2019 Submission - Royal Commission into Victoria's Mental Health System

Organisation Name
N/A

Name
Mr Allan Pinches

What are your suggestions to improve the Victorian communitys understanding of mental illness and reduce stigma and discrimination?
Anti-stigma campaigns and community education around mental illness issues in our society, have undoubtedly made a sizeable contribution for more than a decade, especially in encouraging Australians to be more willing to talk about this once taboo topic and allowing mental health matters to gain a more prominent place in policy, provision and budget. Stigma and discrimination are definitely implicated in a great deal of emotional distress and hardship in the lives of people who have encountered mental health issues and can be viewed as a significant barrier to progress individually and at the level of government and service responses. This can include: the stereotyping, mocking, blaming or ""demonising"" of people with mental health issues, within popular culture, in films, TV, or or online, and reflected in mainstream media often sensationalist and misleading portrayals of people with supposed mental illness. Public perceptions of this diverse range of people tend to slide into in ""get tough"" government austerity welfare policy making, tend to add to poverty, disenfranchisement, and inadequate social and economic participation, and limitations on a large number of people's ability to have a voice as citizens. Horrific and pseudo-religious imagery of supposed mad people from throughout history are hard to dislodge in social perceptions and behaviours. They play out in prejudices of some employers, real estate agents, policy makers, bureaucrats and the mental health system itself. Many consumers/ service users/ survivors must suffer the embarrassment of weight-gain, being poorly clothed, having the ""shakes"" when handing over change, or having a strange gait because of years of high medication, and so it goes. Stigma and discrimination, about perceived ""madness"" and various other personal traits has been part of the human story for time immemorial. Groupings may inflict social exclusion or somehow punish such people, seems a deeply ingrained pattern across many times, places, and cultures. Issues of mental health can be viewed as sitting within a very central place in westernised countries, partly because of the intersectional nature of the issues involved and partly because of the many issues the mental health system and associated apparatus are tasked to solve in our society. It seems to be a highly complex, complicated, multi-factorial, highly intersectional field, with often, controversial, set of concepts. There appear to be many areas of divergence in explaining areas of cause and effect in relation to what is often called the ""mental health crisis."" The formulation of meaningful and effective strategies seems to be very constrained, and would seem to point toward more networked approaches which link research, and new forms of advocacy, requiring a wider range of conversations across a wider range of forums. (Pinches, A. (2015.) Despite all these obvious burdens of stigma and acknowledging that the anti-stigma and mental health awareness campaigns of the past decade have made a significant contribution, this approach now needs to be built upon, taken to the next level, and developed into a set of initiatives which would provide real and tangible improvements in people's lives. I believe an increasing number of consumer advocates want to now want to take this community education and community development type work forward, in ways which would address many complex, structural underpinnings of mental

health problems, including socio-economic factors. The Social Determinants of Health are a well-established concept, Commission on Social Determinants of Health. (2008). Many consumers and many others have long argued that the dominant medical model and the focus on individual pathologies, and harmful othering in the system and society are implicated in many problems in the field. Many consumer writers and others take issue with the stigma focus, for various reasons, including the claim that it only reaches the low hanging fruit in the issue; tends to reinforce the naturalness of stigma; keeps the problem in the individual realm and need to adapt or respond; is an easy catchcry for politicians or others, in in some ways avoiding the need for more difficult or costly solutions; and many more argument. The next level would likely mean harnessing this virtual giant cloud of community goodwill and awareness that has been generated by these campaigns around mental health, especially pertaining to the lived experience of a significant and diverse range of people in our society. It would be good to utilise this unusually powerful accumulation of social capital -- accompanied by sufficient financial capital -- towards a range of projects and programs, particularly using the knowledge, skills and innovative research and development capacities of the consumer movement. (See the next section about the mental health consumer movement.) The key message I want to get across to the Royal commission is that despite serious and persistent problems in the mental health field, which would be evident in the thousands of submissions so far, there are also many areas of possible reforms and solutions, as informed long-term and increasingly sophisticated work of the mental health consumer movement. It now just so important to listen to the voices of mental health consumers/ service users and to really understand the motto: Nothing about us without us. As a lived experienced mental health consumer consultant, writer and researcher, my work over some 26 years has brought me into contact and active participation with many mental research and development and advocacy projects, which considered toegether have already made an enormous. contribution to innovation and change in the mental health field in this country. I will detail some of these developments later in this document and include a summary of my nearly completed Master Of Social Work By Research candidature project, titled: A Strategic History Of The Mental Health Consumer Movement In Australia. The study is based on the mental health consumer movement's own increasing body of innovative, landmark research projects and a large amount of consumer articles and grey literature, which reveals a wealth of collective knowledge, insights, strategies and methods, in which I have been a participant/ observer. The consumer movement work, which has been expanding and diversifying, has been a powerful informant and catalyst for change. It seems to hold promise to be increasingly transformative, if it is given the reasonable support and resources it needs. Consumer research often comes with highly effective and creative ways to work within a partnership and collaboration framework; it can help find improved processes to work through conflicted issues, enhance consumer recruitment and reduce many barriers; it can harness the learnings from consumer experiences, expression of needs and wants and facilitate ways for consumers to tap into practice wisdom from experience; and in a powerful and direct sense noted by emerging groups of consumer researchers, consumer-based research can help remove pre-conceptions around various issues that effectively prevent the generation of viable solutions. The work of the consumer movement is relatively little known in the wider Community. However, there is a huge proliferation of mental health type support groups, advocacy groups, and campaigning sites on social media. The consumer movement was an early adopter of the internet and social media, and this has underpinned its growth and increasing influence. Mainstream media seems keen on mental health stories but many consumers think these reports are often stereotyped, negative, filled with horrific imagery, lacking in meaningful context and generally unhelpful. Mental Health has acquired a new cache as a charity field, corporate or sporting feelgood PR boost, a vehicle for celebrities, and a good field to work in, or an explanation

for everything that goes wrong in human behaviour. Except all very specialised ministers and bureaucrats in the Health area, the consumer movement has a fairly low recognition level in various parts of governments, with the exception but hopes of some local government. For the politicians and officials who are aware of the existence and work of the consumer movement, and may occasionally sign off on modest funding approvals for our organisations and projects, for which we are grateful, I do want to draw attention to the fact that the consumer movement has grown up and developed a lot in the past more than two decades since consumer participation work began As a part response to deinstitutionalisation of the mental health system. The 1993 Burdekin Report had trenchant criticism of the lack of backup services to accompany the movement of hundreds of people from big psychiatric hospitals, into the community. Many associated problems come and go in waves, and many consumers, carers, community allies including many service providers are disappointed and understandably angry about what is often referred to as the mental health crisis. While this barely contested, there are huge differences in the various stakeholder's assessment of the causes and effects, or what should be the next steps. The work of consumer consultants has now diversified into many different areas of focus. From humble beginnings, around gathering feedback consumers from consumers about their experience is with services, advocacy to management or state authorities, and locally based projects the work has evolved into a more networked and sophisticated level, building in new roles and activities such as consumer peer support work, and consumer education for expanded roles. And consumers running research projects on a wide range of topics. We as a community must build upon that with new policy and programs initiatives developed in the past several decades by the lived experience. In particular, for policymakers, and the total community to listen to the voices of the consumer movement. An immediately helpful strategy would be for government to maintain the funding and further development of the (MHCSS) Mental Health Community Support Services, which have for more than two decades have provided highly specialist services such as mental health rehabilitation, supported housing, referrals to education and vocational services, within a framework of personal recovery and community participation. There are widespread reports that the transition to the NDIS system in Victoria could put many of these services at jeopardy. However, it is now time for consumer-led services to be brought into the community, for and by people with lived experience around the impacts of mental health issues, consequences, strategies for coping and recovery, and ways people can re-position themselves into the world, perhaps finding strength in doing things more in their own terms. These more ""participating lives"" as they are sometimes described, are based on working with consumers within the community from a ""personal recovery approach"" which seeks to empower people toward greater control over their lives and destinies. Broadly this is about supporting and resourcing people in a range of ways, with information, access, knowledge, good-quality referrals, education and work links, peer support, etc. This is based on ideas of building on personal strengths and aspirations, and not individual pathologies clinical ""deficits. of symptoms. Importantly such approaches do not rely on clinical recovery or remission, but relates to the person's coping and quality of life, with or without symptoms, Sometimes, clinical recovery actually happens too. There are many lingering problems in the mental health system -- arguably part of a long and troubled history which relates to wide range of factors, in many ways bound up in the elemental nature of mental functioning within the human condition. Harms or alleged abuses within the mental health system, whether arising from localised human-level causes or more impersonal and process-bound systemic ones, are often reported upon in mainstream and social media. Mental health consumers -- who sometimes identify as ""survivors"" -- constantly raise these matters, often with passion, anger and feelings of injustice. In recent decades there have been many attempted reforms in mental health laws, policy, and practices, together with a growing

number of innovative research and development projects, and there have been some successes -- but change remains painfully slow and reforms which look good on paper can sometimes remain quietly unsupported, when it comes to being translated into reality, or be officially worked around to maintain the status quo. The mental health consumer movement in Australia, like its counterpart organisations in the US and UK, New Zealand and several European countries, is playing a key role in advocating and researching towards positive change. My current Master of Social Work by Research study at LaTrobe, A Strategic History of the Mental Health Movement in Australia, confirms that movement has been a major contributor to change and reform in the mental health Where a few decades ago there was silence in terms of constructive discussion about mental health, or -- nasty jokes using an endless number of synonyms for madness -- today there is a deafening roar, amplified by government $millions for several community awareness agencies and the effects of social media. The movement and its allies face a challenge to try to capture, shape and build the potential momentum of this soundscape into a critical mass of social concern which can help bring about new and meaningful responses to a wide range of human rights and social justice issues which cluster under the heading of mental health. We live in a stressful world, with increasing social and economic competition and pressures, a widening gap between rich and poor, increasing social disadvantages in stark terms among many groups where individuals bear the brunt of wider changes, and seemingly intractable conflicts, social dislocation and divisions are a staple daily problem. Key social institutions which were once seen as an influence for stability and cohesion, are now challenged on questions of relevance and underlying authority. A combination of powerful influences, including the pursuit of neoliberalist economics, globalisation, technological change, labour market and employment dislocation, population pressures, geopolitical conflict, climate change and other environmental factors tend create winners and losers, with many people becoming disadvantaged, and many vulnerabilities. It hardly seems surprising that such social difficulties may translate into increased mental illness/ mental health problems/ emotional issues. Consumer advocates sometimes describe mental illness ""a normal reaction to abnormal situations in our society."" Some factors which seem to support to notion that genuine progress being made in trying to balance an understanding/ critique of on-the-ground problems and being open to creative alternative approaches: Growth and development of community-based Mental Health Community Support Services (psychosocial support, recovery-based approaches, and rehabilitation) with deep and active consumer participation, consumer design, research and evaluation; and increasing employment of consumers (and family carers) in lived experience key support worker roles. Recovery based approaches in mental health, which have been a major part of policy and practices in the field since the 1990s, with mixed reviews but signs of benefits from expanded options for consumers compared to clinical-only services. Consumer movement organisations, including state and territory peaks, such as the VMIAC and a counterpart in NSW, BEING, with other consumer peaks in SA, WA, and other places, working in a more networked way over time, including research, advocacy, communication and campaigning. Renewed consumer movement calls for a National Consumer Run Peak Organisation have generated much support among consumers, but little enthusiasm from government. There are many large mental health advisory at a state and federal level, many including service providers and some consumers are family carers. But there is no dedicated consumer peak, which could advocate, advise of strategic policy, coordinate consumer research, be active online. Consumer led research, writings and discussions often refer to aspects of mental health beyond an individual level, which are often seen as social, economic, cultural, environmental, and some would call ""spiritually-related"" factors -- often termed Social Determinants of Health. (On Twitter see #SDoH) Consumer/ service user researchers, a strongly emerging lived experience workforce in itself, are increasingly networking in Australia and overseas, and identifying a growing list of items

for a research agenda which would build on the collective knowledge, skills, and insights of the mental health consumer movement and its allies, which could encompass many areas of inquiry. See: Consumer feedback, evaluation and research in mental health services and beyond could be enhanced by a wider range of participation methods: eg, forums, projects, writing and media opportunities, co-production research, Participatory Action Research, etc, and for consumer movement leadership to be inclusive, promote participation, encourage educative approaches about advocacy and speaking to power, and engage constructively with services, policymakers and other stakeholders. Widespread outcry over the NDIS (National Disability Insurance Scheme) rollout in relation to mental health and a growing crisis in funding, legislation, problems in definitions of mental health, disability, and in the eligibility guidelines, reportedly leaving several hundred thousand MH consumers to miss out on support, with reports of frustration and even some reports of suicides occurring. The underlying principles of the NDIS were largely good and enlightened, but appear inadequately funded and hampered in implementation. The Victorian Mental Health Act 2014 despite some long advocated-for enlightened amendments, in practical terms falls short of its potential to reduce restrictive and coercive practices in the mental health system and provide consumers with enhanced partnership and choices in their treatment. Populist/ post truth narratives tend to result in politics which increases the suffering, stigma, and discrimination for disadvantaged groups: eg perceptions of welfare dependency (""bludgers""), the criticism of homeless people on the streets and begging and rapid resort to associating violent crimes with mental illness is misleading, stigmatising, and unhelpful to people trying hard to recover. A little compassion, adequate benefits to live on, available housing, and a ramping up social participation opportunities like education and employment, would go a long way towards upstream prevention of mental ill health and heavy downstream human and budgetary costs. There is some evidence that advocacy itself may need to become a protected species from governments increasingly averse to constructive criticism of policy. But social service and community organisations maintain that advocacy can provide valuable, economical, people-focused and accurate information towards effective policy making. "

What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?
N/A

What is already working well and what can be done better to prevent suicide?
N/A

What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.
" A Strategic History of the Mental Health Consumer Movement in Australia: From hindsight to insight and a stronger vision A Master of Social Work by Research study at Latrobe University is emerging as a vision quest for the Mental Health Consumer Movement in Australia, by drawing upon the movement's collective knowledge and insights, contained in its ""grey literature"" and qualitative research reports, and seeking to translate historical lessons into possible future directions. Drawing upon a wide range of consumer-generated documents, thie study, now nearing completion, seeks to construct a Strategic History of the Mental Health Consumer Movement in Australia. It examines the movement's growth and evolution as a vehicle for innovation and change in the mental health field and an increasingly significant voice, not only in

mental health but also broader social justice and human rights. In the policy and practice arena in the mental health field, consumer participation, and a growing range of consumer advocacy and project and program developmental activities, consumer lived experience people and groups are becoming increasingly recognised for good best contribution to: improving mental health health and wellbeing of consumers by encouraging an understanding of individual and holistic factors; strengthening personal recovery potential; counteracting stigma and discrimination; and expanding opportunities for consumers to participate in the wider community. The project explores a rapidly expanding catalogue of consumer designed, lived experience approaches to mental health difficulties which offer possible alternatives to medical model approaches, based on insights from shared experience, mutuality, peer support, personal and community connection, and creating spaces of hope and personal affirmation. These things are somewhat hard to find in the busy, and competitive society, but often transpire to become things that consumers, with empathy and understanding can do for each other, both in friendship or working for change. Visions and strategies to help progress the Mental Health Consumer Movement in its work. It will explore a wide range of initiatives that have made a positive difference for consumers, consider key lessons from consumer-generated documented sources in consumer history, and explore further challenges and further possibilities. Lived Experience of this Researcher of Mental Ill-Health, a Curving Recovery Journey, and Working for Systemic Change in The Mental Health Field: THE DEVELOPMENT AND RISE OF THE CONSUMER MOVEMENT In part, the mental health consumer movement seems to have been urged into being by the stigma and discrimination in society and some elements within services, towards people seen as mentally ill. This has persisted over many centuries, and have been reflected in horrific institutions from an era of custodial care, and widespread mistreatment. The research will demonstrate how the achievements of the Mental Health Consumer Movement in Australia, in line with several other countries, particularly the US and UK, have been widespread and deep. In recent years, community awareness/ anti-stigma campaigns, in which many consumers have been involved, seem to be having some positive impacts on social attitudes about people with mental health issues. Mental health seems a more acceptable discussion topic. The movement is going through an exciting and activated time with talented leadership, often with professional qualifications and entrepreneurial flair; growth in numbers, influence and sophistication of operations and issues; increasing cohesion and camaraderie; and an influx of young people who are tech savvy, energetic and full of ideas. There has been a rapidly increasing range of Consumer-designed projects, services, programs, and publications. But there is still so much potential and many problems still needing to be addressed. The proposed methodology is a form of qualitative synthesis, intended to accommodate the sorting, selection, synthesis, interpretation, and discussion of a somewhat wide and disparate range of consumer-generated qualitative Research and Development reports and significant grey literature documents, with a range of methodologies, styles and content, which have informed discussion and debate over the past approx. 30 years post-deinstitutionalisation. This researcher will work to ensure that the adapted qualitative synthesis approach to be used, while allowing for some flexibility based on consumer lived-experience knowledge and generally less formalised and linear approaches in the source materials than regular academic research, the required overall veracity and transparency remains a high priority . The study will rely mainly on consumer-generated documents, and some reports from collaborative projects with services or academia. The proposed study will review and synthesise existing documents and will not involve any new interviews, focus groups or surveys. Five key ""high-activity"" domains emerging in the scoping of the project: 1. THE CONSUMER MOVEMENT AS A LEADING SOCIAL CHANGE/ HUMAN RIGHTS GROUP OF ITS OWN ACCORD: Many people within the consumer movement choose to work in advisory or project

roles, such as Consumer Consultants within MH services, described as working collaboratively as advocates of positive change from the inside of the system. This often involves a balancing act. With a wide spectrum of beliefs regarding the medical model of psychiatry, some consumers choose -- or circumstances dictate -- to work as activists outside the tent of the system -- believing they can speak out more freely. Some activists may uphold banners such as Mad Pride thus re-appropriating pejorative term in a similar way to how GLBTI activists embrace the word queer. There are strong influences of the Civil Rights Movement of the 1960s and 70s and consumers may identify as survivors of the psychiatric system. Aspirations towards a movement based on participatory democracy, valuing the lived experience of consumers, and aspire to hearing even the quietest voice. A strong sense of mission; seeking its own sense of a facilitative, enabling, mentoring leadership style; Strong, reasonably well-defined and coherent set of epistemological and ontological traditions, social justice, and human rights values; 2. CONSUMER PARTICIPATION AS A KEY PROCESS IN MENTAL HEALTH SERVICES: Consumer Consultants and Consumer Advisory groups are the focus of growing area of activity. This includes: systemic Advocacy towards service improvement, innovation and change. Consumer Information, Forums, Education, Surveys, etc. Growing Consumer role in Service Standards, and Clinical Governance. Consumer participation in Staff Selection Panels. Participating in Service Improvement and Development Projects. . debates are taking place about what is true ""consumer perspective."" 3. INDIVIDUAL ADVOCACY AND STATE-WIDE AND SYSTEMIC ADVOCACY: Embedded Consumer Membership of the government statutory bodies and panels around the amended Mental Health Act of 2014. Working as an active partner in the implementation of the much-amended Mental Health Act of 2014. Working collaboratively with Victorian Government on the new 10-year mental health plan. Co-development of a diverse Lived Experience Workforce, with government, services and carers. Consumer run Internet, social media, video, arts, music, community education projects, and growing collaboration with alternative cultural spaces and forums, such as creative writing, storytelling for change, and pop-up community learning venues. 4. CONSUMER LIVED EXPERIENCE WORKFORCE BASED SERVICE DELIVERY, INCLUDING PEER SUPPORT: A major growth area for the consumer movement in Australia, in what has become known as the lived experience workforce, is for the employment of such people in direct service roles, including new and innovative approaches. In this major breakthrough, some areas include: Many Peer Support Workers becoming employed in Mental Health Community Support Services and clinical service jobs, including new programs such as Peer Hubs. Trauma informed services with consumers involved in all stages of development and delivery. New methods like Recovery Colleges, Recovery Camps, Hearing Voices Vic(which aims to be non-judgemental of the experiences of consumers and affirm people's search for what is meaningful to them.) Trauma informed services which have had consumers involved in all stages of development and delivery, including the Open Dialogue approach and Intentional Peer Support. (IPS.) Consumer run services now exist to support, inform, and help advocate for consumers applying for NDIS coverage. (eg, VMIAC) Mental Health First Aid and alternative methods of suicide prevention, such as Alt2Su (Alternatives to Suicide). Consumer run Internet, social media, video, community radio, arts, music, drama, community education projects, Mad Pride comedy events, alternative cultural spaces. The consumer movement, in many ways, has increasing links and is present within large numbers alternative community venues such as creative writing, storytelling for social change, performance poetry events, pop-up community learning venues, including numerous Meetup groups. Such spaces, apart from their inherent value, can help reduce social isolation and promote personal recovery. 5. CONSUMERS' GROWING ROLE AS RESEARCHERS AND EDUCATORS: The involvement of the consumer movement as researchers in many settings is a burgeoning area of interest and activity. There are now dedicated dedicated Australasian

conferences on consumer research such as the Servcice Users Academia Symposium in its ninth year in 2019 and several consumer conferences with a high research component, and emerging innovative events. Consumers are becoming more widely involved as Educators and Trainers for service providers and fellow consumers with a focus on recovery-based methods. There are increasing numbers of of consumer generated Research and Development reports, articles, and social media materials,building up daily, within the realms of consumer organisations, academic organisations and service provider sites. There are growing numbers of Consumer Academics carrying out specialized work at universities in Australia, reflecting trends here, and including the US, UK, New Zealand, and parts of Europe. A project called Learning Together: Education and Training Partnerships in Mental Health, in 1999 as part of the National Mental Health Strategy has become known as The Deakin Papers, and made an enduring case for consumers as educators and researchers. Merinda Epstein and Daniel Rechter as reference group delegates, wrote (1999). 24 If we can guarantee the valuing of consumer perspectives, then we can begin to differentiate various roles users might have as representatives of our body of expert knowledge: as consultants, educators and trainersAs consultants to services our role is one of change agent. Where individual users are unable to articulate what they want, because such services cannot be imagined in the present, or more commonly they are not being listened to, consumer consultants can function as a kind of litmus test' for change. The mental health consumer movement and lived experience workforce has intensively developed and brought into the mental health field a valuable collection of research tools and methods, consistent with its broad collective knowledge, insights and skillsets. These include largely qualitative research and development approaches, which are now becoming widely used in the field, in rewarding ways. These method, involving much creative input from consumers, often in collaborative projects with various services often with a Community Development influence, include: Participatory Action Research, Strategic Questioning , Co-production research, Experience Based Co-design; Co-production research (where consumer researchers are, ideally, equal partners); using online survey software like Survey Monkey in particular ways; various types of workshops and focus groups; and many more methods, which have been very productive, even in difficult stuckareas of policy and practice. Not only could these approaches capture consumer experiences in the system or their social experiences. They could bring out other dimensions beyond mere feedback encourage consumers to reflect on what things would really help them, how the systems could be better run and set up, ideas and aspirations of hope and personal recovery, community participation, and get many opportunities to express these things. The volume of consumer generated Research and Development writings within the academic and service provider worlds is rapidly increasing. There are growing numbers of Consumer Academics carrying out specialized work at universities. This is like trends in the US and UK, where consumer/ survivor research is burgeoning. Consumer Co-production Research and Development is becoming increasingly welcomed and accommodated by services, consumer groups, and in the academic world as a source of data which is enriched within an environment of cooperation, seeking common understandings. (Some examples of consumer research appear in other parts of this document.) Consumer research manifestos in UK and Australia Comprehensively designed prospective research agendas -- or manifestos-- have been formulated by the Australia-based Consumer-Led Research Network NSW Consumer Led Research Network, 2016), and The UK's National Survivor Research Network with many project ideas. (National Survivor User Network, (2018). Australian network convenor Dr Katherine H Gill, wrote (Summer, 2017-18) 51 about the growing role of consumer researchers in mental health, and growing official recognition. Consumer researchers are not just researchers with a lived experience of mental illness/ mental distress, but researchers who are skilled at harnessing their lived experience purposefully, alongside their professional training, experience and qualifications,

to contribute to the research at all stages throughout the research processes According to Gill, there was no shortage of qualified consumer researchers but there was a shortage of opportunities to participate. In 2000 Cath Roper was appointed as Australia's first Consumer Academic at the Centre for Mental Health Nursing Research and Practice, Melbourne University. She wrote (2016) about what consumer perspectives could contribute to co-production research. Over time consumers have developed unique ways of knowing, theorising and thinking about those experiences that constitute a unique discipline in the field of mental health, known in Australia as consumer perspective.' When using consumer perspective, consumers offer their own analyses of their experience and the services and systems they encountere.' 18. An explicit goal of co-production is to reposition people who have traditionally been thought of as passive consumers' of services to being regarded as people with necessary expertise who can lead thinking and innovation. 19. Such methods can support a consumer perspective approaches , with an enhanced focus on consumers' experiences, responses, and suggestions for change; they can encourage a sense of inclusion and collaboration for participants; and foster a reflective, holistic approach to solution seeking, including a focus on factors which can contribute towards consumer recovery and enhanced awareness of broader social determinants of health."

What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

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What are the needs of family members and carers and what can be done better to support them?

N/A

What can be done to attract, retain and better support the mental health workforce, including peer support workers?

N/A

What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

N/A

Thinking about what Victorias mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

N/A

What can be done now to prepare for changes to Victorias mental health system and support improvements to last?

N/A

Is there anything else you would like to share with the Royal Commission?
N/A

Royal commission – Allan Pinches submission.

Anti-stigma campaigns and community education around “mental illness” issues in our society, have undoubtedly made a sizeable contribution for more than a decade, especially in encouraging Australians to be more willing to talk about this once taboo topic and allowing mental health matters to gain a more prominent place in policy, provision and budget.

Stigma and discrimination are definitely implicated in a great deal of emotional distress and hardship in the lives of people who have encountered mental health issues and can be viewed as a significant barrier to progress individually and at the level of government and service responses.

This can include: the stereotyping, mocking, blaming or "demonising" of people with mental health issues, within popular culture, in films, TV, or or online, and reflected in mainstream media often sensationalist and misleading portrayals of people with supposed mental illness.

Public perceptions of this diverse range of people tend to slide into in "get tough" government austerity welfare policy making, tend to add to poverty, disenfranchisement, and inadequate social and economic participation, and limitations on a large number of people's ability to have a voice as citizens.

Horrific and pseudo-religious imagery of supposed mad people from throughout history are hard to dislodge in social perceptions and behaviours. They play out in prejudices of some employers, real estate agents, policy makers, bureaucrats and the mental health system itself. Many consumers/ service users/ survivors must suffer the embarrassment of weight-gain, being poorly clothed, having the "shakes" when handing over change, or having a strange gait because of years of high medication, and so it goes.

Stigma and discrimination, about perceived "madness" and various other personal traits has been part of the human story for time immemorial. Groupings may inflict social exclusion or somehow punish such people, seems a deeply ingrained pattern across many times, places, and cultures.

Issues of mental health can be viewed as sitting within a very central place in westernised countries, partly because of the intersectional nature of the issues involved and partly because of the many issues the mental health system and associated apparatus are “tasked” to solve in our society. It seems to be a highly complex, complicated, multi-factorial, highly intersectional field, with often, controversial, set of concepts. There appear to be many areas of divergence in explaining areas of cause and effect in relation to what is often called the "mental health criris." The formulation of meaningful and effective strategies seems to be very constrained, and would seem to point toward more networked approaches which link research, and new forms of advocacy, requiring a wider range of conversations across a wider range of forums. (Pinches, A. (2015.)

Despite all these obvious burdens of stigma and acknowledging that the anti-stigma and mental health awareness campaigns of the past decade have made a significant contribution, this approach now needs to be built upon, taken to the next level, and developed into a set of initiatives which would provide real and tangible improvements in people’s lives.

I believe an increasing number of consumer advocates want to now want to take this community education and community development type work forward, in ways which would address many complex, structural underpinnings of mental health problems, including socio0-economic factors. The Social Determinants of Health are a well-established concept, Commission on Social Determinants of Health. (2008). Many consumers and many others have long argued that the

dominant medical model and the focus on individual pathologies, and harmful “othering” in the system and society are implicated in many problems in the field. Many consumer writers and others take issue with the stigma focus, for various reasons, including the claim that it “only reaches the low hanging fruit” in the issue; tends to reinforce the naturalness of stigma; keeps the problem in the individual realm and need to adapt or respond; is an easy catchcry for politicians or others, in in some ways avoiding the need for more difficult or costly solutions; and many more argument.

The next level would likely mean harnessing this virtual “giant cloud” of community goodwill and awareness that has been generated by these campaigns around mental health, especially pertaining to the lived experience of a significant and diverse range of people in our society. It would be good to utilise this unusually powerful accumulation of social capital -- accompanied by sufficient financial capital -- towards a range of projects and programs, particularly using the knowledge, skills and innovative research and development capacities of the consumer movement.

(See the next section about the mental health consumer movement.)

The key message I want to get across to the Royal commission is that despite serious and persistent problems in the mental health field, which would be evident in the thousands of submissions so far, there are also many areas of possible reforms and solutions, as informed long-term and increasingly sophisticated work of the mental health consumer movement.

It now just so important to listen to the voices of mental health consumers/ service users and to really understand the motto: “Nothing about us without us.“

As a lived experienced mental health consumer consultant, writer and researcher, my work over some 26 years has brought me into contact and active participation with many mental research and development and advocacy projects, which considered toegether have already made an enormous. contribution to innovation and change in the mental health field in this country.

I will detail some of these developments later in this document and include a summary of my nearly completed Master Of Social Work By Research candidature project, titled: A Strategic History Of The Mental Health Consumer Movement In Australia.

The study is based on the mental health consumer movement’s own increasing body of innovative, landmark research projects and a large amount of consumer articles and “grey literature”, which reveals a wealth of collective knowledge, insights, strategies and methods, in which I have been a participant/ observer. The consumer movement work, which has been expanding and diversifying, has been a powerful informant and catalyst for change. It seems to hold promise to be increasingly transformative, if it is given the reasonable support and resources it needs.

Consumer research often comes with highly effective and creative ways to work within a partnership and collaboration framework; it can help find improved processes to work through conflicted issues, enhance consumer recruitment and reduce many barriers; it can harness the learnings from consumer experiences, expression of needs and wants and facilitate ways for consumers to tap into “practice wisdom” from experience; and in a powerful and direct sense noted by emerging groups of consumer researchers, consumer-based research can help remove pre-conceptions around various issues that effectively prevent the generation of viable solutions.

The work of the consumer movement is relatively little known in the wider Community. However, there is a huge proliferdation of mental healty type support groups, advocacy groups, and

campaigning sites on social media. The consumer movement was an early adopter of the internet and social media, and this has underpinned its growth and increasing influence. Mainstream media seems keen on mental health stories but many consumers think these reports are often stereotyped, negative, filled with horrific imagery, lacking in meaningful context and generally unhelpful. Mental Health has acquired a new cache as a charity field, corporate or sporting “feelgood” PR boost, a vehicle for celebrities, and a good field to work in, or an explanation for everything that goes wrong in human behaviour.

Except all very specialised ministers and bureaucrats in the Health area, the consumer movement has a fairly low recognition level in various parts of governments, with the exception but hopes of some local government.

For the politicians and officials who are aware of the existence and work of the consumer movement, and may occasionally sign off on modest funding approvals for our organisations and projects, for which we are grateful, I do want to draw attention to the fact that the consumer movement has grown up and developed a lot in the past more than two decades since consumer participation work began As a part response to deinstitutionalisation of the mental health system. The 1993 Burdekin Report had trenchant criticism of the lack of backup services to accompany the movement of hundreds of people from big psychiatric hospitals, “into the community.” Many associated problems come and go in waves, and many consumers, carers, community allies – including many service providers – are disappointed and understandably angry about what is often referred to as the “mental health crisis.” While this barely contested, there are huge differences in the various stakeholder’s assessment of the causes and effects, or what should be the next steps.

The work of consumer consultants has now diversified into many different areas of focus. From humble beginnings, around gathering feedback consumers from consumers about their experience is with services, advocacy to management or state authorities, and locally based projects the work has evolved into a more networked and sophisticated level, building in new roles and activities such as consumer peer support work, and consumer education for expanded roles. And consumers running research projects on a wide range of topics.

we as a community must build upon that with new policy and programs initiatives developed in the past several decades by the lived experience. In particular, for policymakers, and the total community to listen to the voices of the consumer movement.

An immediately helpful strategy would be for government to maintain the funding and further development of the (MHCSS) Mental Health Community Support Services, which have for more than two decades have provided highly specialist services such as mental health rehabilitation, supported housing, referrals to education and vocational services, within a framework of personal recovery and community participation. There are widespread reports that the transistion to the NDIS system in Victoria could put many of these services at jeopardy.

However, it is now time for consumer-led services to be brought into the community, for and by people with lived experience around the impacts of mental health issues, consequences, strategies for coping and recovery, and ways people can re-position themselves into the world, perhaps finding strength in doing things more in their own terms.

These more "participating lives" as they are sometimes described, are based on working with consumers within the community from a "personal recovery approach" which seeks to empower people toward greater control over their lives and destinies. Broadly this is about supporting and resourcing people in a range of ways, with information, access, knowledge, good-quality referrals,

education and work links, peer support, etc. This is based on ideas of building on personal strengths and aspirations, and not individual pathologies clinical "deficits. of symptoms. Importantly such approaches do not rely on clinical recovery or remission, but relates to the person's coping and quality of life, with or without symptoms, Sometimes, clinical recovery actually happens too.

There are many lingering problems in the mental health system -- arguably part of a long and troubled history which relates to wide range of factors, in many ways bound up in the elemental nature of mental functioning within the human condition.

Harms or alleged abuses within the mental health system, whether arising from localised human-level causes or more impersonal and process-bound systemic ones, are often reported upon in mainstream and social media. Mental health consumers -- who sometimes identify as "survivors" -- constantly raise these matters, often with passion, anger and feelings of injustice.

In recent decades there have been many attempted reforms in mental health laws, policy, and practices, together with a growing number of innovative research and development projects, and there have been some successes -- but change remains painfully slow and reforms which look good on paper can sometimes remain quietly unsupported, when it comes to being translated into reality, or be officially worked around to maintain the status quo.

The mental health consumer movement in Australia, like its counterpart organisations in the US and UK, New Zealand and several European countries, is playing a key role in advocating and researching towards positive change. My current Master of Social Work by Research study at LaTrobe, A Strategic History of the Mental Health Movement in Australia, confirms that movement has been a major contributor to change and reform in the mental health

Where a few decades ago there was silence in terms of constructive discussion about mental health, or -- nasty jokes using an endless number of synonyms for madness -- today there is a deafening roar, amplified by government $millions for several community awareness agencies and the effects of social media. The movement and its allies face a challenge to try to capture, shape and build the potential momentum of this soundscape into a critical mass of social concern which can help bring about new and meaningful responses to a wide range of human rights and social justice issues which cluster under the heading of mental health.

We live in a stressful world, with increasing social and economic competition and pressures, a widening gap between rich and poor, increasing social disadvantages in stark terms among many groups where individuals bear the brunt of wider changes, and seemingly intractable conflicts, social dislocation and divisions are a staple daily problem. Key social institutions which were once seen as an influence for stability and cohesion, are now challenged on questions of relevance and underlying authority.

A combination of powerful influences, including the pursuit of neoliberalist economics, globalisation, technological change, labour market and employment dislocation, population pressures, geopolitical conflict, climate change and other environmental factors tend create winners and losers, with many people becoming disadvantaged, and many vulnerabilities.

It hardly seems surprising that such social difficulties may translate into increased mental illness/ mental health problems/ emotional issues. Consumer advocates sometimes describe mental illness "a normal reaction to abnormal situations in our society."

Some factors which seem to support to notion that genuine progress being made in trying to balance an understanding/ critique of on-the-ground problems and being open to creative alternative approaches:

Growth and development of community-based Mental Health Community Support Services (psychosocial support, recovery-based approaches, and rehabilitation) with deep and active consumer participation, consumer design, research and evaluation; and increasing employment of consumers (and family carers) in lived experience key support worker roles.

Recovery based approaches in mental health, which have been a major part of policy and practices in the field since the 1990s, with mixed reviews but signs of benefits from expanded options for consumers compared to clinical-only services.

Consumer movement organisations, including state and territory peaks, such as the VMIAC and a counterpart in NSW, BEING, with other consumer peaks in SA, WA, and other places, working in a more networked way over time, including research, advocacy, communication and campaigning.

Renewed consumer movement calls for a National Consumer Run Peak Organisation have generated much support among consumers, but little enthusiasm from government. There are many large mental health advisory at a state and federal level, many including service providers and some consumers are family carers. But there is no dedicated consumer peak, which could advocate, advise of strategic policy, coordinate consumer research, be active online.

Consumer led research, writings and discussions often refer to aspects of mental health beyond an individual level, which are often seen as social, economic, cultural, environmental, and some would call "spiritually-related" factors -- often termed Social Determinants of Health. (On Twitter see #SDoH)

Consumer/ service user researchers, a strongly emerging lived experience workforce in itself, are increasingly networking in Australia and overseas, and identifying a growing list of items for a research agenda which would build on the collective knowledge, skills, and insights of the mental health consumer movement and its allies, which could encompass many areas of inquiry. See:

Consumer feedback, evaluation and research in mental health services and beyond could be enhanced by a wider range of participation methods: eg, forums, projects, writing and media opportunities, co-production research, Participatory Action Research, etc, and for consumer movement leadership to be inclusive, promote participation, encourage educative approaches about advocacy and speaking to power, and engage constructively with services, policymakers and other stakeholders.

Widespread outcry over the NDIS (National Disability Insurance Scheme) rollout in relation to mental health and a growing crisis in funding, legislation, problems in definitions of “mental health,” “disability,” and in the eligibility guidelines, reportedly leaving several hundred thousand MH consumers to miss out on support, with reports of frustration and even some reports of suicides occurring. The underlying principles of the NDIS were largely good and enlightened, but appear inadequately funded and hampered in implementation.

The Victorian Mental Health Act 2014 despite some long advocated-for “enlightened” amendments, in practical terms falls short of its potential to reduce restrictive and coercive practices in the mental health system and provide consumers with enhanced partnership and choices in their treatment.

Populist/ “post truth” narratives tend to result in politics which increases the suffering, stigma, and discrimination for disadvantaged groups: eg perceptions of welfare dependency ("bludgers"), the criticism of homeless people on the streets and begging and rapid resort to associating violent crimes with mental illness is misleading, stigmatising, and unhelpful to people trying hard to recover.

A little compassion, adequate benefits to live on, available housing, and a ramping up social participation opportunities like education and employment, would go a long way towards upstream prevention of mental ill health and heavy downstream human and budgetary costs.

There is some evidence that advocacy itself may need to become a protected species from governments increasingly averse to constructive criticism of policy. But social service and community organisations maintain that advocacy can provide valuable, economical, people- focused and accurate information towards effective policy making.

A Strategic History of the Mental Health Consumer Movement in Australia: From hindsight… to insight… and a stronger vision

A Master of Social Work by Research study at Latrobe University is emerging as a “vision quest” for the Mental Health Consumer Movement in Australia, by drawing upon the movement's collective knowledge and insights, contained in its "grey literature" and qualitative research reports, and seeking to translate historical lessons into possible future directions.

Drawing upon a wide range of consumer-generated documents, thie study, now nearing completion, seeks to construct a Strategic History of the Mental Health Consumer Movement in Australia.

It examines the movement’s growth and evolution as a vehicle for innovation and change in the mental health field and an increasingly significant voice, not only in mental health but also broader social justice and human rights.

In the policy and practice arena in the mental health field, consumer participation, and a growing range of consumer advocacy and project and program developmental activities, consumer lived experience people and groups are becoming increasingly recognised for good best contribution to: improving mental health health and wellbeing of consumers by encouraging an understanding of individual and holistic factors; strengthening personal recovery potential; counteracting stigma and discrimination; and expanding opportunities for consumers to participate in the wider community.

The project explores a rapidly expanding catalogue of consumer designed, lived experience approaches to mental health difficulties which offer possible alternatives to medical model approaches, based on insights from shared experience, mutuality, peer support, personal and community connection, and creating spaces of hope and personal affirmation. These things are somewhat hard to find in the busy, and competitive society, but often transpire to become things that consumers, with empathy and understanding can do for each other, both in friendship or working for change.

Visions and strategies to help progress the Mental Health Consumer Movement in its work. It will explore a wide range of initiatives that have made a *positive difference* for consumers, consider key lessons from consumer-generated documented sources in consumer history, and explore further challenges and further possibilities.

Lived Experience of this Researcher of Mental Ill-Health, a Curving Recovery Journey, and Working for Systemic Change in The Mental Health Field:

THE DEVELOPMENT AND RISE OF THE CONSUMER MOVEMENT

In part, the mental health consumer movement seems to have been urged into being by the stigma and discrimination in society and some elements within services, towards people seen as “mentally ill.” This has persisted over many centuries, and have been reflected in horrific institutions from an era of “custodial care,” and widespread mistreatment.

The research will demonstrate how the achievements of the Mental Health Consumer Movement in Australia, in line with several other countries, particularly the US and UK, have been widespread and deep. In recent years, community awareness/ anti-stigma campaigns, in which many consumers have been involved, seem to be having some positive impacts on social attitudes about people with mental health issues. Mental health seems a more acceptable discussion topic.

The movement is going through an exciting and activated time – with talented leadership, often with professional qualifications and entrepreneurial flair; growth in numbers, influence and sophistication of operations and issues; increasing cohesion and camaraderie; and an influx of young people who are tech savvy, energetic and full of ideas.

There has been a rapidly increasing range of Consumer-designed projects, services, programs, and publications. But there is still so much potential and many problems still needing to be addressed.

The proposed methodology is a form of qualitative synthesis, intended to accommodate the sorting, selection, synthesis, interpretation, and discussion of a somewhat wide and disparate range of consumer-generated qualitative Research and Development reports and significant “grey literature” documents, with a range of methodologies, styles and content, which have informed discussion and debate over the past approx. 30 years post-deinstitutionalisation.

This researcher will work to ensure that the adapted qualitative synthesis approach to be used, while allowing for some flexibility based on consumer lived-experience knowledge and generally less formalised and linear approaches in the source materials than regular academic research, the required overall veracity and transparency remains a high priority . The study will rely mainly on consumer-generated documents, and some reports from collaborative projects with services or academia. The proposed study will review and synthesise existing documents and will not involve any new interviews, focus groups or surveys.

Five key "high-activity" domains emerging in the scoping of the project:

1. THE CONSUMER MOVEMENT AS A LEADING SOCIAL CHANGE/ HUMAN RIGHTS GROUP OF ITS OWN ACCORD:

· Many people within the consumer movement choose to work in advisory or project roles, such as Consumer Consultants within MH services, described as working “collaboratively” as “advocates” of positive change “from the inside of the system.” This often involves a balancing act.

· With a wide spectrum of beliefs regarding the medical model of psychiatry, some consumers choose -- or circumstances dictate -- to work as activists “outside the tent” of the system -- believing they can speak out more freely. Some activists may uphold banners such as “Mad Pride” thus re-appropriating pejorative term in a similar way to how GLBTI activists embrace the word “queer.”

· There are strong influences of the Civil Rights Movement of the 1960s and '70s and consumers may identify as "survivors" of the psychiatric system.

· Aspirations towards a movement based on participatory democracy, valuing the "lived experience" of consumers, and aspire to hearing even the quietest voice.

· A strong sense of mission; seeking its own sense of a facilitative, enabling, "mentoring" leadership style;

· Strong, reasonably well-defined and coherent set of epistemological and ontological traditions, social justice, and human rights values;

2. CONSUMER PARTICIPATION AS A KEY PROCESS IN MENTAL HEALTH SERVICES:

· Consumer Consultants and Consumer Advisory groups are the focus of growing area of activity.

· This includes: systemic Advocacy towards service improvement, innovation and change.

· Consumer Information, Forums, Education, Surveys, etc.

· Growing Consumer role in Service Standards, and Clinical Governance.

· Consumer participation in Staff Selection Panels.

· Participating in Service Improvement and Development Projects.

. debates are taking place about what is true "consumer perspective."

3. INDIVIDUAL ADVOCACY AND STATE-WIDE AND SYSTEMIC ADVOCACY:

· Embedded Consumer Membership of the government statutory bodies and panels around the amended Mental Health Act of 2014.

· Working as an active partner in the implementation of the much-amended Mental Health Act of 2014.

· Working collaboratively with Victorian Government on the new 10-year mental health plan.

· Co-development of a diverse Lived Experience Workforce, with government, services and carers.

· Consumer run Internet, social media, video, arts, music, community education projects, and growing collaboration with alternative cultural spaces and forums, such as creative writing, storytelling for change, and pop-up community learning venues.

4. CONSUMER "LIVED EXPERIENCE" WORKFORCE BASED SERVICE DELIVERY, INCLUDING PEER SUPPORT:

A major growth area for the consumer movement in Australia, in what has become known as the lived experience workforce, is for the employment of such people in direct service roles, including new and innovative approaches. In this major breakthrough, some areas include:

· Many Peer Support Workers becoming employed in Mental Health Community Support Services and clinical service jobs, including new programs such as Peer Hubs.

· Trauma informed services with consumers involved in all stages of development and delivery.

New methods like Recovery Colleges, Recovery Camps, Hearing Voices Vic(which aims to be *non-judgemental* of the experiences of consumers and affirm people's search for what is meaningful to them.)

Trauma informed services which have had consumers involved in all stages of development and delivery, including the Open Dialogue approach and Intentional Peer Support. (IPS.)

Consumer run services now exist to support, inform, and help advocate for consumers applying for NDIS coverage. (eg, VMIAC)

Mental Health First Aid and alternative methods of suicide prevention, such as Alt2Su (Alternatives to Suicide).

Consumer run Internet, social media, video, community radio, arts, music, drama, community education projects, "Mad Pride" comedy events, alternative cultural spaces.

The consumer movement, in many ways, has increasing links and is present within large numbers alternative community venues such as creative writing, storytelling for social change, performance poetry events, pop-up community learning venues, including numerous "Meetup" groups. Such spaces, apart from their inherent value, can help reduce social isolation and promote personal recovery.

5. CONSUMERS' GROWING ROLE AS RESEARCHERS AND EDUCATORS:

The involvement of the consumer movement as researchers in many settings is a burgeoning area of interest and activity. There are now dedicated dedicated Australasian conferences on consumer research – such as the Servcice Users Academia Symposium in its ninth year in 2019 – and several consumer conferences with a high research component, and emerging innovative events.

· Consumers are becoming more widely involved as Educators and Trainers for service providers and fellow consumers with a focus on recovery-based methods.

There are increasing numbers of of consumer generated Research and Development reports, articles, and social media materials,building up daily, within the realms of consumer organisations, academic organisations and service provider sites. There are growing numbers of Consumer Academics carrying out specialized work at universities in Australia, reflecting trends here, and including the US, UK, New Zealand, and parts of Europe.

A project called Learning Together: Education and Training Partnerships in Mental Health, in 1999 as part of the National Mental Health Strategy has become known as "The Deakin Papers," and made an enduring case for consumers as educators and researchers. Merinda Epstein and Daniel Rechter as reference group delegates, wrote (1999). 24

"If we can guarantee the valuing of consumer perspectives, then we can begin to differentiate various roles users might have as representatives of our body of expert knowledge: as consultants, educators and trainers…As consultants to services our role is one of change agent. Where individual users are unable to articulate what they want, because such services cannot be imagined in the present, or more commonly they are not being listened to, consumer consultants can function as a kind of 'litmus test' for change."

The mental health consumer movement and lived experience workforce has intensively developed and brought into the mental health field a valuable collection of research tools and methods,

consistent with its broad collective knowledge, insights and skillsets. These include largely qualitative research and development approaches, which are now becoming widely used in the field, in rewarding ways. These method, involving much creative input from consumers, often in collaborative projects with various services often with a Community Development influence, include: Participatory Action Research, Strategic Questioning , Co-production research, Experience Based Co-design; Co-production research (where consumer researchers are, ideally, equal partners); using online survey software like Survey Monkey in particular ways; various types of workshops and focus groups; and many more methods, which have been very productive, even in difficult "stuck"areas of policy and practice. Not only could these approaches "capture" consumer experiences in the system or their social experiences. They could bring out other dimensions beyond mere "feedback" encourage consumers to reflect on what things would really help them, how the systems could be better run and set up, ideas and aspirations of hope and personal recovery, community participation, and get many opportunities to express these things.

· The volume of consumer generated Research and Development writings within the academic and service provider worlds is rapidly increasing. There are growing numbers of Consumer Academics carrying out specialized work at universities. This is like trends in the US and UK, where consumer/ survivor research is burgeoning.

· Consumer Co-production Research and Development is becoming increasingly welcomed and accommodated by services, consumer groups, and in the academic world as a source of data which is enriched within an environment of cooperation, seeking common understandings. (Some examples of consumer research appear in other parts of this document.)

Consumer research "manifestos" in UK and Australia

Comprehensively designed prospective research agendas -- or "manifestos"-- have been formulated by the Australia-based Consumer-Led Research Network NSW Consumer Led Research Network, 2016), and The UK's National Survivor Research Network with many project ideas. (National Survivor User Network, (2018).

Australian network convenor Dr Katherine H Gill, wrote (Summer, 2017-18) 51 about the growing role of consumer researchers in mental health, and growing official recognition.

"Consumer researchers are not just researchers with a lived experience of mental illness/ mental distress, but researchers who are skilled at harnessing their lived experience purposefully, alongside their professional training, experience and qualifications, to contribute to the research at all stages throughout the research processes…"

According to Gill, there was no shortage of qualified consumer researchers but there was a shortage of opportunities to participate.

In 2000 Cath Roper was appointed as Australia's first Consumer Academic at the Centre for Mental Health Nursing Research and Practice, Melbourne University. She wrote (2016) about what consumer perspectives could contribute to co-production research.

"Over time consumers have developed unique ways of knowing, theorising and thinking about those experiences that constitute a unique discipline in the field of mental health, known in Australia as 'consumer perspective.' When using consumer perspective, consumers 'offer their own *analyses* of their experience and the services and systems they encountere.' 18.

"An explicit goal of co-production is to reposition people who have traditionally been thought of as passive 'consumers' of services to being regarded as people with necessary expertise who can lead thinking and innovation." 19.

Such methods can support a consumer perspective approaches , with an enhanced focus on consumers' experiences, responses, and suggestions for change; they can encourage a sense of inclusion and collaboration for participants; and foster a reflective, holistic approach to solution seeking, including a focus on factors which can contribute towards consumer recovery and enhanced awareness of broader social determinants of health.

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• *My Masters project was supported by an Australian Government Research Training Program Scholarship.*

Allan Pinches _ bio notes:

I bring to the study more than 25 years' experience of consumer advocacy roles in the mental health sector, particularly as a Consumer Consultant for Mental Health -- an advocacy, service improvement, and consumer facilitation role based on lived experience of mental health difficulties, acquired knowledge of mental health services and collective consumer movement knowledge.

I believe my lived experience of mental ill health, my own undulating recovery journey, and my work in the field would permit me a reasonable licence for participant observation in this project, including navigating source materials within the study. My mental health difficulties and personal loss and grief issues are probably similar to many who have gone through the "mill of mental illness" and somehow survived -- partly through special "peer support" friendships among fellow consumers.

I bring a complex consumer “lens” to this Masters project including: essential knowledge on consumer themes, events, debates, successes and setbacks over time in which I was often an active participant. I have also collected my own large and intentionally formed archives of consumer - generated research reports and writings, in both hard-copy and digital form. I will also canvass for suitable reports from broader consumer networks and regular data bases.

As a former journalist, whose much-loved career was cut short by a devastating breakdown, I have found solace in becoming something of a chronicler of the mental health consumer movement, with articles appearing in various consumer-friendly journals and on the internet, as well as project documents and research papers.

In 1990 I became the first consumer to serve on the board of the Richmond Fellowship of Victoria (now Mind Australia) and remained for 12 years. From 1995 to 2002 I also served on the board of Neami Inc, (including a period as Vice-President.)

I have played key leadership roles in many service improvement projects, through my work as a Consumer Consultant with Northern Area Mental Health Service. Two projects I initiated won national TheMHS Conference Awards.

In these roles, and through a combination of practical experience and formal studies, I have developed many skills such as group facilitation, training and development, social research, project work, and a working knowledge of public health policy and practice, including strategic thinking. I aim for a facilitative approach which would “bring forward the best knowledge in the room.”

I graduated with a Bachelor of Arts in Community Development (VU), in 2004. In that year, I self-published a report “Pathfinders,” a progress overview of consumer participation, based on my final research project: Pinches, A. (2004).

My most recently completed project was Principal Researcher in a project funded by a competitive Fellowship grant from the Department of Health and Human Services Fellowship grant project towards the possible establishment of a peer support program at the Northern Community Care Unit within the City of Darebin. The final report was titled: The Northern CCU Peer Support Research and Development Project: “Putting the community into Community Care Unit.” (Pinches, 2011.)