

# PALLIATIVE CARE IN PRISONS PROJECT

UTS: IMPACCT

## Message from Project Lead

PROFESSOR JANE PHILLIPS



Welcome to Issue 4 of the Palliative Care in Prisons (PiP) Project Newsletter. It has been a busy start to 2021 for the PiP Project, and we are excited to share our progress with you.

This Newsletter showcases our stakeholders from Victoria – Investigators Professor Jenny Philip and Dr Stacey Panozzo, and Project Partner Christine Fuller from Correct Care Australasia.

As April 15, 2021 marked the 30th anniversary of the 1991 Royal Commission into Aboriginal Deaths in Custody, we considered it was timely to ask our colleagues A/Professor Megan Williams and Professor Liz Lobb to provide some insights into the impact of disenfranchised grief and unresolved bereavement on people in prison and their families (page 2 and page 3).

I am pleased to report the PiP Project team has made considerable progress with NSW ethics. Given the complexity of the ethics applications process, we have decided to focus on collecting comprehensive baseline data only. This will give us more time and resources to put towards the co-design process. Figure 1 below, depicts the Overview of the PiP Project Gap Analysis and helps to illustrate the different elements of the new design.

We hope you enjoy reading this Newsletter and thank you again for your continued support of the Project. Please do not hesitate to get in touch with myself or the team, should you have any questions or comments.

Kind regards,

Jane Phillips

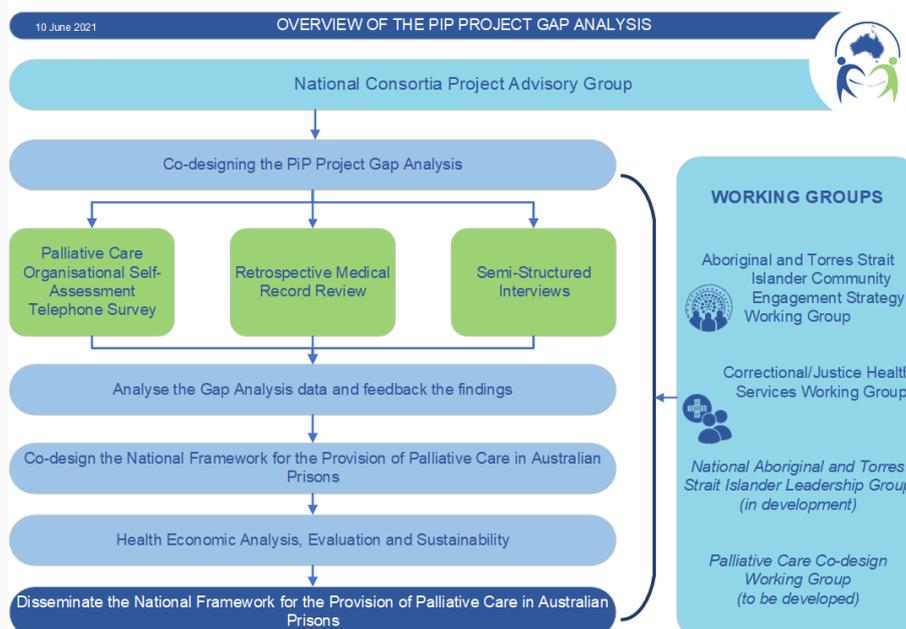


FIGURE 1-Overview of the PiP Project Gap Analysis

# ABORIGINAL AND TORRES STRAIT ISLANDER BEREAVEMENT IN PRISON

A/PROFESSOR MEGAN WILLIAMS



I was a grade 12 student on April 15, 1991, when the recommendations of the Royal Commission into Aboriginal Deaths in Custody were released. I was shocked by the extent of Aboriginal and Torres Strait Islander deaths then, and even more shocked in 2001 when one of my own cousins died in a prison I'd briefly worked in. April 15, 2021 marked the 30th Anniversary of the Royal Commission recommendations calling for comprehensive social change, prison safety reform, investigations into prison deaths and juvenile justice diversion programs. Private consultants claim most recommendations have been implemented. However scant evidence exists to support these claims, as argued in an [ANU](#) paper I co-authored with colleagues. More deaths in custody have occurred, including five in the weeks preceding the 30th anniversary.

People in prison have worse health outcomes than those in the community. Incarceration rates of Aboriginal and Torres Strait Islander people are increasing, reflective of a 78% increase in the last decade in prison population incarceration rates of those aged over 45 years. Aboriginal and Torres Strait Islander people account for 20 per cent of all deaths in custody despite being 3 per cent of the community ([ABS, 2020](#)), yet there is no strategy for highly effective Aboriginal and Torres Strait Islander community controlled health services to work in prisons, and severe limits on prison visits even outside a pandemic.

Aboriginal and Torres Strait Islander people can hardly be expected to escape compounding trauma and disenfranchised grief. An Aboriginal and/or Torres Strait Islander person passing on in prison, away from family and Country – it's the most inhumane thing I've known in my almost 30 years of working. The coronial process that follows can make it worse. Together with a Koori family, we are writing a submission to the [Select Committee on the coronial jurisdiction in NSW](#). We urge others to do the same, by June 27, 2021.

See more from Megan at [Croakey's #RCIADIC30Years](#), [#RuralHealthJustice](#) and [The Conversation](#).



 **HEAL COUNTRY!**

**NAIDOC Week**  
4-11 JULY 2021

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## NATIONAL ABORIGINAL AND TORRES STRAIT ISLANDER LEADERSHIP GROUP

Recruitment for the National Aboriginal and Torres Strait Islander Leadership Group is happening. This group will be a key structure through which Aboriginal and Torres Strait Islander people help shape the PiP Project, its research and the National Framework for Provision of Palliative Care in Australian Prisons.

We are seeking participation of Aboriginal and Torres Strait Islander community members who have experience in palliative care, prison health service delivery and palliative care in prisons – professional and/or personally – to join us. We will meet online, and can provide sitting fees.

An invitation to the Leadership Group is attached.

All project partners and any people you know who may be interested in membership are welcome to attend the first meeting, date to be advised. Let Megan Williams know if you are available to join on:

[megan.williams@sydney.edu.au](mailto:megan.williams@sydney.edu.au)

# DISENFRACTISED GRIEF AND UNRESOLVED BEREAVEMENT IN PRISON



PROFESSOR LIZ LOBB

Disenfranchised grief has been described as the grief that people experience when they occur a loss that is not, or cannot, be openly acknowledged, publicly mourned, or socially supported. It recognises that societies have “grieving rules” that attempt to specify who, when, how, how long and for whom, people should grieve (Doka 1999). Society sets rules and assigns sympathy to people who experience loss. People who are in prison, and their families, can experience disenfranchised and ambiguous grief at many levels which may not be socially accepted, supported, or even recognised.

The identified losses of prison life include the loss of liberty, family contact, material possessions, sexual contact, privacy, personal autonomy and personal security (Hendy 2009). It is important to recognise that not all grief reactions result from a death. Grief is a normal response to loss and the family and friends of people who are incarcerated can experience disenfranchised grief. Families of people who die in prison may have to deal with the possibility of them dying alone, with no family present to support them, no last goodbyes, and no opportunity for reconciliation. For people in prison, dying in prison may mean the lack of opportunity to atone for their behaviour, which would come from the opportunity of reconnecting with family and living as a law-abiding citizen (Aday & Wahidin 2016).

In disenfranchised grief often, the relationship with the person who is incarcerated is not recognised, the death is not acknowledged, the griever is not recognised and this will inevitably influence the ways in which these individuals grieve. The period of internment can also lead to disenfranchisement of siblings and other family members such as grandparents, skin ties, step parents and other relations.

The grief can be intensified after the death as usual social supports are missing and often there are intensified reactions for families because of the physical exclusion of family members from the dying process and the inability to participate in meaningful rituals. The concurrent crises that many families face when perhaps the breadwinner of the family, or a parent is incarcerated and then dies can also be a risk factor for bereavement.

Ways in which we can help those bereaved by a death in prison is by showing sensitivity to the loss, validation of the loss and the power of naming what has been lost (Aday & Wahidin 2016).

Grief is not a time bound process that ends in detachment either when the person is incarcerated or when they die.

[1] Doka, KJ (1999) Disenfranchised grief, *Bereavement Care*, 18:3, 37-39.

[2] Hendry, C (2009) Incarceration and the tasks of grief: a narrative review. *J. of Adv Nursing* 65(2), 270-278.

[3] Aday, R & Wahidin, A. (2016) Older Prisoners' Experiences of Death, Dying and Grief Behind Bars *The Howard Journal of Crime & Justice* Vol 55 No 3. September.

## PROFESSOR JENNIFER PHILIP

Professor Jennifer Philip and Dr Stacey Panozzo collaborate in their work within the Palliative Nexus research group, University of Melbourne and St Vincent's Hospital. Jennifer is a palliative care doctor and researcher whose clinical work in consultation services and health services research interests have led to developing and testing improved models of palliative care delivery to patients with brain tumours, COPD and in the emergency department.

Jennifer leads the Palliative Nexus research group, a vibrant academic research team which has a particular focus on improving equity in the delivery of supportive and palliative care, and ensuring care is underpinned by high quality evidence. She holds the Chair of Palliative Medicine at University of Melbourne and St Vincent's Hospital in collaboration with Victorian Comprehensive Cancer Centre (VCCC) and also co-chairs the Health Equity Working Group for the VCCC. Both Jennifer and Stacey have a long and shared interest in ensuring equity of provision of high quality care to those with advanced illness who are underserved including those people who are in prison.



## DR STACEY PANOZZO

Stacey Panozzo is a Research Fellow working with Palliative Nexus, St Vincent's Hospital and The University of Melbourne. Stacey is a researcher whose particular areas of interest include improving supportive and palliative care access and delivery for patient groups experiencing vulnerability.

Her current work involves the management of and/or collaborative involvement in several mixed methods research projects nationally and internationally focusing on understanding and improving care provision for those who experience incarceration, people who identify as Aboriginal and Torres Strait Islander, people who use illicit drugs and those who experience homelessness/structural vulnerability. Stacey is a member of the Health Equity Working Group for the Victorian Comprehensive Cancer Centre and the European Association for Palliative Care Prisoner Taskforce.



## COLLABORATING WITH THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE'S PRISONER TASK FORCE

The PiP Project would like to acknowledge the collaboration with the European Association for Palliative Care (EAPC) Prisoner Taskforce for sharing and allowing us to adapt their question route for the proposed semi-structured interviews with Correctional/Justice Health Clinicians, Correctional Services personnel and Specialist Palliative Care Professionals.

In particular we would like to thank our Co-Investigators, Professor Jennifer Philip and Dr Stacey Panozzo who, as members of the EAPC Prison Taskforce, will help assist with the semi-structured interviews with Correctional Officers, Justice Health Clinicians and specialist palliative care stakeholders in Victoria. The EAPC has recently published an [article](#) in BMJ Supportive & Palliative Care.

# PROJECT PARTNER BIOGRAPHIES

## CHRISTINE FULLER

Christine Fuller is the Deputy CEO / Chief Nursing Officer at Correct Care Australasia (CCA), a private healthcare provider delivering primary health care to approximately 6,000 prisoners across 15 prisons and a treatment centre and also to young people across two youth justice facilities in Victoria. Christine is a registered nurse with 35 years' experience working in diverse roles in the public and private healthcare sector.

She holds a Diploma of Nursing, a Bachelor of Nursing Administration and a Masters of Health Administration. Christine is also the Vice-President and a Board Director of the Australian Primary Nurses Association (APNA). Christine has been working in correctional health for the last 10 years and has responsibility for clinical operations and policies, quality and professional conduct of nurses. Her areas of interest and experience are consultative leadership, developing the professional role of nurses and facilitating quality care to patients.

Correct Care's mission is 'healthcare without judgement' which aligns with Christine's passion for ensuring high quality care to patients regardless of their circumstances. Correct Care run a nurse-led model in correctional health where nurses have the opportunity to greatly influence the outcomes for patients, with participation in the Palliative Care in Prisons Project being one of them. With an ageing, complex and vulnerable population of patients in the correctional setting; Christine welcomes the opportunity to participate and advise on the development of a much-needed palliative model of care for prisoner patients.



## PROJECT LEAD

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PALLIATIVE CARE  
IN PRISONS PROJECT

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IN PARTNERSHIP WITH:

### SPHERE

Sydney Partnership for  
Health, Education,  
Research and Enterprise



## NEXT MEETINGS

ABORIGINAL AND TORRES STRAIT  
ISLANDER COMMUNITY ENGAGEMENT  
STRATEGY WORKING GROUP  
Tuesday 13 July 2021  
17:00-18:00 (AEST)



CORRECTIONAL/JUSTICE HEALTH  
SERVICES WORKING GROUP  
Wednesday 14 July 2021  
14:00-15:00 (AEST)



NATIONAL CONSORTIA PROJECT  
ADVISORY GROUP  
Wednesday 1 September 2021  
14:00-15:30 (AEST)

