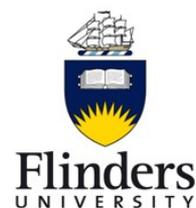




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# **Partnerships in Care:**

## **Attributes of successful care coordination models which improve health care networks for people with intellectual disability**

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## Executive Summary

People with intellectual disability in rural areas experience a 'double disadvantage' in relation to the healthcare they receive, due to both their disability and geographic location. This research project sought: to discover: how rural people with intellectual disability establish and maintain their care networks; to identify models of care coordination that have supported health care for this group, and to develop and test a short term intervention of two localised models of care coordination in rural communities. The project was designed to identify key attributes of care coordination and understand how, and in what circumstances they function to provoke a systemic change that will lead to the outcomes of holistic and universal care for rural people with intellectual disability.

## METHODS

This research project used a Realist Evaluation methodology to evaluate what worked, how and for whom, in a care coordination intervention for rural people with intellectual disability. Interviews, focus groups and pre and post analysis of health summary information were conducted, to analyse how specific attributes of care coordination triggered positive changes and in what circumstances the changes occurred. Realist Evaluation is helpful in understanding what, when and how particular attributes of a program might be effective. This enables more effective transfer of models from one setting to another.

This was a two phase study. In Phase 1 the researchers investigated a trial Care Coordination project in a town, 'Kanawinka' (population approximately 7000) in rural Victoria that had demonstrated promising results. The findings from this reference model were shared with stakeholder groups in two rural settings in South Australia (a region of population 38,000, 'Murray', and a town of approximately 5,000, 'Limestone') who were also canvassed about their expectations of effective care coordination for people with intellectual disability. In Phase 2 of the project, two test models of care coordination for people with intellectual disability were created and implemented by local stakeholder groups. These interventions were studied to better understand how care coordination worked to improve healthcare for people with intellectual disability.

## MAIN FINDINGS

From Phase 1, stakeholders identified their expectation that successful care coordination programs for people with intellectual disability would produce the following outcomes:

- > **Prioritisation** of care for people with intellectual disability
- > **Tailoring** of care to population-specific needs
- > **Multidisciplinary team-based care** including coordination and collaboration among services and
- > **Person-centred care.**

In turn, these models were expected to support **universal** access and **holistic** primary health care for people with intellectual disability, taking account of wider social factors and care networks that impact on healthcare access.

For Phase 2, two very different models of care coordination were developed by stakeholder groups. One model was a Care Facilitation model, where a registered nurse was employed to identify needs and facilitate the journey of people with intellectual disability through the health system to address those needs. The other model was a multidisciplinary Case Conference model, where a care coordinator was employed to facilitate multidisciplinary team meetings between relevant health professionals, the person and those who support them, with a view to plan care and review progress. A national standardised health assessment, the Comprehensive Health Assessment Program (CHAP) designed specifically

for people with intellectual disability was used to facilitate health screening and collection of health data from participants in this study.

The results of Phase 2 demonstrated that there were four main ways that these Care Coordinators **were** able to effect changes in the health system to improve health outcomes for people with intellectual disability:

- > **Joining** the care network
- > **Facilitating navigation** of the health care system
- > **Linkage and knowledge exchange** between stakeholders,
- > Building knowledge and **improving quality** of care

### Joining: Care Coordinator acting as part of the care network

Care Coordinators were a source of advice about health care access to people with intellectual disability, their carers and support organisations. The information collected in the process of history taking using the CHAP enhanced the Care Coordinators' understanding of the care networks and health needs of individual people with intellectual disability. With this information Care Coordinators broadened the organisational supports for their clients and began to support health professionals to draw on clients' care networks to build self-determination and self-reliance.

### Facilitating navigation: Care Coordinator as trusted navigator

People with intellectual disability have difficulty navigating services and programs within the mainstream health sector. The Care Coordinators had a nursing background and so brought knowledge of health conditions and health systems and were able to operate effectively as health system 'insiders'. They were accomplished at enabling the person with intellectual disability to access the services that they required and were able to navigate through the different targeted programs and their complex eligibility criteria to address the specialised health needs of their clients. Furthermore, people with intellectual disability, carers and guardians became more willing to access the system in a timely manner with the assistance and support of their trusted navigator.

When clinicians do not have specific knowledge relating to the care of people with intellectual disability, the Care Coordinator involved in pre-assessment can filter and re-frame information for the General Practitioner (GP) or other clinician. In this study, it was important that the Care Coordinator was someone with specialised disability knowledge and advocacy skills in order to 'bridge' the divide between Health and Disability services, and so support health professionals to provide tailored care. Importantly, the role of trusted navigator was found to be pivotal. When the care coordination program did not provide this role there was little capacity for linkage and exchange or quality improvement, particularly in areas experiencing the time pressures resulting from health workforce shortages.

Where a Medicare Local partnered with a Division of General Practice the intervention was able to use the well-established relationships between GP practices and Division staff to gain access to and engage general practitioners. By contrast where the intervention did not have the benefit of long-term systemic engagement with general practices, the same traction was not achieved within the timeframe of the research. Location within an organisation that has credibility and established links with general practice is important in rural areas where GPs, or their Medicare authorised proxies, are the first port of call for health care.

### Linkage and knowledge: Care Coordinator as linkage and knowledge exchange and brokerage

In this project, bringing together local health and disability stakeholders highlighted where the strategic priorities of these two sectors overlap, resulting in shared understanding of the

regional healthcare needs; and the development of a context specific Care Coordination intervention.

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 were able to facilitate linkages within and between the health and disability sectors, and with the person's broader social networks. These linkages lead to a strengthening of each person's capacity to work more effectively and better use the system structures. Healthcare was more effective when the Care Coordinator had both health and disability knowledge as this enabled them to broker the most effective services and networks for the person with intellectual disability and their families.

The use of a standardised, comprehensive, intellectual disability focused health assessment tool was a prompt for exploration of a wide range of health issues known to be common in this population and was a critical component of a comprehensive and holistic approach to healthcare.

### **Building knowledge: Care Coordinator as knowledge creator and quality improvement planner**

When Care Coordinators saw 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.

Within the new environment of National Disability Insurance Scheme<sup>1</sup>, people with intellectual disability will become increasingly empowered and able to resolve some of the daily burdens and obstacles that inhibit their prioritisation of healthcare. Local Care Coordination interventions have the potential to facilitate these emergent patterns of engagement, and to work with the person, their carers and healthcare providers to ensure optimal health and wellbeing for this vulnerable and currently disadvantaged population

## **RECOMMENDATIONS**

### **1. Introduce sustainable, long-term models of local health care coordination to improve health outcomes for people with intellectual disability**

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 is crucial to success of care coordination models. 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. Specifically, carers and disability support workers are integral to healthcare access for people with intellectual disability, and must be engaged in care coordination for success to be achieved.

People with intellectual disability and their carers will not invest in a change to known care networks if they feel they will soon change again. Rural health professionals can also be

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<sup>1</sup> From 20 September 2013, the name DisabilityCare Australia reverted to the National Disability Insurance Scheme

resistant to change, particularly where workforce shortages and health service demands are challenging. Therefore, it is essential that care coordination interventions are planned and maintained for a minimum of five years to facilitate investment in the change by local stakeholders, improve health outcomes for people with intellectual disability during the intervention and provide opportunity of ongoing health system improvement.

## **2. Situate care coordinators in local primary health care organisations which have effective working relationships with General Practice to leverage engagement**

Health outcomes for people with intellectual disability can be improved through a Care Coordinator with both health and disability expertise who sits within the local primary health system. There are major advantages to embedding Care Coordination within the primary health care system and closely engaging 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 care coordinators are enabled to perform as a trusted navigator for clients and service providers, including supporting GPs in the use of a standardized comprehensive annual 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 health system, and similarly supporting health professionals to 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 navigate the 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 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 an 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 both focused on system linkages and collaboration between health and disability services, and upon health outcomes**

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 coordination can be enablers in ensuring this outcome is achieved in local community settings.

In this project, bringing together local health and disability stakeholders highlighted priority overlap between organisations that resulted in shared understanding of the regional healthcare context; and the development of a context specific Care Coordination intervention. 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.

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## Introduction

People with intellectual disability<sup>2</sup> have been referred to as an “invisible population”<sup>1</sup> located within the spatially, economically, socially and culturally distinct sphere of rural Australia<sup>2</sup>. Between two and three percent of the Australian population has an intellectual disability<sup>3</sup>. Many have disorders of, or vulnerabilities to, physical or mental illness that are due to their disability<sup>4</sup>. Their health may be further complicated by a limited ability to communicate their symptoms to carers and health professionals<sup>4</sup>.

Previous studies have identified that health disparities between people with intellectual disability and the broad population are largely preventable and include health risk factors that are unrelated to any specific disability<sup>5</sup>. People with intellectual disability are more likely than the general population to have diabetes, hypertension and heart disease<sup>6</sup>. They are also more likely to suffer obesity, to smoke and to have reduced levels of physical exercise<sup>7</sup>. They have higher frequency of mental health issues such as psychological distress and depression<sup>7, 8</sup>.

People with intellectual disability have reduced access to the social determinants of health such as employment, sufficient finances to support healthy behaviours, social networks and transport to medical facilities<sup>1</sup>. Many people with a disability are living in stressful conditions with inadequate support. Nearly 600 people with the highest identified level of need in South Australia are awaiting a place in supported accommodation<sup>9</sup>. This plethora of difficulties culminate in an average lifespan some 20 years less than the non-disabled population for people with severe intellectual disability, and around 9 years for those with a moderate intellectual disability<sup>10</sup>.

### Challenges for rural people with an intellectual disability accessing healthcare

People with intellectual disability have difficulty accessing mainstream services due to their own limitations and to issues related to physical, attitudinal, and institutional attributes of health service. Rural health services are further limited by distances and workforce shortages. This leads to a double disadvantage for rural people with intellectual disability<sup>11</sup>.

The term ‘intellectual disability’ applies to people with an wide range of different abilities, capacities and personalities, however some difficulties in accessing healthcare and maintaining optimal health are common to most due to a range of social, communication-related, and practical challenges<sup>3</sup>. They may have behaviours which challenge health systems and accepted methods of care<sup>4</sup>. They have reduced ability to comprehend health promotion strategies and integrate them into their lives<sup>4</sup>.

Australia’s health system is complex, and navigation amongst the various parts can be especially difficult for many people with a disability and their carers. Aspects of care can be provided by multiple organisations with conflicting criteria for access, and client quotas can apply. For example of the people in South Australia with a disability rated Category 1, the highest level of need, around 1300 are on a waiting list for services such as respite, therapy and behavioural interventions<sup>9</sup>. People with intellectual disability have the same right to health care under the Medicare Act as all other Australians and should not face discrimination and diminished options on the basis of their disability.

Low population density in rural Australia frequently necessitates generic health services to meet the needs of culturally and demographically diverse population groups at the expense of more tailored care for people with special needs<sup>12</sup>. In reality, General Practitioners provide the overwhelming majority of Medicare funded primary health care services in Australia. Despite the best efforts of general practice, there are significant inequities of access between people in rural and urban communities<sup>13</sup>; and between mainstream and marginalised or vulnerable population groups such as people with intellectual disability<sup>14</sup>

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<sup>2</sup> A glossary of terms including ‘intellectual disability’ is provided in Appendix 1

These inequities in access are due to factors such as rural workforce shortages and limited specialist services in rural areas<sup>15</sup>; as well as cost, with bulk-billing comparatively rare in rural Australia. The inherent difficulties in providing care for people with an intellectual disability in rural areas are well understood but little progress has been made in overcoming them<sup>16</sup>. Care coordination strategies are recognised as a solution to the inequities faced by vulnerable health consumers such as those with intellectual disabilities. This study sought to define the underlying theories of action of Care Coordination models which are transferable to generalist health services responsible for the healthcare of people with intellectual disability living in the many current and rapidly changing Australian rural health contexts.

### Variable engagement with disability services

A significant proportion of people with intellectual disability, as defined by World Health Organisation, are not registered with Disability Services in South Australia. Reasons for this remain anecdotal but may include: fear of social services intervention; loss of tenancy and removal of children; changes to benefits; or reduced access to generic health services which limit access to people who have access to alternate specialised services. Consequences of non-registration may include an inability to access some specialised services that support people with disability.

### Introduction of National Disability Insurance Scheme (NDIS)

For the several decades, political commentators have highlighted the discrepancy between a stated focus on social inclusion, and a lack of political support for a policy focus on inequities in Australia, either in relation to health, or more broadly<sup>17</sup>. A recent Productivity Commission inquiry examined reform in Disability Care and Support, and recommended increased funding, strengthening the choice and control experienced by people with disabilities, and a focus on participation in the social and economic life of the community<sup>18</sup>.

National Disability Insurance Scheme is currently being launched in a number of sites throughout Australia. This scheme is not intended to replace current services, but enable people with disabilities to have choice and control over the supports that they need to live their lives productively with dignity and respect. Healthcare provision for people with intellectual disability will remain the responsibility of the healthcare system; however the social and medical components of care for people with intellectual disability are irrevocably intertwined. In order to improve the morbidity and mortality of people with intellectual disability, this population will continue to need support to access and navigate the complexities of the healthcare system. Thus, access to care coordination to facilitate navigation of local services is essential.

### Introduction of Medicare Locals

The structure of community healthcare in Australia is under review. The Commonwealth Government established in 2011 and 2012 a network of 61 Medicare Locals. These organisations have a stated goal of tackling the fragmentation in the health system and introducing programs to integrate care for people with chronic health, mental illnesses and /or morbidity associated with ageing. There is an expectation that Medicare Locals will have an important role in bridging the divide between salaried community health services and independent small business model of general practice as well as promoting cross-sectorial collaboration essential for people with intellectual disability to experience coordinated healthcare and social inclusion supports<sup>19</sup>. Medicare Locals are in early development, and their role in provision of care coordination for vulnerable groups such as people with intellectual disability is not yet well established.

### Health service provision through enhanced primary care

The National Primary Health Care Strategy emphasises that primary health care (PHC) requires health professionals working together to provide comprehensive, continuous and

person-centred care<sup>20</sup>. Planning and delivery of health services needs to recognise the social determinants and where necessary build partnerships across sectors to address specific issues in a community. For our stakeholders, the issue of intellectual disability health particularly demands such a cross-sectoral approach and recognition of the importance of social inclusion in health. People with intellectual disability who have lifelong and complex disabilities require multidisciplinary care for both day-to-day healthcare needs. Medicare currently provides

- > Comprehensive health care assessments and annual healthcare planning through the person's GP and
- > Access to limited allied health through Enhanced Primary Care packages.

The uptake of Enhanced Primary Care referrals remains low, due to lack of knowledge by health professionals, underfunding of the packages themselves and difficulties in workforce retention in rural communities<sup>21-23</sup>.

### Comprehensive Health Assessment Program (CHAP)

There is now substantial international evidence to show that health screening programs involving the use of an annual national standardised health assessment leads to significantly better detection and management of health issues for adults with intellectual disabilities<sup>24</sup>. In Australia, the Comprehensive Health Assessment Program (CHAP) was developed for this purpose by Professor Nick Lennox at The University of Queensland. It is used by New South Wales, Victorian, Queensland and Western Australian Governments as well as by a number of non-government organisations<sup>25</sup>. The tool is therefore well established and is evidence based having been trialled in a number of studies<sup>26, 27</sup>. It acts as a prompt for regular health screening of adults with intellectual disabilities. The PEACHI research team was given licence to use the CHAP at no cost by Queensland Centre for Intellectual and Developmental Disability for the purpose of the study.

The CHAP is a two part questionnaire. Part A is completed by carers or support workers together with the person with the intellectual disability and builds a comprehensive health history. Part B is completed by the GP together with the person with intellectual disability and his or her carer or other support person. It contains prompts to the GP about health issues which are often missed or not well managed in people with intellectual disability as well as some health conditions that may arise in specific syndromes<sup>24</sup>.

## Methods

This study sought to answer the following questions posed to Australian Primary Health Care Research Institute (APHCRI) for the Coordination and the Vulnerable Consumer Primary Health Care Research Stream:

- > How do people with intellectual disability establish and maintain their care networks?
- > What are the best models of care coordination for people with intellectual disability?

The research project titled 'Partnerships Exploring Attributes of Coordinated Healthcare Implementation' (PEACHI) aimed to answer the research questions by:

- > Exploring a model of care coordination that had been shown to be effective in one rural setting in Victoria
- > Using Realist Evaluation methodology develop hypotheses which might explain the effectiveness of this reference model
- > Facilitate local stakeholder groups to use these hypotheses to develop and implement primary health care coordination interventions in two rural settings in South Australia.
- > Translating the findings from this research study into results to inform middle level policy to enable roll out of successful care coordination programs for rural people with intellectual disability throughout Australia.

## RESEARCH SITES

This research project focused on examining the health services in three small rural locations in Victoria and South Australia. These locations, which we have called Kanawinka, Limestone and Murray region, are described below. Despite being given pseudonyms some information regarding their regional location is provided to allow meaningful comparison with other rural contexts.

'Kanawinka' is a town of population 8000 about 100km from, a large regional centre in Victoria. Medical services are provided through a general practice and GP led hospital with local and visiting allied health professionals. In Kanawinka the trial model of health care coordination for people with a disability was established in early 2011. This model involved a registered nurse, working as a Care Coordinator, whose role included a three pronged approach including: direct health care coordination for clients living in disability housing; professional development of disability support staff and health professionals; and strengthening partnerships and coordination between the health and disability sectors.

'Limestone' is a town of about 5000 people about 50km from a large regional centre in South Australia and a considerable distance from Adelaide. Medical services are provided through a general practice and GP led hospital with local and visiting allied health professionals. Limestone has a generic care coordination service as part of the hospital avoidance program.

'Murray' region is a considerable distance from Adelaide and comprises a number of towns ranging from 2,000 to 8,000 population and several smaller localities and towns with a total regional population of around 35,000. Medical services are provided through general practices and GP led hospitals in each larger town within the region. Government services including Country Health SA and Disability SA are located in the central town of Murray region. Community Health employs local and visiting allied health professionals.

Further background regarding each of the study regions is available in Appendix 2.

## STAKEHOLDER ENGAGEMENT

Two stakeholder reference groups were established; one in Murray region and one in Limestone. These were made up of Health and Disability managers and direct service personnel as well as carers and advocates of people with intellectual disability. During Phase 1 of the project, these stakeholders provided significant advice regarding the context of disability and health services in their local regions. Phase 1 concluded with the realist hypothesis which guided the local stakeholder groups to propose an intervention model they believed to best suit their local context. In Phase 2 members of the stakeholder group assumed control of managing the interventions implemented in each of the two South Australian regions, and recruit participants to the intervention. Stakeholder groups actively participated in the process of developing policy recommendations from the research findings. For further information regarding stakeholder engagement in the study please see Appendix 3.

## RESEARCH PARTICIPANTS

The study participants included rural people with an intellectual disability and additional complex care needs who live either in supported or private accommodation, and were fully dependent on a carer. Participants with intellectual disability were recruited via local community health services, general practices and disability partners. Consent to participate in the research was provided by the person with intellectual disability if they were able to understand the request as demonstrated by a standardised tool (Appendix 4), or otherwise by their next of kin or legal guardian. Health and disability sector professionals and managers in Kanawinka, Limestone and Murray region were also invited to participate in the research during focus group consultations. Finally, the individuals employed as Care Coordinators in each of the three study sites, participated in the study.

## REALIST EVALUATION APPROACH

This implementation research project used Pawson and Tilley's Realist Evaluation Theory<sup>28</sup> to elicit the underlying reasons for the success of a prototype care coordination intervention in Kanawinka (called the Reference Model). This theory recognises that interventions in rural health sectors are embedded in open complex adaptive social systems<sup>29</sup>. Interventions therefore work through active engagement of individuals to change their ways of thinking and behaving. Understanding participants' interpretation of the care coordination interventions therefore is integral in developing and refining theories of relevance to middle level policy. In keeping with Realist methodology, preliminary results were presented as Context(C)-Mechanism(M)-Outcome(O)-Configurations (CMOCs) which describe "what works for whom in what circumstances and how?"

During Phase 2 data collection and analysis, initially posited CMOCs were reshaped and refined to develop a coherent understanding of the best models of Care Coordination for people with intellectual disability, taking into account and building on their broader care networks. For more detailed description of the research methods used in Phase 1 and Phase 2 of this study, please see Appendix 5.

## INTERVENTIONS

### Reference Intervention Model

#### **Kanawinka expectations**

The care coordination trial project in Kanawinka was expected to:

- > Improve confidence of disability workers in managing health needs of residents in supported disability accommodation;

- > Ensure house plans and records were up-to-date, complete and included comprehensive care plans for individuals' chronic diseases;
- > Facilitate formation of partnerships between health and disability sectors; and
- > Enhance the health sector's skills in effectively working with people with intellectual disability.

### **The reference program**

In the first year of the reference intervention, the Care Coordination Project Manager serviced only people in supported accommodation. The Project Manager reviewed each participant's house plan and health documentation in light of the Victorian Government Department of Human Services Residential Practice Manual. Met and unmet needs were identified from the documentation, and disability workers within the supported accommodation houses were supported where necessary to implement any recommendations and manage ongoing health care coordination on behalf of the resident. The Project Manager also provided professional development to disability workers, aimed at empowering them to improve health planning and access to health professionals. As part of the reference intervention, health professional education events were delivered on three occasions by experts from Centre for Developmental Disability Health Victoria ([www.cddh.monash.org](http://www.cddh.monash.org)).

### **Reference program achievements**

A project report written at the end of the first year of the Victorian project, which included the reference project in Kanawinka, highlighted a number of significant achievements. At the individual level, an average of three undiagnosed or under-managed health conditions was identified per client in the disability accommodation. As a result of the audit 80% of care plans were judged to be significantly improved; up to five extra services were accessed per client; and screening and health assessment for residents reportedly increased by 20%<sup>3</sup>. At the health systems level staff from Primary Health and disability accommodation services reportedly improved their collaboration and coordination, and across Victoria over 250 health professionals underwent training in managing the health of people with intellectual disability<sup>iii</sup>. Finally, at a policy level people with intellectual disability became a Priority One group for access to public dental services and community health services in Victoria<sup>iii</sup>.

Disability support workers expressed how they initially saw the Care Coordinator Project Manager's role as an audit of their unit's practises, designed to check whether they were implementing their organisation's guidelines. When they received praise for the good work they were doing, and were offered training to be able to do this even more effectively the Project Manager was seen as a valuable resource.

In Kanawinka, a significant benefit was the use of the CHAP<sup>25</sup> for disability accommodation services residents. Every resident in supported accommodation in Victoria is expected to have an annual review with their doctor. While there were many benefits from this process, weaknesses in the system were the lack of GP ownership of the CHAP process and lack of commitment to prioritise clients' health. Unexpectedly it emerged that the local practice nurse in Kanawinka, who had a long history of working in intellectual disability health and knew many of the Disability Services clients personally, took it on herself to improve their health. She leveraged engagement of GPs and other health professionals by providing practice population data regarding rates of routine screening and chronic diseases.

### **Outcome priorities**

The six outcome priorities identified by Kanawinka, Murray region and Limestone participants in Phase 1 of the study are outlined in Table 1. They include prioritised care, tailored care, person-centred care, holistic care, team-based care and universal care.

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<sup>3</sup> Personal communiqué from project manager of the Care Coordination project in Victoria.

Table 1: Phase 1 Outcome Priorities

Outcome	Description
Prioritised care	Participants described the desire to see evidence of affirmative action and recognition of inequity e.g. GP seeing the person with intellectual disability more often/on a more regular basis, and ordering more investigations, and proactively seeing that the person with intellectual disability does not experience barriers to access.
Tailored care	Participants voiced their preference to see that care for people with intellectual disability takes account of the person's actual physiology, pathology and life circumstances e.g. GP care focuses on particular health needs that relate to the disability (e.g. yearly thyroid function tests and regular hearing and vision testing for people with Down syndrome). Additional steps are made e.g. routine dental care under general anaesthetic
Person-centred care	Participants expressed a desire for care which embodies empowerment of the patient, eliciting and respecting their choices e.g. working with a person to find healthy choices that appeal to them e.g. GP communicates directly with the person and includes them in goal setting and decision making around the management of their health issues as much as possible.
Holistic care	Participants described care which goes beyond the biomedical and incorporates the person's psychological and social needs. This includes a focus on the person's quality of life, aspirations and social and emotional wellbeing, including attention to the person's extended care networks
Team-based care	Participants recognised that people with intellectual disability frequently have multiple complex health needs and sought to ensure that all health professionals involved in an individual's care worked together to bring about the best possible results.
Universal care	The health care system that is available theoretically to all Australians e.g. Chronic Disease Management Plans, routine health checks and addressing barriers to all levels of care. Rural health services provide generic care with little access to specific services for vulnerable groups. Participants described the need to ensure that at a populations level people with disabilities are included in health screening (including cervical, breast and bowel cancer), disease prevention (including immunisation, BP control) and health promotion (including smoking cessation, healthy diet, adequate exercise).

### Understanding the outcomes through Realist Evaluation

Initial Context-Mechanism-Outcome Configurations (CMOCs) were developed by the researchers around these outcomes and were presented as explanatory hypotheses to stakeholder groups in Murray region and Limestone in order to support the development of interventions in these sites which aimed to address these outcomes. These are outlined in Appendix 6.

Significant features included:

- > (C) When disability workers were confused about who had responsibility for providing healthcare services to people with intellectual disability (M) an intervention Care Coordinator with established networks, clinical knowledge and, advocacy experience could (O) enable improved access to healthcare services to identify and resolve health issues.
- > (C) When the service inclusion criteria were confusing, (M) health professionals who had a good understanding of eligibility for services were (O) able to prioritise care for people with intellectual disability in the complex rural health system

- > (C) When Health professionals did not understand the inequity of outcomes for people with intellectual disability, (M) practice or health service data of this group's poorer health status motivated health professionals (such as GPs) to (O) work to improve the health of people with intellectual disability
- > (C) When some health professionals did not have skills to manage people with intellectual disability, (M) people with intellectual disability and their carers clustered around health professionals interested in disability health and this (O) resulted in a special interest network.
- > (C) When complex health needs existed (M) GP and practice nurse collaborated using a standardised annual review process and CDM plans they could (O) bring health care team together around a person
- > (C) When people with intellectual disability have complex convoluted care networks (M) stable meaningful professional relationship between health professionals and disability workers (O) helped HPs recognise influence of social networks on health and provide person-centred, holistic care

## Care Facilitator Model

### Murray region expectations

Murray region stakeholders described wanting to: respect the autonomy of people with intellectual disability; recognise the carer's role in terms of consent, information sharing and in 'knowing the client; move towards hand-held records; facilitate better inter-professional cooperation; reduce the burden of travel; and focus on outcomes. Stakeholders in the region felt that the Care Facilitation model held most promise because all services were stretched and under pressure of cost constraint. There was strong agreement that even though the intervention would effectively be a short term substitution, the ground that could be gained would be valuable evidence of what a dedicated Care Facilitator position could achieve. The rationale for introducing a care facilitation model is outlined in Appendix 6.

Stakeholders expected a care-facilitating model to:

- > Create a central repository of knowledge about services and eligibility criteria which could then be applied to individual clients
- > Create linkages among services
- > Develop in-depth knowledge of intellectual disability health in the Care Coordinators (there is no longer specialty training for nurses in South Australia since mental deficiency nurse training ceased)
- > Facilitate current and new generation of doctors/health staff to engage with people with intellectual disability and their carers
- > Train carers to effectively manage health of people with intellectual disability and use the health system to meet their clients/family member's needs

A more detailed rationale for the Care Facilitator Model is outlined in Appendix 7.

### The Care Facilitator Program

The Murray region model of care coordination trialled in the Phase 2 intervention is labelled Care Facilitation to distinguish from the umbrella term Care Coordination. The two nurses employed (at a combined 3 days per week) to carry out this intervention are referred to as Care Facilitators to emphasise the assistance provided to the client and/or carer to access different parts of the system and to support them to be self-reliant. The goal is to equalise outcomes by giving vulnerable consumers the benefit of insider knowledge and advocacy for empowerment in the consumer driven system that predominates in rural health, with the result of holistic, universal care.

The Care Facilitator intervention had three main components:

- > To recruit or be referred to people with intellectual disability for an annual health assessment. The Care Facilitator would complete Part 1 of the CHAP assessment tool and accompany the client to the GP for Part 2 of the assessment. During the Part 1 assessment they would be responsible for identifying gaps in current health care and existing support networks and bridge any gaps in care. They were responsible for recognising and addressing social determinants of health, recording detailed case histories and working with clients/care networks to facilitate the health literacy and self-care of these individuals.
- > Provision of mentoring in intellectual disability health management to the Care Facilitators
- > Provision of Inter-professional training in Disability care to local health and disability professionals by PEACHI researchers from Centre of Developmental Disability Health Victoria.

### Case Conferencing Model

#### Limestone Expectations

Stakeholders in Limestone designed an intervention based around the case conferencing method of coordination, recognising that effective clinical practice requires a broad focus on the environmental, social and economic determinants of health as well as medical care. Stakeholders in the Limestone region had very positive experience with case conferencing through the Child Development Unit. They were keen to explore whether similar gains could be achieved for adults and others who were not eligible for case conferencing through this service. The rationale for introducing a care facilitation model is outlined in Appendix 6.

Stakeholders expected a case conferencing model to:

- > Address needs holistically
- > Be person-centred
- > Give the person autonomy
- > Create a plan for health management
- > Create accountability to ensure follow-up occurred

#### The Case Conferencing Program

The trial care coordination program was initially designed by stakeholders as a case conferencing model sitting within the local general practice. However, a change of location and adjustment in approach was necessary because shortly after the intervention was finalised, the GP practice's workload increased substantially without warning due to two other local practices losing their doctors. Stakeholders agreed that the same model could be implemented through Homecare Plus/Paraquad SA, an organisation that supports people with intellectual disability in their homes and runs supported accommodation.

It was envisaged that the intervention in Limestone would involve:

- > As in Murray region, Case Conference Coordinator to recruit or be referred people with intellectual disability for an annual health assessment. The Case Conference Coordinator would complete Part 1 of the CHAP assessment tool and accompany the client to the GP for Part 2 of the assessment. During the Part 1 assessment they would be responsible for identifying gaps in current health care and existing support networks and bridge any gaps in care. They were responsible for recognising and addressing social determinants of health, recording detailed case histories and working with clients/care networks to facilitate the health literacy and self-care of these individuals.
- > Facilitation of a case conference for each participant, based on the Child Development Unit model highly valued in Limestone

- > Provision of Inter-professional training in National Disability Insurance Scheme to local health and disability professionals by PEACHI researchers.

## Findings

A description of the participant numbers and distributions is outlined in Appendix 8. This study found that Care Coordinators had four main impacts on the health system:

- > Joining as part of the care network
- > A system navigator/enabler role
- > A linkage and knowledge broker role, and
- > A knowledge creator and quality improvement role.

## CARE COORDINATOR AS PART OF THE CARE NETWORK

Participants reported that the person's social context often had a significant bearing on their access to health care. They recognised that the broader social determinants of health such as social isolation, poverty, low literacy and transport issues that affected health care access for many in rural communities were especially problematic for people with intellectual disability in their communities. Carers and family supports were often: reliant on employment; had other children reliant on them; or were elderly or themselves. These commitments compounded difficulties experiences with hospital stays, travel for specialist appointments and managing multiple health care needs through different providers.

A number of the questions in the first part of the CHAP booklet explored social issues. Care Facilitators were able to act as a source of advice about health care access to people with intellectual disability, their carers and support organisations. They started to explore local health services to understand what was available to support the health of their clients and shared this information with clients and their carers. The Care Facilitators also extended their reach beyond health service providers. For example, they assisted several people to register with Disability Services and linked them with a case manager so that they could access benefits that would improve their social inclusion.

The Murray region Care Facilitators and Kanawinka Project Manager became part of the client's care network for people who were in supported accommodation. When these people had complex care needs, health was a particular challenge for disability support staff who had very limited training in health care. For this group, the Care Facilitators were seen as a valuable resource for the disability service managers as they could explain why certain things were required or not for the client's health and could help them to plan and manage their clients' health care proactively. In the Limestone region, the Case Conferencing Coordinator already had a role as part of the care network for people registered with the organisation with which she was employed, however this care network contribution did not extend to other clients during the term of the Limestone intervention.

Care Facilitators assisted their clients living independently to make informed choices about their health care and supported them to ask questions, gain information and access healthcare, disability and other Government services for support, as well as assisting them with paperwork. The Care Facilitators recognised the limited capacity of some people with intellectual disability to make informed choices, opting for small incremental changes in lifestyle rather than provoke anxiety and erode trust in the doctor-patient relationship. Their work with a diverse group of organisations such as special education and respite providers meant the Care Facilitators could also be accessible to people with intellectual disability, as part of their care network, who were not participating in mainstream health care.

CMOCs identified in the project included:

- > (C) When people with intellectual disability have complex convoluted care networks (M) stable meaningful professional relationships between health professionals and disability workers (O) helped health professionals recognise the influence of social networks on health and provide (O) person-centred, holistic care

- > (C) Where disability workers were unfamiliar with the health system and did not have a nursing background (M) access to a Care Coordinator with nursing background led to identification and appropriate triage of issues for attention of the GP and other health professionals leading to (O) Universal care

## CARE COORDINATOR AS HEALTH SYSTEM NAVIGATOR

The initial investigation of the Kanawinka Care Coordination trial and discussion with stakeholder groups in Murray region and Limestone revealed several interrelated phenomena that impeded health service access for people with intellectual disability. These included:

- > The 'parallel universe' phenomenon where health and disability sectors both assume that the other sector is responsible for health care and build in exclusionary criteria apparently based on this assumption
- > Active discrimination or 'othering' where health professionals and other staff in the system avoid responsibility to people with intellectual disability or are disrespectful.

Participants from health and disability sectors overwhelmingly reported that it was beneficial for the Care Facilitator to be a registered nurse embedded in primary health care who had experience and empathy with people with intellectual disability and relevant skills and knowledge.

As the intervention progressed, research participants described the Care Facilitators as navigators who helped people with disability and their carers to find their way through the health system. In the Murray region intervention, the Care Facilitators and carers reported being able to work it out together and some carers expressed relief in having an avenue of support to decide how to get appropriate action for complex problems.

Care Facilitators had an ability to identify people with intellectual disability with unmet health needs, identify health priorities and engaged these clients in the system appropriately by accessing appropriate appointments. The Care Facilitators reported that they could not fix gaps in services, but there was some evidence that they were able to use their knowledge of the health system and their own positional power as insiders to gain access to services where previously their clients had experienced road blocks. The Murray region Care Facilitators and the Kanawinka Program Manager were able to make the existing system 'work' for people with intellectual disability. However, some carers in Murray region expressed caution at engaging with the Care Facilitator model as they were anxious about the effort involved in handing over responsibility for care coordination of their family member with intellectual disability when the Care Facilitation Model was only promised as a short-term pilot intervention.

The organisation contracted to coordinate the case conferences in Limestone did not fulfil the role of health system navigator. There was no capacity within the Case Conferencing model to support people to navigate the health system at their own pace and skill level. The Case Conference Coordinator was not embedded in primary health care and was not able to engage health professionals effectively to improve care coordination.

The Murray region Care Facilitators, Kanawinka Practice Nurse and Limestone Case Conference Coordinator used the CHAP booklet for the two stage health assessment which was a key resource in facilitating better navigation of the system and improved health care.

In the first part of the CHAP, the initial screening with the person and their carer, these Care Coordinators sorted through the issues and worked out what to present to the GP and how. In the second part at the GP consultation this information was presented using medical knowledge and terms that aided the GP to rapidly assess and make decisions and recommendations. Despite Murray region and Limestone having no previous experience

with the tool, the benefits were very quickly apparent to participants in all groups. The CHAP identified issues that were previously unknown and prompted screenings which had been overlooked previously. It was reported to: make it easier and faster to find relevant information; enable prompt referrals for follow up care; streamline health data to present key information; and was expected to enable comparison of health status from one year to the next.

Sometimes GPs with limited experience in intellectual disability and who did not know the 'bigger picture' of their patient's daily living did not immediately see how a patient could benefit from particular treatment or therapy. There were instances where the Care Facilitators were able to use their positional power as an informed insider to influence GPs use of Enhanced Primary Care so that people could get therapies and assistance to improve their daily living (for example: mobility, pain relief, weight management and communication). Care Facilitators and Project Managers also used their insider knowledge to find 'work arounds' or unconventional solutions to their clients' clinical problems.

Almost all parents and carers could describe one or more occasions when their own knowledge of the person they are caring for was vastly undervalued by health professionals who did not seem to understand that people with intellectual disability could present very differently with medical emergencies such as an asthma attack and that the carer's understanding of what is normal behaviour for that person is often vital in assessing the severity of illness and making a diagnosis. Only the Care Facilitators supported health professionals at the time of consultation to adjust their usual practice to meet the needs of people with intellectual disability, by navigating their more complex care requirements. Frequently they could 'draw information out' from carers to determine what issues needed priority attention. They advocated for people with intellectual disability to their doctors to make sure problems were not sidelined because of the complexity involved in engaging with the patient. Unlike the experience reported by disability workers and carers, the Care Facilitators were viewed by GPs and health professionals as professional colleagues who spoke the same language. Care Facilitators also reported the capacity to address occasional 'othering' attitudes of a minority of health professionals who thought they could abdicate responsibility for the health care of people with intellectual disability believing this cohort could either access health care from others, or that their needs were too complex to be dealt with locally.

CMOCs identified in the project included:

- > (C) Where there were ambiguous or discriminatory service inclusion criteria (M) health professionals who had established networks and were driven to advocate for people with intellectual disability could work the system to obtain appropriate services leading to (O) Prioritised/Universal Health Care
- > (C) When there is State Government mandate for use of a comprehensive assessment tool (M) GP and practice nurse collaborated with carers using a standardised annual review process and Chronic Disease Management plans they could (O) bring the health care team together to provide a Person Centred, Team Based, Tailored Care
- > (C) Where health professionals believed that there was a 'parallel universe' where alternative health care existed for people with intellectual disability (M) positioning of intervention Care Coordinator with disability expertise and advocacy in primary health care lead to demystification of disability sector and clearer understanding of obligations to provide equity of outcomes leading to (O) Universal care

## CARE COORDINATOR AS A LINKAGE AND KNOWLEDGE BROKER

Health care networks were extended through Care Coordination programs. In this research project inviting stakeholders in Murray region and Limestone to come together with a

common purpose to plan local interventions resulted in a very high level of stakeholder engagement. Carers, advocates, disability, health and broader social inclusion stakeholders re-examined the status quo in the Murray region and Limestone regions and participated in critical discourse to develop a common understanding of the issues, and problem-solved to come up with new approaches to coordinated care for local people with intellectual disability. Even in Kanawinka a healthcare manager with disability background described the usefulness of 'shining the torch from the other angle' to promote genuine discussion between different parties about how to improve the system. This process of linkage and knowledge exchange at a mesosystem level could not be separated from that occurring at an individual client microsystem level.

During the intervention Care Coordinators in each model began to share their knowledge with clients, carers, GPs and other health professionals about the importance of health care and about individual patients and their particular needs. By connecting clients living independently with other organisations and services, early evidence suggested that the Kanawinka Program Manager and Murray region Care Facilitators were able to use their understanding of the general practice and community health environments to educate and in some circumstances, empower people with intellectual disability and their carers to initiate their own self-care. In Limestone, the Case Conferencing Coordinator reported empowering clients' knowledge brokering and linkage within her substantive role as nurse-lead for an organisation that supports people with intellectual disability in their homes and runs supported accommodation, however this linkage did not occur in any substantial way in her role as Case Conferencing Coordinator.

The CHAP acted to provide all parties with a common summary of the client's status and facilitated health professionals to be 'on to the same page' for planning and prioritising health care of the person with intellectual disability. In Kanawinka the CHAP booklet enabled health professionals to work with disability support workers to progressively encourage people with intellectual disability to exercise regularly in enjoyable social settings and have a healthier diet resulting in measurable decreases in weight and blood pressure in the group of houses run by the Department of Human Services.

Disability workers and managers in the Kanawinka Program Manager model, and in the Murray region Care Facilitator model gained understanding of services available and pathways to access care in their region. For example disability managers became more knowledgeable about incontinence nursing options, dietician services and access to diabetic educators. Similar client and carer empowerment was demonstrated in the Murray region Care Facilitator model. Although linkage and exchange was the primary intention of the Limestone Case Conferencing model, this was ultimately not successful. Participants acknowledged that if not handled correctly, case conferencing could be an intimidating and disempowering process. If the conference is not in response to a self-identified crisis, concern was expressed that feeling of disempowerment could be exacerbated when a person with intellectual disability and their carer were faced with a meeting with a number of articulate knowledgeable health professionals. The process for ensuring a person feels empowered and comfortable was reported to be time-intensive. High workload pressures made case conferencing difficult to organise and strategies to fund GPs, and health professionals from government, Medical Local and private practice sectors, to attend were not always clear. Finally, although case conferencing could be especially useful in times of crisis, this was also reportedly the time when securing family participation could be most difficult. In planning the initial intervention, stakeholders wanted case conferencing to be held within the general practice because this is one of the only common points of contact for people with intellectual disability and ensured convenience for GPs; however the change of venue to Homecare Plus meant this was not possible.

There were many examples where health professionals acted as advocates for people with intellectual disability because of their understanding and knowledge of individual people with intellectual disability. Disability managers valued health professionals (including GPs,

ambulance paramedics, allied health professionals and practice nurses) who gained exposure to people with intellectual disability in their own home/accommodation and reported that this resulted in health professionals developing familiarity, acceptance, understanding and confidence providing universal and tailored care. Rural GPs who had knowledge and understanding of intellectual disability reportedly took complications in their stride and made adjustments to accommodate people with intellectual disability. These health professionals with interest and expertise tended to become known within the disability sector and by the collective of local carers of people with intellectual disability. They also became aware of other health professionals with interest and expertise developing a special interest network. Murray region Care Facilitators and the Kanawinka Program Manager were able to extend this network by connecting other health professionals. In Limestone, the Case Conferencing Coordinator did not behave as an informed insider, and was only able to become a peripheral member of this special interest network, rather than a central member able to influence the size and shape of the network for the benefit of local people with intellectual disability. Once new links in the health care networks were established, the Care Coordinators were no longer required to navigate these linkages for clients in the health system.

In all regions researchers from Centre for Developmental Disability Health Victoria provided local inter-sectorial professional development sessions. Where these sessions were attended by a mixed cohort of health and disability personnel, feedback reported individuals established or consolidated personal relationships, developed greater understanding of the each sector, and felt more confident that they could contact professionals they had met at these sessions. As a consequence of established linkages maturing over the course of the intervention, one local special school in Murray region began investigating methods of incorporating health planning with their current multidisciplinary transition-from-school planning sessions. CMOCs identified in the project included:

- > (C) When there is State Government mandate for use of a comprehensive assessment tool (M) GP and practice nurse collaborated with carers using a standardised annual review process and Chronic Disease Management plans they could (O) bring health care team together around a Person Centred, Team Based, Tailored Care
- > (C) Where there is widespread lack of health professional knowledge and specialisation in intellectual disability, (M) people with intellectual disability and their carers cluster to doctors with interest and empathy (O) leading to experience and increasingly specialised skills and Tailored and Person-Centred Health Care
- > (C) Where special interest networks provide care for people with intellectual disability (M) Care Coordinators and inter-sectorial education can build on these by linking additional health professionals to this network resulting in broader engagement of health system personnel resulting in (O) Team-based and Universal care,

## QUALITY IMPROVEMENT THROUGH KNOWLEDGE CREATION

Health professionals occasionally viewed people with intellectual disabilities as having additional supports available to them in comparison to many other disadvantaged people living alone such as: nursing home occupants, elderly living alone, and Aboriginal people. These health professionals perceived that people with intellectual disabilities had one on one support in disability supported accommodation, or had a carer who advocated for them. There was a belief by some health professionals that the disability sector had a parallel health system.

In Kanawinka a practice nurse was systematically doing part of the CHAP assessments for over 100 disability housing residents in preparation for GP consultations. As she screened and tested people over time, she began to see strong population trends so she collated the

data. She described how when the GPs in her practice were shown the inequity of health outcomes for people with intellectual disability in their practice (including BMI, cholesterol, BP) the GPs became motivated to prioritise people with intellectual disability as an issue of equity. Importantly, all Care Coordinators reported the potential for system change through review of CHAP data for evidence of health outcomes for people with intellectual disability.

The Kanawinka and Murray region care coordination models revealed how measuring and benchmarking create an impetus for change. In Kanawinka, the review of disability housing care plans led to detection of gaps in knowledge of some aspects of health care leading the Care Coordinator to arrange education sessions for disability personnel. The belief that the care coordination trial was an audit in itself led disability workers to update plans before the arrival of the Care Coordinator. However it was clear that documentation by itself, whether through the annual health assessment or systems within a support organisation do not create change. It was individual health professionals within the system (Care Facilitators, and a Practice Nurse) with specialised knowledge of both the health system and the client group who made the problem real to other health professionals and so created the environment where health assessments and care plans became tools for audit and quality improvement.

While evidence of this longer term effect of care coordination was not expected in the brief Murray region intervention, a Care Facilitator did discover that some clients were missing out on services and support because they were not registered with Disability Services. She sought to remedy this by obtaining registration packs and assisting clients to fill them out. For those who were registered she followed up with case managers to ensure they understood the implications of the CHAP assessments.

In our interventions the short time frame did not permit significant findings of quality improvement; however health managers, health professionals and carers generally concurred that this function should be built into the role of any Care Coordinator for people with intellectual disability for continuous quality improvement at a local level. These findings reinforced stakeholders' views that medium to long term stability and sustainability was necessary for care coordination to be of any benefit.

Our findings suggested that the annual health assessments would be able to be absorbed into medical practices' workloads with the support and triaging of the Care Facilitator so the Medicare items which support regular health assessments and enhanced primary care have the potential to be better utilised for long term sustainable gains in health for rural people with intellectual disability. Continuity in the role of Care Coordinator was also perceived as important so that once the knowledge of clients and the local health system was built up it was retained, especially with regard to individual people with intellectual disability, some who had extremely rare conditions or syndromes.

CMOCs identified in the project included:

- > (C) When health professionals provided consumer driven care without attention to the needs of vulnerable groups (M) population data generated by routine annual health assessments provide evidence to justify prioritisation of chronic disease management for people with intellectual disability leading to (O) Universal health care

## QUANTIFYING OUTCOMES

Thirty-two people with intellectual disabilities were included in this study. Eighteen of the participants had health summaries from their GPs and 11 had a CHAP assessment collected by the Care Coordinators. The Care Facilitators and Case Conferencing Coordinator also completed an activity sheet detailing their observation of specified aspects of the consultation between the person with a disability, their support worker and their GP for 17 of the participants. Twenty four of the participants provided the researchers with

information about their medical issues, either in the form of a Health Summary from their GP, or in the form of a copy of their CHAP. The following data refers to these twenty four participants.

The age of 19 adult participants ranged from 19 to 59 years of age. Five children with disabilities were also included in the study. Their ages ranged from 3 to 13. Participants comprised 10 boys and men and 13 girls and women.

The complexity of health issues experienced by adult participants in the study was evident in both the health summaries and CHAPs. The average number of health conditions in adults identified in the health summaries was 4.7, and 4.14 in the CHAPs. The range was one to eight (health summaries) and two to six (CHAPs). Child participants had fewer health issues clearly identified in the health summaries with a range of zero to five. In the CHAPs for these children the identified problems ranged from zero to seven. Common general population health issues were seen in this group of people with osteoarthritis (four), diabetes (two), skin cancer (one).

Adult participants tended to be on multiple medications with Health Summaries recording adults taking an average of 4.9 medications regularly (with a range of one to nine) and CHAPs recording participants taking between one to seven medications with an average of 4.1. Some people were also taking had additional PRN and over the counter medications.

The nature of the medications was also of interest. Five adults were taking antipsychotic medications, although only one person had a clear diagnosis of psychotic illness recorded. It is not clear why these medications were prescribed, although behavioural issues were mentioned in several of these files. Twelve of the twenty-three adults were prescribed antidepressant medication. A further individual was noted to have depression in their health summary. It is of note that abuse was identified within the past history of two of these participants. Five people were noted to have epilepsy and another four people were on anticonvulsant medication, presumably either for epilepsy or as a mood stabiliser. Another remarkable feature of the health issues experienced by this group of people was the frequency of gastro-oesophageal reflux (GORD) with seven people prescribed medication for this disorder. Treatment for constipation was included in the medication lists for four people.

Vision and hearing impairments were noted in eight people with concerns about another three people who were unable to be tested. Clarity with respect to the degree of sensory loss was therefore not achieved for these participants. The physical examination recorded in the CHAP noted wax++ in the ear canals of two participants, one of these was noted to have a hearing impairment. It was unclear if the wax partially or fully accounted for the hearing loss noted.

The cause of the person's disability was not known in 17 of the study participants, although two people were noted to have dysmorphic features and four had a family history of intellectual disability. No referrals for genetic review were recorded. Six people had a genetic disorder identified, with five having Down syndrome.

In summary, participants in this study had chronic and complex health issues. The management of these issues included the use of multiple medications. The complexity of multiple health conditions, in the context of people with cognitive and communication impairments highlights the need for coordinated multidisciplinary healthcare.

## CASE STUDY – LUKE

Luke is a 40-year old man from the Murray region. He works at a supported employment service, and lives with his girlfriend (who also has an intellectual disability) and her daughter. Luke has struggled with emotional regulation for much of his life and has a history of depression. He describes, an abusive childhood. He identifies as a stoic and self-reliant person. His income is managed through Disability SA.

Luke's story illustrates some of the difficulties that people with intellectual disability living independently may experience. These include a lack of confidence in navigating the health system, insufficient understanding of how to take medications and a poor memory for doing so, and lack of an ongoing relationship with any particular health provider. His level of health literacy was low, and he felt being independent meant 'going it alone'.

### **Pre-intervention**

Prior to the care coordination intervention, Luke took his prescribed antidepressants irregularly. He had six molars removed and had made two appointments for denture fitting previously, but had attended neither. He also had chronic rhinitis. Luke's identified feelings that he "didn't want to ask for help", contributed to his physical, mental and dental health needs remaining inadequately addressed.

### **Luke's CHAP and Care Coordination**

For Luke, the Care Facilitator acted as a trusted navigator of the health service system and he experienced her involvement as being very supportive. She re-opened a gateway into the health system for him and made him feel more comfortable about attending appointments. She also ensured that he understood what was needed and assisted him to complete any recommended treatment.

"[Care Facilitator 1] encourages me, has a talk to me, but encourages me to go to these appointments. And she makes me feel relaxed and feel comfortable to go."

"Just having that extra support, someone that can actually explain to me what's going on, what the doctor..., and explain to the doctor what's going on with me"

The Care Facilitator also filtered and prioritised health information for the GP to ensure that problems were clearly articulated. The process of gathering information for the CHAP assisted in this process.

"So when I go to the doctor sometimes I forget to let the doctor know what ... like stuff that's going on, so she explains to the doctor in a way that he can help me, understand what I need."

"I kept going to doctors that say you haven't got no problem, but I went to ... the doctor that I have now, and he picked it up straight away and he's fixed up my problem... he's got me on the spray, and the spray's working for my nose"

The Care Facilitator acted as a linkage and knowledge exchange broker for Luke. A misunderstanding of some kind meant that Luke believed that he could not have dental treatment because it could not be paid for under the conditions of his income management arrangement. The Care Facilitator liaised with both Disability SA and the dentist to arrange the treatment and payment, ensuring that he received the care he needed within his limited financial means.

The Care Facilitator linked Luke to a new GP, with whom he plans to build a relationship over time. Prior to this he had been seeing different doctors for episodic care.

"I just got shifted around so much with doctors... they'd get me in but I wouldn't get the same doctor every time that knew the history of me ... So hopefully now I'm going to [Murray town], I'm staying with the right doctor, and it's going to be alright".

The Care Facilitator's intervention also changed Luke's ideas about what it meant to be independent, empowering him to be more proactive about his health in the future and willing to engage with the health care system on a regular basis:

"No, they didn't do blood tests or something like that but I'm hoping to get that done soon, so I'll probably do that when, I'm going to do that myself ... Because I want to see if I get diabetes, or, um, I've been getting like headaches too so I'm going to go back to the doctor soon".

Through engaging with his care network, the Care Facilitator also encouraged him to incorporate his family in his social support network. Likewise Luke's girlfriend was encouraged to be involved in his health care.

"The thing I had, I've got some, my girlfriend now reminds me to take the tablets, and her daughter, the other thing is, helping me with reminding me to do, I never used to clean my teeth very much and I used to have trouble cleaning my teeth, but she reminds me to clean my teeth. So that's something else, that I've got that extra support at home now".

The Care Facilitation intervention was able to identify simple, inexpensive solutions to some of the barriers Luke was experiencing to receiving good health care. Luke now has a regular GP, and plans have been made for him to have annual health assessments. This will enable proactive health care and monitoring of his health status. The intervention was therefore very positive for Luke.

## Discussion and recommendations

### HOW PEOPLE WITH INTELLECTUAL DISABILITY ESTABLISH AND MAINTAIN THEIR CARE NETWORKS

Social inclusion recognises the importance of meaningful interactions with others, including engagement in employment and education. Social inclusion is now recognised as a fundamental prerequisite for health<sup>30</sup>. In this project the researchers took a broad view of the term 'care network' to include a person's family, school, services within the disability sector such as supported day activities and accommodation services, as well as contacts who fall within the health sector, such as GPs, community health services and tertiary care staff.

When considering the health of people with intellectual disability it was particularly difficult to disentangle physical and mental health from general wellbeing and social inclusion. The social determinants of health such as access to: education, good housing, diet, security and income; were all, to some degree, only attainable for many people with intellectual disability if they had the determined assistance of carers and advocates. Furthermore, it requires a great deal of activism, cost and hard work on the part of supporters to achieve a level of functional independence for those able to do so. This research demonstrated that social isolation reduces the capacity for people with intellectual disability to hear about how others recognise and deal with common health problems, access common sources of health information, as well as navigate the health system. People with intellectual disability also have limited literacy and numeracy and this further restricts their access to information about healthy behaviours, health issues and health services. Care in terms of support for day-to-day activities and needs were often prioritised over health, with potential to result in further decline in health and social inclusion. Acting as part of the care network Care Coordinators can facilitate person-centred care leading to timely, effective holistic health care.

#### **Recommendation 1: Introduce care coordinators as a sustainable resource for people with intellectual disability within local primary health care**

Where Care Coordinators had capacity to interact directly with people with intellectual disability, and their carers they could support people to become more health literate and empowered in accessing the health care system. The Care Coordinators also learnt firsthand how the social determinants of health shaped the health outcomes of people with intellectual disability in their region. Care Coordinators then became an important source of information for health professionals to enable them to take account of this information and

move to providing more tailored care for individuals, as well as advocating for system change to ensure universal access to local and metropolitan health services.

In this study some carers were reluctant to accept assistance that was only short-term as the time and effort spent bringing the Care Facilitator up to speed was not perceived to be compensated for by the value they could bring in the period of the intervention. Similarly, the Care Facilitators and Case Conferencing Coordinator were reluctant to push themselves onto people with intellectual disability because they knew the intervention was short-term and their relationship with these individuals may not continue. People with intellectual disability often have highly valued, but limited and fragile, social networks. Some carers and disability support organisations, who typically invest many years into achieving good outcomes for their clients, felt short term interventions and planning were disruptive, of limited value and were potentially counterproductive.

In the PEACHI study researchers took particular care to ensure that intervention participants recognised the short-term nature of the study interventions. Despite this there has been considerable rise in local expectation regarding ongoing support by the University, health service agencies and disability sector to contribute to maintaining the Care Coordination intervention. Initially the researchers believed that the study design, which included resourcing interventions from the grant funding, was a generous gesture aimed at ensuring rural people with intellectual disability, their carers and support agencies would benefit immediately from the APHCRI funded research. However, with the withdrawal of the Murray region and Limestone interventions at the conclusion of the research project, there is ongoing concern regarding the ethics of applying for funding for short-term interventions. The project validated local need for improved care coordination for people with intellectual disability in Murray region and Limestone and highlights this is an ongoing issue. Policy partners have a responsibility to act on the findings of reports and this needs to be addressed in any national or state-based roll out of a program developed to support care coordination for rural people with intellectual disability.

Carers and disability support workers are integral to healthcare access and implementation of care coordination models for people with intellectual disability, and must be engaged in primary care provision. It is therefore recommended that care coordination interventions to improve health outcomes for people with intellectual disability are maintained for a minimum of five years or stakeholders may not invest in the change.

Care coordination has been defined as coordinated care for targeted 'at risk' or vulnerable people which incorporates assessment of medical, functional, social, and emotional needs and the provision of optimal treatment, education, and integrated services to meet these needs<sup>31</sup>. Furthermore, care coordination involves support and assistance in navigating the broad health system and monitoring of progress for the betterment of each person<sup>31</sup>. A large Australian care coordination trial showed improvement in overall wellbeing in clients with a wide range of chronic disease when provided care coordination<sup>31</sup>.

Care coordination is based on collaboration and takes a prospective and preventative approach to health. The prevention and treatment of chronic health problems has been shown to be *most* effective in integrated systems where there is active collaboration between clients and health workers, as well as among health care professionals themselves<sup>32-34</sup>. Whilst there is evidence to suggest that a lack of care coordination impedes the effectiveness of health management efforts<sup>35, 36</sup>.

Key components of the care coordination include: a 'problems and goals approach', a care plan, and service coordinators working with general practitioners and clients, with the key determinant to care coordination being self-management<sup>31</sup>. This however, is based on the assumption that people requiring care coordination have the understanding of and capacity for self-determination and self-management.

It has been argued that the main theoretical link between improved coordination and improved health and wellbeing lies in reducing preventable complications of chronic illness

through proactive care planned around individual needs<sup>37</sup>. The theory around care coordination can be difficult to translate into practice. “The elements that constitute coordinated care are not clearly defined, nor completely understood. Rather, the term is used simultaneously and interchangeably to conceptualize the structure, process, philosophy and interpersonal dimensions of care delivery”<sup>38</sup>. Capturing the rich and multifaceted implications of care coordination in a single, simple term can cause those within the system to assume that fragmentation of health delivery can be addressed by singular and simple methods<sup>38</sup>. Although the many dimensions of care coordination have been heavily researched in the last decade, few actionable models exist<sup>38</sup>.

Local, State and Commonwealth Government health policies significantly impact the success or otherwise of care coordination programs for people with intellectual disability in rural areas. Previously, researchers have been criticised for failing to recognize adequately the contexts in which disability research is situated especially the social, cultural, economic and political forces that shape the design and delivery of services<sup>39</sup>. To translate research effectively into practice, sensitivity to context, participation of communities and production of evidence based in practice is critical<sup>40</sup>.

### **Recommendation 2: Situate care coordination programs in primary care close to general practice**

Participants in all regions recognised the central role of rural GPs in accessing health services for both new and established health issues. Rural general practice remains a small business customer-based model of practice which often suffers from workforce shortages. In Murray, where Medicare Locals was able to build on Divisions of General Practice established networks effectively, these organisations were the provider of choice for care coordination. In contrast, the Case Conferencing Coordinator in the Limestone intervention was not embedded in primary health care and was not able to engage GPs and health professionals in coordinated care. Similarly, the Kanawinka Project Manager made considerable impact on care coordination for people within disability accommodation services, while the Practice Nurse had a direct impact on the health care system. These findings demonstrate there are strong advantages to embedding care coordination within the primary health care system at an organisational level closely engaged with general practice. Where care coordination interventions were located within an organisation that had credibility with general practice they had established relationships to leverage practice engagement and increase the relative priority of people with intellectual disability.

### **Recommendation 3: Build in a ‘Trusted Navigator’ function to care coordinator roles**

The Murray region Care Facilitation model demonstrated that health outcomes for people with intellectual disability can be improved through a Care Coordinator with both health and disability expertise sitting within the primary health system. These Care Coordinators need to ensure people with intellectual disability are supported to navigate the health and disability systems. The Limestone stakeholders envisaged a compelling collection of benefits to be gained from case conferencing; enabling participants to ‘sing from the same hymn sheet’, to bridge the health and disability sectors, provide holistic care and ensure person-centredness and accountability. However, the trusted navigator role was de-emphasised in this design. Without this trusted navigator role the Limestone service professionals did not have additional capacity to bridge the health-disability divide, and organisational inertia prevailed despite strong stakeholder engagement in seeking to develop an intervention to improve health outcomes for people with intellectual disability. The Limestone Case Conferencing Coordinator and stakeholders agreed in the final meeting that case conferencing should not be the foundation of care coordination. In contrast there was overwhelming recognition that the ‘Trusted Navigator’ function needed to be the foundation of a care coordination intervention. This is an important finding as the trusted navigator role is therefore not simply a substitution mechanism. This role engages all players in the change process because they quickly see improved access for individual

patients, and role models the value of learning with, from and about other care providers in order to improve team-based, tailored and holistic care.

For people with disabilities, their social support is provided through disability services, while healthcare is provided through the health sector. The inter-connectedness of these two aspects of people's lives necessitates those providing care, from the disability/social sector and the health workforce, to collaborate in effective partnerships. However, the numbers of people with intellectual disability in any one general practice is small, so establishing expertise in the care of people with intellectual disability and a knowledge of relevant social and community networks and services is difficult to acquire. Conversely, disability support workers are not trained in health and can find navigating the health sector to achieve appropriate and timely care for the people they support difficult.

This study demonstrates the utility and importance of a Care Coordinator with both health and disability knowledge being able to facilitate in-the-consultation learning by health professionals and better understanding among disability and health care networks.

The researchers recommend that health outcomes for people with intellectual disability can be improved through accessing a Care Coordinator with health and disability expertise who sits within the primary health system. This role can support the system work for people with intellectual disability and can support health professionals to engage in the provision of universal rather than generic health care, by tailoring their approach to the individual.

#### **Recommendation 4: Introduce a national standardised annual health assessment to foster gold standard comprehensive care**

Standardised annual health assessments have been shown to be effective in identifying common and important health issues in people with intellectual disability<sup>41</sup>.

In regional areas, a limited number of services stretch to meet all the many and varied needs of the population. These include the needs of people, a range of ages and from different racial, economic and social backgrounds. Disability adds further diversity to the population. People with disabilities are a highly heterogeneous group with very different cognitive, physical, sensory and social abilities, and health needs both associated with and independent of their disability. Despite the heterogeneity of need, however, there are common themes, including communication difficulties, the involvement of carers and advocates and the complexity of inter-related health and social issues.

In all three Care Coordination intervention sites, health outcomes for people with intellectual disability were improved when people with intellectual disability had an annual health assessment based on the Comprehensive Health Assessment Program. This tool allowed health and disability professionals to develop a common understanding of each individual's health status and current priorities of care. The social circumstances of each patient were made explicit, new health problems were frequently identified, and incremental changes could be negotiated, monitored and built upon.

A key difference between health care of people with and without an intellectual disability is the need for annual comprehensive health assessments in order to identify, prevent and manage illness. Care Coordinators have a central role in ensuring people with intellectual disability have an annual health assessment. The researchers recommend the national introduction of a standardised comprehensive, intellectual disability-focused health assessment. Such a tool is critical to good healthcare provision as it provides an evidence-based structure to gather health information, assess health status regularly, and prompt the exploration of issues known to be more common in people with intellectual disability. These assessments guide GPs with limited specialised training and knowledge in the particular health needs of this population. A structured assessment facilitated health and disability professionals to work effectively together.

### **Recommendation 5: Engage stakeholders in developing local models of Care Coordination**

An important result of the PEACHI study has been the unexpected high level of stakeholders' engagement in coming together to re-examine the status quo, problem-solve and come up with new approaches to coordinated care for people with intellectual disability. The PEACHI project acted as a catalyst in moving a loose collective of people committed to improving outcomes for people with intellectual disability in Murray region and Limestone from diffuse awareness of inequity to concrete plans for the future. Research Stakeholder Meetings evolved into an action research intervention model, improving the capacity for a successful intervention. The use of Realist Evaluation supported stakeholders to look beyond the original care coordination model to consider the mechanisms or supporting contexts for outcomes. This focus on meta-processes of how people's attitudes and behaviours were changed enabled stakeholders to develop context relevant interventions, rather than focus on the mechanics of the reference model.

The researchers recommend that successful care coordination interventions require time, financial resources and leadership capacity to engage local stakeholders (including people with intellectual disability, health care professionals, carers, disability advocates, disability support groups, and other supports or local community members) in the meta-process decision making in order to tailor care coordination models to the local contexts. Commonwealth policy should be prescriptive about outcomes while recognizing that these outcomes will be achieved through different interventions in different contexts.

Successful Care Coordination programs require engagement of local stakeholders in the decision making in order to tailor care coordination programs to the local context. Stakeholders include 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.

### **Recommendation 6: Introduce accountability of the health sector to enforce formal system-level linkages with disability services.**

In each of the three rural areas in this study, special interest networks existed involving health professionals with knowledge and motivation to provide universal and holistic care for people with intellectual disability. The Kanawinka Project Manager and Murray region Care Facilitators demonstrated that having someone performing the dedicated role of a regionally based Care Coordinator provided a 'bridge' between disability and health services. This created the capacity to bring additional members of the health and disability sector into these special interest networks, building their size and sustainability. Once health and disability professionals developed knowledge of and relationships with other professionals who could support them to care for their patients with intellectual disability, referral patterns and team-based care processes continued independently of the Care Coordinator. In rural areas where the health workforce is frequently transient, the role of an ongoing 'trusted navigator' is essential in facilitating and maintaining these linkages.

National Disability Insurance Scheme (NDIS) has introduced a strengths based empowerment framework for people with a disability. This presents an opportunity for new approaches to navigate the health care system for people with intellectual disability. Although health is not within the scope of NDIS, health status profoundly affects the ability of individuals to participate in the social and economic life of the community, a stated priority of the legislation<sup>42</sup>. The researchers recommend that NDIS formally link with Medicare Locals or other rural primary care organisations to foster opportunities to develop meaningful professional relationships across the disability health divide and between services within the health sector. These entities, and individual members of these entities, would be mandated to take responsibility for building, maintaining and utilising these linkages for the benefit of their clients. By creating partnerships between the Care Coordinators and local NDIS services the capacity for individuals with intellectual disability and their carers to achieve

improved health outcomes will have significant benefits for their wellbeing and social inclusion.

### **Recommendation 7: Mandate universal access in health care policy**

*Equality* of health service provision (providing the same service to everyone) is not the same as providing *universal* services (services which are tailored to the individual and aim to ensure the same *outcomes* for everyone) (see Glossary).

Findings from this study demonstrate that in rural areas, when health workforce shortages and limited resources grapple with excessive demands, services are at risk of providing equal services to their community, without recognising and positively discriminating toward those vulnerable groups with poorer health outcomes. This is more likely to occur when services have some element of small business customer-based element. Health services need to be accountable against criteria which include demonstrating they are universally accessible and documenting their programs which seek to provide universal and equitable health outcomes for the communities they service.

### **Recommendation 8: Measure and benchmark health outcomes**

The health information gathered on 25 people with intellectual disability in this study highlighted the complexity of medical and social issues, and the need for Care Coordination. Particular health issues identified as more prevalent in this group of people include: poly-pharmacy, sensory impairment, epilepsy and gastrointestinal disorders including GORD and constipation and disorders of mental health. The findings in the study are consistent with the literature <sup>43</sup>. The high prevalence of depression reflects the biopsychosocial risk factors experienced by this vulnerable group.

Findings from the Kanawinka Project Manager demonstrated the effectiveness of data collection to support quality improvement of care coordination for people living in disability housing. Also the Kanawinka Practice Nurse was able to act as a change agent by using local data she collated from the GP practices and making the problem real to her GP colleagues. The success of the Murray region intervention may also be attributed to the choice of host organisation as an agency already responsible for quality improvement in health care. Location within an agency such as a Medicare Local, separate from but providing services to medical practices, proved helpful in this study. Medicare Locals are responsible for identifying areas of local need, planning and funding extra services to meet those needs. Research data identified the existence of a culture of quality improvement in both rural general practices and the Medicare Locals, a factor which has been highlighted as one of the pivotal factors in the success or otherwise of chronic care interventions <sup>44</sup>.

Care Coordinators need to be positioned as local quality improvement agents for disability health care who are responsible for carrying out the plan-do-study-act cycle. They can collect data, review and report outcomes and influence health system changes over an extended period of time.

## Conclusions

This study was a response to the identified clinical reality of the health disadvantage and inequity of health outcomes experienced by people with intellectual disability in Australia, with a particular focus on the issues experienced by people living in regional and rural communities. The researchers set out to identify ways people with intellectual disability established their care networks within the context of three regional towns across two states and aimed to explore the application of models of Care Coordination within these communities. Each community was unique, and each model was a response to local need and built on local networks and services. The ways in which disability and health services worked together varied in each context, but common themes were complexity of need and the requirement for coordinated, tailored care to meet the complex health and social issues of the people with disabilities in these communities.

The project also demonstrated the value of having health professionals experienced in and committed to the care of vulnerable populations such as those with intellectual disability. Each region had 'change champions' and this project was able to identify individuals and services within the community that enabled and facilitated access to and better integration of care.

Health status is intimately related to quality of life and community participation. Wellness or illness impact on the ability of the individual to be optimally independent and to engage and participate in the social and economic life of the community. Conversely social circumstances and opportunities profoundly impact on health.

The research found that stakeholders saw universal care and holistic care as the overarching outcomes. Care coordination is a 'meta-service' which is highly valued and should be available within our health system to people with intellectual disabilities to enable equity of health outcomes.. Care coordination programs were most successful when Care Coordinators fulfilled the following roles: participant in the care network, trusted navigator, linkage and knowledge exchange, knowledge creator of quality improvement. When these attributes existed people with intellectual disability were prioritised for care so that their healthcare and outcomes approached those in the general population. Care Coordinators supported health professionals to tailor care provision for people with intellectual disability ensuring care was holistic, timely and comprehensive, in accordance with best practice. Care coordinators were able to bridge the divide between health and disability services, bringing members of the health care team together to work in a more integrated and effective way for the person with intellectual disability.

# Appendix 1

## GLOSSARY

**Care coordination:** Care coordination<sup>38</sup> involves identification of both patient- and physician-defined health concerns; goal setting and planning for achievement; connection to services supporting self-management, information and material needs; and sustained follow up, creating a cycle of coordination. Care Coordination describes structural, procedural, philosophical and interpersonal elements of care delivery<sup>38</sup>.

**Care Coordinators:** this term with capitalised letters refers specifically to the roles developed in the three care coordination study sites. In each case these were nurses who worked in the primary health care sector. In the course of the research it was recognised there were specific advantages for these individuals to have experience in both the Health and Disability sectors and to be based in primary health services with good working relationships with general practice.

**Care Facilitator model:** This model of care coordination was implemented in an inland South Australian community given the pseudonym of Murray region in this research project. Stakeholders envisaged that an identified person with nursing background and experience in disability could provide people with intellectual disability with a resource to facilitate health assessment, prioritise and examination of the person and inform an action plan of progress and follow up.

**Comprehensive Health Assessment Program (CHAP):** The CHAP is a health assessment program developed for adults with intellectual disability. It involves a two part booklet used to record a person's medical history and to guide general practitioners through a comprehensive health assessment. The booklet provides prompts for areas of health that require particular attention for people with intellectual disability and about the need for follow up care.

**Context:** In Realist Evaluation<sup>45</sup> mechanisms will only activate under particular circumstances. Context describes the key features of the circumstances which are specifically relevant to enabling a mechanism.

**Context Mechanism Outcome Configuration (CMOC):** To paraphrase Pawson & Tilley<sup>28</sup>, in Realist Evaluation these descriptors comprise models indicating how interventions alter behaviour (mechanism), amongst whom and in what conditions (context) to bring about change (outcome)<sup>28</sup>.

**Dignity of risk:** A term used in healthcare to denote respect for autonomy and self-determination of health behaviour, even though health professionals may believe a practice or habit to be 'risky'. For example, a person may choose not to take a medication, to continue to smoke cigarettes or take drugs, or not to utilise a service although a health professional recommends against the action. This must be balanced with the duty of care for people with limited capacity to comprehend the information required to legally consent in an informed manner.

**Generic or mainstream care:** In this project, these terms refer to mainstream health or social care which aims to provide the same service to every person, regardless of individual capacities and preferences. This care offers the same inputs to every person – to provide *equality*. Discrimination against those with different abilities may occur, however, effectively excluding them from certain services. For example, a person whose disability prevents them sitting still with their mouth open may be denied access to effective dental care; or a person who cannot retain and apply health promotion information may be denied smoking or weight loss interventions because the current systems do not cater for these differences. It is contrasted with Universal care.

**Holistic care:** Holistic care takes into account the impact of psychological, social, political and economic factors on disease development and progression. Holistic care aims for health as conceptualised by the World Health Organization: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”<sup>46</sup>. This was one of the six PEACHI focus outcomes as conceptualised at the end of phase 1.

**House plan:** For the purposes of this report, a house plan is a document or files with details of managing a client’s day to day care including: their personal management of hygiene, nutrition, mobility, autonomy and health. It is important to recognise that people with intellectual disability who live in supported accommodation have house plans which are often referred to by disability workers and carers as their care plan. House plans are not health care plans as they document current day to day health management strategies, not ongoing management and future primary and secondary prevention plans.

**Intellectual Disability:** This project uses the World Health Organisation definition of intellectual disability, which is: “A significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends not only on a [person’s] health conditions or impairments but also crucially on the extent to which environmental factors support the [person’s] full participation and inclusion in society”<sup>47</sup>

**Mechanism:** In Realist Evaluation a mechanism is defined as the process of how subjects interpret and act as a consequence of an intervention.

**PEACHI:** The short title for the research project. Acronym for ‘Partnerships Exploring Attributes of Coordinated Healthcare Implementation’.

**Person-centred care:** Care which accommodates individual and cultural differences as well as a person’s own choices. Person-centred care should also be provided in accordance with the other principles of primary health care, that is, accessibility, acceptability, and affordability<sup>48</sup>. This was one of the six PEACHI focus outcomes as conceptualised at the end of phase 1.

**Primary health care (PHC)** In Australia, PHC is defined as “socially appropriate, universally accessible, scientifically sound first level care provided by a suitably trained workforce supported by integrated referral systems and in a way that gives priority to those in most need, maximises community and individual self-reliance and participation and involves collaboration with other sectors. It includes: health promotion, illness prevention, care of the sick, advocacy and community development”<sup>49</sup>

**Prioritised care:** The term ‘prioritised care’ describes the processes used by health professionals to attempt to achieve equitable access and outcomes or Universal Care for people with intellectual disability. It is equivalent to positive discrimination. This was one of the six PEACHI focus outcomes as conceptualised at the end of Phase 1.

**Realist Evaluation:** A research/evaluation methodology which uses both qualitative and quantitative data to examine not only whether something worked, but how it worked, for whom and in what circumstances. This is achieved by developing context-mechanism-outcome-configurations (CMOCs) which define the circumstances in which individuals change their attitudes or behaviours in such a way as to deliver a desired effect.

**Reference model:** In this report, the reference model was a type of care coordination trialled in a town in Western Victoria. The town was given the pseudonym Kanawinka, after the Geopark in the region. The trial involved a registered nurse seconded by Victoria’s Department of Human Services as a Project Manager to improve care in Disability Accommodation Service houses by enhancing the organisation and completeness of health documentation, enhancing access to primary care, and breaking down barriers between the health and disability sectors, improving the capacity of health systems and professionals to work with people with disability.

The research team used the CMOCs identified from this model, filtered through the contextual expertise of the local stakeholders in the Murray region towns and Limestone towns, to design the two trial interventions.

**Social inclusion:** Social inclusion is full participation in society in areas such as education, employment, friendship and contributing to the community and society. It is a prerequisite for good health under the biopsychosocial model. Ensuring social inclusion is an aspect of providing Holistic Care.

**Team-based care:** Health care in which multi-disciplinary team members, and often the person's carer as an 'expert in the person', communicate and collaborate to assess, plan, implement and evaluate health care. This was one of the six PEACHI focus outcomes as conceptualised at the end of Phase 1.

**Universal care:** In this project, 'Universal care' is considered to be health or social service provision which aims to provide care *regardful* of a person's capacities and preferences, utilising these to ensure that the same outcomes are gained by every service user. Universal care aims to provide every person with the same outcomes – it provides *equity*. This is also known as 'subjective equality', or the 'needs rule'<sup>50</sup>. Positive discrimination may be required to ensure equitable outcomes.

This is contrasted with 'Generic care', which aims to provide the same service to every person, *regardless* of individual capacities and preferences. In this project, generic care is defined as offering the same inputs to every person. Discrimination against those with different abilities may occur, effectively excluding them from certain services. For example, a person whose disability prevents them sitting still with their mouth open may be denied access to effective dental care; or a person who cannot retain and apply health promotion information may be denied smoking or weight loss interventions because the current systems do not cater for these differences.

## Appendix 2

### STAKEHOLDER ACKNOWLEDGEMENTS

Local stakeholders from Murray region and Limestone were engaged initially in the research at the time of original application, providing letters of support following initial consultation and information sharing on the potential research project. Once the research project was funded by APHCRI, two stakeholder reference groups were established in the two South Australian intervention sites. These were made up of health and disability managers and direct service personnel as well as carers and advocates of people with intellectual disability. In Limestone the stakeholder group was developed de-novo, through a snowball effect of engaging known carers, health and disability personnel and then asking these people to recommend others. In Murray, the genesis of the stakeholder group was a former network of health and disability professionals coordinated by community health who offered to renew the group for the purpose of the project. Former members were asked to recommend other stakeholders and most key service providers were represented. At the first stakeholder meetings the groups were asked for their opinion about including people with intellectual disability as a consumer voice on the stakeholder group. Both stakeholder groups chose not to include a consumer representative as inclusion risked being viewed as tokenism. Reasons for this included concern about providing a respectful environment for the individual and a meaningful role for them within the terms of reference of the stakeholder group.

During Phase 1 of the project stakeholders provided significant advice regarding the context of disability and health services in their regions. At the end of Phase 1 the local stakeholder groups took responsibility to propose an intervention model based on their own expertise of their context and on the Realist Evaluation results developed from the study. In Phase 2 members of the stakeholder group assumed control of managing the interventions implemented in each of the South Australian regions, and recruit participants to the intervention. Finally, research results were reported back to Murray region and Limestone stakeholder groups to create construct validity by ensuring the results "made sense" to the stakeholder groups. Stakeholder groups actively participated in the process of developing policy recommendations from the research outcomes.

The research team would like to take this opportunity to formally acknowledge the following stakeholders who agreed to be named:

- Homecare Plus & Paraquad SA;
- Lifestyle Assistance and Accommodation Service, Loxton
- Orana Incorporated, Riverland
- Riverland Special School
- Disability SA
- Community Living and Support Service (CLASS)
- Riverland Office Community Health, Country Health SA Local Health Network
- Riverland Division of General Practice Inc
- Country South SA Medicare Local
- TAFE SA Renmark Campus (Disability and community services stream)
- South East Disability Advocacy Service
- South East Region Community Health, Country Health SA Local Health Network
- The local Medical Clinic
- Homecare Plus & Paraquad SA;
- Wattle Range Council
- Two parents/carers

## Appendix 3

### CONSENT FOR PEOPLE WITH INTELLECTUAL DISABILITY TO PARTICIPATE IN RESEARCH

At the suggestion of a stakeholder organisation (supported accommodation and day options for people with intellectual disability) in the Murray region, the team created a short DVD to introduce the two team members who conducted interviews to potential participants. It was felt that a personal, visual introduction would be more meaningful and allow for the person to give a more informed consent for the interview process.

The DVD was six minutes long. It gave an overview of the research, the process of arranging an interview, the consent form, the content of the interview. In recognition of the fact that many people with intellectual disability are motivated to please (Finlay & Lyons 2002), potentially at the cost of their own preferences, it stressed the fact that the entire process was voluntary and the participant had control over continuation at every stage.

#### Standardised Assessment of Competence to Consent

- a) "What will I be talking to you about?"
- b) "What will I be writing on the paper?"
- c) "Are there any good things about talking to me ?"
- d) "Are there any bad things about talking to me ?"
- e) "What can you do if you decide you won't want to talk to me any more?"

In every case, carers and contacts were in agreement with interviewers regarding competence to consent. If a carer felt that a person with intellectual disability was not able to consent, interviewers did not make a separate assessment. No person put forward for survey/interview by a carer was judged incompetent to consent by the interviewer.

## Appendix 4

### PHASE 1 METHODS

The project occurred in two phases. In Phase 1 the care networks and access to health care for people with an intellectual disability were investigated in three rural sites across Victoria and South Australia, known as Kanawinka, the Murray region and Limestone.

The team wanted to ensure that people with intellectual disability had the opportunity to participate in the research to actively shape the outcomes, as people with intellectual disability rarely have the opportunity to participate in and take ownership of research<sup>51</sup>. In each of these research sites, people with intellectual disability and their carers were invited to participate in supported surveys to determine their current health status. Data collected included: descriptive information regarding age, gender, diagnosis and ethnicity; a generic tool used to identify health status and utilisation of health services; and additional information about social inclusion and wellbeing using a customised tool based on the Personal Wellbeing Index (PWI-intellectual disability) and Social Impairment Scale (SIS).

A purposive sample of participants with intellectual disability and their carers was invited to participate in interviews to explore their perceptions of access to primary health care and care networks, the level of social isolation experienced by the consumer, and their carer's confidence to adapt and self-manage in the face of social, physical and emotional challenges<sup>52</sup>.

Study participants were invited to describe the attributes of their ideal care coordination service. This information was used to inform the researchers of the outcomes of care coordination which were perceived by participants as most important for people with intellectual disability. All data collection was conducted by one of three team members to balance consistency with the logistics of working across three geographically distributed regions.

Interviews and focus groups of health and disability professionals were performed to determine the current context of healthcare for people with intellectual disability in each of the three rural sites being studied. The interviews in Kanawinka specifically focussed on identifying the context and mechanism factors that enable this intervention to successfully meet the outcomes identified in the initial research work.

All interviews and focus group data were transcribed verbatim. The transcripts were de-identified and assigned an alpha-numeric identifier to ensure confidentiality.

In Phase 1, a grounded theory approach was used to analyse the data as it allowed for detailed exploration of participants' narrative responses. All transcripts were entered into NVivo 10 for coding. Initial coding was performed by three members of the research team who met frequently to compare coding and resolve any discrepancies. Similar codes were grouped into analytical categories, which were compared to explore the relationships between those categories and develop the initial Context-Mechanism-Outcome-Configurations. These in turn were grouped under the six original Outcomes identified through Phase 1. Definition of factors and of the optimum configurations of these findings were used to develop the conceptual model describing the potential attributes of effective coordinated primary care models for people with intellectual disability. This conceptual model was used to inform Phase 2 interventions in the two South Australian sites.

Ethics approval was obtained through the Southern Adelaide Clinical Human Research Ethics Committee (Project number: SAC HREC 34.12), and Monash University Human Research Ethics Committee (Project number: CF13/727 – 2013000312).

## PHASE 2: METHODS

In Phase 2 of the study the Care Facilitation model developed in consultation with the Murray region stakeholder group was implemented in the region. Similarly the Case Conferencing model developed with the independent Limestone stakeholder group was trialled in Limestone, after some initial delays. These interventions were proposed as context-specific care coordination interventions aimed at meeting the outcomes identified in Phase 1 of the study. Phase 2 interventions were funded through the research project as approved in the original APHCRI grant, with an additional contribution made to the Murray region project by the Medicare Local to extend the original capacity of the project.

People with intellectual disability were recruited to participate in the two trial interventions through carers, health professionals and disability personnel involved in the two local stakeholder groups, and through the social and professional networks of these stakeholders. Disability accommodation providers were able to refer directly to the Care Coordinators, and some carers spontaneously sought involvement in the project through word of mouth.

In both care coordination models data was collected from people with intellectual disability accessing the new service by the Care Coordinators and provided to the research team in a de-identified form. This included: original patient-held or GP-held health summaries (if they were available to the Care Coordinator); results of the CHAP assessment; and the post-intervention care plan or health summary held by the person with intellectual disability, their carer or GP.

For each client accessing the new care coordination services in Murray region and Limestone, the Care Coordinators completed an activity sheet which consisted of likert scale questions regarding how the local health service had responded to the needs of the client and how well the Care Coordinator felt the local health service had been able to meet the intended outcomes of the intervention. These questionnaires were used to prompt Care Coordinators in monthly interviews which sought to explore their experiences in terms of the rudimentary CMOCs.

Again a purposive sample of people with intellectual disability and their carers, who accessed the new care coordination interventions in Murray region and Limestone, were invited to participate in interviews to explore their experiences of the care coordination interventions.

Interviews and focus groups were held with health and disability professionals in both sites both early and late in the intervention implementation to refine the preliminary Context-Mechanism-Outcome-Configurations. Consent was obtained from stakeholder groups to record and utilise Stakeholder meetings as focus groups for Phase 2 of the study.

Interview and focus group data were again transcribed verbatim professionally, and entered into NVivo 10 for analysis. Quantitative and qualitative data from the Phase 2 intervention trial was analysed as described above and results used to test the assumptions made in the initial conceptual model and articulate the theoretical framework to inform middle level policy.

Health summary data was collated and descriptive statistics used to determine frequency of new problems found and additional management strategies instigated.

Ethics approval was obtained through the Southern Adelaide Clinical Research Ethics Committee (Project number: SAC HREC 39.13), and Monash University Human Research Ethics Committee (Project number: CF13/727 – 2013000312).

## Appendix 5

# BACKGROUND INFORMATION OF THE THREE RURAL COMMUNITIES

### Kanawinka background

Kanawinka town has been largely defined by the past existence, and dismantling in 1993, of a large institution that supported both people with intellectual disability and people with psychiatric disorders for over a century. There was also a large accommodation service based at a neighbouring town since the 1930s. For most of that time the local medical practice provided support to specialist nursing staff working for the institution. As such, the medical practitioners were relatively familiar with and experienced at supporting people with intellectual disability. When the institution closed, many of the individuals living at the institution moved to shared supported accommodation within the Kanawinka community. While the reorganisation of health supports moved from an institution-based model to being supported by the local general practice some of the nursing staff continued to provide support but in a primary health care setting. This provided a somewhat unique level of expertise within that community, which is not duplicated in most other towns.

### Murray region background

Following the International Year of the Disabled in 1981, a group of Murray region people with disabilities and their families lobbied successfully for funding to support people with intellectual disability. The region had already established an accommodation service and day program for people with milder intellectual disability. In contrast to Kanawinka town the region had no institution and there were no locally based services for people with severe intellectual disability. Currently in the Murray region, people with intellectual disability are generally cared for in the family home, with some scattered supported accommodation services. Estimates of the population size vary from 100 to 300. Day options programs and supported employment services exist, and both a special school and supported mainstream education services are available. The primary points of contact for new health issues are the GP or the emergency department. It may take four to six weeks to access the preferred GP, however immediate access is available for urgent health issues. Allied health services are accessible through GP referrals, direct referrals to community health, and internal referrals through the hospital or other allied health services. However, public allied health services may be accessible only with a long waiting period or on a limited basis, with difficulties recruiting professionals to the region. No specialist disability health services exist, and mental health services are not specialised for people with intellectual disability. Referrals can be made to speech pathology and mental health from the special school. In accessing all health services, age- and ability-based criteria frustrate health providers attempting to coordinate care.

Around 200 people with intellectual disability are registered with Disability Services. The Centre for Disability Health (CDH) in Modbury and the Child Development Unit (CDU) of Women's and Children's Hospital in Adelaide is utilised by local people with intellectual disability. However transport issues limit access to the CDH and clients must be registered with Disability Services for access. It is acknowledged that a substantial population exists who either cannot or prefer not to engage with services including Disability Services and general health services.

### Limestone background

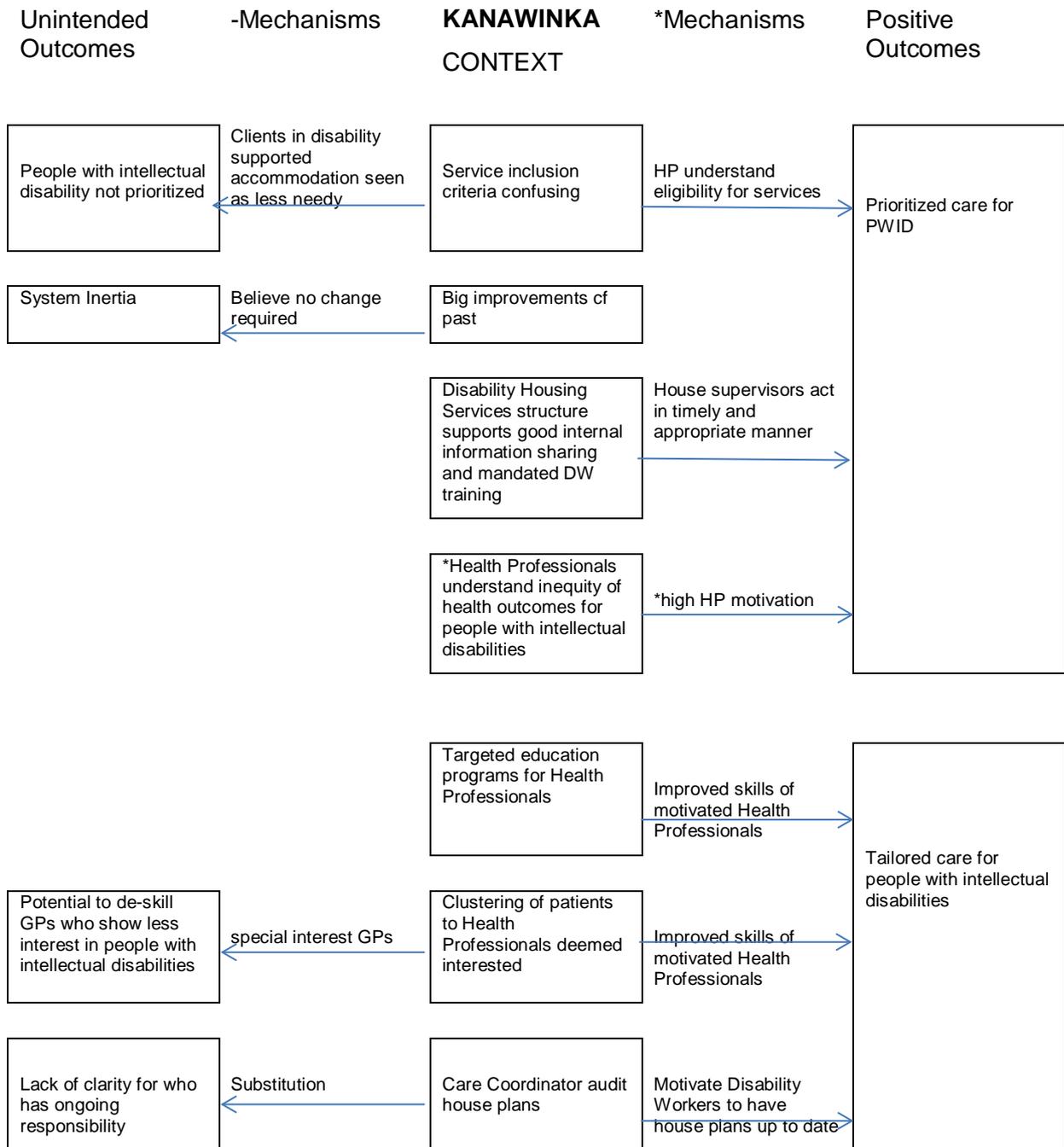
Limestone is a small community of around 5,000. There is one surgery, one GP led hospital of 20 plus beds. There is a not for profit employer of people with intellectual disability located in the main street. Estimates of the number of people with intellectual disability living in

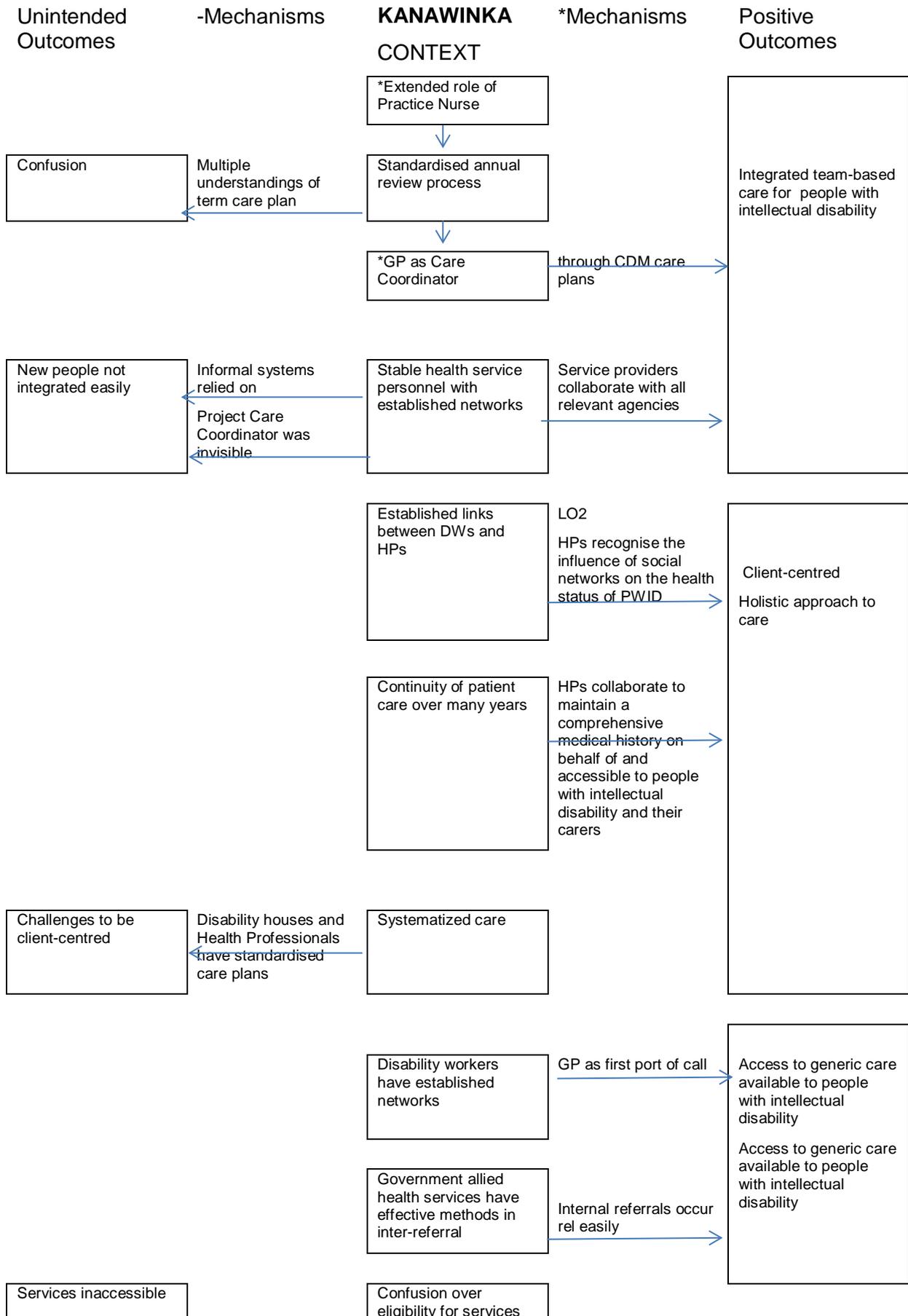
Limestone and surrounding districts varied from 40 or 50 to several hundred. All stakeholders agreed that it was at least 50 and potentially much higher. The nearest large centre, where people with intellectual disability living in Limestone can access a special school, some specialist services, some employment services and respite care, is within 100kms.

In Limestone, people with intellectual disability primarily access medical care and to a degree, allied health services on an as needs basis which can contribute to fragmented care. There was some evidence that people who have a parent or carer to support them are able to access a doctor who is committed to good health care who provides both person-centred and prioritised care. Disability health as a specialty is not present and some people have had very positive outcomes from attending specialist disability health services in Adelaide, several hours drive away. It was thought that there are significant numbers of people who, having reached adulthood and not having the benefit of a well-educated or highly motivated carer or family member may not be able to attract social supports and may not find out about services or be picked up or prioritised by them. However, the small rural community advantages of social networks and visibility can be a positive influence on health care access. There is a valued model of care coordination in operation in the region which is accessed by people in Limestone, called the Child Development Unit. This is a person-centred, holistic approach to health care coordination using team conferencing, and is specifically focussed on children. Public allied health services are mainly located in a regional centre within 100km. Locally delivered discrete allied and community health services are largely restricted to one day per week or per fortnight.

# Appendix 6

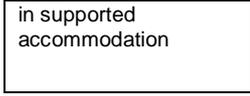
## INITIAL CMOCS







HP deprioritize people  
with intellectual  
disability



in supported  
accommodation



## Appendix 7

### RATIONALE FOR CARE FACILITATOR MODEL

Intervention Component	Rationale/Mechanisms	Relationship to PEACHI Outcomes
Care Coordinator nurse to identify gaps affecting physical, mental and social health, prioritise resolution with the person, identify existing supports to be utilised	Health depends on various social, mental, spiritual economic and other factors	Recognise the influence of social networks Person centred Collaborating with preferred networks
Support for GPs to complete annual health assessments using the CHAP and Medicare care plans	Facilitates development of a history which transcends individual carers and the person's ability to communicate their history	Appropriate access to prevention, CDM and acute care with evidence of incremental goals
Training and mentoring in intellectual disability health for Care Facilitators	Knowledge of physical elements of syndromes causing intellectual disability allows for planning and awareness of particular problems	Specific knowledge relating to appropriate care
In complex needs cases, work with mentor to determine strategy and negotiate among support and care networks to carry strategy out		Collaborate with person's preferred networks
Record and maintain detailed case history and notes of issues raised	Facilitates development of a history which transcends individual carers and the person's ability to communicate their history	Comprehensive medical history
Develop knowledge of and promote programs and services for which individual clients are eligible	Health enabling services are under-utilised; "You don't know what you don't know"	Consciously health enabling
Facilitate self-care and health literacy in person and support network	Body checks by carers are labour intensive; self-care and symptom identification is a more effective method for early detection	Person centred approach Consciously health enabling
Include all people who meet the WHO definition of intellectual disability in the intervention	Higher functioning people with intellectual disability miss out on services with more restrictive eligibility criteria but do not have the	People with intellectual disability who meet WHO definition facilitated to get services which are accessible to mainstream

	necessary support to optimise health	without a formal diagnosis of intellectual disability
Training in managing health issues facing people with intellectual disability for all relevant health/disability staff in the region	Inadequate GP training in interacting with people with intellectual disability causes incorrect diagnosis of health problems.  60% of Murray region GP workforce is overseas trained, some come from countries where disability is not recognised or not visible.	Specific knowledge relating to appropriate care  Appropriate access to prevention, CDM and acute care with evidence of incremental goals
Assignment of volunteer participants to rural clinical school medical students for 12 months	Raise awareness of intellectual disability and associated health issues in the future health workforce. Currently many are not engaged because they aren't interested.	Motivated to prioritise people with intellectual disability as a matter of equity
Sector-wide training for health and disability professionals on locally available services/programs and their eligibility criteria	Eligibility criteria are confusing, causing client, carer and health/disability staff frustration	Prioritisation as a matter of equity  Appropriate access to prevention, CDM and acute care with evidence of incremental goals

## RATIONALE FOR CASE CONFERENCING MODEL

Intervention Component	Rationale/Expected Mechanisms	Expected Outcomes
A monthly case conference based around that experienced in Limestone based in local general practice	General practice is the only common point of contact among people with intellectual disability in the region. Many people are not registered with Disability Services.	Health and disability agencies collaborate with a person's preferred networks (GP) to optimise wellbeing
A monthly case conference facilitated by a practice nurse	Nurses engender trust and openness in clients, who feel that nurses are less time-poor than doctors	Service providers work from a person-centred approach incorporating care-social networks  Service providers are consciously health-enabling in their approach
Chair selected by the client/their advocate	Facilitates person-centeredness in the sessions	Collaborate with a person's preferred networks  Person centred approach
All organisations involved with client's care attend (not just health professionals)	Breaks down silos and encourages inter-sectorial awareness and collaboration, and also  Holds organisations accountable for their progress towards client goals  Allows for knowledge-sharing among professionals  Allows for the social determinants of health to be addressed	Collaborate with preferred networks  Person centred approach  Recognise influence of social networks  Specific knowledge relating to appropriate care
Administrative staff support time	A broad supportive structure to ensure Care Coordinator can focus on core role for client	Integrated team-based care for people with intellectual disability
Training in managing health issues facing people with intellectual disability for all relevant health/disability staff in the region	Knowledge of potential physical abnormalities allows carers to be alert and obtain medical assistance when necessary  Different techniques are needed to obtain information from clients	Health professionals health specific knowledge relating to the appropriate care of people with an intellectual disability

<p>Training in locally available services and programs for the practice nurse</p>	<p>Eligibility criteria for services is confusing and potentially inequitable</p> <p>Confusion causes frustration for both clients and the care network</p>	<p>Health and disability agencies collaborate with a person's preferred networks to optimise wellbeing</p>
<p>Support for GPs to complete annual Medicare comprehensive health assessments and Medicare care plans</p>	<p>Facilitates development of a history which transcends individual carers and the person's ability to communicate their history</p>	<p>HPs collaborate to maintain a comprehensive medical history on behalf of and accessible to people with intellectual disability</p> <p>Person-centred approach</p> <p>Consciously health-enabling</p>

## Appendix 8

### RESEARCH INTERVIEW AND FOCUS GROUP PARTICIPANTS

		Consumers and carers	Disability sector	Mixed disability and health sector	Health sector
Kanawinka	Post intervention		KDP1, KDP2, KDP3, KDP4, KDP6, KDP7, KDM1		KHP1, KHP2, KHP3, KHP4
Murray	Pre-intervention	MCP10, MCP11, MCP12, MCP13, MCP14, MCP15, MCP16, MCP17, MCP18,	MG5 (2 DM)	MG2(1DP,1HM) MG3(2DM,1HP) MG4(1DP,1HP) MG6(1DM,1HM)	RHP1, RHP2, RHP3
	Early Intervention	MCP18, MCP17			MHP2, MHP3, MIDHCC1, MIDHCC2
	Late intervention	MCP19, MCP20	MDM3, MDM4, MDM5, MDP1,		MIDHCC1, MIDHCC2, MRHP4, MHP5, MHP6, MHP7, MHM2, MHM1,
Limestone	Pre-intervention	LCP1, LCP2, LCP3, LCP4, LCP5, LCP6&7, LCP8	LDM1, LDM2		LHM1, LHM2, LG1 (4xHP)
	Early Intervention		LDM3		LIDHCC1, LHM2, LCP3
	Late intervention				

Participant code: The first letter indicates the study region (K= Kanawinka, M=Murray region and L=Limestone); the following initials indicate the participant category or professional group (CP= care provide; DP= disability worker, DM= disability manager, HP= health professional, HM=health manager, G= focus group with participants added in brackets); the number at the end of the participant code indicates the chronological order of interviews in each region.

## Appendix 9

# POTENTIAL LIMITATIONS OF THE RESEARCH

### Recruitment of people with intellectual disability

The team encountered difficulty in recruiting people with intellectual disability and their carers to the project. In Kanawinka this occurred due to Disability Housing policies which prevented consent processed used in this study being introduced to residents. In Murray region and Limestone there were no system policy barriers, however some carers and disability workers expressed concern regarding participation in a short term intervention. Only 21 consumers and carers were interviewed, when the initial intention was to interview around 30. The voice of people with intellectual disability was still well represented in the study. The issue of sensitive, ethical and meaningful engagement of people with intellectual disability has been recognised in the literature previously<sup>53</sup>.

### Naturalistic study

This implementation research consisted of a naturalistic study of only three rural sites during a time in Australian history where the health and disability sectors are in significant flux with the introduction of National Disability Insurance Scheme, and transfer of governance of community and allied health services from State Community Health departments to newly developed Medicare Locals. In addition to these factors, each of the three towns studied had unique elements to their history and current condition which are likely to have influenced the implementation of Care Coordination models. For example, in Kanawinka some elements of the reference project (such as use of the CHAP) were in place for many years prior to the intervention. Additionally, the form of care coordination that existed organically and separate to the designed intervention had been occurring for some time. Initial CMOCs were therefore influenced significantly by the context of the health and disability services in the region. These limitations are partly overcome through the use of Realist Evaluation; however this research methodology is relatively new in the field of health services research generally and care coordination specifically.

### Engagement of local stakeholders

The research team was highly successful in engaging local stakeholders in the research stakeholder groups in Murray region and Limestone. It is difficult to separate this component of the research from the implementation process of the Care Facilitation and Case Conferencing interventions. Results were interpreted with some caution by the researchers, actively seeking out evidence of a Hawthorn effect where desired outcomes occur during research because study participants are aware that the researchers are looking for these outcomes. Stakeholder engagement in the research and involvement of health providers in focus groups, may have had a compounding effect on the results, particularly the theme "Care Coordinator as a linkage and knowledge broker". The research team believe they were careful to take account of the linkage which occurred due to participation in the stakeholder group and that this theme was clearly and separately found as a consequence of Care Coordinator activity in the Murray region Care Facilitator model.

### Limited time of intervention

Again results were interpreted with caution by the researchers, recognising that some participants anticipated findings in the future which there was limited evidence of during the term of the study. For example: although the Murray region Care Coordinators felt positive about their ability to affect future systems-level change, the researchers found limited evidence that confirmed this function of a Care Facilitator in data from our test intervention.

## References

1. Brolan C, Ware R, Lennox N, Gomez M, Kay M, Hill P. Invisible populations: parallels between the health of people with intellectual disability and people of a refugee background. *Australian Journal of Primary Health*. 2011;17(3):210-3.
2. Bourke L, Humphreys JS, Wakerman J, Taylor J. Understanding rural and remote health: a framework for analysis in Australia. *Health & Place*. 2012;18(3):496-503.
3. AIHW. Disability in Australia: Intellectual Disability Canberra: Australian Institute of Health and Welfare bulletin no. 67. Cat. no. AUS 110.; 2008. Available from: <http://www.aihw.gov.au/publication-detail/?id=6442468183> Accessed Sept 2013.
4. Centre for Developmental Disability Health Victoria. Fact Sheet: Working with people with intellectual disabilities in healthcare settings 2008. Available from: Available at <http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf> Accessed Sept 2013.].
5. Robertson J, Emerson E, Gregory N, Hatton C, Turner S, Kessissoglou S, et al. Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in developmental disabilities*. 2000;21(6):469-86.
6. Department of Health Victorian population health survey of people with an intellectual disability 2009. State Government of Victoria, Melbourne.2011. Available from: <http://www.health.vic.gov.au/healthstatus/survey/vphs-id.htm> Accessed September 2013.
7. AIHW. Health of Australians with disability: health status and risk factors. Canberra: Bulletin 83, cat no. AUS 132, AIHW; 2010. Available from: <http://www.aihw.gov.au/publication-detail/?id=6442472401> Accessed September 2013.
8. Cooper S-A, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*. 2007;190(1):27-35.
9. Disability Services Community and Home Support SA. The Provision of Disability Services in South Australia: Government of South Australia, Department of Communities and Social Inclusion; 2012. Available from: <http://www.sa.gov.au/upload/entity/1646/DS%20documents/unmet-needs/The-provision-of-Disability-Services-in-South-Australia.pdf> Accessed September 2013.
10. Bittles A, Petterson B, Sullivan S, Hussain R, Glasson E, Montgomery P. The influence of intellectual disability on life expectancy. *Journals of Gerontology Series A- Biological Sciences & Medical Sciences*. 2002;57(7):M470-2.
11. Gething L. Sources of double disadvantage for people with disabilities living in remote and rural areas of New South Wales, Australia. *Disability & Society*. 1997;12(4):513-31.
12. Pashen D, Chater B, Murray RB, Sheedy V, White C, Eriksson L. The expanding role of the rural generalist in Australia: A systematic review. Mt Isa: Australian College of Rural and Remote Medicine. . 2007.
13. McGrail M, Humphreys J, Joyce C, Scott A, Kalb G. Howdo rural GPs' workloads and work activities differ with community size compared with metropolitan practice? *Australian Journal of Primary Health*. 2012;18:228-33.
14. Iacono T, Humphreys J, Davis R, Chandler N. Health care service provision for country people with developmental disability: an Australian perspective. *Research in Developmental Disabilities*. 2004;25:265-84.

15. Australian Institute of Health and Welfare. Medical workforce 2011 Canberra: AIHW; 2013.
16. Australian Government National Health Reform. Improving primary health care for all Australians 2011. Available from: <http://www.healthissuescentre.org.au/documents/items/2011/02/363952-upload-00001.pdf>.
17. Lewis J. Partnerships, primary health care and health inequalities: problems and possibilities. Australian Journal of Primary Health. 2004;10(3):38-45.
18. Drews S, Rennox C, Hitt L, Parmenter T, Robinson R, Sparrow P, et al. Self-directed Services and Personal Budgets: Strategy Paper 2012-2013 [18/5/2013]. Available from: <http://www.partnerships.org.au/NationalSteeringGroup.htm>.
19. Australian Medicare Local Alliance. Clinical Engagement and Cross Sector collaboration 2013. Available from: <http://amlalliance.com.au/medicare-local-support/clinical-engagement-and-cross-sector-collaboration> Accessed September 2013.
20. Department of Health and Ageing. National Primary Health Care Strategic Framework: Primary Health Care in Australia: Standing Council on Health; 2013. Available from: [http://www.health.gov.au/internet/publications/publishing.nsf/Content/NPHC-Strategic-Framework/\\$File/nphc\\_strategic\\_framework\\_final.pdf](http://www.health.gov.au/internet/publications/publishing.nsf/Content/NPHC-Strategic-Framework/$File/nphc_strategic_framework_final.pdf) Accessed September 2013.
21. Jones M, Humphreys J, Prideaux D. Predicting medical students' intentions to take up rural practice after graduation. Medical Education. 2009;43(10):1001-9.
22. Mitchell GK, Tieman JJ, Shelby-James TM. Multidisciplinary care planning and teamwork in primary care. Medical Journal of Australia. 2008;188(8):S61.
23. Yates R, Wells L, Carnell K. General Practice Based Multidisciplinary Care Teams in Australia: Still some unanswered questions. A discussion paper from the Australian General Practice Network. Australian Journal of Primary Health. 2007;13(2):10-7.
24. Robertson J, Roberts H, Emerson E, Turner S, Greig R. The impact of health checks for people with intellectual disabilities: a systematic review of evidence. Journal of Intellectual Disability Research. 2011;55(11):1009-19.
25. Queensland Centre for Intellectual and Developmental Disability. CHAP: Comprehensive Health Assessment Program. Version 13. Brisbane: University of Queensland; 2013.
26. Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. International Journal of Epidemiology. 2007;36(1):139-46.
27. Lennox N, Bain C, Rey-Conde T, Taylor M, Boyle FM, Purdie DM, et al. Cluster Randomized-Controlled Trial of Interventions to Improve Health for Adults with Intellectual Disability Who Live in Private Dwellings. Journal of Applied Research in Intellectual Disabilities. 2010;23(4):303-11.
28. Pawson R, Tilley N. Realistic Evaluation. 1 ed. London: Sage Publications Ltd; 1997.
29. Rhydderch M, Elwyn G, Marshall M, Grol R. Organisational change theory and the use of indicators in general practice. Quality in Health Care. 2003;13:213-7.
30. Victorian Health Promotion Foundation. Disability and health inequalities in Australia: Research summary. In: VicHealth, editor. Carlton South: Victorian Health Promotion Foundation; 2012.
31. Battersby M. Health reform through coordinated care: SA HealthPlus. British Medical Journal. 2005;330(7492): 662–5. .

32. Wagner E, Austin B, Von Korff M. Improving outcomes in chronic illness. *Managed care quarterly*. 1995;4(2):12-25.
33. Heisler M, Bouknight R, Hayward R, Smith D, Kerr E. The Relative Importance of Physician Communication, Participatory Decision Making, and Patient Understanding in Diabetes Self-management. *Journal of General Internal Medicine*. 2002;17(4):243-52.
34. Youngwerth J, Twaddle M. Cultures of interdisciplinary teams: how to foster good dynamics. *Journal of Palliative Medicine*. 2011;14(5):650-4.
35. Lawn S, Battersby M, Lindner H, Mathews R, Morris S, Wells L, et al. What skills do primary health care professionals need to provide effective self-management support? Seeking consumer perspectives. *Australian Journal of Primary Health*. 2009;15(1):37-44.
36. Sabaté E. Adherence to long-term therapies: evidence for action Geneva: World Health Organisation; 2003. Available from: <http://apps.who.int/medicinedocs/en/d/Js4883e/> Accessed September 2013.
37. Kalucy L. Evaluating Coordinated Care: Complex Problems do not Have Simple Solutions. *Australian Journal of Primary Health*. 1999;5(3):32-42.
38. Ehrlich C, Kendall E, Muenchberger H, Armstrong K. Coordinated care: what does that really mean? *Health & social care in the community*. 2009;17(6):619-27.
39. Parmenter TR. Has social policy left research behind? *Australia & New Zealand Journal of Developmental Disabilities*. 1991;17(1):1-6.
40. Lawn S. Top tips for embedding chronic condition self-management support into practice. *Aust J Prim Health*. 2010;16(4):334-43. PubMed PMID: 21138702. Epub 2010/12/09. eng.
41. Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *International Journal of Epidemiology*. 2007;36:139-46.
42. Act No.20 of 2013 An Act to establish the National Disability Insurance Scheme. . Administered by: Families, Housing, Community Services and Indigenous Affairs.
43. Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, et al. Primary care of adults with developmental disabilities Canadian consensus guidelines. *Canadian Family Physician*. 2011;57(5):541-53.
44. Pearson ML, Wu S, Schaefer J, Bonomi AE, Shortell SM, Mendel PJ, et al. Assessing the implementation of the chronic care model in quality improvement collaboratives. *Health services research*. 2005;40(4):978-96.
45. Tilley N. Realist Evaluation: An Overview. Founding Conference for Danish Evaluation Society 2000.
46. World Health Organisation. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19 June - 22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.
47. World Health Organisation. Definition: Intellectual Disability Geneva: World Health Organization; . . 2013:Available from: <http://www.euro.who.int/en/what-we-do/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability>. Accessed September 3.

48. PricewaterhouseCoopers. Submission response: Governance, accountability and coordination – the keys to person-centred health care. In: Commission NHaHR, editor. Sydney 2008.
49. Australian Government Department of Health and Ageing. Primary Health Care Reform in Australia: Report to Support Australia's First National Primary Health Care Strategy 2009. Available from: [http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nphc-draftreportsupp-toc/\\$FILE/NPHC-supp.pdf](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nphc-draftreportsupp-toc/$FILE/NPHC-supp.pdf) Accessed September 2013.
50. Cook KS, Hegtvedt KA. Distributive Justice, Equity, and Equality. Annual Review of Sociology. 1983;9(ArticleType: research-article / Full publication date: 1983 / Copyright © 1983 Annual Reviews):217-41.
51. McDonald KE, Kidney CA, Nelms SL, Parker MR, Kimmel A, Keys CB. Including Adults With Intellectual Disabilities in Research: Scientists' Perceptions of Risks and Protections. Journal of Policy and Practice in Intellectual Disabilities. 2009;6(244-252).
52. Godlee F. What is health? British Medical Journal. 2011;343:d4817.
53. Lennox N, Taylor M, Rey-Conde T, Bain C, Purdie D, Boyle F. Beating the barriers: recruitment of people with intellectual disability to participate in research. Journal of Intellectual Disability Research. 2005;49(4):296-305.