



## **WITNESS STATEMENT OF DOUGLAS HOLMES**

I, Douglas Holmes, General Manager, of MH-worX, 1 Macquarie Street, Boolaroo in the state of New South Wales, say as follows:

### **Background**

- 1 I am currently the General Manager of MH-worX, an organisation I co-founded in 2016. MH-worX provides consultancy services to hospitals and organisations who work with homeless people and people with a mental illness to transform recovery practices in the mental health sector.
- 2 I have a Diploma in Training and Assessment: Comprehensive Systematic Review Training, and a Certificate IV in Training and Assessment. I am currently studying a Bachelor of Arts, majoring in English and Creative Writing, at the University of Newcastle.
- 3 I was diagnosed with bipolar affected disorder in 1992, at which time I started my own personal journey with mental illness and understanding mental illnesses.

### **My experiences**

- 4 Since around 1996, I have worked or volunteered in the mental health services industry and have a particular interest in the consumer and peer worker movements. Some of the roles that I have held are as follows.
- 5 I was a founding member of the Australian Mental Health Consumer Network (**AMHCN**), a consumer group established at the 1996 Brisbane TheMHS Consumer Day (I describe the TheMHS Consumer Day on page 7). The AMHCN aimed to represent consumers at a national level as the peak consumer body in Australia.
- 6 In 2008 the AMHCN realised they needed assistance to be able to meet all the requirements to operate professionally. This led to the formation of The Consumer Reference Group (**CRG**).
- 7 Mental Health Australia worked in partnership with the CRG to develop the foundations for a sustainable organisation built on good governance, governed by and for, people with lived experience of mental illness and mental health issues. The National Mental Health

*Please note that the information presented in this witness statement responds to matters requested by the Royal Commission.*

Consumer Organisation (**AMHCO**) Establishment Project<sup>1</sup> worked towards establishing a new national peak organisation for mental health consumers.

- 8 The Project commenced in June 2012 and finished at the end of May 2015. Unfortunately, ongoing funding has not yet been secured to launch the organisation.<sup>2</sup>
- 9 On 7 March 2014, the CRG and the Mental Health Council of Australia (**MHCA**) hosted a National Stakeholder Workshop in Melbourne. The workshop brought together 12 representatives from mental health consumer focussed groups, organisations and peaks from across the country. These were:
- (a) NSW Consumer Advisory Group – now Being.
  - (b) Flourish (Tasmania).
  - (c) Victorian Mental Illness Awareness Council (**VMIAC**).
  - (d) Health Consumers Alliance of South Australia.
  - (e) ACT Mental Health Consumer Network.
  - (f) Queensland Voice for Mental Health.
  - (g) Mental Illness Fellowship Australia (National).
  - (h) GROW National.
  - (i) National Mental Health Consumer and Carer Forum (NMHCCF).
  - (j) Mental Health in Multicultural Australia.
  - (k) Consumers of Mental Health Western Australia.
  - (l) Private Mental Health Consumer Carer Network (Australia).
- 10 These stakeholders brought to the workshop an impressive wealth of knowledge and experience of the mental health consumer sector. Through facilitated workshop activities, participants engaged in robust and thoughtful discussion about many key issues.

### **The start of my volunteering and advocacy journey**

- 11 From 1997 to 1999 I was a member of the NSW Consumer Advisory Group Mental Health Inc (**NSW CAG**) (now known as Being).<sup>3</sup> From 2000 to 2006 I was also the Executive Officer of NSW CAG. NSW CAG was originally established as a committee of consumers

<sup>1</sup> <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-r-nmhcores>.

<sup>2</sup> Resources developed through the NMHCO Establishment Project are available at <https://mhaustralia.org/https%3A/mhaustralia.org/national-mental-health-consumer-organisation-nmhco-establishment-project-completed-may-2015/project-resources>. Communiques providing historical information about project activities are available at: <https://mhaustralia.org/https%3A/mhaustralia.org/national-mental-health-consumer-organisation-nmhco-establishment-project-completed-may-2015/communiques-and-updates>.

<sup>3</sup> <https://www.nswcag.org.au/history-of-nsw-cag.html>.

and carers who provided advice to the NSW Minister for Health in response to the National Mental Health Strategy.<sup>4</sup> NSW CAG became an incorporated organisation in 1993 and remains (under the name 'Being') as a mental health advocacy body in NSW for mental health consumers and carers.

12 Between 2000 and 2010 I was a member of The Mental Health Service (**TheMHS**) Awards Committee<sup>5</sup> and between 2000 and 2016 I was the coordinator for the TheMHS Consumer Day Committee.

- (a) The TheMHS Awards receive funding from both the Australian and New Zealand governments. The awards are given by the TheMHS Learning Network to recognise best practice, excellence and innovation in mental health service delivery. In this role I coordinated the judges of the awards.
- (b) In relation to the TheMHS Consumer Day Committee, my role was to liaise between the organising committee and the local consumer organising committee. This included keeping new committees updated with feedback from previous days.

13 Between 2006 and 2016 I was the Consumer Participant Officer at Inner City Health Program, St Vincent's Hospital, Sydney. The primary objectives of the role were to:

- (a) assist in the process of improving the quality of mental health service delivery;
- (b) assist in the development and expansion of consumer participation and partnership with St. Vincent's Mental Health Service (**SVMHS**);
- (c) provide input into decision making about health service planning and delivery, policy development and implementation, setting priorities, training and quality improvement related issues;
- (d) in conjunction with the Quality Improvement Manager, monitor and evaluate consumer participation within SVMHS;
- (e) encourage and expand consumer participation in the Sector Community Consultative Committee (**CCC**), the SVMHS Patient Care Committee (**PCC**) and the various working parties and committees; and
- (f) act as the main contact person for consumers sitting on working parties/committees within SVMHS to address their needs for effective participation.

<sup>4</sup> <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-strat>.

<sup>5</sup> <https://www.themhs.org/the-awards/>.



- 14 I have held various positions on boards and committees in the health industry, including: with TAMHSS, Neami National, Hearing Voices Network NSW, Mental Health Recovery Network, Inner City Super Group, Oz Voices and Callan Park Peers.
- 15 In addition to the above:
- (a) In 2008 I was involved in forming Transforming Australia's Mental Health Services Incorporated (**TAMHSS**). TAMHSS was formed at the 2008 TheMHS Conference and provides a means for the Australian community to become involved in the transformation of our mental health service systems.
  - (b) In 2014 I received the TheMHS Exceptional Contribution award.<sup>6</sup> The award recognises an individual who has made an outstanding contribution to mental health service delivery.
  - (c) In 2016 I was involved in starting the SUPER CRO,<sup>7</sup> an unincorporated association that has been given charity status.
  - (d) In 2018 I was awarded an Order of Australia Medal<sup>8</sup> (OAM) for service to community health.
  - (e) In 2019 I was elected as the National Secretary for the Australian Mental Health Party.<sup>9</sup>
- 16 Attached to this statement and marked 'Attachment DH-1' is a copy of my curriculum vitae.
- 17 I am giving this evidence in my own personal capacity and not on behalf of any organisations with which I am associated.

## Contributing lives

### ***The National Mental Health Commission and its 'contributing life framework'***

- 18 The National Mental Health Commission (**NMHC**) has adopted a 'Contributing Life Framework'. This framework is a whole-of-person, whole-of-system, whole-of-life approach to mental health and wellbeing through which the NMHC views and reports their work, and which is used to inform reform in mental health.

<sup>6</sup> <https://www.themhs.org/award-winners/>.

<sup>7</sup> [www.supercro.com](http://www.supercro.com).

<sup>8</sup> <https://honours.pmc.gov.au/honours/awards/2001556>.

<sup>9</sup> [www.amhp.org.au](http://www.amhp.org.au).



- 19 In summary, a 'Contributing Life' is when people living with a mental health illness should expect the same rights, opportunities and health as those without a mental health illness. As summarised on the NMHC's website,<sup>10</sup> a 'Contributing Life' includes:
- (a) thriving, not just surviving;
  - (b) effective support, care and treatment;
  - (c) having something meaningful to do, and something to look forward to;
  - (d) connections with family, friends, culture and community; and
  - (e) feeling safe, stable and secure.
- 20 Alan Rosen's article<sup>11</sup> *Australia's National Mental Health Strategy in Historical Perspective: Beyond the Frontier* showed there was a significant amount of work done before the NMHC was established in 2012.
- 21 From around 2011, consultations coordinated by the Australian Health Ministers' Advisory Council were held with people with lived experiences, during which people provided feedback and were consulted about how to approach recovery-oriented mental health practice and service delivery.
- 22 As part of these consultations, I worked with Dr Leanne Craze (of Craze Lateral Solutions) and she reported back to the NMHC with feedback from the consultations with consumers from around Australia.
- 23 The 2013 NMHC Contributing Life 'national report card'<sup>12</sup> contains information from those consultations. The NMHC then conducted a national review of mental health programs and services. The focus of the review was on assessing the efficiency and effectiveness of programs and services in supporting individuals experiencing mental ill-health, their families and other support people to lead a contributing life and to engage productively in the community.<sup>13</sup>
- 24 A national framework for recovery-oriented mental health services<sup>14</sup> was established in 2014. After it was established, the NMHC then adopted the 'Contributing Life Framework'.

<sup>10</sup> <https://www.mentalhealthcommission.gov.au/social-determinants/contributing-lives-thriving-communities>.

<sup>11</sup> [https://www.cambridge.org/core/services/aop-cambridge-core/content/view/5B7A4C7EBC65DC139D40FDCC982822DD/S1749367600004987a.pdf/australias\\_national\\_mental\\_health\\_strategy\\_in\\_historical\\_perspective\\_beyond\\_the\\_frontier.pdf](https://www.cambridge.org/core/services/aop-cambridge-core/content/view/5B7A4C7EBC65DC139D40FDCC982822DD/S1749367600004987a.pdf/australias_national_mental_health_strategy_in_historical_perspective_beyond_the_frontier.pdf).

<sup>12</sup> <https://www.mentalhealthcommission.gov.au/getmedia/62e98949-980b-4791-a90a-4ae92adbf2a3/2013-National-Report-Card-on-Mental-Health-and-Suicide-Prevention.pdf>.

<sup>13</sup> A copy of the review is available here: <https://www.mentalhealthcommission.gov.au/monitoring-and-reporting/national-reports>.

<sup>14</sup> <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-recovgde>.

- 25 From my perspective, the adoption of a 'Contributing Life Framework' by the NMHC was important because it meant that people with lived experiences were being listened to, and the bureaucracy was listening to what we'd been saying for some time.
- 26 I have been advocating for the voices of people with lived experiences to be incorporated into mental health service delivery and reform since around 1996, which is when my work in mental health really started.

### **The TheMHS Conference**

- 27 In 1996, I attended the TheMHS Conference in Brisbane. The TheMHS Conference<sup>15</sup> (organised by The Mental Health Services Learning Network) is held in a different state each year and attracts around 1,000 delegates from a diverse range of personal and professional backgrounds. It provides an opportunity for consumers to come together to develop solutions to some of the issues affecting people with mental illness. The Commonwealth Government funds some consumers to attend the Conference through bursaries each year.
- 28 TheMHS also organises a 'Consumer Day' which is held prior to the main conference. I understand that TheMHS is currently reviewing the purpose and objectives of this day, which are currently as follows:
- (a) to enable mental health consumers, carers and families to meet, present papers/ideas and debate about issues of national importance from their own perspectives and to meet like-minded people prior to the main three day conference;
  - (b) to plan and conduct an educational forum which will assist in keeping up to date with best practice in mental health and to know what to expect of services;
  - (c) to provide a networking opportunity to learn about what is happening in Australian states and territories and New Zealand;
  - (d) to provide a forum to develop plans, policy and structures to further the aims of the mental health consumer movement, carer movement and for indigenous peoples; and
  - (e) to provide a pathway to participation in developing and managing services and initiating and maintaining consumer-run, carer-run or indigenous-run services.
- 29 In 1996, about 300 consumers came together at the TheMHS Conference as part of a 'Consumer Day' to talk about the process of developing an Australia-wide network so that

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<sup>15</sup> <https://www.themhs.org/annual-conference/>.

we could start telling government and organisations, and whoever else would listen, about what we thought needed to be fixed with the system.

- 30 In 1999, VMIAC led the TheMHS Consumer Day in Melbourne.<sup>16</sup> Steven Pitcher attended this Consumer Day and was nominated as the coordinator for the Consumer Day in Adelaide in 2000. It was in 1999 that he saw the work that had been developed by consumers, and believed that this work was important, and that action was needed. He decided that it was time to stop talking about what was wrong and encourage people to develop solutions that had some relevance and meaning for consumers.
- 31 On 28 August 2000, at the Adelaide Convention Centre, 235 people experiencing a mental illness came together as part of the 2000 Consumer Day to talk about and develop solutions to 20 issues considered to affect people with a mental illness at the time. These issues had appeared in previous reports, including the 1992 'Burdekin' Report,<sup>17</sup> the 1994 National Community Advisory Group Report "Let's talk about Action",<sup>18</sup> and the 2005 MHCA (in association with the Human Rights and Equal Opportunity Commission) "Not for Service" Report.<sup>19</sup> All reports expressed the failures in the mental health system and the need for change for services in Australia.
- 32 As a result of the 2000 Consumer Day, two outcomes were achieved:
- (a) the addition of three more issues to make a total of 23 issues considered to affect people with a mental illness; and
  - (b) the creation of a document detailing the work of the day. The document, entitled 'The Most Important Issues Affecting People with a Mental Illness or Disorder' (known to most people as the 23 Big Issues), provided a background to each of the issues and proposed solutions developed by the people at the forum.<sup>20</sup>
- 33 The document was presented to Dr Michael Woolridge, Commonwealth Minister for Health, at the 2000 Youth Roundtable forum. Feedback from the forum can be found here from an extract from Hansard.<sup>21</sup>
- 34 Steven Pitcher passed away in 2010 aged 31 years of age. He is sadly missed by the TheMHS family and the consumer movement. For me, the fact that the Australian Government came on board and adopted this 'contributing life', which I've referred to in paragraph 18 above, when the NMHC was established in 2012 was really important, as

<sup>16</sup> [https://www.themhs.org/wp-content/uploads/2018/06/23\\_Big\\_Issues\\_2010\\_Update.pdf](https://www.themhs.org/wp-content/uploads/2018/06/23_Big_Issues_2010_Update.pdf).

<sup>17</sup> <https://www.humanrights.gov.au/about/news/speeches/burdekin-national-inquiry>.

<sup>18</sup> <https://auspwn.files.wordpress.com/2014/05/summary-of-the-1994-lets-talk-about-action-report.pdf>.

<sup>19</sup> [https://www.humanrights.gov.au/sites/default/files/content/disability\\_rights/notfor-service/documents/NFS\\_Finaldoc.pdf](https://www.humanrights.gov.au/sites/default/files/content/disability_rights/notfor-service/documents/NFS_Finaldoc.pdf).

<sup>20</sup> [https://www.themhs.org/wp-content/uploads/2018/06/23\\_big\\_issues\\_Report\\_original.pdf](https://www.themhs.org/wp-content/uploads/2018/06/23_big_issues_Report_original.pdf).

<sup>21</sup> [https://parlinfo.aph.gov.au/parlInfo/search/display/display\\_w3p;db=CHAMBER;id=chamber%2Fhansardr%2F2000-04-11%2F0075;query=Id%3A%22chamber%2Fhansardr%2F2000-04-11%2F0075%22](https://parlinfo.aph.gov.au/parlInfo/search/display/display_w3p;db=CHAMBER;id=chamber%2Fhansardr%2F2000-04-11%2F0075;query=Id%3A%22chamber%2Fhansardr%2F2000-04-11%2F0075%22).



it recognised what consumers had been advocating for through the TheMHS Conference, since at least 1996.

***Whether ‘contributing lives’ is a useful approach for a mental health system to adopt***

- 35 In my view, ‘contributing lives’ is a useful approach for a future mental health system to adopt. I appreciate that there may be some resistance from some people about the idea of a ‘contributing life’. I think that some people believe that the idea of a ‘contributing life’ is about people giving back to society and they see this as being paternalistic in a way. In my experience, some people feel they’re owed something because of their own experiences. I don’t see it this way. For me, a ‘contributing life’ approach is the right approach. I have seen it work, and I have been fortunate to be part of its development over time.
- 36 For me, a ‘contributing life’ is about having something meaningful to do. What is it that you are going to jump out of bed for in the morning? What is going to get you excited about getting out of bed? For me the answers to these questions depend on the stage of a person’s journey. I know what it’s like to be depressed. I was diagnosed with bipolar affected disorder in 1992 and I just couldn’t work out what it was that would be meaningful enough for me to get out of bed. But I have seen it happen so many times with people – once they find they have a purpose; it seems to make a difference to their journey.
- 37 On 19 May 1994, I became a recipient of the disability support pension. This allowed me to access a range of services that I know assisted me to become involved in a new workforce from 1996.
- 38 As part of the National Mental Health Strategy, the National Mental Health Workforce Strategy<sup>22</sup> developed a plan to support a well-led, high performing and sustainable mental health workforce delivering quality, recovery-focused mental health services. The focus of this strategy and plan is the workforce, whose primary role involves early intervention, referral, treatment, care or support to people with a mental illness, in a mental health service or other health service environment, including non-government community mental health services.
- 39 The workforce includes mental health nurses, psychiatrists, general registered nurses, enrolled nurses, general and other medical practitioners, occupational therapists, social workers, psychologists, Aboriginal mental health workers, Aboriginal health workers, mental health workers, consumer workers and carer workers. It encompasses workers in a range of settings, including hospitals, health care and community mental health services

<sup>22</sup> <https://www.aihw.gov.au/getmedia/f7a2eaf1-1e9e-43f8-8f03-b705ce38f272/National-mental-health-workforce-strategy-2011.pdf.aspx>.

and correctional facilities across metropolitan, regional and remote areas of Australia. These workers are engaged in public, private and non-government (NGO) services.

- 40 In my view, the NSW Mental Health Consumer Peer Work Hub<sup>23</sup> shows the results of NSW Health getting this right. I was fortunate to be involved from the very beginning with the consumer workforce during my recovery journey. The following is taken from its website:

*"Mental illness is no longer a life sentence. The sun will come out and there's a lot to enjoy."*

*As he nears retirement, it's easier to ask Douglas Holmes what he hasn't done rather than what he has done over the course of his working life. What he has done makes for a very long list. He's come a long way for a young man who loved the t-shirt and thongs lifestyle of his native Newcastle in the Hunter region. Until the age of 42 he had a good career as a long-distance transport driver and union delegate, with a strong work ethic. Then Douglas was diagnosed with bipolar affective disorder. Since that time, he's been a key participant in many developments in mental health, including the consumer and peer worker movements.*

- 41 I was introduced to research by the University of Kansas on the Strengths Model,<sup>24</sup> a recovery-oriented case management practice that empowers individuals to focus on their individual strengths rather than fixating on their problem or diagnosis. Both Charles Rapp<sup>25</sup> and Patricia E. Deegan<sup>26</sup> were keynote speakers at the 1996 Brisbane TheMHS conference and they inspired me to become involved in the Australian Government's 20-year National Mental Strategy to change mental health services so that other consumers could have a better recovery journey than me and my family.
- 42 More information on the history of the Strengths model can be found on page xviii in Charles Rapp and Richard Goscha book 'The Strengths Model: Case Management with People with Psychiatric disabilities'.<sup>27</sup>
- 43 I have been privileged to visit Kansas 12 times in the last 10 years and worked with Rick Goscha on further developing the model in Australia.<sup>28</sup>

<sup>23</sup> <http://peerworkhub.com.au/resources/profiles/douglas-holmes/>.

<sup>24</sup> <https://socwel.ku.edu/strengths-perspective>.

<sup>25</sup> See <https://pdfs.semanticscholar.org/91ff/9106dd1d07cc7b1fd4d8e6af1b31620f9e40.pdf>.

<sup>26</sup> See <https://www1.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-n-recovpol-toc~mental-pubs-n-recovpol-ref>.

<sup>27</sup> <https://books.google.com.au/books?id=eVP3n4IxAGsC&pg=PR18&dq=rick+goscha+pat+deegan&hl=en&sa=X&ved=0ahUKewjt6YbOhpTpAhWfzDgGHY2nAvoQ6AEIJzAA#v=onepage&q=rick%20goscha%20pat%20deegan&f=false>.

<sup>28</sup> [https://recoverylibrary.unimelb.edu.au/data/assets/pdf\\_file/0007/1391551/the\\_strengths\\_core\\_training\\_manual\\_june\\_2014.pdf](https://recoverylibrary.unimelb.edu.au/data/assets/pdf_file/0007/1391551/the_strengths_core_training_manual_june_2014.pdf).

- 44 This has resulted in a community of practice established in both Victoria and NSW and supported by Dr Melissa Petrakis from Monash University.

***Useful ways of embedding the contributing lives approach and supporting or challenging factors in doing so***

- 45 In 2001 the NSW Mental Health Branch started to develop the Mental Health Consumer Perception and Experience of Services (MH-CoPES) project,<sup>29</sup> which provides a useful example to me of how the contributing lives approach can be embedded into the system. I co-lead this project for five years with Robyn Murray from the NSW Centre for Mental Health.
- 46 The project was a partnership between NSW CAG and the Centre for Mental Health, NSW Health. The aim of the project was to identify or develop a measure and process to collect, collate, report and respond to consumers' views of mental health services. Attached to this statement and marked 'Attachment DH-2' is a copy of the 2003-2004 NSW CAG annual report, in which the introduction of the MH-CoPES project is explained at page 19.
- 47 As part of the MH-CoPES project, a group of eight consumers and three professionals worked together over five years across various stages and produced three different reports. We developed an evaluation framework which detailed some of the considerations necessary to conduct a consumer-directed evaluation of mental health services; established a questionnaire for people who were using mental health services (both inpatient and community) to get their perceptions and experiences of services; conducted stakeholder consultations and workshops with consumers and service providers to develop the questionnaire; and analysed the data from the questionnaires to then help develop tailored implementation plans for each Area Mental Health Services (AMHS) with identified strategies.
- 48 I was heavily involved in this process, particularly in the initial stages as the Executive Officer of NSW CAG. NSW CAG ran 11 workshops across NSW, sometimes with 60 to 150 people attending, and recorded what they said. There are several reports on how this project was developed and reported on. In relation to the stages and the reports:
- (a) Stage 1 Project (2004 - 2005). During this stage, a state-wide approach to measuring and responding to consumer perceptions and experiences of services was developed.<sup>30</sup>

<sup>29</sup> <https://www.nswcag.org.au/mh-copes.html>.

<sup>30</sup> For more information see [https://www.nswcag.org.au/mh\\_copes\\_stage\\_1\\_project.html](https://www.nswcag.org.au/mh_copes_stage_1_project.html).



- (b) Stage 2 Project (2005 - 2009). During this stage the MH-CoPES Framework and Questionnaires were tested and refined so they could be ready for state-wide implementation.<sup>31</sup>
- (c) Stage 3 Project (September 2009 - September 2010). This was prepared for NSW mental health services to implement the MH-CoPES Framework.<sup>32</sup>
- (d) A report on Year 1 Statewide Implementation of the MH-CoPES Framework (October 2010 - Current). This was a decision to support the implementation of the MH-CoPES Framework across NSW and work towards a wider strategy to research the development and inclusivity of the MH-CoPES Framework and questionnaires within minority population groups.<sup>33</sup>

49 The image below shows the process developed during the MH-CoPES project. It was a 4-step process to collect the questionnaires which would be sent to an external body. The results would then be sent back to the NSW local health districts, who would be encouraged to publish a summary of the report and consider the three things they needed to improve. NSW CAG developed training workshops and resources<sup>34</sup> to assist with understanding how local health districts could use MH-CoPES to demonstrate they were listening to consumers who were accessing their services.



50 After this time, the national YES Survey (Your Experience of Service Survey) was established, which was developed by representatives all around Australia.<sup>35</sup> The YES Survey is designed to gather information from consumers about their experiences of care, and aims to help mental health services and consumers to work together to build better services. It was developed by a project team consisting of staff from the Victorian Department of Health, the Ipsos Social Research Institute and researchers from VMIAC.

<sup>31</sup> For more information see [https://www.nswcag.org.au/mh\\_copes\\_stage\\_2\\_project.html](https://www.nswcag.org.au/mh_copes_stage_2_project.html).

<sup>32</sup> For more information see [https://www.nswcag.org.au/mh\\_copes\\_stage\\_3\\_project.html](https://www.nswcag.org.au/mh_copes_stage_3_project.html).

<sup>33</sup> For more information see [https://www.nswcag.org.au/year\\_1\\_implementation.html](https://www.nswcag.org.au/year_1_implementation.html).

<sup>34</sup> <https://www.nswcag.org.au/mh-copes-resources.html>.

<sup>35</sup> Australian Mental Health Outcomes and Classification Network, <https://www.amhocn.org/your-experience-service-surveys>, accessed 10 March 2020.

For me, the Yes Survey is a fundamental way in which the 'contributing life' approach is embedded into the way in which we can improve mental health services.

- 51 The factors that supported the rollout of the Yes Survey in NSW included the work that had taken place during the development of MH-CoPES since 2001. We now have several years of the Yes Survey in NSW that shows that it is working, and changes are being made by all local health areas and special health networks.<sup>36</sup>
- 52 As to the factors that were more challenging, the hardest part was often the change in leadership in Local Health Districts that occurs when a state has a change of Government at a state election. At the time the work was being done on the MH-CoPES project, we had 18 Local Health Districts, which following a change in government in NSW, was reduced to eight. This has changed again; we now have 15 Local Health Districts, and three Special Health Networks.
- 53 My experience was that each time this happens, there is a change of leadership, and a change in people, and it takes time for each health district to understand who is responsible and who is reporting to whom.
- 54 In relation to consumers providing their own perspectives of their experiences, I often sensed a concern by some of the mental health professionals that this was like a 'witch hunt' – that perhaps one person might fill in 15 to 20 of the same surveys to make it seem like there was a bigger problem than maybe there was. But my experience was that once the mental health professionals got involved in the process of how the questionnaires were being handed out and what controls there were to ensure this did not happen, the concern was alleviated.
- 55 For example, in NSW, each mental health unit were given their own stamp to put a unique identifying number on the questionnaires and they knew where the returns were being posted too. The real win was that the service professionals were involved in the process of looking at the results to work out what needed to be addressed.
- 56 We held state-wide days where services would come in and demonstrate what they were doing, and I found that the Mental Health Directors became serious about the results and setting goals – they would establish their KPIs based on what the survey results said.

### **People with mental illness and the disability sector**

- 57 In the last couple of years, I've commenced a Bachelor Arts at the University of New South Wales, and one of the things I've been looking at is how we – people with complex

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<sup>36</sup> <https://www.health.nsw.gov.au/mentalhealth/participation/Pages/partners.aspx>.

mental health illness or distress – have somewhat excluded ourselves from the disability sector.

58 1981 was the International Year of Disabled Persons (a day proclaimed by the United Nations General Assembly). In 1986, the *Disability Services Act 1986* (Cth) was introduced, two of the purposes of which were to:<sup>37</sup>

- (a) assist persons with disabilities to receive services necessary to enable them to work towards full participation as members of the community; and
- (b) promote services provided to persons with disabilities that assist those persons to integrate in the community and achieve positive outcomes.

59 Contained in the *Disabilities Services Act* is the ability for organisations to provide ‘advocacy services’, being services that support persons with disabilities to exercise their rights and freedoms, and which seek to introduce and influence long-term changes to ensure the rights and freedoms of persons with disabilities are attained and upheld to positively affect their quality of lives. When the *Disabilities Services Act* was reviewed in 2014, it was identified that 64 organisations provided advocacy services across Australia for people with disabilities.

60 In 1992, the *Disability Discrimination Act 1992* (Cth) was introduced.<sup>38</sup> It is in that Act that a total or partial loss of a person’s mental functions was first included in the definition of ‘disability’. Recently, I have wondered why it is that the consumer movement in the mental health space has struggled to get some of the issues that are causing distress to people recognised.

61 I believe that the majority of people with lived experience don’t see us as part of the disabilities movement. I’m focussing on how we can change the perception that we don’t sit within that movement, or that we don’t feel like we are included. As a result, I’m suggesting more education around the *Disability Services Act* and how we can lobby governments and establish that there is an unmet need within that movement, and that we need more funds allocated to it. That’s what I’m going to focus on over the next five to eight years.

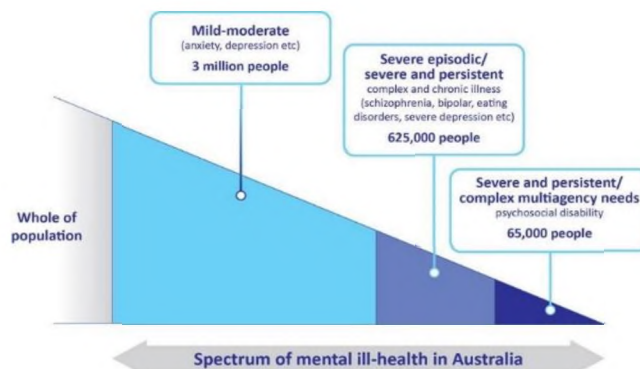
62 This image<sup>39</sup> is taken from page 7 of the National Mental Health Commission 2014 Contributing Lives Review.

<sup>37</sup> <https://www.legislation.gov.au/Details/C2018C00146>.

<sup>38</sup> <https://www.legislation.gov.au/Details/C2018C00125>.

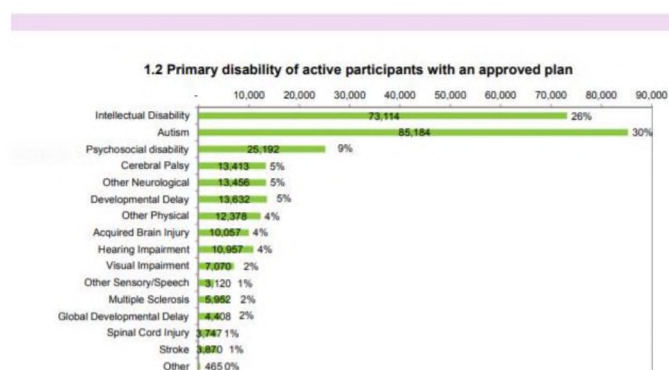
<sup>39</sup> <https://www.mentalhealthcommission.gov.au/Monitoring-and-Reporting/national-reports>.





- 63 The Commonwealth Government tasked the NMHC with conducting a national review of mental health programs and services. The focus of the review was on assessing the efficiency and effectiveness of programs and services in supporting individuals experiencing mental ill-health and their families and other support people to lead a contributing life and to engage productively in the community.
- 64 The National Disability Industry Agency (NDIA) provides quarterly reports to the COAG Disability Reform Council with information (including statistics) about participants in each jurisdiction and the funding or provision of supports by the NDIA in each jurisdiction. The report showed that there were 65,000 people who had been identified as being eligible to receive a National Disability Insurance Scheme (NDIS) package in 2015, but only 22,199 had been accepted by the NDIS in 2019.

30 June 2019



- 65 The COAG Disability Reform Council provide Quarterly Reports with information (including statistics) about participants in each jurisdiction and the funding or provision of supports by the NDIA in each jurisdiction. The NDIA provides these reports to COAG following the end of each quarter by 31 January, 30 April, 31 July and 31 October.

- 66 Note: there have been some minor amendments to the versions of these reports provided to the COAG Disability reform Council to de-identify personal data within small population figures. Previous Quarterly Reports can be found on the archive page.<sup>40</sup>
- 67 My view is that there needs to be at least one agency in each state that can advocate for the large number of people with complex needs that are not having their NDIS packages approved. This could be funded under the *Disability Services Act* - see Division 3—Grants for advocacy services of that Act.<sup>41</sup>

***Approaches that mental health services should take to facilitate access to other services to live a contributing life***

- 68 In 2002, in a different context, I was asked to consider, broadly, what approaches mental health services should take to facilitate access to other services such as housing, employment or education supports to live a contributing life, by Professor Beverley Raphael, an academic, psychiatrist, general practitioner and leader in the mental health field.
- 69 What I said at the time is that my concern is that mental health services are trying to do everything for everybody. I think it would be much better if mental health services worked with others who provided other services. As an example, if we had somebody that needed accommodation, it's not about the mental health services having carriage over housing. It would be good to set up a system where they do not have the mental health services providing those services, but instead we had a housing provider involved in providing housing, we had disability support provided by another provider, and we had the consumer actively involved in each of the conversations.
- 70 There are some examples that demonstrate this type of approach. I've set out some of these below.

**HASI – NSW**

- 71 In NSW, there is HASI<sup>42</sup> – the Housing and Accommodation Support Initiative. HASI aims to provide adults with a mental health diagnosis with access to stable housing, clinical mental health services and accommodation support. It was initially funded for \$15m to support 100 people in 2002 and 2003. To get one of those 100 support packages at the time, a person needed to have been in hospital for 187 days in the previous 12 months – that was one of the criteria.

<sup>40</sup> <https://www.ndis.gov.au/about-us/publications/quarterly-reports/archived-quarterly-reports-2018-19>.

<sup>41</sup> <https://www.legislation.gov.au/Details/C2018C00146>.

<sup>42</sup> <https://www.health.nsw.gov.au/mentalhealth/Pages/services-hasi-clis.aspx>.

## Neami National

- 72 Neami National is based in Victoria and provides community-based mental health, homelessness and suicide prevention services, including short to medium-term residential support and a targeted approach to support long-term housing. In 2003 Neami National was awarded a large part of the original HASI package (42 of 100 packages) referred to above, which allowed Neami National to show that the model they had created in Victoria could be used in other states and territories.

## Let's Get to Work

- 73 Let's Get to Work<sup>43</sup> is an employment strategy based on a program developed in Queensland. It was developed by the Mental Health Council of Australia following almost 12 months of background research, consultation, and extensive drafting and revision, and provides a way to address one of the most important productivity and health issues in Australia. It outlines the actions that need to be taken and provides a detailed background and rationale to these recommended actions.
- 74 Let's Get to Work is about moving beyond rhetoric to action. Work is one of the most important defining aspects of who we are – it provides a sense of meaning, value and belonging. The therapeutic value of work cannot be overstated. There are many people with mental illness whose participation in work has been limited by policy settings, a lack of support resources, and a lack of information and awareness. This limited participation is not only impacting negatively on Australia's productivity, but also on the wellbeing of individuals, families and communities. It is evident that Australia lags well behind other countries in addressing the employment of people who experience mental health issues.
- 75 This is despite many sets of words proclaiming a commitment to improving the rate of employment amongst people with a mental illness. If we are serious about increasing the employment of people with a mental illness, in my view we have to do more than write new policy statements. We need a strategy that details specific activities and sets real benchmarks. We need a strategy that is about real action and real change.

## Examples in the United States

- 76 There are also overseas examples. In 2010 I visited Kansas to see what they were doing with the 'Strengths Model' which I've referred to on page 9. During my many visits to Kansas I found a lot of evidence to support the consumer-run organisations they had there. This included:

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<sup>43</sup>[https://mhaustralia.org/sites/default/files/imported/component/rsfiles/publications/Let's\\_Get\\_To\\_Work\\_Employment\\_Strategy.pdf](https://mhaustralia.org/sites/default/files/imported/component/rsfiles/publications/Let's_Get_To_Work_Employment_Strategy.pdf).



- (a) The Substance Abuse and Mental Health Services Administration (**SAMHSA**).<sup>44</sup> This is an agency within the US Department of Health and Human Services which has oversight for both substance abuse and mental health services across the 50 states and territories in the United States. Its aim is to make substance use and mental disorder information, services and research more accessible.<sup>45</sup>
- (b) In Georgia in the United States, there are respite centres which are operated by people with lived experience. The Georgia Mental Health Consumer Network<sup>46</sup> (**GMHCN**) employs about 92 full-time equivalent people to provide a variety of services, which includes running five houses across the state of Georgia with 15 respite beds. There are no clinical people involved – it's totally run by consumers. I was fortunate to have visited the network in 2018 and spent time in each of the respite centres for a period of two weeks observing how they are operated. I believe the service provided by GMHCN is the missing link in our own mental health services. Information about the background<sup>47</sup> on how this service is supported<sup>48</sup> and funded<sup>49</sup> can be found in the files included as footnotes.

## Lived experience workforce

### *The meaning of lived experience*

- 77 The term 'lived experience' is now widely used in Australia to explain the dual role of both consumer and carers in the system. The term lived experience has been co-opted by governments, non-government organisations and service providers - originally the term was 'Consumer Perspective and Carer Perspective'.
- 78 On page 256 of *The Kit: The advocacy we choose to do*<sup>50</sup> the following definitions are used for these terms:
  - (a) **carer perspective:** a way of seeing the world through the eyes of someone who has experienced the role of 'caring about' a person who lives with mental illness/distress. Includes a recognition of the emotional strain and despair of seeking appropriate services and support for oneself and for a loved one. Also includes a feeling of solidarity with others in the same or similar situations, and a determination to bring about improvements; and

<sup>44</sup> <https://www.samhsa.gov/find-help/recovery>.

<sup>45</sup> This is an example of one of their resources: <https://www.samhsa.gov/brss-tacs/recovery-support-tools/peers>.

<sup>46</sup> <https://www.gmhcn.org/>.

<sup>47</sup> <https://www.gmhcn.org/behavioral-health-planning-advisory>.

<sup>48</sup> [https://www.dca.ga.gov/sites/default/files/dbhdd\\_office\\_of\\_adult\\_mental\\_health\\_and\\_doj\\_settlement\\_dr\\_timberlake.pdf](https://www.dca.ga.gov/sites/default/files/dbhdd_office_of_adult_mental_health_and_doj_settlement_dr_timberlake.pdf).

<sup>49</sup> <https://www.samhsa.gov/grants-awards-by-state/ga/discretionary/all/details?page=1>.

<sup>50</sup> <https://auspwn.files.wordpress.com/2014/05/austgov2009aquitetotheadvocacywechoosetodothekit.pdf>.

- (b) **consumer perspective:** a way of seeing the world in the light of experience/s of mental/emotional distress. Includes experiences of seeking support (of various kinds), of stigma in the community and within services. Also incorporates a sense of solidarity with others who have had similar experiences.

***Why peer work and the peer workforce are important***

- 79 I started my work as a lived experience worker in around 1994, about two years after I received a diagnosis of bipolar affected disorder. I was living in the Hunter Health catchment area at the time, and I was invited to participate in some consumer consultations. Out of those consultations, a group called the Lake Macquarie Consumer Community Consultation Group (**CCC Group**) was formed. I lived in Lake Macquarie at the time and we used to have regular meetings as part of the group.
- 80 At the time, one of the conditions of receiving a service in one of the services group homes was that I had to do something as part of my activity, so I chose to go to the CCC Group meetings. I then decided to do ten pin bowling. I ended up getting coached and my average improved from 120 to 185 per game - I was competing in an A grade competition.
- 81 This was while I was being assessed for the Disability Support Pension. It's amazing what these sorts of activities can do – I started to believe in myself. And I thought to myself, *'well if I can do that, if I can start to put that same effort into other areas, I might end up with a different result'*.
- 82 Two things happened out of the CCC Group. First, the National Mental Health Strategy was endorsed in 1992 as a framework to guide mental health which required services to involve consumers and carers in the way they were planning the services. I was fortunate that Hunter Health took the strategy seriously, and as a result they sent four of us who were taking part in the CCC Group to the TheHMS conference in 1996. After seeing over 300 consumers from across Australia I believed that opportunities were going to unfold for consumers and carers to get involved in mental health reform, particularly because of the National Mental Health Strategy.
- 83 In 1997, I got a four-hour per week paid position at Macquarie Hospital on a pilot project. I also applied for another position with what was then called the Richmond Fellowship (now called Flourish) and ended up with an eight-hour a week position. That meant me moving from Newcastle, and leaving public housing, but I saw it as a real opportunity. I still have the letter that I tabled at the Hunter Central Community Consultative Committee to allay people's fears that I had not gone high, and I was starting out on an adventure that I don't regret. I now have numerous awards to demonstrate my achievements since 1996.

- 84 As a result of my work, I started to network with various people and a group of us came together and created what was called the New South Wales Consumer Worker Forum.<sup>51</sup> We had a committee that used to meet regularly on the first Monday of the month, and we would host a forum once a year. Now it's become a regular annual event, held over two days<sup>52</sup> and we have around 180 or so people attend the forum each year. I use that as one example of how being involved can lead to a person feeling better; to giving them a sense of doing something that has meaning and can help to improve the way things work.
- 85 People with lived experience of mental distress hold expertise<sup>53</sup> that is incredibly valuable. Employing people with lived experience in peer worker roles to support others brings a tremendous range of benefits. Peer workers know what it is like to experience mental illness and can share experiences of personal recovery with consumers. People who are living well with mental illness represent hope that is often missing in people's lives.
- 86 Peer work can improve a service or organisation's culture and enhance its recovery focus. Working with peer workers helps other mental health staff understand that the people they care for can and do recover; improving empathy and understanding towards the consumers and carers they support.
- 87 One of the key benefits of peer support is the greater perceived empathy and respect that peer supporters are seen to have for the individuals they support. Peer support also has benefits for peer support workers themselves, increasing levels of self-esteem, confidence and positive feelings that they are doing good.

### ***Supporting the participation of peer workers***

- 88 The thing that I have found most useful in my roles as a peer worker over my career in terms of supporting my work is to have a strong champion in the service that is willing to support the position and also believes that it was important and necessary as their own.
- 89 In addition, another thing that I have found really important in supporting my role as a peer worker is going into a role with a clear job description, and a commitment by the service to support me and my role. A peer worker should turn up to work, and have the same rights as all other staff.
- 90 I've also found it important to have a couple of key people in the organisation who I can talk to about anything I was concerned about. I worked for 12 years at St Vincent's Hospital across the Emergency Department and the Acute Unit, as well as in the community. One of my roles was to help change staff's attitude towards people with a

<sup>51</sup> <https://www.nswcag.org.au/consumer-workers-forum-project.html>.

<sup>52</sup> <http://being.org.au/category/consumer-worker-forum/>.

<sup>53</sup> <https://nswmentalhealthcommission.com.au/mental-health-and/the-peer-workforce>.



mental illness, such as when people were treated when coming into the Emergency Department. In this role, I would often come across people that were extremely distressed. I found that I needed someone I could go to and talk openly with about my concerns.

- 91 I think it is also important that there is an opportunity for lived experience workers to give feedback information about issues that are coming up with the work consumer workers are doing at a state and national level. In 1996 in NSW we held a forum called *From Consumer to Citizen*<sup>54</sup> about what consumers and carers thought would improve the mental health system in the next 20 years. We listed ten issues that would need to be addressed by 2016 to know that we had made progress. Unfortunately there has been no audit of the issues and NSW has lost an opportunity to see what progress they have made. As part of that forum I created an image to show how issues could be sent to both State and Commonwealth policy makers to understand how to involve consumers and carers into the system. In the report I was listed as an 'artist'.
- 92 By way of another example, the National Mental Health Consumer and Carer Forum<sup>55</sup> releases several statements<sup>56</sup> to feedback information from lived experience workers.
- 93 The World Health Organisation (**WHO**) produced a report in 1992 - the World Health Organisation Consumer Participation Manual<sup>57</sup> - that identified two reasons why consumers need to be involved and six issues that needed to be addressed to allow participation. They also included six solutions that show services what is required. Unfortunately, in 2020 there is no uniform implementation of the six issues. Where services have taken on board the suggestions, in my view, the lived experience workforce has flourished.
- 94 I understand that by developing the Peer Workforce Development Guidelines under the Fifth National Mental Health and Suicide Prevention Plan (**Fifth Plan**), the National Mental Health Commission<sup>58</sup> is leading the development of a peer workforce and expects to produce guidelines by 2021. This project will help support the peer workforce through providing formalised guidance for governments, employers and the peer workforce about support structures required to sustain and grow the workforce. Although local and regional peer workforce frameworks exist, the development of national guidelines will ensure consistency across Australia. National guidelines will also be a step towards professionalising the peer workforce.

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<sup>54</sup> <https://auspwn.files.wordpress.com/2014/05/from-consumer-to-citizen-v-1-original-230106.pdf>.

<sup>55</sup> <https://nmhccf.org.au/content/history>.

<sup>56</sup> <https://nmhccf.org.au/resources/publications>.

<sup>57</sup> <https://auspwn.files.wordpress.com/2014/05/1993-consumer-participation-manual.pdf>.

<sup>58</sup> <https://www.mentalhealthcommission.gov.au/mental-health-reform/mental-health-peer-work-development-and-promotion/peer-workforce-development-guidelines>.

### ***Supporting the expansion of the lived experience workforce***

- 95 As to what could be done to better support the expansion of the lived experience workforce, the answer is that more does need to be done, but the key issues are around where the money is going to come from, and who we are going to take it from. It's always helpful when governments put in the money, and they have at different times, but at times a lot of the funding goes to new ideas and is time limited. I think in part it is about how current managers of organisations manage their current budget – for example by allocating some staff positions to consumer participation.
- 96 In my view, VMIAC has a great track record in terms of accessing funding and advocating for consumer workers being embedded into the system. My comments come from having watched VMIAC since 1997 under the leadership of Isabella Collins and observed a variety of programs as follows:<sup>59</sup>
- (a) People with a consumer lived experience were first employed in Victorian Mental Health services in 1996. Four roles were created at Royal Melbourne Hospital following the completion of the Understanding and Involvement Project. (Epstein & Wadsworth, 1994).
  - (b) These roles, originally called Consumer Staff Collaboration Consultants were initiated in 1996 to lead quality improvement projects in each area mental health service. Within a short time, the funding for the positions became recurrent and the title shortened to Consumer Consultants.
  - (c) These roles were often isolated and evolved in unique ways that were dependent on: the management of the service, the consumers' needs within the service, and the individuals filling the roles.
- 97 Within a short time, the funding for the positions became recurrent and the title shortened to Consumer Consultants. These roles were often isolated and evolved in unique ways that were dependant on factors such as the management of the service, the consumers' needs within the service, and the individuals filling the roles.

### ***Strategies to retain lived experience workers***

- 98 I'm aware that there are some retention issues in relation to the lived experience workforce – the 1992 WHO report referred to on page 20 addressed this as one of the barriers to a lived experience workforce working effectively. In my experience, there are a few issues that can give rise to a retention issue:

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<sup>59</sup> <https://www.vmiac.org.au/info/consumer-workforce/>.

- 99 In the early days when lived experience workers were employed, the only thing they needed to demonstrate is that they have some sort of connection with mental health services, but there was not always a consideration of the skills that people need to do these jobs. Someone might be expected to work eight to ten hours a week and expected to implement this miraculous cultural change. The literature used the term Agent of Change.<sup>60</sup>
- 100 If people didn't have a lot of previous work experience they may not understand some of the boundaries involved in being able to work effectively, or some of the strategies they need to put in place to avoid what is called 'burn out' in mental health services.
- 101 Another issue is the sharing of personal information with other consumers. I've experienced some people in the past ending up in relationships with consumers, and that's a big no-no, but unfortunately when you're sharing part of yourself, people get to know you and it can be a risk.
- 102 The other issue that I would like to raise is that in my opinion the lived experience workforce has weakened the consumer perspective and you now have people who have limited experience being involved in developing policies and procedures that allow people to become involved with limited experience in the system.
- 103 Some of the ways these issues have been handled are better than others but often it's the case of:
- (a) ensuring proper induction. Sometimes there is not enough proper orientation when a person comes on board, and there needs to be;
  - (b) ensuring the worker has someone they report to on a regular basis;
  - (c) providing access to the worker to an employee assistance program (EAP), and ensuring they are aware of its existence; and
  - (d) putting the worker in touch with other consumer workers and making it part of their paid work to network with them. That's one of the reasons why we started the NSW Consumer Worker Forum – so that people are not isolated, and so that you can build your knowledge on other issues. I'm an expert on bipolar affected disorder and I've witnessed a lot of stuff, but I've never been in hospital so I need to learn about that.

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<sup>60</sup> <http://www.ourconsumerplace.com.au/consumer/helpsheet?id=3440>.



***What staff could do differently to help consumers feel more confident and supported in their recovery***

- 104 In 1992 I was in Bateman's Bay and I went along to my general practitioner (GP), and he referred me to the mental health team in that area. What I didn't know at the time was that the Mental Health team had started a program called SAFE – Southern Area First Episode. What that meant was anybody who fronted up for the first time was given additional support, and that meant more time with the case manager. I had been trying to find out what had been wrong with me since 1965. And here I was, some 27 years later, finding someone that I connected with – my case manager – with whom I am still have contact today.
- 105 It may well be that I could have gone to another service where I may have been put in hospital or locked behind a door and not been able to leave, and my experience would have been different. Fortunately Bateman's Bay did not have any inpatient beds and they kept me at home for two months and I had a lot of contact with the team. And that's one of the things that I think is missing today – it's hard to get access to services. And so, a lot of what I do today is trying to replicate what happened to me in 1992.
- 106 I was lucky enough at the time to go to Black Dog Institute and be properly assessed, which is another thing that I think does not happen on a regular basis today. They suggested that I try a particular medication. By that stage I had built trust in my case manager, Graeme, and I thought, '*what have I got to lose*'? I said I was happy to give it a try.
- 107 For me Lithium worked after eight days and my mind was able to be stilled. I continued to take medication until 1999. I was lucky enough to have a manager at Richmond Fellowship that worked with me and my support team to achieve withdrawal from all medication over a couple of years. One of the things that assisted this process was in developing an Advance Agreement that I continue to review on a regular basis and use today to guide my ongoing recovery.

**Lived experience in governance**

***Successful examples or best practice where people with lived experience are represented in governance structures and decision-making***

- 108 I have had extensive experience in both NSW and at a national level with providing input into governance including NSW Health, NEAMI National, Black Dog Institute, Beyond Blue, Richmond Fellowship of NSW, Hearing Voices Network, Australia Mental Health Consumer Network, SUPER CRO and other organisations.

- 109 My understanding of governance structures comes from studying Edward Deming,<sup>61</sup> an eminent scholar and teacher in American academia for more than half a century. He published hundreds of original papers, articles and books covering a wide range of interrelated subjects - from statistical variance, to systems and systems thinking, to human psychology. He was a consultant to business leaders, major corporations, and governments around the world. His efforts lead to the transformation of management that has profoundly impacted manufacturing and service organisations around the world, and he is considered by many to be the master of continual improvement of quality, as well as their overall operation.
- 110 In my view, what VMIAC has done with embedding consumer participation across Victoria is one of the better examples of co-design. VMIAC was able to organise funding to employ consumer consultants in each of the health districts very early on in the National Mental Health Strategy.
- 111 Another example I witnessed in Georgia (referred to in paragraph 76(b) above), in my view is an example where they have been able to identify unmet needs and place peer workers into the system. In my view there appears to be a lot more collaboration between the consumer network and other services.
- 112 I will also give a couple of examples from NSW Health. In 1997 I was invited to participate in a committee by Professor Raphael that involved working with around 25 people from a variety of the different stakeholder groups in mental health. From this initial committee, NSW Health created the NSW Mental Health Implementation Committee in 2001.
- 113 The Consumer Sub-Committee of the Mental Health Program Council was established in 2009 to ensure consumer participation in mental health at a state-wide level. It is jointly chaired by the Chief Executive Officer of Being and the Executive Director, Mental Health Branch. The sub-committee provides advice to the Mental Health Program Council and the NSW Ministry of Health on policy, planning and strategic issues related to mental health consumers in NSW.
- 114 In addition, the Mental Health and Wellbeing Consumer Advisory Group<sup>62</sup> is funded by the NSW Ministry of Health. The membership comprises:
- (a) a consumer worker from a rural or remote local health district;
  - (b) a consumer worker from a metropolitan local health district;
  - (c) a consumer representing forensic mental health;
  - (d) two consumers representing young people;

<sup>61</sup> <https://deming.org/deming/deming-the-man>.

<sup>62</sup> <http://being.org.au/>.

- (e) a consumer representing people from culturally or linguistically diverse (CALD) backgrounds;
- (f) two consumers representing Aboriginal and Torres Strait Islander peoples;
- (g) a consumer representing the NGO sector;
- (h) a consumer representative who is not employed in a consumer position;
- (i) a consumer representing people in the gay, lesbian, bisexual, transgender, intersex and queer (LGBTIQ) community;
- (j) a consumer representing older people; and
- (k) a consumer representing people with an intellectual disability.

### **The Mental Health Act**

115 I have reviewed Victoria's *Mental Health Act 2014* (Vic) and in my view that Act is more advanced with providing a recovery-oriented approach than others. The language reflects what consumers have been asking for with a patient centred approach. In my view, NSW still has a very medical approach.

### ***Mechanisms or structures to ensure people with lived experience have a meaningful and enduring voice in decision-making at all levels***

116 In my view there are several mechanisms or structures that could be implemented to ensure that people with lived experience have a meaningful and enduring voice in decision-making at all levels of system design and service delivery.

117 First, in my view, as we become more recovery-focussed, the work ought to be recognised in legislation like the *Mental Health Act*. Peer workers will then have the status as some other people that are mentioned in the Act, such as authorised officer (means an authorised officer appointed under section 146; authorised person means— (a) a police officer; or (b) an ambulance paramedic; or (c) a registered medical practitioner employed or engaged by a designated mental health service; or (d) a mental health practitioner; or (e) a member of a class of prescribed persons).

118 Secondly, in my view the government needs to put in dedicated funding to run consumer-run organisations.<sup>63</sup> As an example, there should be a branch in each of the local health districts where there is a peer worker and support services so that people can meet face-to-face with peer workers.

119 Thirdly, there remains a need to address stigma – some call it discrimination – but there are a lot of internal issues that people have to address in their own journey. In New

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<sup>63</sup> See for example [https://auspwn.files.wordpress.com/2014/05/drop\\_in\\_program\\_manual.pdf](https://auspwn.files.wordpress.com/2014/05/drop_in_program_manual.pdf).



Zealand, the Let's Get Real<sup>64</sup> program is an example of how a program can work to reduce stigma.

- 120 Finally, I think it is important to recognise the contribution of peer workers. I was fortunate in 2018 to receive an Order of Australia medal in relation to raising awareness with respect to mental health, and in 2014 I was given an exceptional contribution award at the TheMHS Conference. These initiatives all recognise the work of peer workers.
- 121 As to common approaches to engaging and embedding the voice of people with lived experience in the planning, design and delivery of services, most states have participation frameworks.<sup>65</sup> My suggestion would be for consumers to become more aware of how they can become involved in developing these frameworks.
- 122 As to what could be done to facilitate more service provider organisations that are governed and delivered by people with lived experience, my opinion we could learn from services like NEAMI National<sup>66</sup> about how they have engaged consumers over many years. Another way would be to do an audit of all organisations to see how they are meeting the *Disability Services Act* and have it publicly reported.
- 123 I have found the quarterly NDIS reports<sup>67</sup> a useful tool to understand what is being reported on. I believe that there needs to be more information about how the 64 organisation who are funded under the *Disability Services Act* are reporting on the numbers of people who are using the services and how many complaints are being specifically being addressed and how those concerns are being reported on.

sign here ► DG Holmes

print name Douglas Holmes OAM

date 04/05/2020

<sup>64</sup> <https://www.tepou.co.nz/uploads/files/resource-assets/Lets-Get-Real-Challenging-Stigma-and-Discrimination-Essential-Level-Learning-Module.pdf>.

<sup>65</sup> See for example <https://www.dhhs.vic.gov.au/sites/default/files/documents/201910/client-voice-framework-for-community-services.pdf>.

<sup>66</sup> <https://www.neaminational.org.au/about-us/our-approach/participation-and-co-design/>.

<sup>67</sup> <https://www.ndis.gov.au/about-us/publications/quarterly-reports>.



**Royal Commission into  
Victoria's Mental Health System**

## **ATTACHMENT DH-1**

This is the attachment marked 'DH-1' referred to in the witness statement of Douglas Holmes dated 04/05/2020.

Resume  
of  
Douglas Holmes OAM

October 2019



## **Personal Details**

### **Ongoing Aims and Overview**

I have a stimulating role participating with Mental Health consumers & carers that enables them to make informed choices about their own care, accommodation, & mental health care and allows me to use the skills I have gathered during my life and provides me a reasonable reward.

Following my diagnosis with Bipolar Affective Disorder in June 1992, my road to recovery allowed me to see the many needs of consumers & carers. My determination, good humour and belief in a better world has helped me grow, and at the same time allowed me to help a large number of consumers.

I am continuing to enjoy that experience in my later years.

## **Functional Summary**

- Experienced with organising projects for consumers, cares, NGO's and the community
- Represented consumers & carers at Local, Regional, State and National level
- Experienced on community based management committees
- Public relations and public speaking
- Experienced with funding submissions and budgets
- Computer experience
  - MSOffice suite of products, MYOB, Corel Draw, Adobe PageMaker,
  - Database construction and data entry
  - Desktop publishing experience
  - Web page design and maintenance
  - Import and export of graphics from a range of formats
  - Experience with Wide Area Networks & Local Area Networks
  - Individual tuition for all Windows based products

## **Education**

- Enrolled in Bachelor of Arts with a English and Creating Writing Major
- Comprehensive Systematic Review Training, Joanna Briggs Institute
- Company Directors Course – Australian Institute of Company Directors (2012)
- Statement of Attainment in Small Business Management (2002)
- Diploma in Training in Assessment Systems (2001)
- Assessment Workplace Place Training Certificate (Cat 2) (1999)
- Orientation for Consumer Consultants
  - Northern Sydney Area Health (1996)
  - Central Sydney Area Health (1997)
- Department of Transport Bus Driving Accreditation Course (1995)
- Job search training course (1994)
- Intermediate Certificate (1965)

## **Employment History**

### **General Manager and Founder MH-worX 2016 - Current**

### **Mental Health Consumer Participation Officer St Vincent's Hospital Inner City Health Program 2006 - 2017**

The position was a permanent position and the main duties include:

- Assist in the process of improving the quality of mental health service delivery.
- Assist in the development & expansion of consumer participation across St. Vincent's Inner-City Health Program (SVICHP) and develop partnerships with the Inner-City Community & the various working parties and committees.
- Provide input into decision making about health service planning & delivery, policy development and implementation, setting priorities, training and quality improvement related issues.
- In conjunction with the Quality Improvement Manager monitor and evaluate consumer participation within SVICHP and across the Inner City.
- Act as the main contact person for consumers sitting on working parties/committees within SVICHP in order to address their needs for effective participation.

The Consumer Participation Officer is required to work within the philosophy of the Sisters of Charity and the overall objectives of St Vincent's Hospital and have high-level communication skills, a thorough understanding of the NSW Mental Health system, and policy analysis.

### **NSW Consumer Advisory Group – Mental Health inc 2001 – 2006**

- The position was a permanent contract position. NSW CAG currently has recurrent funding. NSW CAG is the peak body for mental health consumers and carers in NSW. Main duties include representing mental health consumers and carers, liaising with government and non-government organisations, managing projects and staff, overseeing the dissemination of information and working with the Trustees. The coordinator is required to be experienced in all aspects of community management, have high-level communication skills, a thorough understanding of the NSW Mental Health system, and policy analysis.

### **Greater Murray Area Health Service - Consumer Advocate Coordinator 1999 – 2001**



- The position was full time with a role to provide networking support, advocacy and information to consumers and carers who live in the Greater Murray Area, to ensure the sustainable development of a network of Consumer Advisory Groups (CAG) across the Greater Murray Area Health Service, including one area-wide CAG and to achieve long term, promotion and co-ordination of consumer participation and consumer and carer initiatives within the Greater Murray Area

### **Richmond Fellowship of NSW**

1997 – 1999

- Maintenance Officer (30 hours per week from 1998)  
The position entailed the development and design of a database to record and track maintenance requests, with regular reporting to management committee & team leaders, as well as co-ordination of maintenance requests for 25 houses
- Consumer Advocate (8 hours per week)  
While the primary role was the organisation of resident activities, I expanded it to include a monthly residents committee meeting, a monthly residents committee newssheet and annual residents meeting. I also developed a resident's satisfaction survey.

### **New South Wales Association for Mental Health**

1996 – 1998

- Database manager  
Management of the Mental Health Information for Rural Remote Australia (MHIRRA) database and provision of general administrative assistance

### **Consumer Advocate (Various)**

1996 – 1999

- During this period, my involvement as a consumer advocate grew with work at Morisset Hospital (1996), Gladesville Macquarie Hospital (1997) and Institute of Psychiatry (1996 – 1999)

### **Transport depot manager**

1995 – 1996

- My part time role with Blueline Transport involved managing Newcastle depot with 25 trucks, drivers and sub-contractors at its peak.

### **Truck Driver**

1985 – 1992

- This was a full time position with Aztec Transport

## **National Involvement with Mental Health Consumer Representation**

### **Australian Mental Health Party**

**2018 – Current**

- National Membership Secretary

### **SUPER CRO**

**2010 – Current**

- Membership Project

### **NSW Hearing Voices Network NSW**

**2008 – 2017**

- Monthly Management Committee meeting

### **Mental Health Council of Australia Homelessness Working paper**

**2008 - 2010**

- Developed a work plan and
- A response to the Commonwealth Green paper on Homelessness

### **MAD Pride Australasia**

2001 – current

- One major event each year in NSW currently supporting South Sydney Youth Service to focus on youth based events

### **Bright Blue Voice – Beyond Blue**

2000 – 2007

- 2 yearly face to face forum Melbourne
- Bimonthly teleconference

### **TheMHS Secretariat**

1996 – 2017

- Monthly Management Committee meeting
- Sydney Consumer Day Committee (1997 - current)
- TheMHS Awards Committee Co-ordinator (1999 – current)

### **NEAMI - Director**

2007 – 2017

## **23 BI Knowledge Base**

**2006 – current**

The primary role is to organise the responses from the workshops, forums and surveys from people interested in the 23 Big Issues which started at the TheMHS 2000 Consumer Forum. A document entitled *The Most Important Issues Affecting People with a Mental Illness or Disorder* (known to most people as the 23 Big Issues) has more information about the issues with some proposed solutions. The document can be found at [www.themhs.org](http://www.themhs.org)

**What is the 23BI Knowledge Base?**

Raw information is sometimes called data. When it is analysed in the right way it becomes knowledge. So rather than creating a data base of responses, we are creating a Knowledge Base.

As we collect the survey responses, we will input them into a computer in a form that can be extracted in a number of ways providing trends and comparisons that are not available at present.



## **NSW Statewide Involvement with Mental Health Consumer Representation**

**NSW Health Mental Health Priority Taskforce - member  
2003 - 2008**

**NSW Health Official Visitors Selection panel  
2001 - 2010t**

**NSW Housing Accommodation Support Initiative steering Committee  
2001 - 2007**

**NSW Smoke Free Taskforce working group -member  
2007 - 2011**

- Held a statewide forum on 13 June a report was prepared for the taskforce August 2008 meeting, with a recommendation to develop a statewide survey to monitor progress with the progression of this Policy Directive
- On a local level working with NGO's to develop the 'Be Smoke Free project to support consumers with their plans to stop smoking

## **NSW Consumer Workers Forum – Past Chairperson**

- **Life Member**

**2006 – 2017**

The NSW Consumer Workers Forum was started in 1998. The Centre for Mental Health-NSW Health has provided funding for the Consumer Workers Forum Organising Committee to examine the function and role of Area Health Service Mental Health Consumer Workers '. The NSW Mental Health Consumer Workers ' Project will examine and report on areas such as job titles, position descriptions, and work conditions, codes of conduct roles and policies and procedures. The committee has undertaken to establish a statewide set of documentation around the role of Mental Health Consumer Workers ' with the results of the project.

## **Morisset Flames – Facilitator**

**2003 – 2014**

The FLAMES (Forensics Learning Achieving Monitoring Empowering Supporting) Group was developed with support when I was the Executive Officer of the NSW Consumer Advisory Group Mental Health Inc (NSW CAG). The group has continued to meets on the first Monday of the month at Morisset. FLAMES started on a trial basis in March 2003 with the following objectives:

- To develop an understanding of forensic mental health consumer needs;
- To provide an understanding of the issues for the forensic community;
- To introduce forensic consumers to the structure, funding and policy content of mental health service in NSW;

- To provide forensic consumers with a variety of tools to understand, change and improve the system.
- Member of the FLAMES group have participated the NSW Health Ministers yearly cricket match since 1999.
- Development of a DVD: an entry for the 2008 Hope Awards
- Hunter New England received a commendation in there lasted AHS accreditation with a recommendation that they have the program evaluated

## **Area Involvement with Mental Health Consumer Representation**

### **Beacon site demonstration**

This is a project that is being coordinated in 11 sites across Australia to try to eliminate seclusion and restraint from 3 sites.

### **Coat Workshop**

I developed the audit tool called CoAT (Consumer Audit Tool) while working in Greater Murray Area Service. The tool was developed using a participative action research methodology that allows consumers, carers and services providers to develop a common understanding of the National Standards for Mental Health Services. South East Sydney Illawarra area health service has been using the tool for the last three years to develop a consistent approach for consumer and carer participation.

### **Involvement within the Inner City with Mental Health Consumer Representation**

During my time in the Inner City as Consumer Participation Coordinator I have spend a portion of my time using a Community development focus. This involves identifying agencies willing to host an issues workshop that involves holding a public forum and invite locals to identify issues that want changed.

The Surry Hilly Public Tenants Association which covers the Northcott Department of Housing estate was one of the first to take up the offer and we have now been involved for 18 months, hold regular monthly meetings where groups of residents and staff from a variety of agencies meet to plan communities events like;

- 3 days in November
- Events during mental health week
- The Mental Health Recovery Network is planning the launch of a web site [www.cosnp.info](http://www.cosnp.info)
- The Team Marbles is in it's 7<sup>th</sup> year

During this time there has been a marked decrease from residents raising mental health issues at the quartly meeting organised by the local member & Sydney Lord mayor Clover Moore. Through this work I have now been invited to manage a similar process with residents of another Inner City Department

of Housing estate at Woolloomooloo, Redfern, Glebe Waterloo and Potts Points called The Cadre Project

Finally there has been a marked increase with the numbers of groups and individuals involved in the Consumer and Carer participation in the Inner City





**Royal Commission into**  
Victoria's Mental Health System



## **ATTACHMENT DH-2**

This is the attachment marked 'DH-2' referred to in the witness statement of Douglas Holmes dated 04/05/2020.



Mental Health Inc



# ANNUAL REPORT

2003-2004





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# Background

## Vision

Our vision is empowered mental health Consumers and Carers who experience their rights to respect, dignity and self-determination every day.

## Mission

The mission of NSW CAG is to:

- Provide independent representation and a strong, informed voice for the diversity of Consumers and Carers in NSW in all policy and service development, implementation and evaluation;
- Ensure empowerment of Consumers and Carers through education across all sectors of the community;
- Articulate and defend the rights of Consumers and Carers;
- Work in partnership with all stakeholders in mental health to achieve best practice in mental health care for all.

## Activities

The activities of NSW CAG are to:

- 1 Provide direct linkages with state and national mental health policy makers and advisory bodies;
- 2 Promote and validate the value of Consumers' and Carers' 'lived' experience, which must be recognised and utilised as the basis for mental health Consumer and Carer participation within mental health policy, service development, implementation and evaluation of mental health services in New South Wales;
- 3 Work in partnership with government and non-government agencies to promote Consumer and Carer participation representation and advocacy;
- 4 Respond to policy documents and strategies that affect Consumers and Carers;
- 5 Provide Consumer and Carer representatives to participate in relevant consultations, working parties and committees;
- 6 Facilitate communication with local Consumer Advisory Groups throughout the state;
- 7 Facilitate awareness of and ensure others recognise psychiatric disability in the wider disability context.





## Members

### JUNE–DECEMBER 2003

Anna Saminsky – Chair  
 Kerrie Dissegna – Deputy Chair  
 George Dibley – Treasurer  
 Mark McMahon – Secretary  
 Jodie Brown  
 Laraine Toms  
 Paula Hanlon  
 Christine Cole  
 Elizabeth Pemberton  
 Joan Wakeford  
 Suzanne Rix  
 Kylie White

### JANUARY–JUNE 2004

Anna Saminsky – Chair  
 Kerrie Dissegna – Deputy Chair  
 Gillian Holt – Treasurer  
 Jenny Mackellin – Secretary  
 Kylie White  
 Elizabeth Pemberton  
 Brenda Spencer  
 Jenny Coleman  
 Robert Cairns  
 Clare McCormack  
 Karen Wells

## Secretariat

Douglas Holmes (Executive Officer)  
 Yvette Cotton (Communications Officer)  
 Maureen O’Keeffe (Information Officer)  
 Gillian Malins (MH-CoPES Project Officer)





## Chairperson's report

Welcome to our 2004 Annual Report. This year has been a challenging one for NSW CAG. We celebrated our 10th birthday as an incorporated association by launching the MH-CoPES Project at the Mary McKillop Centre in North Sydney. I am pleased to announce that we have been granted three year recurrent funding which will enable us to carry out our business and strategic plan more professionally.

Our website is fully operational. It is full of interesting details and I urge you to delve into it to keep abreast of NSW CAG's activities and the organisation generally. I represent NSW CAG on the following committees: National Consumer and Carer Forum (NCCF), National Health Priority Action Council (NHPAC), Mental Health Implementation Taskforce, Official Visitors Advisory Committee, Joint Guarantee of Service for People with Mental Health Problems and Disorders (JGOS) jointly with Paula Hanlon who will be writing about the project later in this document, and the Consumer Advocacy Course Committee. I shall be writing elsewhere in the Report about the NCCF and NHPAC, however will bring you some news about the other committees in this Report.

The Mental Health Implementation Advisory Taskforce was established to respond to the Legislative Council Select Inquiry into Mental Health in NSW. This committee is in its infancy but has all the potential to be of real benefit to consumers. I have found it to be far from tokenistic.

The Official Visitors Advisory Committee has virtually a whole new committee with full strength in numbers and is looking forward to an invigorated future with a new Principal Visiting Officer, Ms Jan Roberts. The Official Visitors system has gone into a joint venture with the Mental Health Association for their new call centre. Visiting Officers are now able, in certain circumstances, to visit hospitals without a doctor. This is a real breakthrough as some areas, particularly rural, were not being visited due to a shortage of doctors on the Official Visitors program. The Consumer Advocacy Course under the auspices of the NSW Institute of Psychiatry and coordinated by Sandy Watson should be mandatory for all consumers who are employed by Area Health Services. COPMI presented its findings from the surveys in which we participated by way of two booklets which are an aid to help families who experience mental health issues and are being widely distributed in GP surgeries and relevant childhood health centres.

NSW CAG has been busy with the review of the Mental Health Act by holding workshops for consumer and carer input and writing submissions.

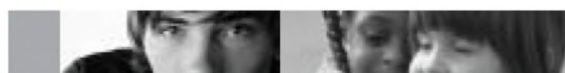
I attended the TheMHS Conference in September where I was pleased to accept an award on behalf of NSW CAG from Professor Alan Fels for our Youth Project 'Scream on the Green'. The conference was run in tandem with the Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFHA), which enabled attendees to swap between conferences making it a very interesting and informative week.

I would like to thank Professor Beverley Raphael and her assistant Ms Robyn Murray from the Centre for Mental Health for their undaunting support during the year.

Finally, I would like to thank Douglas Holmes without whom I would find my job very difficult and the other staff at NSW CAG: Yvette Cotton, Maureen O'Keeffe, Gillian Malins and my fellow members for their voluntary service.

I wish you a prosperous and happy 2005 and trust that you will continue to support NSW CAG and its role of advocacy for consumers and carers for a better mental health system.

Anna Saminsky







# Executive officer's report

The last twelve months at NSW CAG have been extremely busy and exciting. As 2004 draws to a close, it is interesting to reflect on the progress that NSW CAG has made since we started to develop a written strategic and business plan in 2001.

Not having a written plan for me would be like driving a car around at night on a busy road, without the headlights turned on hoping that you would not bump into things along the way.

Policy documents that needed to be formally responded to have distracted us from some of the things we would have liked to work on. These documents included:

- Legislative Council Select Committee of Inquiry 2002
- Government Response to Select Committee of Inquiry 2003
- Attorney General audit of Emergency Department
- Issues paper No 1 and 2 Mental Health Act

However, NSW CAG has made steady progress and some of the projects that have been advanced include:

- Confirmation of recurrent three year funding
- MH-CoPES project
- Network NSW
- The National Standards quilt being displayed 14 times during the last year
- Planning of a media workshop
- Involvement in HASI, JGOS and Mental Health Information Steering Committee and other committees

(These projects are covered in more detail later in the report)

We have received some good feedback about the National Standards quilt. For example:

"I just wanted to drop a quick note to you to thank you for arranging for the display of the Mental Health Standards quilt at our recent community day at Wests Leagues Club. There was quite a bit of interest in the quilt on the day with many people commenting on the workmanship and initiative. We have also recently received several positive comments through our feedback forms from seminar participants, indicating it was another interesting facet of the day. Again, my sincere thanks!" (Carleen Plowright, Management Secretary, Newcastle Mental Health Service).

## From the kit P217 The advocacy we choose to do

Groups and organisations are not unlike business in that, to be successful in the long term, they need to plan for it. The business plan is a map for the future of the group and can fulfil several functions to:

- Motivate and focus the group
- Ensure all members agree on the direction
- Enable all members to know the part they play
- Satisfy requirements of potential funding bodies







I believe that NSW CAG's three major tasks during the next twelve months will be to:

- Launch the recommendations from the MH-CoPES project at the Forging our Future 3 conference that will be held in Wollongong on the 9–10 December 2005.
- Seek agreement from the NSW Health Area Mental Health Directors for three areas to participate in the Our Standards, Our Rights project that will provide information about:
  - NSW CAG's role in Consumer and Carer participation
  - Highlight the NSW CAG quilt
  - Network NSW
  - MH-CoPES
  - Consumer Rights and Responsibilities
- Recruit new NSW CAG members to replace the members whose terms will finish in December 2005.

In partnership with Marrickville Council and Marrickville Youth Council, NSW CAG won a Silver Award in the TheMHS 2004 Achievement Awards section for Health Promotion. The award was in recognition of working together for Youth Week 2003 to stage a live music festival "Scream on the Green", to engage young people, disseminate information about mental health issues and raise community awareness.

I need to thank the staff Yvette Cotton, Maureen O'Keeffe and Gillian Malins for their continued support during the last 12 months. I would also like to thank Anna Saminsky and all the NSW CAG members for their contributions behind the scenes. I would also like to thank all the staff from the Centre for Mental Health for their guidance and support during the last 12 months.

Finally, I would like to thank a number of the consultants who have contributed to NSW CAG becoming a stronger organisation. These include: Tracy Jordan of Citywide Business Services, Bruce Lawrence of O'Neill and O'Brien; and Peter Gates from the Mercury Centre.

It would also be unrealistic to think that all the problems for Consumers and Carers have been solved in NSW. However NSW CAG is now in a position to solicit feedback from a wide cross section of Consumers and Carers in NSW.



Douglas Holmes







# National committee representation

## Communications Network

The Communications Network is a national network of people who work in communications positions in mental health organisations across Australia. The aims and objectives of the communications network include: supporting communications personal; information dissemination; and lobbying. So far I have participated in one of the two teleconferences that have been held. Member contact details have been circulated and a mechanism for sharing up-coming events has been established.

Members include representatives from: SANE Australia; OT Australia; Carers Australia; AICAFMHA; Australian Counselling Association; General Practice Mental Health Standards Collaboration; The Queensland Alliance of Mental Illness and Psychiatric Disability Groups Inc; Beyond Blue; ORYGEN Youth Health, ORYGEN Research Centre; and MHCA.

Yvette Cotton

## Clinical Practice Improvement Network For Early Psychosis (C-PIN EP)

"The National Health and Medical Research Council (NHMRC) has recently funded a project to develop methodologically sound strategies for routinely evaluating the care and treatment of early psychosis. The project is called the NHMRC Clinical Practice Improvement Network ('C-PIN' or the 'Network' for short). The aim of C-PIN is to evaluate the effectiveness of early psychosis services and interventions and to determine whether adherence to the clinical practice guidelines improves consumer outcomes.

"The C-PIN project is led by a group of independent psychiatric researchers and health service managers. Consultative input from a broad range of mental health clinicians around Australia has been obtained in designing evaluation procedures. The procedures will use clinical information systems already in routine use. The evaluation will be based on the Commonwealth Consumer Outcomes standardised measures and clinical information recording systems, such as the New South Wales Mental Health Outcome Assessment Tools (MH-OAT). Importantly, early psychosis indicators selected for their clinical utility by early psychosis clinicians in New South Wales will be adopted by C-PIN and welded into a robust scientific framework. These developments create for the first time in Australia, an opportunity for clinicians and service managers to routinely evaluate the effectiveness of their clinical practice and service functions in relation to early psychosis.

"As the evaluation progresses clinical records will be copied and, after identifying information of patients and staff has been removed, forwarded to the project for coding. Aggregated coded information will then be used to determine relationships between service functions, clinical practice, and consumer outcomes. Six months after the prospective evaluation begins, patient and carer feedback about treatment experience will be collected using the Consumer Feedback Interview. This interview provides an opportunity to obtain important information from the perspective of the consumer and carer and, to allow an independent check on the service ratings of the Commonwealth Consumer Outcome standardised measures.

"C-PIN will aim to better describe appropriate service models for early psychosis in remote and indigenous communities. This will be achieved by qualitatively reviewing services that have a special interest in these communities in relation to early psychosis.

"The ultimate aim of the evaluation is to provide the service and clinician with feedback about what seems to







be the most effective and efficient aspects of what they are doing. This information will be used to evaluate the clinical practice guidelines, potentially for use in their revision.

"The project has involved consumer and carer representation at all stages of its development." (from the C-PIN brochure by Professor Stanley Catts, University of Queensland).

Judy Hardy (SA), Laraine Toms (NSW), Fay Jackson (NSW), and Douglas Holmes (NSW) were invited to represent consumers' and carers' views on the project.

Douglas Holmes

### **National Consumer and Carer Forum (NCCF)**

At its March meeting this year, the Australian Health Ministers' Advisory Council National Mental Health Working Group agreed to provide additional funding to the NCCF to undertake two projects. The first was the Implementation of the National Consumer and Carer Participation Policy. An external consultant, Dr Leanne Craze of Craze Lateral Solutions, has been engaged to undertake the project. It is now well under way.

The second project is the development of a new consumer and carer participation model based on the NCCF. This has been undertaken with a view to improving the operation of the NCCF. Dr Craze is also conducting this research process. Both projects are due for completion by the end of the year.

At the October meeting, in Melbourne, topics discussed were better outcomes in mental health care initiatives, co-morbidity and substance abuse, training schedules by RANZCP, consumer operated mental health services, quality of mental health services, discrimination in the workplace and in education, primary health care work between GPs and psychiatrists and mental health reform in states/territories. As you can see a one-day NCCF meeting covers a tremendous amount of territory and is money well spent on furthering better outcomes for consumers and carers across Australia.

Anna Saminsky

### **National Health Priority Action Council (NHPAC)**

The NHPAC convened a stakeholder workshop in June to discuss the development of the National Chronic Disease Strategy. The NHPAC's role is to identify, advocate and facilitate action across the continuum of care in the NHPACs (including prevention, detection, management, rehabilitation and palliation) and to drive improvements in health services to achieve better outcomes in these NHPACs, including for disadvantaged groups.

The key elements of the strategy to achieve this end are: self management in its broadest definition; empowering and supporting communities and moving service provision closer to where it is needed; funding models to support system change and flexibility in application; attitudinal change amongst health service providers; realigning the health system to a primary/prevention focus; and strengthening linkages with the acute sector. The final strategy is expected to be provided to the Minister within 12 months.

Anna Saminsky





### **Network of Australian Community Advisory Groups (NOAC)**

Anna Saminsky is the NSW representative on NOAC, which consists of representatives from several states of Australia.

NOAC is a member of the Mental Health Council of Australia but currently the re-accreditation process for MHCA member organisations has been put on hold until the MHCA has been able to restructure. This will be in one or two years time.

NOAC will retain its seat on the MHCA board in the Carer category as it was elected to this position last year (Board members are elected for two-year periods). However, this means NOAC is not eligible to stand in the Consumer category on the MHCA board as an organisation cannot hold a seat in two categories if there are other organisations eligible in the second category. Therefore, NOAC cannot hold a position in both the Consumer and Carer categories, as there are now enough organisations to fill all positions in those categories. Previously, NOAC could hold a position in both categories because there were spare seats. (Information from Steve Morris, MHCA Sept 2004).

Anna Saminsky







# State working groups

## **Centre for Mental Health: MHOAT consumer consultative committee**

The NSW MHOAT Consumer Consultative Committee (CCC) celebrated its 3rd Anniversary on Tuesday 11th May 2004. The MHOAT CCC comprises of two representatives from each Area Health Service in NSW, though not all are currently represented. The purpose of the group in the early days was to provide consumer consultation on the development and implementation of MHOAT across NSW.

The group has support from the Centre for Mental Health who provide the venue and catering for each meeting. Professor Beverley Raphael attends each meeting to consult with the representatives on a broad range of issues, with the group developing into a consultative resource, broader than MHOAT.

Since the group's inception it has been responsible for developing a number of projects including the MH-CoPES and the Consumer Recovery Training Package. The logo of the MHOAT CCC is the 'Recovery Bus', designed in the colours of the National Standards for Mental Health Services and promotes the concept of consumers' participation and rights in planning and monitoring their own recovery and relapse prevention plans.

Douglas Holmes

## **Centre for Rural and Remote Mental Health-Community Advisory Committee**

Douglas Holmes and Joan Wakeford are on this committee.

### **Role of the Committee**

The Committee will provide advice to the Director on all matters relating to the mission, goals and objectives of the Centre for Rural and Remote Mental Health. In order to fulfil its role in enhancing the future of the Centre, the Community Advisory Committee may be asked for specific advice on any of the following:

- academic programmes and educational initiatives relevant to the Centre's profile;
  - cooperative research and consultancy opportunities directly relevant to health professionals, community organisations and industry;
  - improvement in the quality of education and research provided by the Centre;
  - methods of seeking donations, sponsorship and bequests to augment the Centre activities; and the enhancement of the Centre's corporate image within the rural communities."
- (from [www.crrmh.com.au/pages/about/committees.cfm](http://www.crrmh.com.au/pages/about/committees.cfm))

## **Housing and Accommodation Support Initiative (HASI)**

In late 2002 NSW CAG was asked to participate in the HASI project. The NSW Government announced new funding for the Housing and Accommodation Support Initiatives (HASI). In summary, its aims are to:

- Provide high-level accommodation support for over 100 individuals with mental disorders;
- Reduce pressure on hospital beds;
- Provide additional supported housing for low income people with mental disorders;
- Maintain functional status and mental health of the population;
- Establish a more efficient and effective system to assist people with mental health problems and high levels of disability to participate fully in the community.

The Initiative is a partnership between NSW Health and Housing departments.







NSW Health will be providing clinical mental health services and funding non-government organisations to provide accommodation support services.

The NSW Department of Housing will purchase and lease properties with supported housing management for Initiative clients provided by non-government housing associations, or by Public Housing Client Service Teams.

This initiative will be linked with other new acute and non-acute inpatient initiatives of the Centre for Mental Health and will provide a substantial improvement to the availability of housing and accommodation support resources for people with mental disorders and psychiatric disabilities who require a high level of accommodation (disability) support to participate in community life. It also complements a number of other supported housing projects being undertaken by the Department of Housing to assist people with complex needs.

Douglas Holmes

### **Joint Guarantee of Service (JGOS) for people with Mental Health Problems and Disorders living in Aboriginal, Community and Public Housing**

#### **Review and Development Phase:**

The Working Group coordinating the review of the 1996 "Joint Guarantee of Service (JGOS) for people with Mental Health Problems and Disorders living in Aboriginal, Community and Public Housing" comprises the following agencies:

- NSW Consumer Advisory Group (CAG)
- NSW Health; Centre for Mental Health (CMH)
- NSW Department of Housing (DOH)
- NSW Department of Community Services (DOCS)
- NSW Aboriginal Housing Office (AHO)
- Aboriginal Health and Medical Research Council of NSW (AHMRC)

The second edition JGOS (2003) outlines the guiding principles of a partnership with the above agencies that coordinates the delivery of services to assist people living with mental health problems and disorders to:

- "better assist and enhance the well being of existing social housing tenants whose tenancy may otherwise be at risk; [and to]
- assist housing applicants who may be homeless or at risk of homelessness to successfully establish a tenancy." (JGOS 2003 p3)

The five service delivery agencies are signatories to the JGOS Memorandum of Understanding (MOU) effective from April 2003. The roles and responsibilities outlined in the JGOS provide the framework for the agencies at a local level to establish efficient partnerships to achieve cooperative planning.

The MOU acknowledges the importance of cooperative planning to identify, with the participation of the person living with the mental health problem/disorder, the best housing option and optimal supports required to achieve health and well being.

Some of the template forms from the first Joint Guarantee of Service (1996) have not been reproduced in the







second edition (2003). These forms will be developed with broad consultation and included in a "Resources and Training Package" that will be provided to all member agencies. The Joint Guarantee of Service (2003) identifies clear responsibilities around confidentiality and privacy in respect of the amended Privacy Act, and in the development and monitoring of the individual service plans.

The JGOS defines 'advocacy' and outlines the role of 'systemic (at local and area meetings) and individual advocacy.' The latter is provided when requested by the consumer, with the 'advocate' being a person of their choice. The JGOS identifies the role as including the:

- "provision of information on rights and responsibilities;
  - support through explanation and discussion of options and strategies; and
  - attendance with or on behalf of at a JGOS meeting (with a signed release of information form)."
- (JGOS p 17)

The JGOS, launched by NSW Governor Marie Bashir during Mental Health Week 2003, is a process of agency partnerships that promotes a respectful approach to the holistic care that is directed by the National Mental Health Policy (1991), the National Standards for Mental Health Services (1996) and the second and third National Mental Health Plans (1998 and 2003 respectively). The JGOS provides clear direction for local and area committees in establishing their memoranda of understanding. The challenge for all parties involved is to transfer the policy document, 'paper partnership', into an effective quality process whereby the implementation is efficiently promoted, trained, monitored and evaluated across NSW to ensure the realisation of the admirable objectives.

#### **Implementation and monitoring phase:**

The implementation and monitoring phase will be overseen by an "Implementation Reference Group." This group consists of 27 members from a range of government and non-government agencies from urban, region and rural NSW. There were three consumer representatives (two from NSW CAG) and one Aboriginal consumer representative selected by the Aboriginal organisations. The first meeting of this reference group was held on Wednesday 21st April 2004.

This phase involves:

- Promotional workshops across NSW;
- Reviewing relevant forms (e.g. consent forms);
- Overseeing the development of the "Resource and Training Package";
- Establishing evaluation and monitoring processes.

The reference group have an opportunity to provide a holistic service to consumers that respects the consumers' rights to have options and choice about the type of accommodation, advocacy and support when required. I believe the work of the reference group can set a benchmark for other policy documents in how to maintain a holistic approach, create a transfer from the written document to action in the community and prevent the document from becoming another book on a shelf that staff know nothing about.

The workshops were held across NSW to promote the reviewed JGOS in the second half of 2004. Participants were from all of the JGOS members including consumers. In addition, the day prior to each workshop a specific





consumer and carer half-day workshop was held to provide a detailed review of the document with particular emphasis on the representation and advocacy roles as identified in the JGOS.

NSW CAG would like to encourage any consumer workers or representatives who wish to discuss the JGOS implementation at their local and/or area levels to contact the JGOS representative through NSW CAG.

Paula Hanlon

NSW CAG Representative, NSW JGOS Implementation Reference Group, May 2004

### **Mood Discovery Support Group Planning Meeting**

This is a group organised by the Depression and Mood Disorders Association of NSW, a standing committee of the Mental Health Association NSW. The main aim of the group is to set up new support groups for people with bipolar disorder and/or depression and/or their friends and relatives. My main role in this group as a representative of NSW CAG is to help publicise the group in the NSW CAG INFO\_LINK to help find more people who may be willing to set up groups. This group has had one meeting so far.

Yvette Cotton

### **NSW Carers Coalition**

NSW CAG is a member of the NSW Carers Coalition.

#### **"Purpose**

The NSW Carers Coalition is a community umbrella group committed to supporting, recognising and valuing carers. It is our intention to work holistically through a family and friends centred approach.

#### **Role**

- Policy development, policy work and advocacy;
- Information exchange.

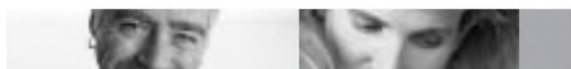
#### **Objectives**

- To provide opportunities for information exchange;
- To encourage good practice by disseminating information, joint training programs and collaborating on projects ;
- To provide broad advice to the local, state and federal governments and influence our own sectors and wider community;
- To influence policies and work for their implementation from a carers perspective;
- To develop position papers, distribute and seek engagement with government thereon.

#### **Membership**

- State, regional and local not-for-profit organisations who have a concern, interest or responsibility for carer support;
- Invite government representatives to participate as observers".

(from the Carers Coalition 2004 Terms of Reference)







### Main activities in July 2003–June 2004

- Production of an issues paper on “ageing carers of a younger person with a long-term disability”;
- Collecting comments on the paper, and developing the paper;
- Field testing questions on the paper;
- Planning a half day consultation on the paper on July 1 2004;
- Guest speakers on topics relevant to the coalition;
- Information exchange;
- Strategic planning.

Yvette Cotton

### NSW Carers Program Advisory Group

The NSW Carers Program Advisory Group is a committee that advises the Department of Health on carer issues. The NSW Carers Program was previously known as the ‘Care for Carers’ Program. The Program is concerned with addressing the needs of all carers, including those caring for people who are elderly or disabled, or who have illnesses, including mental illness. The Group includes members from NSW Health, the NSW Department of Ageing, Disability and Homecare and the Federal Department of Health and Ageing. It also includes members of some key state-wide advocacy groups, including Carers NSW, the Alzheimer’s Australia NSW and the Multicultural Disability Advocacy Association. I have been fortunate to represent mental health carers on this advisory group. A major task of the committee this year was advising on the NSW Carers Program local and state funding grants. These grants have enabled the funding of a broad range of projects across NSW to support carers.

Gillian Holt

### NSW Health Participation Council

Over the past year I have attended meetings of the NSW Health Participation Council (HPC), which at present, is the only state-level body of consumers and community members (I am not clear as to the distinction between these two groups, but it is noteworthy that the Council has included a number of medico people) whose role it is to advise the NSW Health Minister and the NSW Department of Health.

The term of the HPC was due to conclude in mid-2004 but it has been extended to the end of the year. Whether there will be another Health Participation Council, and what form it will take, is not yet clear. On the current HPC, there was one position allocated to NSW CAG.

With the change in the number of NSW Area Health Services, announced in about August, the chairperson of the HPC, Wendy McCarthy, AO, and the Rt Hon Ian Sinclair, AC, travelled the State to consult with the community on the newly proposed Clinical and Community Advisory Group (CCAG). This is the basis for the founding of the Health Care Advisory Council (HCAC)—being a combination of clinicians and community members (non-medico consumers)—which was recommended in a major report reviewing NSW Health prepared by the NSW Independent Pricing and Regulatory Tribunal (IPaRT Report) in 2003. The Terms of Reference of the HCAC state that the HCAC is to provide advice to the Minister and the Director-General of NSW Health on a range of health matters.







Similarly, there is to be a number of Health Priority Taskforces formed for each of the following areas:

- Acute care (elective surgery, emergency departments);
- Chronic, aged and community health care;
- Information management and technology;
- Mental health;
- Metropolitan clinical taskforce;
- Sustainable access.

The work of these taskforces is to provide “direction and leadership” in each area. For example, the “Purpose of Taskforce” for the Mental Health Taskforce is: “Provide direction and leadership for the development of integrated mental health service policy for NSW, which reflects best practice national and international standards”. The secretariat and policy development for this taskforce is to be done by the Centre for Mental Health. The Taskforce is to have on it medical people and consumers (carers?).

At the present time people are being nominated for the Health Care Advisory Council (HCAC) and the Health Priority Taskforces (HPTs). To date the work of the Health Participation Council has mostly focused on State public health care, especially hospital care, although the NSW State Government does also have responsibility for what happens in private hospitals (lest we forget Chelmsford). It is not clear to me at this time how the Department is deciding who is to be selected as members of these Taskforces, but in my opinion it would be important to have people on the Mental Health Taskforce who have had recent experience in one or more of the following ways: as

- being scheduled into the public hospital mental health system;
- being a non-scheduled patient in the public hospital mental health system;
- a mental health public community care system patient;
- a mental health patient in a private hospital;
- a mental health patient suffering from some form of addiction who has received treatment somewhere in the public/private system.

The formation of the Mental Health Taskforce will mean for the continued funding/existence of NSW HPC is yet to be seen.

Working on the Health Participation Council to date has been a somewhat frustrating exercise. Making this statement gives rise to many complicated issues. Should we have been consulted more on Departmental matters? How can we be expected to offer any advice of value when this usually entails substantial reading to gain sufficient knowledge on whatever topic before giving any advice. Yet we are not being paid to devote those hours and hours required to this work to enable us to do this (to keep bread on our own table). Is there scope for consumers to give insight – a resource not as yet being properly tapped by the Department? Who is a health consumer? Should the Department be satisfied with including medicos in that role as it is true that we are all consumers? Is the Department (a multitude of people) ready to hear ideas from non-medico consumers? It seems we are in early days with consumer involvement in NSW Health. South-West Sydney showed the HPC what vital work they are doing there in the face of the much publicised difficulties. As consumers we do have a valuable contribution to make and gradually that will be more and more utilised. But the fundamental changes involved take time.

Elizabeth Pemberton







### NSW Mental Health Implementation Taskforce

A NSW Mental Health Implementation Taskforce was formed in 2004 to monitor and oversee the implementation of the NSW Government Response to the Select Committee Inquiry into Mental Health Services. NSW CAG was invited to nominate a person to the Taskforce to represent the interests of mental health consumers. Anna Saminsky was nominated and attended her first meeting on 7 June 2004. The appointments to the taskforce were made for the period up to and including 31 January 2007.

"The NSW Mental Health Implementation Taskforce is a Ministerial Advisory Committee established under section 20(4) of the Health Administration Act. The Terms of Reference of the Taskforce are to:

- Monitor and oversee the implementation of NSW Government Response to the Select Committee Inquiry into Mental Health Services in NSW;
- Monitor and oversee the Government's response to recommendations of the NSW Mental Health Sentinel Events Review Committee;
- Identify and promote linkages across government and between government and non-government organisations involved in mental health care to advance mental health, as identified by the governments response to the inquiry and recommendations of the Sentinel Events Review Committee;
- Liaise with the Human Services CEOs Forum to ensure that cross-government mental health issues remain on the agenda of this Forum;
- Review any other issues with regard to mental health as directed by the Minister;
- Report directly to the Minister for Health through the Chairman of the Committee".

Anna Saminsky

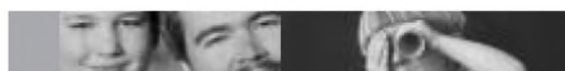
### NSW Mental Health Information Steering Committee

The NSW Mental Health Information Steering Committee replaced the MH-OAT Initiative Standing committee. MH-OAT is an important initiative that aims to improve the quality and effectiveness of mental health services in NSW. It is assisting Area Health Services to train all clinical mental health staff in mental health assessment, standard documentation and the implementation of routine collections of standard outcome measures. As of March 2004 all of the mental health clinical staff in Areas had been trained in assessment, outcomes and case-mix measurement. The next crucial stage was to mainstream this initiative in mental health services.

The proposed terms of reference for the committee were as follows:

Responsibility for overseeing:

- The implementation of:
  - ▮ standardised assessment documentation in NSW mental health services and overseeing and monitoring a quality framework of assessment and documentation;
  - ▮ standardised outcome measures in NSW mental health services;
  - ▮ evaluation of the extent/penetration and effectiveness of the initiative.
- the consultation process with consumers regarding the implementation of uniform assessment documentation, consumer and clinician rated outcome measures and the Mental Health Consumer Perception and Experience of Mental Health Services (MH-CoPES) project;





- the training of all Area Mental Health Services direct care mental health staff in mental health assessment;
- standardised assessment documentation and mental health outcome and case mix measurement;
- the development of strategies for the analysis and use of the outcomes and case mix data;
- the mainstreaming of MH-OAT activities into local quality and information development strategies.

A work plan is being developed.

Douglas Holmes

### **NSW Mental Health Promotion Advisory Committee**

I represent NSW CAG on the NSW Mental Health Promotion Advisory Committee. The activities of this committee are centred on the organisation of mental health week in NSW, as well as other activities such as exploring the feasibility of a state-wide mental health promotion campaign. The planning of mental health week includes advising on: the launch; the theme; the stress less tips; the images for posters etc.

The committee consists of representatives from the Mental Health Association, the board of the Mental Health Association, Consumer representatives, Lifeline, Mental Health Promotion workers from Western Sydney Area Health Service and New England Area Health Service, Mental Health Coordinating Council, Arafmi, Schizophrenia Fellowship NSW and NSW CAG. Expertise is also sought from other organisations. For example, this year the focus for mental health week is on people over 65 so organisations that cater for this age group have been asked to speak at meetings.

Yvette Cotton

### **NSW Mental Health Review Systems Committee**

In 1997 a committee was established to investigate review processes then operating in the NSW mental health system. The committee met on five occasions from March to October, 1997 and investigated a range of issues including:

- critical incident reporting;
- consumer access to making complaints and the management of complaints by mental health services;
- escalating violence in mental health settings;
- the respective roles of review agencies;
- the implementation of the National Standards for Mental Health Services.

After a break of four years, during which time a number of major policy and procedural initiatives were implemented at state and area level in response to the above mentioned issues, the committee reconvened. The committee included senior representatives from the following organisations:

- Official Visitors' Program
- NSW Consumer Advisory Group – Mental Health Inc.
- Mental Health Advocacy Service
- Health Care Complaints Commission
- Mental Health Review Tribunal







- Executive Support Unit, NSW Health
- Performance Support Unit, NSW Health
- Mental Health Coordinating Council
- The Australian Council on Health Standards
- Guardianship Board
- Area Mental Health Services
- Magistrates

The current activities of this working group are:

- Input into reviewing the Mental Health Act;
- Feedback on the 237 reviews of mental health acute units;
- Opportunity for all organisations to report back on mental health issues related to their agency.

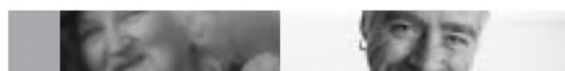
Douglas Holmes

### **Streetwize Bipolar Disorder Comic – Steering Group**

I represent NSW CAG on this group. We have had a few meetings so far discussing the aims and objectives of the comic, the target audience, and the type of message we want to get across to young people with bipolar disorder. We have had one meeting with representatives from Streetwize Comics and have discussed the process of producing the comic.

Other members on the steering group have included representatives from the Staff of the Mental Health Association, the board of the Mental Health Association and The Depression and Mood Disorders Association of NSW. New members soon to come on board are representatives from Beyond Blue, Reach Out, and The Black Dog Institute.

Yvette Cotton





# NSW CAG projects overview

## **Mental Health Consumer Perception And Experience Of Services (MH-CoPES)**

The MH-CoPES Project is a partnership between NSW CAG and the Centre for Mental Health, NSW Health. The aim of MH-CoPES is to identify or develop a measure and process to collect, collate, report and respond to consumers' views of mental health services. During 2003, the Technical Working Group for the project was established, with eight, three mental health professionals, an expert in evaluation and a representative from the Centre for Mental Health forming this group. In late January 2004 I commenced work with NSW CAG as the MH-CoPES Project Officer.

The working group members met twice in 2003 to establish ground rules and develop the Project Officer position, and since the whole team has been on-board, we have held two working group meetings; in March and June 2004.

Our main focus this year has included:

### **Establishing the scope and criteria for MH-CoPES**

For the Technical Working Group this has meant using the original project brief to answer the question: what is it that we are looking for? We have established a set of guidelines to work with in identifying or developing the tool and process although we expect this will be work we continue doing until the project finishes.

### **Conducting the background literature review**

We have reviewed literature relating to consumers' views of services and satisfaction surveys and identified tools and processes in use internationally to collect information about how consumers evaluate the mental health services they use.

### **Promoting the project by informing key-stakeholders about MH-CoPES**

I have presented information about MH-CoPES at several conferences, often collaborating with working group members. I have also presented at a range of stakeholder meetings including:

- MHOAT CCC meetings in February and May;
- The Mental Health Information Forum at the Centre for Mental Health, in April;
- Area Mental Health Directors Meeting in May;
- The Consumer Workers' Forum, at Cumberland Hospital in Sydney in June.

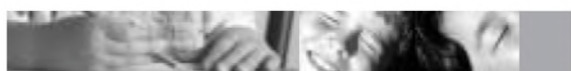
I have also presented at the NSW CAG Policy and Project Development Consultation Day in March.

- Surveying mental health services to find out what is already happening in NSW services to collect and respond to consumers' feedback;
- Planning the official Project Launch, scheduled for 29th July 2004; and
- Planning our consultation approach.

Consultation with consumers, staff and other stakeholders will occur later in 2004 and early 2005.

The first six months I have been involved with MH-CoPES have been challenging and rewarding, and I am sure the final 12-months of the project will be too, as we move closer to making our recommendations to NSW Health.

Gillian Malins







## NSW CAG Website

The NSW CAG website was designed for NSW CAG by Irene Vasilas, who was an HSC student from Riverside Girl's High School. It was launched at the NSW CAG AGM in Dec 2002. Since that time I have attended a course in Dreamweaver at WEA which has enabled me to make updates to the website and add extra pages. Irene has also helped us with some of the more complex changes.

Since the design of the website and its launch a number of changes and additions have been made. Often these changes have involved discussions with the NSW CAG members at meetings (eg. 29th March, 2004) and/or by e-mail. There was also discussion at a meeting before the NSW CAG 2003 AGM. The changes include:

- A change to the name at the top of every page from:  
"MENTAL HEALTH Inc  
NSW Consumer Advisory Group (NSW CAG)" to:  
"NSW CAG  
Consumer Advisory Group – Mental Health Inc";
- A "hit counter";
- A change to the "About" page. It is now somewhat different, with more information and links to other pages;
- Addition of the constitution and another historical document to the "History" page;
- Deletion of the month calendar on the "Activities" page and addition of link to another site with a calendar of mental health events;
- Addition of a "member's profiles" and "past member's profiles" to the "Member's" page. This is a work in progress. A letter was sent to all members and past members to ask if they would like a profile on the website;
- The "News" page now has the links to the last two Annual Reports and up to Issue 5 of the NSW CAG INFO\_LINK newsletter;
- The "Links" page has been reformatted to include more linked pages with many more links in categories such as "Mental Health Organisations in NSW" etc;
- The "Projects" page now also includes links to "Committees" and "Reports". Many projects, committees and reports were added, mostly from last year's annual report. Some have been up-dated since, such as MH-COPES and JGOS. Contact e-mails were added for contact people for each project;
- The "Contact" page now has a link to "Staff" and individual staff's names, positions and contact details are listed.

I presented a poster about the website at the Mental Health NGO Conference on 25th–26th March 2004 at Wollongong.

Yvette Cotton





### Western Riverina Community Care

Western Riverina Community Care (WRCC) is a non-government organisation based in the Riverina that offers support to people with disabilities. NSW CAG has been working with Griffith CAG and WRCC in several ways including being the catalyst for an event during Mental Health Week that used the National Standards Quilt as a backdrop during the event.

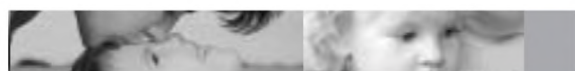
The Network 1 Mental Health Week Expo was held at Griffith Regional Theatre from 7th–10th October 2003. Network 1 is in the North West of the Greater Murray Area Health Service. Griffith is the main centre.

The expo consisted of an art show and a one-day forum.

The objectives of the expo were to:

- Find ways that consumers, carers and family members as individuals and groups can participate positively and with respect in all aspects of Mental Health and service delivery;
- Think outside the square for creative ways of working together;
- Raise the issues and profile of Mental Health in Network 1; and
- Effectively share information between other services, consumers, carers, family members and the community.

Kerrie Dissegna







# Submissions and reports

## Privacy and Confidentiality

This issues paper came about as a first stage in a response to the first discussion paper from the NSW Department of Health on the proposed changes to the Mental Health Act: Carers and Information sharing.

The report is available on our website [www.nswcag.org.au](http://www.nswcag.org.au) The following is an extract from the paper:

"The genesis of this issues paper was the development of a response to a review by NSW Health of the Mental Health Act. NSW Health issued a discussion paper entitled Carers and Information Sharing in February 2004.

"NSW CAG considered the most appropriate way of responding to the discussion paper, and concluded that the development of a position paper that canvassed the areas of privacy and confidentiality would be the best use of its resources.

"As our response began to take shape, it became clear that the issues surrounding privacy and confidentiality for consumers and carers were many and complex, and needed to be placed in the context of mental health.

"It also became apparent as the position paper evolved that privacy and confidentiality went to the core of the relationships between consumers, carers and service providers.

"Therefore, it was felt more appropriate to produce an issues paper given the significance of the areas and themes canvassed, and that a discussion was required amongst the constituency of NSW CAG to allow a considered position to emerge.

"This paper does not reach conclusions as such. Rather it seeks to lay out a range of related information to allow a dialogue to commence in the consumer and carer community.

"An extended period of consultation is proposed with a view to reaching a consensus on the issues that face consumers and carers in the area of privacy and confidentiality, and on a response to those issues.

"For readers of this paper that are not in the consumer and carer community, we offer two definitions that have been taken from the Third National Mental Health Plan and may be of assistance.

"Consumer: A person who is currently utilising, or has previously utilised, a mental health service.

"Carer: A person whose life is affected by virtue of a family or close relationship and caring role with a consumer".

Douglas Holmes





# Conference attendance and presentations

## **International Society for Bipolar Disorders Regional Group Conference**

Sydney, 5–7 February 2004

Attendances:

- Yvette Cotton

A more detailed report of this conference is available in the NSW CAG INFO\_LINK July 2004 available on our website [www.nswcag.org.au](http://www.nswcag.org.au)

## **9th NSW Rural Mental Health Conference**

March 16–18, Armidale NSW.

Oral presentation

- MH-CoPES – Gillian Malins and Shirley Kirk, NSW CAG

## **NSW NGO Conference**

NGOs, Mental Health and the Community: Turning the tide. 25–26 March 2004 Novotel Northbeach Wollongong.

Oral presentations

- MH-CoPES – Gillian Malins and Phil Escott, NSW CAG
- Degrees of Empowerment Audit Tool – Douglas Holmes – NSW CAG

Workshop

- Linking the Networks – Carer Participation – Vivienne Munro –North Sydney Mental Health Carer Network and Gillian Holt – Carer member for NSW CAG

Poster presentation

- The NSW CAG Website – Yvette Cotton – NSW CAG, Douglas Holmes – NSW CAG and Irene Vasilas

A more detailed report of this conference is available in the NSW CAG INFO\_LINK July 2004 available on our website [www.nswcag.org.au](http://www.nswcag.org.au)

## **10th Annual Hunter Mental Health Conference**

14th May 2004

Poster presentation

- MH-CoPES: Mental Health Consumers' Perceptions and Experiences of Services – Gillian Malins (NSW CAG) and Allison Kokany (MH-CoPES TWG).







# NSW CAG representation on committees

The following table provides a list of NSW CAG representation on committees during the financial year 2003–2004.

## Commonwealth

Communications Network	Yvette Cotton
C-PIN EP	Douglas Holmes
National Consumer and Carer Forum	Anna Saminsky
National Health Priority Action Council	Anna Saminsky
Network Of Australian Community Advisory Groups	Anna Saminsky

## State

Centre for Mental Health: MH-OAT consumer consultative group	Douglas Holmes
Centre for Rural and Remote Mental Health-Community Advisory Group	Douglas Holmes and Joan Wakeford
HASI (Housing and Accommodation Support Initiative)	Douglas Holmes
Mood Discovery Support Group Planning Meeting	Yvette Cotton and Douglas Holmes
NSW Carers Coalition	Yvette Cotton
NSW Carers Program Advisory Group	Gillian Holt
NSW Health Participation Council	Elizabeth Pemberton
NSW Mental Health Implementation Taskforce	Anna Saminsky
NSW Mental Health Information Steering Committee	Douglas Holmes
NSW Joint Guarantee of Service (JGOS) for people with Mental Health Problems and Disorders living in Aboriginal, Community and Public Housing	Paula Hanlon and Anna Saminsky
NSW Mental Health Promotion Advisory Committee	Yvette Cotton
NSW Mental Health Review Systems	Douglas Holmes
Official Visitors Program	Anna Saminsky
Seclusion and Restraint Committee	Anna Saminsky
Streetwise Bipolar Disorder Comic – Steering Group	Yvette Cotton
The Black Dog Institute	Douglas Holmes







Following on from the development of the Strategic Plan and Business Plan, in June 2002 the following three committees were created to assist with the implementation of the NSW CAG planning process:

### **1 Governance and finance subcommittee**

Convenor: Gillian Holt

Members: Douglas Holmes.

### **2 Education and training subcommittee**

Convenor: Kerrie Dissegna

Members: Kylie White, Douglas Holmes.

### **3 Policy and research subcommittee**

Convenor: Anna Saminsky

Members: Jenny Mackellin, Brenda Spencer, Douglas Holmes, Elizabeth Pemberton.

Other committees during the year were:

#### **Editorial subcommittee**

Convenor: Yvette Cotton

Members: Peter Schaecken, Robyn Sanderson, Meg Smith, Anna Saminsky, Anne Blake, Chris Maxwell, Douglas Riley, Jenny Coleman, Lynda Hennessy, Mark McMahon.

#### **Employment subcommittee**

Convenor: Anna Saminsky

#### **Recruitment of new members committee**

Convenor: Kerrie Dissegna





## Treasurer's report

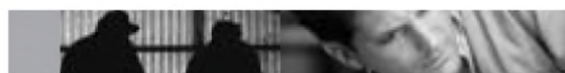
I am pleased and proud to present the Treasurer's Report for the financial year 2003–2004 to our members, associate members, the Centre for Mental Health and other interested people. This year has been an exciting one for NSW CAG, as we have entered a time of increased expansion due to progress to the next stage of the MH-CoPES Project. We completed the year with a small surplus of funds.

Over the past few years NSW CAG has focussed on improving and consolidating their sound financial management. The accounts reflect this commitment and endeavour.

Thanks to all those who have made my position as Treasurer such a pleasure. In particular I would like to acknowledge Douglas Holmes and Tracy Jordon who ensure that the accounts are always accurate and in order.

Our auditors, in particular Bruce Lawrence from O'Neill and O'Brien Financial Services Pty Ltd, have prepared an auditors statement for this Annual Report. We appreciate the role of our auditors in the review of the NSW CAG accounts. The Auditor's Report to members is qualified due to the ongoing insecure funding environment within which NSW CAG operates. Up until now, the organisation has received its operating funding on a 12-monthly basis. We have been working actively over the past financial year to achieve a three-year funding agreement, which would ensure the ongoing viability of the organisation. Should NSW CAG be successful in achieving this more secure funding environment, I am confident that the organisation is in an excellent position to continue to progress Mental Health Consumer and Carer Participation in NSW in line with the NSW CAG strategic plan.

Gillian Holt





# Auditor's report

**NSW CAG Mental Health Inc.**

**Financial Statements for the year ended 30 June 2004**

## **Contents**

- Auditors report
- Declaration by directors
- Statement of financial position
- Statement of financial performance
- Notes to financial statements
- Trading account
- Detailed statement of financial performance







## NSW CAG Mental Health Inc.

ABN 82 549 537 349

### Auditor's Report to the Members

The entity has again incurred a deficit and relies on the support of the NSW Health Department. It is attempting to increase its grant income however without this financial support and reducing its cost structure the entity may not be able to continue as a going concern. If the entity is unable to continue as a going concern, it may be required to realise its assets and extinguish its liabilities other than in the normal course of business and at amounts different from those stated in the financial report. The financial report does not disclose this fact and does not include any adjustments relating to the recoverability and classification of recorded asset amounts or to the amounts and classification of liabilities that might be necessary should the entity not continue as a going concern. In our opinion, knowledge of the significant uncertainty affecting the entity's ability to continue as a going concern is necessary for a proper understanding of the financial report.

Subject to the above qualification we have audited the accounts set out on the following pages in accordance with Australian Auditing Standards.

In our opinion, the accounts of the Company are properly drawn up in accordance with the provisions of the Corporations Law, and so as to give a true and fair view of:

- (i) the state of affairs of the Company as at 30th June, 2004 and of the profit for the year ended on that date;
- (ii) the other matters required by Division 4, 4A and 4B of Part 3.6 of that Law to be dealt with in the accounts;

and are in accordance with Statements of Accounting Concepts and applicable Accounting Standards.

O'Neill & O'Brien

Registered Company Auditors

by Bruce Lawrence





## NSW CAG Mental Health Inc.

### Statement by Directors

In the opinion of the Directors of the Company

- 1 (a) The accompanying Statement of Financial Performance is drawn up so as to give a true and fair view of the results of the Company for the financial year ended 30 June 2004.  
  
(b) The accompanying Statement of Financial Position is drawn up so as to give a true and fair view of the state of affairs of the Company as at the end of that financial year.  
  
(c) At the date of this statement, there are reasonable grounds to believe that the company will be able to pay its debts as and when they fall due and meet any obligations or liabilities under guarantees and undertakings given to its subordinates.
- 2 The accompanying Accounts have been made out in accordance with all applicable accounting standards and have been properly prepared by a competent person.

This statement is made in accordance with a resolution of the Board of Directors and is signed for and on behalf of the Directors by:

Anna Saminsky

Gillian Holt

Dated this 10th day of December 2004




**NSW CAG Mental Health Inc.**

ABN 82 549 537 349

**Statement of financial position as at 30 June 2004**

	NOTE	30 JUN 04 \$	30 JUN 03 \$
<b>CURRENT ASSETS</b>			
Cash		83,514.06	30,227
<b>NON-CURRENT ASSETS</b>			
Property, Plant and Equipment	2	30,147.91	40,873
<b>TOTAL ASSETS</b>		<b>113,661.97</b>	<b>71,100</b>
<b>CURRENT LIABILITIES</b>			
Creditors and borrowings	3	111,248.58	7,979
<b>TOTAL LIABILITIES</b>		<b>111,248.58</b>	<b>7,979</b>
<b>NET ASSETS</b>		<b>2,413.39</b>	<b>63,121</b>
<b>SHAREHOLDERS' EQUITY</b>			
Accumulated Profit		2,413.39	63,120
<b>Operating loss</b>			
before income tax		60,707.11	72,483
Income tax expense		—	—
		(60,707.11)	(72,483)
<b>OPERATING LOSS AND</b>			
<b>EXTRAORDINARY ITEMS</b>		<b>60,707.11</b>	<b>72,483</b>
Retained profits at July 1		63,120.50	135,603
<b>PROFIT AVAILABLE</b>			
<b>FOR APPROPRIATION</b>		<b>2,413.39</b>	<b>63,120</b>
<b>RETAINED PROFITS</b>		<b>2,413.39</b>	<b>63,120</b>







## **NSW CAG Mental Health Inc.**

ABN 82 549 537 349

### **Notes to the financial statements**

#### **NOTE**

These financial statements are a special purpose financial report prepared in order to satisfy the accounts preparation requirements of the Corporations Law.

The statements have been prepared in accordance with the requirements of the Corporations Law and the following applicable Accounting Standards and other mandatory professional reporting requirements:

AASB 1002: Events occurring after balance date

AASB 1008: Accounting for leases

AASB 1018: Statement of financial performance AASB 1019: measurement and presentation of inventories in the context of the historical cost system

AASB 1021: Depreciation of non-current assets

AASB 1025: Application of the reporting entity concept and other amendments

AASB 1031: Materiality

AASB 1034: Information to be disclosed in financial reports.

No other applicable Accounting Standards or other mandatory professional reporting requirements have been applied.

The statements have been prepared on an accruals basis. They are based on historical costs and do not take into account changing money values or, except where specifically stated, current valuations of non-current assets.

The following specific accounting policies, which are consistent with the previous period unless otherwise stated, have been adopted in the preparation of these statements:

#### **Income Tax**

No income tax has been brought to account in the financial statements, as the Association is an exempt institution under s50–45 of the Income Tax Assessment Act 1997.

#### **Property, Plant and Equipment**

Property, Plant and Equipment are included at cost, independent or directors' valuation. The depreciable amount of all fixed assets including buildings and capitalised leased assets, but excluding freehold land, are depreciated over their useful lives commencing from the time the asset is held ready for use. Properties held for investment purposes are not subject to a depreciation charge. Leasehold improvements are amortised over the shorter of either the unexpired period of the lease or the estimated useful lives of the improvements.





## NSW CAG Mental Health Inc.

ABN 82 549 537 349

### Notes to the financial statements

	30 JUN 04	30 JUN 03
	\$	\$
<b>NOTE 2. PROPERTY, PLANT AND EQUIPMENT</b>		
Office equipment—at cost	62,841.60	62,841
Less provision for depreciation	38,757.79	29,332
	24,083.81	33,509
Furniture and fittings—at cost	8,663.00	8,663
Less provision for depreciation	2,598.90	1,299
	6,064.10	7,364
	30,147.91	40,873
<b>NOTE 3. CREDITORS AND BORROWINGS</b>		
	\$	\$
Trade creditors	10,465.58	7,979
GST creditor	10,783.00	—
Subsidy received in advance	90,000.00	—
	111,248.58	7,979





	30 JUN 04	30 JUN 03
	\$	\$
<b>INCOME</b>		
Donations	—	726
Interest Received	169.43	976
NSW Health Department	215,000.00	170,000
<b>TOTAL INCOME</b>	<b>215,169.43</b>	<b>171,702</b>
<b>EXPENSES</b>		
Accountancy	1,800.00	954
Advertising and promotion	952.62	1,872
Agency costs	—	523
Bookkeeping	9,419.23	6,284
Bank charges	1,102.46	394
Computer software	3,794.89	3,639
Meetings and conferences	10,248.45	15,619
Development and research	4,703.17	13,122
Consultants fees	10,415.36	—
Depreciation	10,725.60	10,725
Courier and postage costs	3,318.91	3,833
Insurance	2,107.66	2,179
Interest	287.24	—
Legal costs	—	1,115
Member fees	25,845.34	20,024
Printing, stationery and postage	27,211.64	31,345
Staff training	1,289.45	918
Subscriptions and contributions	1,453.90	2,017
Superannuation	11,083.45	8,027
Telephone and Internet fees	1,154.76	1,482
Travelling and subsistence expenses	25,813.33	29,909
Wages	123,149.08	90,204
<b>TOTAL EXPENSES</b>	<b>275,876.54</b>	<b>244,185</b>
<b>OPERATING LOSS</b>	<b>60,707.11</b>	<b>72,483</b>
<b>OPERATING LOSS AND EXTRAORDINARY ITEMS</b>	<b>60,707.11</b>	<b>72,483</b>
Retained profits at July 1	63,120.50	135,603
<b>PROFIT AVAILABLE FOR APPROPRIATION</b>	<b>2,413.39</b>	<b>63,120</b>
<b>RETAINED PROFITS</b>	<b>2,413.39</b>	<b>63,120</b>







# Strategic plan 2002–2005: a time for action

## Introduction

This strategic plan provides a platform for the future. It gives a clear direction for the New South Wales Consumer Advisory Group – Mental Health Inc (NSW CAG).

It addresses the issues surrounding the existence of NSW CAG, and documents what we do, where are we now, how did we get here, why are we in business, where are we going, how will we get there, when will we get there and what it will cost.

We will share the outcomes of our planning with our stakeholders through a shortened version of our plan. This plan is a living document. It does not just sit on the shelf to gather dust to be brought out each year for our planning sessions. Rather it is used as the basis to guide us during the year and measure our successes as we review the year.

## Our values

Integrity	Openness	Empowerment
Determinations	Partnership	Honesty
Diversity	To validate lived experience	To utilise unique perspectives
Equality	Breaking down stigma/prejudice	Ensuring access to services
Promoting recovery	E.E.O. (equal employment opportunity)	

## Fundamental statements

- We are a state-wide body
- We want respect and self-determination
- We want to improve systemic advocacy.

## Our key stakeholders

The key stakeholders of NSW CAG are:

- Consumers
- Carers
- Mental health service providers
- The Centre for Mental Health
- Non-government organisations (NGOs) in the mental health area
- The community
- Federal government

## Funding agreement

The NSW Government has committed to the national approach to mental health arising from the mental health statement of rights and responsibilities and subsequent national mental health strategies and plans. To meet obligations flowing from this commitment, the Centre for Mental Health has a need for a Consumer and Carer state-wide body and funds NSW CAG as that state-wide body imposing goals under the funding agreement.





NSW CAG has moved to a three-year recurrent funding. With the current funding agreement NSW CAG agreed to achieve the following goals:

- 1 to consolidate the unique role of the NSW CAG as a state-wide Consumer and Carer advisory organisation in NSW;
- 2 to create and encourage inter-sectoral links between Consumers and Carers across the state to reflect the community through Network NSW;
- 3 to develop cost effective projects that maximise Consumer and Carer participation in NSW; and
- 4 to provide a Consumer and Carer centre providing information and networking opportunities.

Consumers and Carers in NSW have their own aspirations and needs that their state-wide body, NSW CAG, must address. While the goals of the CMH and Consumers and Carers intersect there are goals over and above those set by the funding agreement.

### Strategic purpose

The reason we exist is to provide systemic advocacy.  
Our strategic goals support this strategic purpose.

### Strategic goals

The following strategic goals are long term ones (five to ten years) that support our mission. They will tend not to change unless there is a major environmental change such as a removal of funding following a change of government.

#### Strategic goal 1: a sound organisation

Build an organisation that is governed well and has good practices.

#### Strategic goal 2: a knowledge base

Provide leadership and an independent, strong, informed voice for the diversity of Consumers and Carers in NSW in all policy and service development, implementation and evaluation.

#### Strategic goal 3: working together

Develop and maintain links with others in the mental health field and be recognised and acknowledged as the expert on Consumer and Carer issues.

#### Strategic goal 4: advocacy

Articulate and assert the rights of Consumers and Carers.

### Relationship of the strategic goals

The four strategic goals are linked and support each other. The two supporting goals of **A Strong Organisation** and **Working Together** are enablers, important components that make it possible to achieve our strategic purpose. The goal of **A Knowledge Base** is to ensure that we have the knowledge about who we are, what are the issues and what we want to change. By working together with other, and having a strong organisation our knowledge allows us to put a forceful case for change through advocacy.







## STRATEGIES

These strategies support each of our long-term goals and will be achieved in one to two years.

### Strategic goal 1: a sound organisation

**Strategy 1.1 a clear direction:** Complete the strategic planning process for period 2002–2005.

**Strategy 1.2 effective controls:** Develop a corporate governance program.

**Strategy 1.3 a relevant structure:** Review the organisation structure to ensure that it best meets the strategic goals.

**Strategy 1.4 a resourced organisation:** Ensure that the resources are available to enable NSW CAG to carry on business.

### Strategic goal 2: a knowledge base

**Strategy 2.1 consultation:** Develop a capacity to consult with Consumers and Carers, identify issues and prioritise them.

**Strategy 2.2 communication:** Develop innovative two-way communication with Consumers and Carers.

**Strategy 2.3 policy:** Develop a capacity to process and prosecute issues.

**Strategy 2.4 research:** Develop research capabilities to meet the needs of consumers, carers and policy makers.

### Strategic goal 3: working together

**Strategy 3.1 a collaborative approach:** Form a productive working relationship with the peak bodies with an interest in mental health.

**Strategy 3.2 partners with the Centre for Mental Health:** Maintain a firm professional working relationship with the Centre for Mental Health.

### Strategic goal 4: advocacy

**Strategy 4.1 talk to the media:** Develop an ability to respond to an event or an issue in the media.

**Strategy 4.2 raise the issues:** Develop a capability for Consumers and Carers state-wide to raise issues with their local community and with local community leaders.

**Strategy 4.3 inform the legislators:** Develop a communication strategy to inform politicians throughout the state of issues relating to mental health.

**Strategy 4.4 education:** Develop a capacity to educate.







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