenditure.

Mental illness touches upon the lives of many people across Australia. It is experienced by almost half of the Australian adult population at some point over their lifetime (45% of the population).¹ Many people with mental illness experience a range of co-existing health issues, along with other socio-economic disadvantages. For these reasons, it is crucial that the Australian health system is able to recognise and respond to the often complex health needs of mental health consumers (people with a lived experience of mental health issues), and that changes to the health system do not present barriers to mental health consumers accessing the healthcare they need.

NSW CAG submission addresses b, f and g of this Inquiry's Terms of Reference. It highlights the impact of additional costs to access healthcare for people with a lived experience of mental illness. This includes the potential impact of the General Practitioner (GP) co-payments and increase of pharmaceutical co-payments proposed in the 2014-2015 Federal Budget Bill. The submission also discusses the importance of engagement with communities and a range of healthcare providers to the better integration and coordination of health services by Primary Health Networks. Lastly, it discusses the need for mental health training and support for GPs.

This submission is informed by a range of our consultative work with mental health consumers. In June 2014, NSW CAG surveyed consumers specifically about the impact of the changes proposed in the 2014-2015 Federal Budget.² In 2012 and 2013, NSW CAG also travelled across different parts of NSW to consult with consumers in different communities.³ Feedback from these activities, as well as from our ongoing work with mental health consumers, has informed our views in this submission. Where possible, we have also included quotes and real life stories from consumers to illustrate specific concerns.

¹ Slade, T, Johnston, A, Teesson, M, Whiteford, H, Burgess, P, Pirkis, J, Saw, S. (2009) *The mental health of Australians 2*, Report on the 2007 National Survey of Mental Health and Wellbeing, Department of Health and Ageing, Canberra.

² NSW CAG report (2014) *Impact of Federal Budget 2014-2015 on mental health consumers*, Available online: http://www.nswcag.org.au/files/NSW_CAG_Report_Impact_of_Federal_Budget_2014-15_on_mental_health_consumers.pdf

³ NSW CAG report (2012) *Border to Border: Vision of Hope*, Available online: http://www.nswcag.org.au/files//board_members_/july/mhc_august_2012_final.pdf

The impact of less affordable healthcare on mental health consumers⁴

The 2014-2015 Federal Budget Bill proposed introducing a \$7 GP co-payment and increasing the pharmaceutical co-payment.⁵ For prescription medications, people would have to pay \$5 more, and Concession Card holders 80¢ more.⁶

NSW CAG is concerned about the potential impact such increases could have on mental health consumers. People with mental illness are much more likely than the general population to be on a low income, with poorer physical and mental health, and poorer access to education and paid employment.⁷ For people in these circumstances, increases in costs to accessing healthcare could mean that people do not seek preventative treatments from GPs, and forgo much needed prescriptive medications, when they are experiencing early and critical warning signs for their physical or mental health conditions.

As recognised by the National Mental Health Commission, access to primary healthcare is very important for people living with mental illness.⁸ Increasing costs of access to primary healthcare would be inconsistent with the Commission's support for a strong primary care approach to delivering health services for people living with a mental illness.⁹

Considering these factors, additional costs to access healthcare, including primary healthcare, would jeopardise the mental and physical health treatment of people with mental illness, and the early intervention of mental illnesses and other health co-morbidities.

The sections below further discuss the impact of additional costs to access GPs and medication on people with mental health issues.

Access to GPs

GPs play an important role in the early intervention of mental illnesses. People experiencing depression, anxiety and common mental health problems usually go first to their GP for help, and then through referral, to a mental health practitioner, such as a clinical psychologist or psychiatrist.¹⁰

Access to GPs is also important for the ongoing mental and physical health treatment of people with mental illness. For example, people with psychotic illness see their GPs almost twice as often as

⁴ Terms of Reference b.

⁵ Australian Government (2014) *Budget measures: budget paper no. 2: 2014–15*, p. 203, Available online: http://www.budget.gov.au/2014-15/content/bp2/html/bp2_expense-14.htm

⁶ Ibid.

⁷ National Mental Health Commission (2012) *A Contributing Life, the 2012 National Report Card on Mental Health and Suicide Prevention*, NMHC, Sydney.

⁸ Ibid., p. 57.

⁹ Ibid.

¹⁰ Hosie, A, Vogl, G, Hoddinott, J, Carden, J, Cormeau, Y. (2013) *Crossroads: Rethinking the Australian Mental Health System*, ReachOut.com by Inspire Foundation, p. 8.

the general population.¹¹ The important role of GPs in mental health is also shown by 86% of mental health-related prescriptions being provided by GPs, with 8% by psychiatrists and 6% by non-psychiatrist specialists.¹²

Currently, many people in Australia aged 15 and over already delay seeing a GP when they needed to see a GP.¹³ Increasing the cost to access GPs would exacerbate this. The stigma and discrimination around mental illness already deters many people from seeking help.¹⁴ People on a low income, and people living in rural or remote areas, also have to consider issues such as the costs of transport to access healthcare. Additional costs to access GPs adds another layer to the significant barriers many mental health consumers need to surmount to seek the help they may require.

If there were additional costs to access GPs, more people would delay seeking early intervention for mental health issues, and more people with mental illness would delay getting the mental and physical health treatment that they need. Therefore, it is essential to ensure that access to GPs is affordable for people with mental illness, taking into account that many mental health consumers have low-income and high healthcare costs.

Access to medications

People with mental illness often have to buy a number of medications for their mental and physical health conditions.¹⁵ Some mental health consumers told us that, even with the current Pharmaceutical Benefits Scheme, they found it difficult to pay for all of their medications. This is a particularly significant problem for consumers who have complex healthcare needs and are also on a low income. This is illustrated in the quotes below.

Consumer feedback, NSW CAG:

"I have to be on ten medications for my heart problems but I'm on Newstart, and they give me \$3 to cover my medication. On a number of occasions, I had to ask for additional money just to get me through, and every time I called Centrelink, the person on the line is really rude, it's just for \$20 but they make you feel like you're worth nothing and you're just greedy." (2012)

¹¹ Australian Government (2011) *People living with psychotic illness 2010, Report on the second Australian national survey*, Department of Health and Ageing, Canberra, p. 65; Sane Australia (2011) *People Living with Psychotic Illness: A SANE Response*, p. 17, Available online: http://www.sane.org/images/stories/information/research/1111_info_response.pdf

¹² Australian Institute of Health and Welfare (2012) *Mental health-related prescriptions - 2012-2013 update*, p. 1, Available Online: <https://mhsa.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=38654706051>

¹³ Australian Bureau of Statistics (2013), *Patient Experiences in Australia: Summary of Findings, 2012-13*, cat. no. 4839.0, ABS, Canberra.

¹⁴ Gulliver, A., Griffiths, K. M., & Christensen, H. (2010) 'Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review', *BMC Psychiatry*, vol 10, p. 113.

¹⁵ See e.g., Australian Government (2011), *People living with psychotic illness 2010, Report on the second Australian national survey*, Department of Health and Ageing, Canberra, pp. 71-72.

“I have a number of medications I am already on... really cuts into your budget... I have to go to the doctor regularly for blood tests [...] so the cost again adds severely to a small income.” (2014)

“Already I don't take all my medications as I can't afford them. Going to the doctor to get scripts which are essential to keep me safe from self harm will cost more as well as the scripts.” (2014)

The high cost of medications as a barrier to healthcare for people with mental illness was also identified as an issue in a 2009 survey by SANE Australia. The survey found that one in six (17%) of the 371 mental health consumers surveyed were spending at least \$100 a month on medications, and almost a third (32%) of the respondents had not registered with the Medicare Safety Net.¹⁶ It also found that over half (54%) of the respondents had not been able to afford treatments recommended by their doctor, and 42% had not filled scripts for medication they had been prescribed because of the expense.¹⁷

It is clear from the above that the cumulative and ongoing costs of medications are already a significant barrier for many mental health consumers to accessing the treatment they need. Increasing the costs of medications would only further exacerbate this problem.

Broader social and economic implications

Increasing costs to access healthcare, such as GPs and medications, would make it difficult for people with mental illness to maintain their health, including mental health, and make them more vulnerable to physical and mental health crises. This would in turn increase their reliance on acute hospital care, which is much more costly than preventative care in the community. It would also increase the social and human costs on people with mental health issues, their carer, family and friends, and the broader community. As such, NSW CAG recommends the Federal Government to ensure that healthcare costs are not increased for mental health consumers, particularly for those who are on low income, or who require ongoing physical and/or mental health care or treatment.

Recommendation:

1. The Federal Government to ensure that healthcare costs are not increased for mental health consumers, particularly for those who are on low income, or who require ongoing physical and/or mental health care or treatment.

¹⁶ SANE Australia (2009) *Research Bulletin 9 - Money and mental illness*, Available online: http://www.sane.org/images/stories/information/research/0907_info_rb9money.pdf

¹⁷ Ibid.

The integrating role of the Medicare Locals and Primary Health Networks¹⁸

The role of Medicare Locals was for the better integration of local GP and primary healthcare services.¹⁹ One of its objectives was to identify the health needs of their local areas and develop locally focussed and responsive services.²⁰ In the 2014-2015 Federal Budget, the Federal Government proposed replacing Medicare Locals with Primary Health Networks from 1 July 2015.²¹ The Primary Health Networks will establish local Community Advisory Committees, and Clinical Councils that have a significant GP presence.²²

Engagement with the community and a broad range of primary care providers is essential to the better integration and coordination of Medicare services. The sections below further discuss the importance of ensuring such engagement in the Primary Health Networks.

Importance of community engagement

Better integration and coordination of healthcare services in a community requires a good understanding of the needs and concerns of that community. To achieve this, meaningful community engagement is necessary to canvas the needs and concerns of the diverse groups across the community.

Recognising this, Medicare Locals were expected to engage directly with people living in their local community.²³ NSW CAG is concerned that the role of Primary Health Networks does not seem to include such direct community engagement. According to the 2014 Review of Medicare Locals, the Primary Health Networks will rely on Community Advisory Committees (CACs) to provide a community voice.²⁴

We agree that CACs are an important element of community or consumer engagement. They can serve as an important mechanism for identifying community concerns that require further investigation. They can also provide links to groups in the community. CACs, however, should be used in conjunction with, rather than substitute, direct community engagement and consumer consultations.

¹⁸ Terms of Reference f.

¹⁹ Council of Australian Governments (2011) *National Health Reform Agreement*, p. 50, Available online: http://www.federalfinancialrelations.gov.au/content/npa/health_reform/national-agreement.pdf

²⁰ Australian Government (2011) *Guidelines for the establishment and initial operation of Medicare Locals & Information for applicants wishing to apply for funding to establish a Medicare Local*, Department of Health and Ageing, p. 4.

²¹ *Budget measures: budget paper no. 2: 2014–15*, above n 5.

²² Ibid.; Australian Government (2014) *Establishment of Primary Health Networks - Frequently Asked Questions*, (last updated 11 July 2014), Department of Health, Available online:

[http://www.health.gov.au/internet/main/publishing.nsf/Content/A21377167057BD14CA257CD300147598/\\$File/Establishment%20of%20Primary%20Health%20Networks%20FAQs%20July%202014.PDF](http://www.health.gov.au/internet/main/publishing.nsf/Content/A21377167057BD14CA257CD300147598/$File/Establishment%20of%20Primary%20Health%20Networks%20FAQs%20July%202014.PDF)

²³ Australian Government (2012) *Medicare Locals Operational Guidelines*, Department of Health and Ageing, pp. 14-16, 39.

²⁴ Ibid., pp. 11, 18; *Establishment of Primary Health Networks - Frequently Asked Questions*, above n 22, p. 3.

A good understanding of the issues in the community requires direct engagement and a direct relationship with the community. It would be tokenistic to expect a CAC, which would consist of a limited number of people, to be able to provide Primary Health Networks with a comprehensive understanding of the diverse local needs. For these reasons, the decision-making process of Primary Health Networks around better integration and coordination needs to include direct community engagement and consultations as well as CACs.

Furthermore, NSW CAG recommends ensuring that the views of communities are given at least equal standing to those of the Clinical Councils. Too often, the traditional notions of professional power and expertise overshadow the value of community experience. Such notions are being increasingly challenged. For example, in the mental health sector, ‘recovery-oriented approaches’ - which respect mental health consumers for their experience, expertise and personal strengths - are progressively being adopted into both policy and practice.²⁵ Any development in the health sector should align with this growing recognition of consumer and community experience and expertise.

To make the most of the resources that had been invested into Medicare Locals, NSW CAG recommends that Primary Health Networks consider the findings from any community engagement conducted by Medicare Locals. Primary Health Networks should also learn from the positive and negative experiences of Medicare Locals in local community engagement, e.g., community engagement methods that were found effective or ineffective for a particular community. These experiences can inform the development of better community engagement practices for the Primary Health Networks.

It would also be beneficial for Primary Health Networks to share learnings about best practices, including around community engagement. This could be through a coordinating body or through innovative use of web-based technologies. For example, the Mental Health Professionals’ Network has discussions through live webinars on improving interdisciplinary mental health and collaborative care practice within Australia.²⁶ NSW CAG recommends examining such communication channels for Primary Health Networks to improve their community engagement and other functions.

Recommendations:

2. The Primary Health Networks to have more scope for direct local community engagement, to identify local healthcare needs, and to inform its decision-making, particularly around service development, planning and delivery.
3. The Primary Health Networks to give the views of communities at least equal standing to the views of professionals in their decision-making process.
4. The Primary Health Networks to utilise the learnings of Medicare Locals, including from and in relation to community engagement.

²⁵ Australian Health Ministers’ Advisory Council (2013) *A National Framework for Recovery-Oriented Mental Health Services: Policy and Theory*, Department of Health, Canberra, p. 3.

²⁶ About Mental Health Professionals’ Network, Available online: <http://www.mhpn.org.au/about>

5. The Federal Government to examine communication channels for Primary Health Networks to share learnings about best practices in relation to community engagement and other functions.

Importance of engaging with the full range of primary healthcare providers

NSW CAG is concerned that the Primary Health Networks will place too great an emphasis on GPs.²⁷ According to the Frequently Asked Questions sheet on the Establishment of Primary Health Networks, GPs are expected to lead the Clinical Councils and to have a much greater involvement in the Primary Health Networks.²⁸ We consider that effective integration and coordination of services requires meaningful engagement with the full range of healthcare providers, including allied health providers.

GPs are fundamental to the access of primary healthcare, but GPs should not be the cornerstone of Primary Health Networks, as this risks a narrow, medical-centric orientation. Like many people in the community, mental health consumers have complex healthcare needs. Many of these needs require expertise beyond what GPs can provide. It is crucial for Primary Health Networks to be able to recognise and respond to the holistic healthcare needs of a person. As such, a diversity of healthcare expertise alongside community experience is required to inform better integration and coordination of services.

Recommendation:

6. The Primary Health Networks to engage with the diverse range of healthcare providers to inform decision-making to ensure better integration and coordination of services.

²⁷ *Review of Medicare Locals*, above n 24, p. 10, Recommendation 3.

²⁸ *Establishment of Primary Health Networks - Frequently Asked Questions*, above n 22, pp. 2-3.

Mental health training and support for GPs²⁹

As discussed on pages 6-7, GPs are important for people to access early intervention and treatment for mental illnesses. It is therefore concerning that many mental health consumers we spoke with have encountered GPs lacking mental health knowledge and skills. It is further concerning that the proposed 2014-15 Federal Budget ceases funding for Mental Health Better Access to Education and Training.³⁰ The funding provided education and training to GPs and other practitioners to enable them to deliver mental health treatment and care funded through the Better Access initiative. Feedback given to NSW CAG from consumers is that many GPs need more mental health training, including knowledge of the clinical and non-clinical supports available for consumers.

Access to support by mental health professionals could also improve GPs' ability to provide mental health assessment, care planning and treatment. For example, the GP Psych Support was a 24/7 phone service providing GPs with free advice from a team of psychiatrists.³¹ NSW CAG recommends examining effective ways to provide GPs with mandatory training and ongoing support in their delivery of mental health care.

Experiences of people trying to access mental health care through GPs:

'Sarah' felt unwell and wanted to increase the dosage of her medication for her mental health condition. Her private psychologist was away so she visited a GP.

The GP said she looked "too normal" for someone unwell, and in fact more "normal than normal people". Sarah tried to explain her dissociations and the GP snapped at her and told her not to use those terms in the GP's office.

She then visited a different GP. The second GP said that Sarah seemed to have very good insight into her mental health and how to manage symptoms, but then didn't believe Sarah when she asked for an increase in her medication.

Both of the GPs she visited treated her suspiciously. She felt the GPs weren't comfortable dealing with mental healthcare, but were also very defensive about their lack of knowledge. She wants GPs to have mandatory mental health training, including counselling and communications skills. (2014)

²⁹ Terms of Reference g.

³⁰ *Budget measures: budget paper no. 2: 2014-15*, above n 5.

³¹ See The Royal Australian Council of General Practitioners, GP Psych Support flyer, Available online: http://www.healthfirst.org.au/site/content.cfm?page_id=65362¤t_category_code=594&leca=222

'Jenny' is in her mid-twenties. She lives in a regional town with her energetic young daughter.

Jenny has a mental illness and a physical health condition which means that she lives with chronic pain.

She visited her GP and told him that she needed mental health help. She also wanted to talk about her physical pain but says that her doctor didn't seem to be able to consider both needs simultaneously. Nor did he seem to understand how living in chronic pain could contribute to her distress.

Even after saying that she needed help with her mental health, her GP didn't refer her to any services. She kept asking though, because she felt desperate and had no idea of where else to get help.

Jenny finally found out how to access community mental health services, but she hasn't had a great experience with them. She characterises these services as offering a 'quick fix'. She has also found support through an NGO managed service, which has been more helpful.

She only learned about this NGO managed service through a parenting program she's enrolled in. Jenny was glad to find it but wonders why community mental health or her GP didn't tell her about it. (2012)

Recommendations:

7. The Federal Government to provide mandatory mental health training for GPs.
8. The Federal Government to provide GPs with professional support in their delivery of mental health care.

Summary of recommendations

1. The Federal Government to ensure that healthcare costs are not increased for mental health consumers, particularly for those who are on low income, or who require ongoing physical and/or mental health care or treatment.
2. The Primary Health Networks to have more scope for direct local community engagement, to identify local healthcare needs, and to inform its decision-making, particularly around service development, planning and delivery.
3. The Primary Health Networks to give the views of communities at least equal standing to the views of professionals in their decision-making process.
4. The Primary Health Networks to utilise the learnings of Medicare Locals, including from and in relation to community engagement.
5. The Federal Government to examine communication channels for Primary Health Networks to share learnings about best practices in relation to community engagement and other functions.
6. The Primary Health Networks to engage with the diverse range of healthcare providers to inform decision-making to ensure better integration and coordination of services.
7. The Federal Government to provide mandatory mental health training for GPs.
8. The Federal Government to provide GPs with professional support in their delivery of mental health care.

Conclusion

Affordable access to primary healthcare and medications is extremely important to early intervention of mental illness, and the ongoing physical and mental health treatment for people with mental illness. Additional costs to access healthcare could undermine efforts invested in preventative care and increase reliance on more expensive acute care. Also, considering the increasing importance of GPs for access to mental health care, GPs need more mental health training and support.

In order to better integrate and coordinate services, the Primary Health Networks will need to engage with diverse groups in communities to understand their needs and concerns. Effective community engagement could be supported by shared learning and drawing on the experience of Medicare Locals. It is also important for the Primary Health Networks to engage with the full range of primary healthcare providers rather than emphasising GPs.

NSW CAG thanks you for considering our submission on the Inquiry into Health Policy, Administration and Expenditure. We look forward to opportunities to provide further input into improving healthcare for people experiencing mental health difficulties.