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POLICY OPTIONS

Partnerships in Care: Attributes of successful care coordination models which improve health care networks for people with intellectual disability

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Assoc. Prof Lucie Walters, Dr Jane Tracy, Assoc. Prof Linda Sweet, Assoc. Prof Robert Davis, Dr Rachael McDonald, Ms Lucy Atkinson, Ms Heather Burton.

Policy context

People with intellectual disability make up 2-3% of the population and have a higher morbidity and reduced life expectancy when compared with the general population. They encounter a range of physical, attitudinal, communication and systemic barriers to accessing mainstream health services which contribute to and compound their disadvantage. People with intellectual disability tend to have multiple, chronic health issues and no one health professional can address all their needs. Input from various members of a multidisciplinary team is therefore required. Moreover, people with cognitive and communication difficulties require advocacy and support in accessing health services and in following through on management recommendations. Additionally, rural health and disability services are limited by resources, distances and workforce shortages which lead to a double disadvantage for people with intellectual disability living in rural Australia.

National Disability Insurance Scheme is intended to support lifestyle, activities of daily living and social inclusion. The arrival of National Disability Insurance Scheme highlights the right of people with disability to participate in community, social and economic life. It specifically does not purport to address the health issues of people with intellectual disability. Health and social inclusion however are inextricably intertwined. Poor health undermines social and economic participation and erodes quality of life. Social exclusion restricts health education and networks, limiting capacity to engage with the health system. The resulting lack of primary and secondary prevention and treatment of disease increases morbidity and mortality.

Care coordination is a mechanism that facilitates the Health and Disability sectors working together to ensure people with intellectual disabilities receive appropriate and timely healthcare, and experience optimal health and wellbeing. There is no current gold standard care coordination model. This study sought to identify key attributes of successful care coordination models to improve health outcomes for people with intellectual disability that live in rural areas.

Key Findings

Three distinct care coordination programs in rural sites across Victoria and South Australia were studied using Realist Evaluation methods. The results demonstrated that there were four main ways that the Care Coordinators were able to effect change in the health system to improve health outcomes for people with intellectual disability. These included 1) joining the care network

2) facilitating navigation of the health care system, 3) linkage and knowledge exchange between stakeholders, and 4) building knowledge and improving quality of care.

Policy Options

Policy development should recognise that the five key attributes of care coordination which build on care networks and improve health outcomes of people with intellectual disability in rural areas, demonstrated from this study are:

1) INTRODUCE SUSTAINABLE, LONG-TERM MODELS OF LOCAL HEALTH CARE COORDINATION

In order to achieve improved health outcomes for people with intellectual disability our research has demonstrated that a sustained and collaborative long-term approach to care coordination is required. Change takes trust and time, and setting up the relationships between the various stakeholders for disability health care is crucial to success of care coordination models.

Specifically, carers and disability support workers are integral to healthcare access for people with intellectual disability, and must be confident to invest in care coordination for success to be achieved.

Successful care coordination programs require collaborative engagement of local stakeholders, including people with intellectual disability and those who support them, health care professionals, disability advocates, disability support groups, and other supports and local community members. When such a collaborative group work together, the decision making required to tailor care coordination programs to the local context is more effective.

2) SITUATE CARE COORDINATORS WITHIN PRIMARY HEALTH WITH EFFECTIVE WORKING RELATIONSHIPS WITH GENERAL PRACTICE

Health outcomes for people with intellectual disability can be improved through a Care Coordinator with both health and disability expertise, and ideally a nursing background, who sits within the local primary health system. There are strong advantages to embedding care coordination within the primary health care system closely engaged with general practice. Our study has demonstrated that where care coordination interventions are located within an organisation that has credibility and effective working relationships with general practice, they will have established relationships to leverage practice engagement.

3) ENSURE A ROLE AS TRUSTED NAVIGATOR AND SUPPORT USE OF A STANDARDISED COMPREHENSIVE HEALTH ASSESSMENT TOOL

Care Coordinators can build capacity for system-wide improvements for people with intellectual disability by leading the way and demonstrating successes to all parties. Their role as trusted navigator includes supporting clients to navigate the complex health system, and similarly supporting health professionals to understand and navigate the disability support system. Care Coordinators with broad knowledge of health conditions and health systems along with specialised disability knowledge were found to operate effectively as system 'insiders' and became increasingly accomplished at guiding the person with intellectual disability to access and benefit from services that they required. When clinicians did not have specific knowledge relating to the care of people with intellectual disability, the Care Coordinator could support GPs and other health professionals to provide health care, particularly when a client's communication and behavioural challenges made the assessment and management more complex.

Integral to this process is the implementation and support of an annual national standardised health assessment specifically for people with intellectual disability, such as the Comprehensive Health Assessment Program (CHAP). The CHAP facilitates disability and health staff to effectively work together in gathering and reviewing all information relevant to the person's health care. It then guides the medical practitioner through the assessment; ensuring areas of health need known to be more common in people with intellectual disability are addressed, and provides a template for ongoing management that enables clear communication between health and disability staff. Care coordination in this context, therefore, includes ensuring people with intellectual disability and the disability and health staff supporting them, are aware of and utilise a standardized comprehensive tool in a mandated annual health assessment to achieve the health benefits known to flow from this process.

4) IMPLEMENT BENCHMARKING OF HEALTH OUTCOMES FOR PEOPLE WITH INTELLECTUAL DISABILITY AGAINST LOCAL POPULATION DATA

When Care Coordinators took a population health perspective of people with intellectual disability in their region, they were in a unique position to gather and report data and coordinate a quality improvement framework (plan-do-study-act) which could create a robust evidence base for improved outcomes and system change. With time, and critical mass, small changes could influence regional healthcare systems to work better for people with intellectual disability resulting in improved health outcomes for this group.

5) ENFORCE ACCOUNTABILITY THROUGH MEASURES FOCUSED ON HEALTH AND DISABILITY SYSTEM LINKAGES AND COLLABORATION

Health care services in rural areas must have policies in place to ensure universal access to services for vulnerable consumers, including people with intellectual disability. The focus should be on equity of health outcomes, rather than access alone. Care Coordinators can be enablers in ensuring this outcome is achieved in local community settings.

In this project, linkages between local health and disability stakeholders highlighted priority overlap between organisations resulting in shared understanding of the regional healthcare contexts; and the development of context specific care coordination interventions. Mutual learning was found to occur when Care Coordinators acted as knowledge brokers and linked people with intellectual disability, their carers and guardians, with their GP and other health professionals. Care Coordinators could facilitate linkages between the health and disability sectors and between the separate parts of the healthcare sector. These linkages resulted in mutual learning and strengthened each person's capacity to work more effectively and use the system structures better. Development, maintenance and utilisation of formal linkages can be reinforced through health service accreditation standards and outcomes based funding.

Within the new environment within National Disability Insurance Scheme, people with intellectual disability will become increasingly empowered and able to resolve some of the daily burdens and obstacles that inhibit their access to and prioritisation of healthcare. Local care coordination interventions have the potential to facilitate new opportunities of engagement with the health system and to work with the person, their carers and healthcare providers to ensure optimal health and wellbeing for this vulnerable and currently disadvantaged population.