

**Title:**

**An 'equity' domain could strengthen the utility of a framework for assessing care coordination for Australian Aboriginal families**

**Short title: Care coordination for Aboriginal families**

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## **Abstract**

Improving the health of Aboriginal people is a national priority and improving coordination of services for Aboriginal families is critical to achieving this goal. A care coordination framework has been developed from a limited range of clinical settings. We reflect on the utility of this framework for assessing service coordination for Aboriginal families in Australia.

We conducted stakeholder consultation, service mapping and in-depth interviews with service providers and an Aboriginal mother, using a tool based on the framework domains. A fragmented range of services support Aboriginal families with complex and changing needs, highlighting the importance of care coordination. Relationships underpinned care coordination, however we identified few opportunities for developing relationships, and several factors that undermined relationships, including unclear accountability mechanisms, resource constraints, anxiety about follow-up and transfer of information to child protection.

The Care Coordination Framework enabled a ‘systems-perspective’ of the main care coordination domains for Aboriginal families, from individual experiences. However there were some limitations in capturing subtle historical and cultural dimensions affecting care coordination in this context where health care practice in large institutions is framed by the dominant culture. An additional ‘equity’ domain would capture these dimensions, address a growing international policy challenge and strengthen the framework.

## **Key words:**

Care coordination; Service coordination; Aboriginal; Indigenous; family

## **Introduction**

Aboriginal and Torres Strait Islander (Aboriginal) children experience markedly poorer health and wellbeing when compared to other Australians (1), and disparities in life expectancy between Indigenous and non-Indigenous people in Australia are frequently cited as the worst among comparable high-income countries (2). Addressing these inequities are a national priority in Australia (3). Growing evidence demonstrates how early experiences impact on health and wellbeing in later life, indicating that investments in early childhood offer significant opportunities to address inequities (4). Hence supporting families and children is a key priority for improving the health and wellbeing of Aboriginal people (5).

It is important to understand the complex historical and societal context of Aboriginal people when assessing how services work together to support Aboriginal families, and how families engage with them. Following colonisation, the introduction of diseases, dispossession from lands and exclusion from resources threatened the survival of Aboriginal people, particularly in Victoria. A number of government Acts were introduced, ostensibly to ‘protect’ Aboriginal people and promote ‘assimilation’ into the European colonial lifestyle (6). These Acts imposed enormous restrictions on the lives of Aboriginal people, who were excluded from virtually all aspects of society and nearly one-third of all ‘registered’ Aboriginal people in Victoria lived in settlements as recently as 1961 (7). Most notably, these Acts enabled state-sanctioned removal of children, and separation of ‘registered’ and ‘part-caste’ Aboriginal people, disrupting and fracturing vital family and social networks (8). The disruption of families has a devastating impact on individuals, and starts a cycle of intergenerational trauma. This legacy impacts on the capacity of families to provide nurturing family environments, as well as the ability to form trusting relationships between government services and Aboriginal families.

To improve support for Aboriginal families, place-based solutions (4), choice of a range of service providers and integration of care have been key recommendations in a number of reviews (9, 10,11). While increasing choice is critical to improving outcomes, it also increases the complexity of a system, creating further challenges, both for Aboriginal families seeking healthcare, and for clinicians' in their capacity to understand and refer to available services. Thus, there is growing interest in understanding the mechanisms involved in 'care coordination' in Australia (12), particularly in the context of support for Aboriginal communities (13), with lack of coordination highlighted in child death reviews (14).

In this article, we reflect on the utility of an international care coordination framework (15) for synthesising and understanding complex contextual and system factors affecting care coordination for Aboriginal families with children 0-5 years, from a family and service provider perspective. An unpublished internal report provided service-specific information, including recommendations (16).

### **Care coordination framework**

'Care coordination' has also become increasingly important internationally, however there has been a lack of clarity around the definitions and core elements (15, 17). Schultz et al. have consolidated these definitions (15) and proposed a framework which incorporates eleven core aspects (*domains*) of care coordination (18), as well as client, service provider and system representative perspectives.

<<insert table 1 about here >>

However, the authors noted limitations that most of the instruments from which the framework domains were identified were from primary care, inpatient facilities and outpatient facilities (18), raising questions as to whether this framework could be reliably

applied to assess coordination between a range of social and health services to support Aboriginal families in Australia. We are not aware of previous studies using the framework for assessing coordination for Indigenous families, which we felt could help to incorporate a ‘systems-thinking’ approach, which ‘examines complex problems, taking into account the bigger picture and context of those problems’ (19). In the context of investigating care coordination for Aboriginal families, we wanted to avoid risks that an investigation could focus on the behaviour of individual families and providers, which is unlikely to generate constructive information, and may result in ‘victim blaming’ or exacerbate sensitive situations.

### **Care coordination review process**

We assessed care coordination between January and December 2015, in a health service in the south east region of Melbourne, Australia, responsible for providing health care for a community of over 961,000 people, including approximately 5,000 Aboriginal people (20), about 12% of whom are aged 0-4 years of age (21). Preliminary consultation was conducted with key stakeholders, including ‘system representatives’, and this study builds on previous work (22, 23). We conducted a review of available services and found 31 services providing a range of medical and social support services for families with children under five years of age (16). Four services were provided by Aboriginal community controlled services for Aboriginal people and the remainder were ‘mainstream services’ accessible to Aboriginal families. We interviewed eight Aboriginal and non-Aboriginal service providers, and one Aboriginal mother regarding their experiences of service coordination. A summary of these interview questions and findings under each of the framework domains, and recommendations, are available on request.

We would like to contextualise these reflections on the utility of the framework by acknowledging that many Aboriginal families, including the family member participating in this study, are strong and able to provide caring and nurturing environments for their children with minimal support from formal services. However, the majority of service providers participating in this study work with vulnerable Aboriginal families who use a range of services, and the focus of this paper is on improving support for these families.

### **Reflections on the utility of the framework for assessing and developing recommendations for improving care coordination for Aboriginal families**

*Strengths: enabling a comprehensive approach and ‘systems-perspective’*

We found that using the care coordination framework (18) systematically captured a range of perspectives on important coordination domains (highlighted in **bold**) from service providers. We identified a complex and **fragmented** system with multiple services provided, exacerbated by a lack of apparent ‘policy and funding coordination’ with services provided by three different levels of government, as well as philanthropic, non-government and Aboriginal community-controlled services. Participants also identified **complex and changing needs** of many families, which suggests that no single service could provide all the expertise required, and that coordination mechanisms are vital.

Developing strong relationships and trust (**interpersonal communication**) were seen as fundamental foundations for improving care coordination for Aboriginal families, however participants suggested there is room for improvement. The axiom that ‘*Trust: takes years to build, seconds to break, and forever to repair*’ resonated here (16). Using the framework enabled us to ‘step back’ and consider individual situations with a ‘systems-thinking’ perspective, and we found several systems factors which would undermine relationships, and few opportunities for providers to develop constructive relationships. For example, we

question if it is feasible for the level of complexity among clients described by service providers to be addressed with the limited time and **resources** available. Participants generally reported that the range of services available was good. However frequent long waiting times cause difficulties keeping families ‘engaged’, and all participants could describe situations where assistance for families could not be accessed when needed. Some described punitive policies which restricted service access to families who missed several appointments. There were particular challenges associated with access to transport, housing, and counselling/mental health services.

Participants reported a lack of clear **accountability and responsibility** mechanisms within the system if they were concerned families’ needs were not being met. They also described the importance of **monitoring and follow-up** of vulnerable families, and the anxiety they experienced if they were not confident they could trust other referral services to provide appropriate care. Placing responsibility for implementing new cultural initiatives with Aboriginal staff could also put these staff in a position where they faced resistance which could be expressed in confronting attitudes. This reaction should be anticipated as part of any cultural change processes (including displaying Aboriginal signage) we recommend these initiatives are provided by or with support of senior staff.

Some service providers believed that notifying child protection that they are concerned about a family would help ensure the family had prompt access to required services. This is concerning given the history of government-sanctioned child removal. Referral to child protection must be the ‘last resort’ for ensuring child safety and inappropriate referrals fundamentally undermine the principles of a strength-based approach to family support (24). In addition, fear of child protection referral created additional concerns about and negatively impacted on **communication and information transfer** between services. Easing restrictions to enable access to support services early, including child support and home help,

before children are considered ‘at risk’ may help to minimise inappropriate child protection referrals.

The complexity of the system, and addressing complex and changing needs of families meant that **linking to community resources** was an important aspect of care coordination in this sector. Most participants relied on informal personal relationships within services to find out about services and make these linkages, however high turn-over of staff in the sector could create challenges. Information technology systems could be improved to support service providers here.

We found that while the framework enabled systematic identification of important factors, many of these domains interacted with each other (e.g. lack of accountability mechanisms and resource constraints impacted on relationships, relationships enabled linkage to community resources). There was strong support for ‘service navigator’ or ‘care coordinator’ roles which had good support and accountability mechanisms they could access to improve access and coordination of care for vulnerable Aboriginal families. There was also strong support for more ‘one-stop shop’ care models, which are provided to a limited degree by Aboriginal community controlled services. Participants unanimously emphasized the importance of having a **proactive plan of care** and **supporting the self-management goals** of families, but this was difficult to achieve within the current system. We felt the motivation of many care providers to advocate for families could offer a constructive driver of system change, highlighting areas that could be better designed so they are not feeling like they need to ‘fight against it’. We suggest providing formal opportunities for providers to network and develop relationships, and discuss how to address some of the system challenges outlined here, is a good place to start.

*Limitations: capturing complex interactions and equity dimensions*

We did experience some challenges using this framework to understand care coordination for Aboriginal families. First, we found that multiple *levels* needed consideration within several *domains*. Collating information from multiple perspectives as recommended in the framework (patient/family, health service professional, and system representative), perhaps using a grid, may help to illustrate factors at these different levels. Second, we felt that some complex findings (e.g. historical and cultural dimensions), may be difficult to address with sufficient ‘depth’, as the framework domains are largely functional. For example, we were unsure which domain to code challenging reactions some participants reported when they tried to install Aboriginal signage in public areas, and decided it aligned most closely with ‘resources’, as it involved creating a ‘culturally welcoming and safe space’. We felt an additional domain specifically encompassing ‘equity’ would have more explicitly enabled consideration of cultural dimensions in our setting. Equity has become an increasingly important consideration internationally and has been incorporated into evidence synthesis methods to help inform policy decisions (25). Thus we feel an ‘equity’ domain would be broadly applicable in many other settings, and would strengthen the existing care coordination framework.

### **Concluding remarks**

While Schultz et al. (2013, 18) noted that few existing instruments were applicable to settings other than primary care, inpatient facilities and outpatient facilities, we found the framework they developed could be largely applied in this complex setting involving care coordination for Aboriginal families in Australia. The framework enabled us to ‘step back’ and assess a broad range of ‘systems’ factors important to care coordination. However, we suggest an ‘equity’ domain would strengthen the framework. We contribute these findings to the discussion as suggested in the inaugural edition of this journal (18).

## **Lessons learned**

The care coordination framework proposed by Schultz et al (18) could:

- Be largely applied to assess care coordination for Aboriginal families in Australia.
- Facilitate developing a systems-perspective on individual experiences.
- Incorporate an ‘equity’ domain to encompass differential experiences affecting care coordination, including cultural considerations.

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## **Conflicts of interest**

GB is an employee of the health service participating in the study. CC, SM, JB, KF and MK have no conflict of interest to declare.

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**Table 1: Care coordination activities (domains) outlined by Schultz et al 2013 (15)**

1. Establish accountability or negotiate responsibility
2. Align resources with patient and population needs
3. Assess needs and goals
4. Communication/Information transfer (combined in this study)
5. Interpersonal communication
6. Facilitate transitions across settings (and time points)
7. Facilitate transitions as coordination needs change
8. Link to community resources
9. Monitor, follow up, and respond to change
10. Create a proactive plan of care
11. Support self-management goals