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Moving from 'stigma reduction' to 'inclusion': development of the inclusion collaborative at Nepean Blue Mountains Local Health District, New South Wales

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Abstract

This commentary outlines the development of an Inclusion Collaborative in a large health district in Sydney, New South Wales Australia. The Collaborative grew out of ongoing efforts to reduce stigma associated with blood borne viruses while recognising that there are many health conditions and situations where people feel judged when attending services for health care. The formation of the Collaborative drew in health workers in other sectors to create a critical mass of voices calling for stigma reduction, move beyond siloed responses to stigma and to reframe conversations about stigma to a more positive description of "inclusion". The involvement of consumer representatives (paid for their time) was a key principle of the Collaborative. The members of the Collaborative identified the common experience of their clients being 'othered' by the mainstream services and that services can be unwelcoming or not supportive of difference, and therefore create a significant barrier to accessing healthcare. The group considered ways to highlight these issues among colleagues from mainstream services and community members who were not 'othered'. The Collaborative designed and carried out a range of activities including a Festival of Inclusion, a series of seeding grants for staff and consumer-focused initiatives, promotion of diversity days and an audit of compliance with strategic priorities. The Inclusion Collaborative is an example of a structured approach for efforts to reducing stigma that draws on the ambitions of many parts of a large, complex public health service to deliver better outcomes for its staff and consumers.

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Introduction: why stigma matters for quality health care

Stigma and discrimination in health care are barriers to people feeling safe to seek the care they need [1–4]. Stigma frequently results in unnecessary suffering, poorer health outcomes, poor experiences and additional costs for the community and health system [5]. Stigma is a social process whereby people are excluded or treated differently by others based on health conditions, identities, and practices that are judged or viewed negatively by members of society. Stigma can manifest in structures (in laws, media, societal norms), organisations (in policies and procedures), interpersonally (in language, behaviour), and intrapersonally (in beliefs of self-worth and esteem) [6].

The 2018 Lancet Commission noted that quality of care is worst for people living with stigmatised conditions and those at the edges of the health system [7]. The literature on stigma reduction tends to be silo-ed by disease or condition, with limited evidence for interventions that address institutional or structural levels of stigma [5, 8], providing little guidance for health services which seek to have a system wide impact. This commentary outlines an approach taken in one Local Health District (LHD)[1] in western Sydney, New South Wales (NSW) Australia that used strategic levers and multi-sectoral collaboration in efforts to reduce stigma for the diverse community that it serves.

Strategic drivers to address stigma in health care

Nepean Blue Mountains Local Health District (NBMLHD) is one of fifteen public health districts in NSW and is responsible for the delivery of local health services across a wide range of settings. NBMLHD is tasked with the de-centralised delivery of public health care for residents within its 9,179 square kilometre boundary. The LHD is home to one large teaching hospital and 5 district hospitals, as well as a wide range of outpatient and community-based services. These services include health protection, primary prevention, early intervention, and chronic care programs. The 2021 census estimated the population of NBMLHD to be 384,742 residents. Of these people, 11% are aged over 70 years, 4.7% identify as Aboriginal or Torres Strait Islander and 20% were born overseas [9]. Approximately 70% of the 6,647 dedicated staff reside either within the Nepean Blue Mountains Local Health District or its surrounding postcodes. This means that many staff have a dual role as both employee and consumers of LHD services, also often caring for people who are their neighbours, family, and friends.

All services within the LHD must adhere to national standards and NSW strategies for health care and staff employed must adhere to the CORE values set out by NSW Ministry of Health. These CORE values (Collaboration, Openness, Respect and Empowerment) are the underpinning philosophy for the NSW public health workforce to ensure that all people employed or seeking care feel safe and are respected. In addition to the NSW Health CORE values, NBMLHD have adopted a local set of guiding principles known as SAFER values. Safety, Agility, Fairness and Equity, Excellence, and Resource Effectiveness enshrine the intentions of local healthcare service delivery.

The Inclusion Collaborative was developed in alignment with these values and principles along with several key national and NSW strategic priorities and builds on contemporary understandings of how to deliver best quality care. The Australian Commission of Safety and Quality in Health Care, sets the standards which are key to the accreditation of health services across the country. Standard 2 (partnering with consumers) is centred on the recognition that trust and mutual respect are needed for best health outcomes [10]. In addition to these overarching documents, each state and territory in Australia has multiple strategic priorities across the health system for addressing specific issues, or health conditions. For example, the Diversity, Inclusion and Belonging Guide [11] indicates the commitment of the NSW Ministry of Health to welcome people of diverse backgrounds and build a workforce that reflects the diversity of communities that it serves. While each of these strategic and high-level policies referenced closely related concepts, the impact of stigma and its effects on health care access and health outcome were not directly included. The Inclusion Collaborative sought to orchestrate a "strategic collusion", that is, drawing together concerns of stigma with those of quality care [12]. While acknowledging that these are not equivalent, the Collaborative aimed to build an approach that was feasible for the LHD executive to support, and which delivered them action towards each of these strategic drivers.

Forming alliances for a sector wide approach to stigma reduction

The impetus for this Collaborative came from the HIV and Related Programs Unit which has decades of experience working to reduce the impacts of stigma in health care for people living with and at risk of HIV and hepatitis C. Despite this experience, the team was simultaneously challenged to create work that leads to a meaningful cultural change in a large health organisation. During brainstorming sessions, the team identified three

[1] LHDs manage public hospitals and health services within the state of NSW, Australia. There are 15 LHDs in NSW covering specific geographic areas; eight cover the Sydney metropolitan area and seven cover regional and rural areas in NSW. See: https://www.health.nsw.gov.au/lhd/Pages/default.aspx.

key aspects that may be hindering progress in reducing stigma. Firstly – HIV and hepatitis C services do not 'own' stigma. There are many health conditions and situations where people feel judged when attending services for health care. Indeed, Pachankis and colleagues [13] developed a taxonomy of 93 stigmatised attributes, identities, and conditions, with their survey research indicating that participants in the United States held, on average, six of these attributes, identities, or conditions. Researchers have highlighted the need to move beyond siloed responses to stigma that focus on individual conditions if we are to tackle stigma as a whole [14]. Secondly, talking about stigma is difficult as health workers do not view this as applying to their own behaviour. Researchers have long discussed the impact of social desirability bias, where people may provide answers based on societal norms and expectations, rather than their own beliefs, to avoid embarrassment and social disapproval [15]. Health workers may genuinely believe that they provide equitable care for all, thus the team identified a need to reframe conversations about stigma. The team believed that reframing 'stigma' to talk about 'inclusion' there was likely to foster broader appeal, less implied criticism, and a positive lens to this issue. Finally, the team believed that there is strength in numbers so by reaching out to colleagues across a variety of traditional silos it would be possible to explore whether a shared concern would emerge.

Inspired by the enthusiasm of colleagues across the District, the HIV and Related Programs team, invited a diverse group of services to nominate a representative to come together and discuss issues of inclusion specific to their populations, and then to identify their shared concerns. It was evident that while labels may vary, the service representatives reported the common experience of their clients being 'othered' by the mainstream services and that services can be unwelcoming or not supportive of difference, and therefore create a significant barrier to accessing healthcare. The group considered ways to highlight these issues among colleagues from mainstream services and community members who were not 'othered'. They encouraged a positive reframing of their collective concerns with the shared vision that by creating a more inclusive environment, these experiences of health services and health outcomes can be improved. The Festival of Inclusion was endorsed as the first activity of the newly formed alliance.

Festival of inclusion (FoI)

The inaugural Festival of Inclusion (FoI) (held 1–5 March 2021) started on Zero Discrimination Day with the aim of promoting inclusion and breaking down barriers and misconceptions about marginalised populations among staff and communities of the district. Through the week-long event, the LHD was able to demonstrate a commitment to equity via presentations, events, curated conversations, workshops, and media. The objectives of the FOI were to:

- Promote inclusion of minority and marginalised groups, across NBMLHD services;
- Recognise and pay tribute to the cultural, social, and economic diversity of NBMLHD staff and communities;
- Promote the NSW Health CORE Value of 'respect', and the NBMLHD-SAFER value of 'fairness and equity' to ensure that 'care' is central to all local health care;
- Begin addressing stigma in health care and improve health outcomes; and.
- Provide information and education on how better to support marginalised populations.

The inaugural FoI provided a platform for conversations and experiences about the impact of discrimination, stigma, and bullying, through the sharing of lived experiences; this enabled staff to reflect on strengthening inclusive practices in their workplace. The activities aimed to encourage managers to consider the diverse needs of staff and to begin addressing some of the challenges that may be present within teams. The focus of the FoI was to communicate to all staff that inclusion was a core principle of NBMLHD operations and provide an opportunity to examine workforce and organisational culture.

In the first year, eleven NBMLHD services embraced the initiative, collaborating on behalf of their frequently marginalised consumer populations, and actively participating in the delivery of FoI content. These services included: Drug & Alcohol; Mental Health; Aboriginal Health; Multicultural Health; Sexual Health Clinical Service; Family Metabolic Services; Health Promotion; Disability Services; Needle and Syringe Program; Sexual Health and Blood Borne Virus Health Promotion Team; and Clinical Governance via their Consumer Engagement team. These services were supported by Corporate Communications and the newly formed Workforce People and Culture – Inclusion and Diversity Team.

This initial planning group was keen to ensure that the voices of consumers would be heard. This resulted in the production of a powerful video called Frank Conversations. Throughout the video, consumers and culturally diverse staff members share experiences of being 'othered' by a system which is set up to provide care. The video was launched at the opening address of the FoI and was a poignant and important reminder of why this work was necessary. Delivered in a sensitive and honest way, LHD staff were able to hear the reality of the human experience without blame or accusation. It was a

reminder that LHD services and staff have opportunities to improve health care delivery.

The FoI was conducted with no dedicated budget. The group focused on 'easy wins' by using existing content as much as possible. Service representatives provided links to events, interviews, articles, and education opportunities that highlighted the diverse voices and experiences of consumers and staff.

Marketing and promotion of the week was managed by the LHD Corporate Communications Team who created a dedicated online space to host the FoI's weeklong calendar of events, an Activation Kit, and regular promotions. In addition to the video *Frank Conversations*, the Aboriginal Health Unit (in partnership with Nepean Studio Productions team), created an ambitious new short film entitled 'Yarning'. This video highlighted Aboriginal staff who shared their experiences in an effort to reduce the impact of discrimination. These powerful short videos both featured in the FoI launch. Other resources developed for launching during the FoI included a series of inclusive service factsheets for people with disability, a staff survey undertaken by the Mental Health service to measure experiences and attitudes to stigma and discrimination, and staff training implemented by Drug and Alcohol Services to empower staff to speak out when witnessing these negative behaviours.

The FoI was opened by and received endorsement from the Chief Executive and the Board Chair of the Local Health District. The official proceedings included a video interview between the Chair and eminent jurist and human rights lawyer and advocate, Justice Michael Kirby. Efforts were made to ensure that the program highlighted each of the specific content concerns represented by the group. It was produced in a way that was entertaining and empowering, providing several opportunities to access information, self-directed education, relevant new resources and documents, links to popular media such as the inclusion of two recommended episodes per day of the ABC's *You Can't Ask That* television series which provides insights into the lives of marginalised populations which matched key populations represented in the District, and self-assessment tools such as the Harvard Implicit Association Test (IAT). The IAT is not a diagnostic tool, but rather a set of publicly accessible questionnaires that help to measure attitudes and beliefs about concepts and stereotypes that people may be unwilling or unable to report. Given the restrictions of the COVID-19 pandemic at that time, most of the content was delivered online, and in an on-demand format, allowing staff on shift to engage with material at a convenient time.

Inclusion collaborative

The inaugural FoI showed that there is interest among staff for breaking down existing silos and creating relationships to facilitate an exchange of skills and information, and the identification of opportunities to collaborate on shared priorities. The FoI has transcended the weeklong event and now serves as a new model for collective impact - the Inclusion Collaborative representing workforce and consumers. The goal of the Collaborative is to contribute to organisational cultural change and grow the momentum for inclusive practice in all services across the LHD. The aims of the Collaborative underpin the vision, values, and goals of the LHD to drive innovation and excellence in health service delivery.

The Collaborative is committed to creating a positive, sustainable culture shift within the LHD. Co-chaired by two distinct departments of the organisation; Population Health and Workforce People and Culture, the Collaborative brings together representatives from participating services committed to working both collectively and independently on issues that inspire continued improvement and culture shift that further builds inclusive practice across the continuum of care. This collective approach aims to contribute to building an inclusive health service which recognises, values, and celebrates diversity of culture, language, religion, socio-economic status, and the human condition. Members continue to develop shared initiatives, while looking inward at practices and opportunities for improvement within their own teams. Outcomes of both these approaches will be highlighted annually across the broader LHD during the FoI.

The work of the Collaborative aims to reinforce the strategic expectation of shared commitment and identify practical ways to support a culture which: recognises and values the diversity of our workforce, generates greater understanding of the needs of our changing consumer populations, and improves access to health care and health outcomes.

In addition to the working group established to plan the annual FoI, the Collaborative has since created two working groups to help progress and embed activities at the LHD wide level. These two groups are responsible for (a) a Seeding Grants program and (b) a calendar of Diversity Days. The Inclusion Collaborative also undertakes shared projects to support strategic change.

Seeding grants

Seeding grants are offered to all teams across the LHD. The rationale for this is the recognition that barriers to inclusive practice are best identified and addressed by those working within specific services or teams, together with the support of their managers and engagement of their consumers and/or staff members. In short, this means that if any staff member has an idea that could promote inclusion and reduce barriers to care, the Collaborative will consider funding it.

The cost of funding the grants program is shared by the two lead partners, Population Health and Workforce People and Culture, with each contributing a small amount. This funding pool allows for two project streams [1] staff focussed initiatives and [2] consumer or population focussed initiatives. Each stream offered approximately five small project grants. Overall the Grants Program aims to:

- Support staff to undertake projects with a focus on improving inclusive practice for consumers and/or staff; and.
- Provide a supportive framework that facilitates these changes in practice, with the intention of ongoing sustainable quality improvement.

See Appendix for examples of projects funded in this scheme.

Diversity days

The competition for focus on specific 'health days' is fierce, as every day sees another condition or concern fighting to capture the interest of health workers and the public. For this reason, the Collaborative determined that the focus of any promotional materials they produce should be on the 'human' condition, rather than the 'health' issue; that is, to focus on the experience of the person rather than awareness of a health condition or disease. The calendar is carefully curated to highlight positive opportunities to make a difference and promotes opportunities to reflect on he lived experience of the affected population.

The working group ensures that the year is peppered with opportunities to reflect and act on days of diversity that capture the importance of inclusion. The year begins with Zero Discrimination Day and then includes: Refugee Week, NAIDOC Week (National Aborigines' and Islanders' Day Observance Committee Week which celebrates the history and culture of Aboriginal and Torres Strait Islander Australians), Wear it Purple (annual LGBTIQA+awareness day), International Day of Older Persons, Mental Health Month, Carers Week, World AIDS Day and International Day of People with Disability. Each of these days provides a chance to share experiences and to profile the importance of person over health condition.

Examples of strategic changes to date

Paying consumer representatives for their expertise Essential to the success of the Collaborative is honouring the voice of consumers. At the point of establishment, an expression of interest was circulated via the consumer engagement network of the LHD, seeking input from two representatives who identified with the purpose of the group and could speak to issues of stigma in healthcare. The initial callout resulted in three passionate consumers whose experiences crossed issues related to disability, mental health, transgender identity, and severe obesity. Two consumers were appointed with the third acting as a proxy when required.

From the outset, the process of engaging consumers highlighted a gap in LHD processes, in that there was no formal mechanism in place for payment. This became one of the first tasks of the Collaborative and after lengthy negotiation and process development, an agreement was reached, and processes put in place to ensure that consumer representatives are appropriately remunerated for their time and expertise. This success was celebrated as an achievement, and the consumers were each back paid commensurate with their participation throughout that previous year. This payment system is now in place and has been adopted by other projects which require the voice of consumers. This was seen as a key success of the Collaborative, as it ensures that the skills and expertise of consumers and people with lived experience of stigma are appropriately recognised and remunerated.

A toilet audit for inclusion The Collaborative conducted an audit of the signage on the toilets located in Community Health Centres across the LHD. There has been debate around the world regarding inclusive/exclusive nature of access to public toilets [16]. What remains central to these conversations is the right of all people, regardless of age, gender, ability, or religion to safely access these essential public spaces. The primary purpose of the audit was to review current practices within the NBMLHD Community Health Centres and to recommend signage that would promote equitable and inclusive access to toilets for everyone, regardless of gender. In achieving this there are benefits for multiple groups. Site visits were made to 11 facilities across the LHD. A total of 69 individual toilets were audited, with findings including.

- 21 toilets already had signage that was gender inclusive and required no change. These were either single toilets with sinks in a lockable room, or individual enclosed toilets with a common sink area.
- 44 toilets were gendered but considered amenable to change requiring a simple change to signage.
- 4 toilets were in stalls so would require further consideration and as such may not be amenable to change.
- No toilets with urinals were found.

As a result of the audit and a review of current literature, a set of recommendations have been made to the LHD Executive. These recommendations show that at minimal cost, minor changes could be made to signage which would remove barriers and ensure that no staff or

visitor is made to feel uncomfortable or excluded from LHD bathroom facilities. The recommendations are currently being reviewed with the hope of the changes being adopted across Community Health facilities, followed by an LHD wide roll-out.

Lessons learnt

The Inclusion Collaborative is an example of a structured approach to reducing stigma that draws on the ambitions of many parts of a large, complex public health service to deliver better outcomes for its staff and consumers. By reframing stigma reduction efforts to focus on inclusion, and drawing on local, state, and national priorities for quality service delivery, the Inclusion Collaborative has been able to involve more than a dozen clinical and professional divisions across the LHD. This is important, as many services seek to reduce stigma and build inclusion for their consumers. Although the program started with the HIV and Related Programs Unit, the appeal of this idea was seen by a diverse range of groups as core to their mission.

Beyond involvement of clinical services, the involvement of the Workforce People and Culture division is vitally important to the Collaborative. There are statutory requirements for employers to proactively support the health, safety, and wellbeing of their employees. Drawing in the institution (via this division) to consider inclusion (or stigma reduction) as relevant to employees is a further way to embed the work of the Collaborative in business-as-usual operations, rather than seeing this program as peripheral or a temporary "add on" initiative.

Stigma reduction programs benefit from champions at all levels from the top of the organisation. The Collaborative sought and received support from the highest levels of the LHD – its CEO and Chair in endorsing and opening the inaugural FoI. The Collaborative sought and received very modest funding to draw attention to its goals and foster champions within services who were resourced to take on projects in their own setting to influence local practices and culture.

The stigma reduction literature points to the need for multi-level interventions but acknowledges that most interventions have focused on staff training [5], as programs to challenge institutional and structural stigma are much more difficult and expensive [17]. The Collaborative has found ways to promote change at these levels. Examples of achieving appropriate payment for consumer expertise, funding small grants to promote inclusion, and producing low-cost changes to inclusive bathrooms indicate what is possible when there is systems-wide collaboration to uncover and act on instances of exclusion and stigma. Further evaluation is needed to examine impact of these activities on access to health services, quality of care, staff attitudes and practices, and on other policies and procedures.

The impetus for the Collaborative came from the HIV and Related Programs Unit. However, this team found like-minded colleagues from many areas of the wider LHD. Bringing together related concepts of stigma, quality, equity, respect and inclusion allowed this work to be framed positively, and to meet a number of strategic priorities of the health service. While the changes achieved by the Inclusion Collaborative to date have been modest and the need for further evaluation remains, the appetite to continue to find and make them is large. Breaking down silos and working with a shared purpose has been integral to the successes, however this can appear to be to be a challenge to the governance structure of a large bureaucracy. Governance across a variety of 'silos' requires a novel approach and willingness to work cooperatively at every level of the organisation.

Supplementary Information

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Supplementary Material 1

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Author contributions

LM conception, design, drafted and revisions BL conception, design FS conception, design AW conception, design JB conception, design LO'C conception, design MCB conception, design LS conception, design UT conception, design DM conception, design LH conception, design EC drafted the main manuscript and revisions CT drafted the main manuscript and revisions All authors reviewed the manuscript.

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