

**From hospital to inclusive
housing:
A literature review for the
'Ready To Go Home' project team**

2020



review • evaluate • consult

for bold new approaches to policy and governance

About us

The Urban Impact Project is an independent research consultancy. We use evidence-based research to review and evaluate policy and programs, enabling you to advocate for bold new approaches to policy and governance.

Based in Walyallup (Fremantle), Western Australia, we work and meet on the lands of the Noongar people. We acknowledge all the Traditional Custodians of the many lands we call Australia, and pay respects to their Elders – past, present and future.

This document serves as summary of 'desktop research' regarding the literature that was reviewed, and the process by which the review was undertaken.

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July 2020

Suggested citation for this report:

Gudka, S (2020). From Hospital To Inclusive Housing: A Literature Review for the 'Ready To Go Home' project team. Urban Impact Project, Fremantle Western Australia.

Funded by the Australian Government Department of Social Services. Go to www.dss.gov.au for more information.

Executive Summary

The 'Ready To Go Home' project team engaged the Dr Gudka from the Urban Impact Project to identify and review published national and international literature associated with hospital discharge processes and planning for people aged 18-64 years with either pre-existing or recently acquired disabilities, with a focus on processes that encourage them to live in inclusive housing, instead of residential aged-care facilities. In particular the project team was interested in knowing: (1) reasons why adults with disability stay longer than necessary in hospital, even though they are medically ready for discharge; (2) interventions, processes, skills or resources that have enabled people with disabilities to live in inclusive housing, once medically ready; and (3) current frontiers in the disability sector with regards to inclusive housing.

Despite the recent emphasis in Australian political, academic, and legislative narratives to more actively promote hospital discharge interventions and real housing choices for adults with disabilities, there were no literature reviews or intervention studies that solely focused on this issue in the disability sector.

In light of this lack of prior research an epistemological assumption that experience is powerful and compelling when attempting to understand the complex reality in people with disabilities, was made. An ontological assumption that the reality of planning and improving hospital discharge process in people with disabilities is different from the generalised non-disability sector, was also made. Consequently, the search strategy to broadened to identify barriers to timely discharge (RQ1), and interventions to improve hospital discharge and reduce non-medical re-hospitalisation (RQ2), from a range of disability sector qualitative studies.

The findings from 17 of the most recent and relevant studies were extracted, examined, themed and summarised for this scoping review. In doing so, it was evident that even with the best hospital discharge and cross-sector system processes, many people with disabilities are forced into housing that is not their preferred choice, or that is unsuitable (e.g. an impractical dwelling, an impractical neighbourhood, group home with strict routine, or a residential aged care facility), due to wider and persistent issues relating to housing availability and housing suitability.

Another significant finding of this review was that some highly innovative and conceptual academic research in disability specific inclusive housing (RQ3) has been conducted, but that findings and recommendations of this research has not become sufficiently manifested in in Australian political, advocacy and legislative narratives, let alone delivery of such housing. Inclusive housing is much more than accessible housing. It includes good design and holistic features that promote a homeliness, privacy, comfort, efficiency of care, convenience of local amenities, social networks, proximity to local services, community services and resources, and appropriate community support. While the 'Livable Housing Australia' initiative is being championed across new homes in Australia to improve accessibility, there appear to be no minimum standards of *inclusive* housing design and development (or redevelopment) for Australians with complex disability *that purposefully and equally consider* all the important physical, psychological and social aspects of wellness and quality of life.

This scoping review provides the 'Ready To Go Home' team with peer-reviewed evidence specific to the disability sector and identifies possible pathways for their current and future work on improving hospital discharge processes. It also identifies possibilities to engage in bold advocacy for new forms of inclusive housing policy.

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1 Introduction

The intention of the 'Ready To Go Home' project, by the National Disability Services Western Australia, is to improve health outcomes and hospital experiences for people with disabilities. This is because many adults between 18-65 years, with either newly diagnosed or pre-existing disabilities, stay longer as an inpatient in hospital than necessary (i.e. beyond their expected medical discharge date) and, upon discharge, are at greater risk of poor housing outcomes.

Discharge from hospital represents a major transition point in the health-disability continuum. It usually occurs when the individual is assessed as medically stable and no longer in need of acute medical treatment.

In the disability sector however, there are a myriad of clinical and system issues that need to be finalised prior to discharge, such as referrals to community-based supports. If the supports and resources are not in place for them to return to their previous living situation, it can result in either unnecessarily extended time as an inpatient, or being transitioned to unsuitable housing such as residential aged care (RAC) facilities.

To understand and advance hospital discharge processes, the 'Ready To Go Home' project team commissioned a review of the literature to examine evidence and frontiers in academic research covering the barriers, challenges and facilitators of timely and effective hospital discharge in people with disabilities. In particular, finding interventions and strategies that could reduce longer than necessary hospital stays, reduce re-hospitalisation, and encourage moving into inclusive housing.

1.1 Definitions

Carer: Under the Disability Services Act 1993 (amended), a carer is a person who provides ongoing care or assistance to a person with a disability. The term does not cover a person providing care and assistance under a contract of service or while doing community work.

Disability: There are various definitions and terminologies that relate to disability. For the purpose of this review we accepted the definitions that follow from the international and national setting as relevant. This is because the term disability is widely used, and there are lessons to be learnt from all the different applications.

- The International Classification of Functioning, Disability and Health (ICF) is the WHO framework for measuring health and disability at both individual and population levels. Within this framework, *disability* is seen as the interaction between individuals with a health condition and social or environmental factors.
- The United Nations Convention of the Rights of Person with a Disability (UNCRPD) is an international treaty that seeks to promote, protect and ensure the full enjoyment of all human rights and fundamental freedoms by all persons with disabilities. Within this context, *persons with disabilities* is applied to all persons with disabilities including those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various attitudinal and environmental barriers, hinder their full, equal and effective participation in society.
- The West Australian Disability Service Act (1993) defines *disability* as an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of those impairments. It adds a number of clarifications, including: (1) which is permanent or likely to be permanent; (2) which may or may not be of a chronic or episodic nature; and (3) which results in substantially reduced capacity of the person for communication, social interaction, learning or mobility and a need for continuing support services.

Discharge planning: refers to the process of planning a discharge for a person before they leave hospital.

Hospital discharge: refers to the process of a person being discharged from hospital to a location outside the health system. This includes transitional care facilities, residential age care facilities and sustainable long-term housing. Clinical handovers from one care team to another within the hospital (from example from one ward to another, or from acute to sub-acute care), or between hospitals are not included in the term discharge for the purpose of this review.

Inclusive housing: allows people with disabilities to live their life in a house where they want to, with the level of support they require to enhance relationships, accessibility of community, safety and social opportunities.

Livable Housing Australia: originated from the highly successful National Dialogue on Universal Housing Design, convened in October 2009. They work closely with industry and government to embrace the Livable Housing Design Guidelines, and provide industry with training and education needed to design and deliver livable homes (*Livable Housing Australia*).

NDIS: refers to the Australian National Disability Insurance Scheme that was introduced in 2013. The purpose of the reform was to provide tailored, personalised funding packages for disability support to Australians living with permanent and significant disability. One of the key overarching aims of the NDIS is to help empower Australians living with disability by providing them with the choice of 'reasonable and necessary' supports to enhance independence, participation and quality of life.

2 Methodology

This methodology was guided by a four-stage literature review framework. In line with an academic literature review, each stage has been documented to ensure transparency and rigor.

2.1 Articulating the review aim and questions

To identify the scope of the review the Prospective Register of Systematic Reviews (PROSPERO) and Population, Intervention, Comparison, Outcome (PICO) frameworks from the National Institute for Health Research International were used (figure 1). This was determined in collaboration with the 'Ready To Go Home' project team.

Figure 1: Using PICO to frame the review questions

Population	<p>People aged 18-64 years being discharged from hospital that:</p> <ul style="list-style-type: none"> • have pre-existing disability; or • have recently acquired a disability
Intervention	<p>Processes, skills, resources, interventions, barriers, challenges, facilitators, enablers associated with:</p> <ul style="list-style-type: none"> • hospital discharge planning and readiness • medical, nursing and allied health staff • NDIS readiness; and • sustainable housing availability and readiness
Comparison	<p>Destination after hospital discharge, including and not limited to:</p> <ul style="list-style-type: none"> • transitional care facilities • aged-care facilities • inclusive housing
Outcome	<p>Outcome measures of interventions in transitioning from hospital, and not restricted to:</p> <ul style="list-style-type: none"> • hospital discharge time-frame • hospital re-admission rates • quality of life indicator; and • patient experiences

2.1.1 Review aim

To identify and review published national and international literature associated with hospital discharge processes and planning, in people aged 18-64 years with either pre-existing or recently acquired disabilities, that encourage them to live in inclusive housing, instead of residential aged-care facilities.

2.1.2 Review Questions

1. Why do adults with disability stay longer than necessary in hospital, even though they are medically ready for discharge?
2. What interventions, processes, skills or resources have enabled people with disabilities to leave hospital, into inclusive housing, once medically ready?
3. What are the current frontiers in the disability sector with regards to inclusive housing?

2.2 Search strategy

Keywords that reflected the PICO were developed iteratively for each database using relevant text-words and subject headings, and were used to search the following databases:

- PubMed, Embase, CINAHL
- Trial register PROSPERO
- Cochrane Database of Systematic Reviews
- speechBITE, OTseeker and PEDro
- Specific journals such as the Australian Health Review, Australian Journal of Public Administration, Health Promotion Journal of Australia, and Australian Journal of Social Work.

Search limits were set to January 2000 and August 2020, to ensure the peer-reviewed articles were recent and relevant for the 'Ready To Go Home' project team. Depending on the database or journal, combination of key words, MeSH terms and/or truncated

words were used. Boolean operators 'AND' and 'OR' were used to combine search terms across concepts and 'OR' to combine within concepts.

All published national and international randomised control trials, reviews, experimental, observational and descriptive studies that met the PICO criteria and review aim were identified and uploaded into the bibliographical management tool, EndNote®. Duplicates records were removed.

2.3 Study selection

Initially, all titles and abstracts were screened against the PICO framework for inclusion. A second, and more thorough screening was conducted to exclude studies that solely focused on people aged 65 years and over, and/or on rehabilitation interventions of stroke. This was because the 'Ready To Go Home' project focuses pre-dominantly on people under the age of 65, and an extensive body of literature on stroke rehabilitation pathways had already been reviewed, elsewhere.

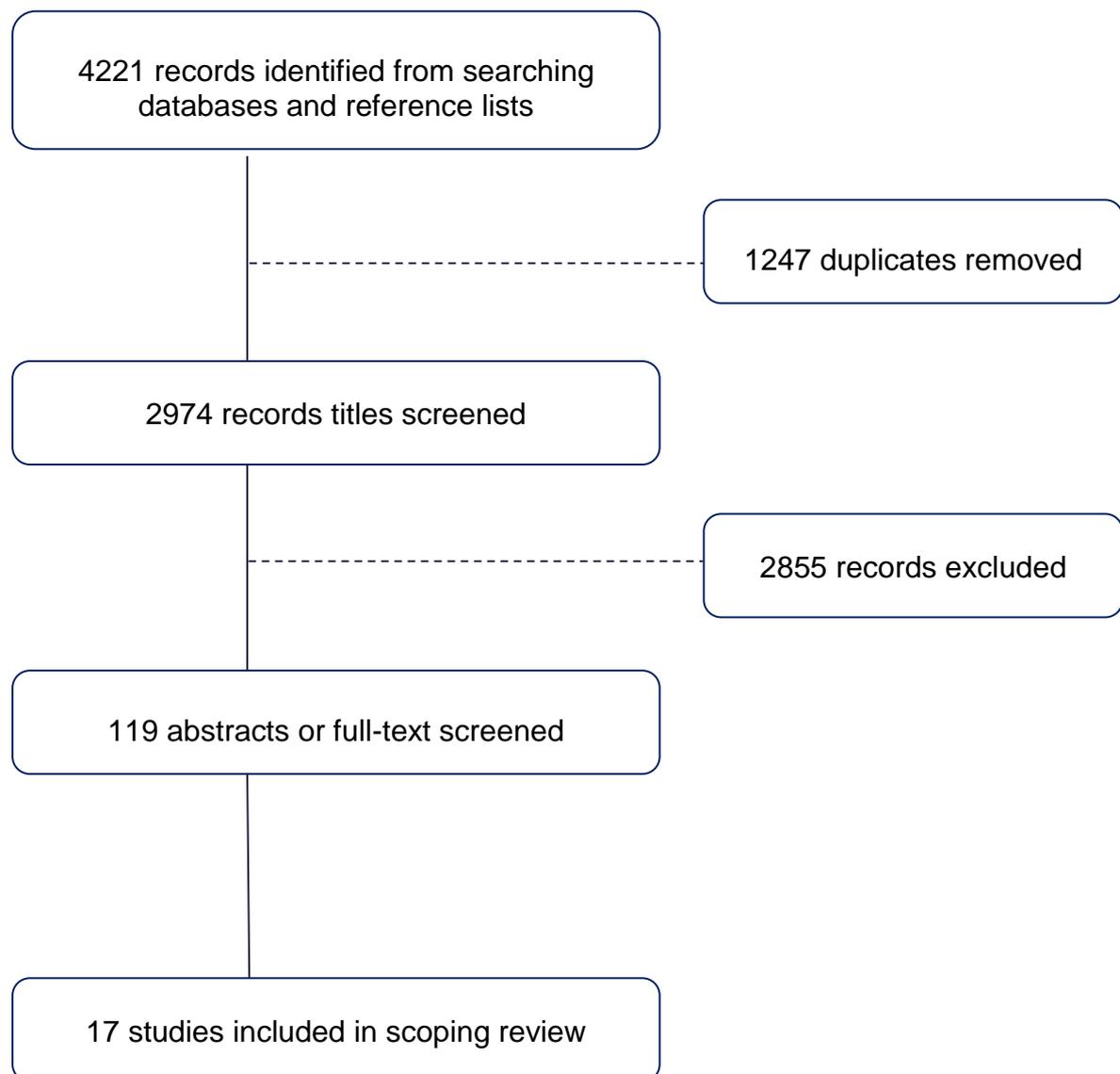
2.4 Synthesis of results

The full-text for all studies that met the inclusion and exclusion criteria were obtained and each paper was read and deliberated on. Where necessary, the key information from each paper was extracted, categorized and organized using Microsoft Excel®.

3 Key Findings

Figure 2 illustrates the study selection process. Of the 4221 records extracted into EndNote®, 119 abstracts and/or full-texts were read. 17 studies that were the most recent and relevant to the review aim and review questions, guided the final findings of this scoping review. The author details, title, study aims, methodology and key findings of each of these 17 studies were extracted, themed and summarised in Appendix 1.

Figure 2: Study selection process for scoping review



3.1 Factors contributing to longer hospital stays than necessary

The first part of the literature review was to understand why adults with disability stay longer than necessary in hospital, despite being medically ready to be discharged.

This topic is very topical and is the central focus of many advocacy groups, policy development and political discussions. However, no literature reviews or intervention studies that solely focused on hospital discharge in adults with disabilities were identified through the search strategy. This lack of cohort specific research and peer-reviewed literature was also noted by Knox et al., 2017 in their work through the Summer Foundation.

Therefore, an epistemological assumption that experience is powerful and compelling when attempting to understand the complex reality in people with disabilities was made. Consequently, the search strategy was broadened, and qualitative studies from the disability sector were identified. This flexible approach led to identifying meaningful and cohort specific experiences, barriers and discussions about the complex clinical and multifaceted cross-sector system hospital processes. These findings were extracted, and the following themes were created:

Uncertain prognosis and predicting length of stay in newly diagnosed cases of disability were cited as reasons as to why discharge planning did not start early enough to undertake all the necessary activities to support a timely and successful discharge (Levack & Thornton, 2017).

Poor communication between the health professionals, the patient and their family were cited by both the patient and their family members. They all said they felt frustrated with the frequency of staff change overs and lack of a key coordinating person. This made communicating information back and forth difficult and fragmented. The family members and primary carers said they felt overwhelmed and underinformed because they were not fully involved in the discharge and rehabilitation decisions, yet they knew that the responsibility to organise on-going care, rehabilitation and appointments once home, would fall upon them (Abrahamson et al., 2017; Braaf et al., 2019; Knox et al., 2017; Larwill, 2017).

Poor collaboration for NDIS readiness between the various health professionals, those involved in making discharge decisions and the patient and their family were identified as key reasons for financial delays in accessing funding for post-discharge disability supports. The patient and carers said they didn't have the skills and capacity to navigate the complex systems of health, disability and funding, especially when it came to accessing funding for house modifications and assistive technology that would be necessary for timely hospital discharge (Abrahamson et al., 2017; Braaf et al., 2019; Houston et al., 2019; Larwill, 2017; Levack & Thornton, 2017; McIntyre et al., 2017; Redfern et al., 2015).

Waiting for supportive needs such as assistive technology, home modifications, appropriate housing or behavioural support were identified as very common reasons for prolonged hospital stays in individuals preparing to return back to their original residence, or into new accommodation with their family. The most recent and comprehensive study conducted by Houston et al. identified that even though NDIS funding was made available to most individuals within the legislated time-frame, many of them stayed longer than necessary in hospital while they waited for access to supportive needs (Houston et al., 2019; Larwill, 2017; Levack & Thornton, 2017; McIntyre et al., 2017).

Lack of, or limited access to, ongoing rehabilitation care, assessment and planning for ongoing care after discharge was another important factor, and was often linked and intertwined with other system issues such as poor collaboration between organisations, delays in accessing funding, and waiting for supportive needs (Abrahamson et al., 2017; Braaf et al., 2019; Levack & Thornton, 2017; McIntyre et al., 2017; Redfern et al., 2015). This barrier was more profound in remote and regional areas of Australia, and in Aboriginal and Torres Strait Islander people. It is well-established that rehabilitation within remote or regional hospitals is restricted due to limited numbers of allied health staff and rehabilitation physicians. This is in addition to a lack of expertise in working with people with complex care needs and disability. Research also shows that Indigenous Australians with a disability have a higher rate of case complexity compared to non-Indigenous Australians, and that they are unlikely

to engage with non-Indigenous services if they experience or perceive that the services lack cultural competence (Ferdinand et al., 2019)

Lack of knowledge about all the alternative accommodation options during hospital discharge was identified as one of the reasons why adults with disabilities ended up in a RAC facility. The individuals felt they had to 'accept life in a care home in the absence of no better alternative', had 'no control or choice', or 'felt residential care was inevitable'(Levack & Thornton, 2017; Smith & Caddick, 2015).

Unavailability, inability, or lack of appropriate next-level-of-care options was identified as one of the most complex and complicated barriers, for it involves and places heavy demands and responsibilities on a third party. The carer has to be available and capable not only to provide varying levels of care, but also has to manage their own stressors, physical health and/or mental health, financial, social and workforce opportunities. In cases where there was no-one was available or capable to provide care, the persons with disabilities had very little choice but to either spend extended periods in hospital or transition into a RAC facility (Levack & Thornton, 2017; Smith & Caddick, 2015).

Lack of available, safe and accessible accommodation options in the community, particularly in rural locations was cited as the most common reason as to why individuals either stayed in hospital longer than necessary, or transitioned to a RAC facility. Due to physical, cognitive, sensory/perceptual, communicative and/or behavioural consequences directly related to their disability or complex needs, many individuals reported to having limited or no choice regarding where they live, how they live and with whom they live. Carers and family members often used the terms 'fight, battle and war' when describing their frustration to negotiate appropriate housing and support pathways (Hay & Chaudhury, 2015; Houston et al., 2019; Levack & Thornton, 2017; McIntyre et al., 2017; Smith & Caddick, 2015; Wright et al., 2016).

Summary

Upon extracting, examining and deliberating on these themes, it was evident that *unless each and every one* of the complex clinical and multifaceted cross-sector system processes are addressed in a timely and efficient manner, the patient will face

discharge delay. They will stay in hospital beyond their discharge date, waiting for resolution on cross-sector system processes such as NDIS or other funding, supportive or assistive needs, availability of capable carer or next-level-support, and housing modifications. If one, or multiple, cross-sector system processes cannot be resolved the person with disability will have very little choice but to reside in unsuitable residential environments which may include RAC facilities.

It is well established that both delayed hospital discharge and RAC placement have a very negative impact on their health and wellbeing, and therefore the importance of coordinated and timely hospital discharge, coupled with availability of inclusive housing with next-level-care options are critical.

3.2 Strategies to improve hospital discharge processes

The second part of the literature review focused on identifying interventions, process, skills or resources in the peer-reviewed literature that have, or could, improve hospital discharge process - with the goal of enabling people with disabilities to leave hospital, into inclusive housing, once they are medically ready.

In 2017, the Summer Foundation conducted a literature review of hospital discharge planning interventions in adults with disability. In the absence of discharge planning interventions specific to the target cohort, they sought and presented evidence in their report from the non-disability sector (Knox et al., 2017). While interventions from general population discharges provided guidance on broad systemic hospital discharge issues (such as initiating discharge planning early and supporting patient centred care), they lacked cohort specific findings for the disability sector and the 'Ready To Go Home' project team.

Taking the ontological approach that the reality of planning and improving hospital discharge process in people with disabilities would be different from the generalised non-disability sector; the search strategy focused on identifying studies that discussed strategies, interventions and recommendations that could/would improve hospital discharge process for the primary individual with disability, their families or carers, and for cross-sector system processes. Details about these studies, including the study

title, author, year published, country of research, study aim, methodology, key findings and recommendations were extracted and are shown in Table 2.

The key recommendations from those studies that could assist in reducing length of hospital stay once an individual with disability is medically ready to be discharged were themed, and are:

1. ***Initiate discharge planning at the earliest possible time*** in admission, possibly within the first 24-48 hours of admission.
2. ***Provide each patient with two highly skilled and knowledgeable coordinators*** – an in-patient coordinator AND a community care coordinator – who will visit the patient regularly, discuss with families to identify their next-level care supports and expectations (both during in-patient stay and after discharge), work with, and across, multiple systems to advocate for the patient and resolve issues as they arise.
3. ***Request NDIS and other funding as soon as possible.***
4. ***Improve communication, collaboration and coordination*** between medical staff, allied hospital staff, patient, family members, community services and key stakeholders; keeping in mind a ‘person-centred’ approach so that the person with disability is placed at the centre of decision making regarding supports and services.
5. ***Engage external advocacy services, neuropsychology supports and communication experts*** that focus on improving communication, relationships and trust between the patient and their carers about issues such as housing and support preferences, while addressing expert medical advice. Continue providing this support post-discharge so that they can all cope with the new way of living, together.
6. ***Provide family and carers training and support*** in preparation for their post discharge roles.

Table 2: Summary of studies that discussed hospital discharge interventions

Author, year	Aims and Methodology	Key Findings	Discharge Planning Recommendations
Redfern et al., 2015 Australia	<p>Aim: To understand discharge planning challenges in people with new or pre-existing disabilities who require time to maximize functional independence.</p> <p>Methodology: Analysed dataset of 80 patients with new or pre-existing disabilities, and interviewed five hospital social workers.</p>	<p>Social workers have historically played a major role in facilitating patient discharge from hospital, addressing transition and community support needs for patients and families. However, there are constraints on social workers because of the complex and multifaceted issues that need to be considered in disability discharges, especially when discharge delays interface with lack of community support, prolonged waiting times for appropriate funding or availability of accommodation, housing.</p>	<ol style="list-style-type: none"> 1. Initiate interventions and referrals to disability services at earliest possible time in admission. 2. Discuss with families to identify their care and expectations, e.g. how they will physically and realistically look after the patient at home. 3. Engage external advocacy services that would regularly visit the patient, 'stick with them' and work with, and across, multiple systems to solve their issues and enhance care options. 4. Improve communication between health staff, patient, carer and community services and key stakeholders.
Smith B, Caddick N., 2015 UK	<p>Aim: To understand the impact of health and wellbeing in people with spinal cord injury and living in RAC facilities.</p> <p>Methodology: Qualitative interviews with 20 people with disabilities living in RAC homes</p>	<p>Living in a care home environment severely damages quality of life, physical health and psychological wellbeing in the short and long-term. Key reasons for being placed in a RAC were lack of knowledge about all the alternative accommodation options during hospital discharge; and lack of available, safe and accessible accommodation options in the community, particularly in rural locations.</p>	<ol style="list-style-type: none"> 1. People should be discharged into adapted property that meets their housing needs and supports their right to independent living. This should ideally be close to their initial home, or in a location of their choosing. 2. Maintain an up-to-date accessible housing register so people can be offered, or themselves find, accessible housing easily. 3. Increase awareness with home-builders and developers of the accessibility AND the liveability standards.

Author, year	Aims and Methodology	Key Findings	Discharge Planning Recommendations
Abrahamson V et al., 2017 UK	<p>Aim: To explore the experiences of individuals with severe traumatic brain injury and their carers - in the first month post-discharge from in-patient to living in the community in the UK.</p> <p>Methodology: Qualitative semi-structured interviews with 10 patients and 9 carers.</p>	<p>Both the patient and carer felt there was lack of communication from the hospital team while in hospital, and during discharge.</p> <p>Carers felt overwhelmed and underinformed because they were not fully involved in discharge and rehabilitation decisions, yet responsibility to organise on-going care, rehabilitation, appointments fell upon them.</p>	<ol style="list-style-type: none"> 1. Provide a dedicated in-patient coordinator. 2. Provide a community care coordinator. 3. Provide ongoing post-discharge neuropsychological support to the patient with disability and their family.
Larwill K, 2017 Australia	<p>Aim: To understand perspectives of a range of participants regarding their experiences of discharge planning and processes for adults with disabilities, and at risk of entering RAC.</p> <p>Methodology: Five stakeholder forums facilitated by the Summer Foundation</p>	<ol style="list-style-type: none"> 1. Lack of collaboration across sectors (health, disability, aged care), characterised by a lack of agreement around respective responsibilities, lack of funding, lack of knowledge sharing. 2. Poor communication between health professionals and those involved in making discharge decisions, resulting in delays in accessing funding for disability supports. 3. Slow processes and limited staff resources resulting in delays and frustration which can lead to pressure to compromise or accept inferior options. 4. Limited knowledge and awareness among relevant staff. 	<ol style="list-style-type: none"> 1. Improve communication between the health professionals, the patient and their family.

Author, year	Aims and Methodology	Key Findings	Discharge Planning Recommendations
McIntyre D et al., 2017 Australia	<p>Aim: To understand transition pathways and choices regarding housing and support in South East Queensland.</p> <p>Methodology: Qualitative semi-structured interviews with 21 people with progressive and non-progressive acquired disabilities living in different housing models including: (1) residential aged care facilities, (2) institutional facilities designed to provide care to adults, (3) group homes and (4) private residences.</p>	<p>There were distinct and diverse needs of adults with high-care needs. There was no one-size-fits-all when it comes to housing support because each individual has varying needs, expectations and preferences to meet their rehabilitation, equipment needs, carer support and community engagement.</p> <p>Carers and family members used the terms ‘fight, battle and war’ constantly when describing their frustration in negotiating appropriate housing and support pathways.</p>	<ol style="list-style-type: none"> 1. Consult with patients and carers about their preferences in housing and support arrangements, alongside needs-based solutions. 2. Provide individualised funding so as to obtain flexibility of care and choice in housing and support for people with disability.
Knox L et al., 2017 Australia	<p>Aim: Hospital discharge planning for young people with severe disability and complex needs: A review of the literature.</p> <p>Methodology: Literature Review</p>	<ol style="list-style-type: none"> 1. Adopt a comprehensive discharge planning process; 2. Engage a dedicated discharge planning and community liaison officer; 3. Use technological solutions to enhance education and improve information handover; 4. Engage the person and their family in all stages of the discharge planning process. 	<ol style="list-style-type: none"> 1. Start discharge planning early - within 24-48 hrs of admission 2. Provide expertly coordinated health and disability knowledge 3. Person-centred engagement in discussions and decisions 4. Family-focussed active involvement 5. Communicate clear and timely information 6. Educate family, health and support workers 7. Outcome-oriented finishes when person has housing and support to live an ordinary life

Author, year	Aims and Methodology	Key Findings	Discharge Planning Recommendations
Braaf S et al., 2019 Australia	<p>Aim: To explore experiences of care coordination in the first 4-years after severe traumatic brain injury.</p> <p>Methodology: Qualitative research 18 semi-structured interviews 48-months post-injury with 6 adults living with sever TBI, and the family members of 12 other adults with severe TBI in Victoria.</p>	<ol style="list-style-type: none"> 1. Most used a number of health and allied health services in the community, yet none of them had a dedicated care coordinator. 2. Family members ended up advocating for person, but said they had little success. They struggled navigating complex systems of health, disability and compensation. 3. Voiced frustrations about lack of accountability, ineffective services, and frequency of staff changes made communication about care and rehabilitation difficult. 	<ol style="list-style-type: none"> 1. Provide an independent care coordinator.
Houston V et al., 2019 Australia	<p>Aim: To examine impact of NDIS on timing of discharge for adults with acquired disability, and requiring NDIS funding to leave hospital.</p> <p>Methodology: Retrospective analysis of inpatients data with SCI or ABI at Metro South Hospital and Health Service, Queensland. Total 54; with 41 having NDIS data.</p>	<ol style="list-style-type: none"> 1. The legislated 21-day NDIS access request was achieved in patients with acute brain injury, but not in spinal cord injury. 2. There were critical points in the NDIS pathway where interface challenges such as requesting NDIS funding, receiving outcome of NDIS funding, planning processes, implementation of plans contributed to longer hospital stays. 3. Other reasons for discharge delays included waiting for assistive technology and home modifications. 	<ol style="list-style-type: none"> 1. Request NDIS funding as soon as possible 2. Support local coordinators to become familiar with local processes and practices so as to facilitate interface working and negotiation of plans. 3. Monitor implementation of NDIS to understand and avert interface problems that impede timely discharge and access.

3.3 Strategies to reduce non-medical re-hospitalisation

Re-hospitalisation of people with disabilities, for non-medical reasons, has been an ongoing issue in the disability sector. No specific intervention studies on reducing non-medical rehospitalisation were identified in the scoping review. However, lack of knowledge and/or lack of availability of relevant community services and health services coupled with family overwhelm were often cited as reasons for people with disabilities returning back to hospital (Abrahamson et al., 2017; Larwill, 2017; McIntyre et al., 2017).

There were some findings and recommendations in the literature around improving system processes, and the importance of providing post discharge supports to the person with disability and their families, so as to reduce the rates of non-medical re-hospitalisation:

1. **Identify local (i.e. West Australian) interface challenges** around the roles and responsibilities of the NDIS, WA Health mainstream health providers, disability service providers and people with disabilities and their families.
2. **Develop and maintain an up-to-date database of resources from public, and non-governmental sectors**, including mainstream health sector staff and hospital sector staff and general practitioners who are skilled and capable of working with people with disabilities, so that there is a continuum of care upon discharge.
3. **Develop and maintain an up-to-date database of skilled community care coordinators** who are familiar with local processes and practices of the various mainstream health services, disability and assistive supports, so as to facilitate interface collaboration and negotiation of funding and support plans.
4. **Develop and maintain an up-to-date inclusive housing database** so people can be offered, or themselves find, the most appropriate accommodation more easily.

Summary

Upon extracting, examining and deliberating on the strategies of improving hospital discharge processes, establishing cross-sector system processes, and providing post-discharge support to the person with disabilities and their families; it was evident that good holistic hospital discharge processes in West Australian hospitals could reduce longer than necessary stays and prevent non-medical re-hospitalisation.

However, it was also evident that even with the best hospital discharge processes and cross-sector system processes, many people with disabilities will be forced to reside in unsuitable residential environments (e.g., an impractical dwelling, an impractical neighbourhood, group home with strict routine, or a RAC), or in housing that is not their preferred option, simply due to the broader and persistent issues relating to housing availability and housing suitability.

3.4 Current frontiers in inclusive housing

Lack of accessible and inclusive housing options remains a contributing factor as to why people with disabilities are often forced to live with ageing parents in the family home, or placed in group home or residential aged care settings with healthcare support. This has led to the recent emphasis in Australian political, academic, and legislative narratives to more actively promote real housing choice for people with disabilities and support needs.

The third part of this literature review focused on reviewing and extracting highly innovative methodological and conceptual research into disability specific inclusive housing. This is research that is recognised by academia, but has not been sufficiently established in Australian political, advocacy and legislative narratives.

A broad scoping search identified that all most all the research around inclusive housing solutions for people with disabilities in Australia was conducted by Wright et al. in Queensland (Wright, Colley, & Kendall, 2019; Wright, Colley, Knudsen, et al., 2019; Wright et al., 2017; Wright et al., 2016).

In their four peer-reviewed papers, the authors discussed that accessible housing to date in Australia has typically addressed the person's functional needs (i.e. physical

accessibility), and has had very little, if any, emphasis placed on design features that enhance the person's social and psychological wellbeing. They also discussed that the location of housing and its neighborhood context is generally not considered, and that developments have traditionally been located in poorer neighborhoods and on the outskirts of a community.

In their work, they authors highlighted that the current approaches to minimum standards of housing principles simply guide the production of more physically accessible dwellings in the private sector. They mention the aptly named Livable Housing Design Initiative, and criticise it for:

- its primary focus on the functional (i.e., physical accessibility) characteristics of the dwelling without deliberate and equal consideration of features that address additional psychosocial, symbolic, and emotional constituents of health; and
- its narrow focus on design features relevant to the dwelling, to the exclusion of important location and neighbourhood considerations.

Acknowledging that there are no minimum standards of housing design and development (or redevelopment) for Australians with complex disability *that purposefully and equally consider all* the important physical, psychological and social aspects of wellness and quality of life, they conducted three very relevant and detailed studies.

In their first study, they discussed that people with disabilities and high care need spend more time indoors and therefore have greater potential to be excluded, rather than included, by the very homes and communities they live in. They recommended that it is necessary and imperative for residential environments to be designed so as to optimise physical, psychological, social, symbolic and emotional wellbeing. They applied evidence-based design principles to the inclusive housing context and concluded by proposing an integrated housing and development framework coupled with physical, social, natural, symbolic and care environment factors that should be set as minimum standard to guide residential design and (re)development for people with complex disabilities (Wright et al., 2016).

In the same year, they published the results of a systematic review of the literature to determine what housing features (inclusive of design, location, and neighbourhood) ought to (or should not) inform housing design and development for adults with neurological disability. They summarised their review with preliminary guiding principles relating to housing design, location and the neighbourhood context for inclusive housing solutions, which included:

Housing design: housing for adults with disability ought to:

- facilitate physical access (e.g., physical accessibility; ease of access to household items and resources; technological features) inside and outside the person's home;
- encompass a homely environment;
- enhance the person's safety, security, and privacy (while not compromising the homely environment);
- improve the comfort of users, client and carer workplace health and safety, and the availability and efficiency of the care provided, and
- provide access to rehabilitation and exercise facilities.

Location: housing for adults with disability ought to be located with good proximity to local amenities, the person's social networks, and local services.

Neighbourhood: housing for adults with disability ought to be constructed in neighbourhoods that:

- promote physical access to public places and spaces;
- provide suitable community services and resources for adults with neurological disability, and
- enable the development of positive social networks, thereby facilitating social support.

In their findings, they also listed example features that *should not* inform future inclusive housing developments such as: technology that is difficult to use; living in isolated locations or in an areas that lack community resources; poor community acceptance; and perceived unsafe neighbourhoods (Wright et al., 2017).

Most recently, in 2019, they published another systematic literature review which synthesised housing supports funded by 20 major insurance-based schemes for Australians with an acquired brain injury or spinal cord injury. Their findings highlighted several interactions and inconsistencies that complicate the funding provided by major

insurance schemes. The gaps and opportunities revealed in their study can be useful for developing policy and advocacy to empower individuals and their families to pursue information about housing supports they may be entitled to in order to improve their housing situation (Wright, Colley, Knudsen, et al., 2019).

Two other discussion papers from the field of architecture that have investigated concepts of good design and its benefits in improving living environments and quality of life for people with disabilities were identified in this review (Bertram, 2017, 2015). In the first paper, the authors discussed the need to move the discussion beyond what are known as 'universal design' principles and to recognise that whilst critical, physical accessibility and functionality are only part of the issue. Through real built examples, the authors demonstrated ways in which design intelligence and creativity was able to create '*dignity-enabling and inclusive home environments*' (Bertram, 2015). In their second paper, they investigated holistic and analytical design-led strategies to inform home modification process for people with sustained spinal cord injury or acquired brain injury (Bertram, 2017).

Summary

Inclusive housing is much more than accessible housing as it includes good design and holistic features that promote a homely atmosphere, privacy, comfort, efficiency of care, convenience of local amenities, nearby social networks, good proximity to local services, adequacy of community services and resources, and appropriate community support. While the Livable Housing Design Initiative is being championed across all new homes in Australia, there appears to be no minimum standards of housing design and development (or redevelopment) for Australians with complex disability *that purposefully and equally consider* all the important physical, psychological and social aspects of wellness and quality of life.

4 Conclusion

Based on the findings of this scoping literature review, several possible interventions could be considered by the 'Ready To Go Home' project team. If any of these interventions are trialled and/or adopted, it is recommended that a rigorous evaluation framework and data collection process be conducted and the results made available in the peer-reviewed literature to ensure future researchers and disability advocacy teams can learn from the successes, failures and considerations.

The first key finding was that *unless each and every one* of the complex clinical and multifaceted cross-sector system hospital discharge barriers are addressed in a timely and efficient manner, the person with disability will face discharge delay. They will stay longer in hospital, beyond their discharge date, waiting for resolutions on cross-sector issues such as: NDIS or other funding; supportive or assistive needs; availability of capable carer or next-level-support; access to community-based care and rehabilitation; and availability of safe, accessible and inclusive accommodation. If the cross-sector issues remain unresolved, evidence from the literature confirms that the person with disability will be transitioned into unsuitable residential environments, which may include RAC facilities.

It has been well established that both delayed hospital discharge and RAC placement has very negative impacts on their health and wellbeing, and therefore coordinated and timely hospital discharge, coupled with availability of inclusive housing with next-level-care options, are imperative.

The second key finding was that a number of suggestions and recommendations on enhancing hospital discharge processes, which in turn could reduce length of hospital stay and prevent re-hospitalisation in adults with disabilities, were found embedded within a broad range of qualitative studies. This finding is of importance because, to-date, most researchers in the disability sector have suggested hospital discharge interventions based on findings from the general medical sector. Therefore, this review may be this first to find, extract and theme key disability sector specific recommendations to enhance hospital discharge processes, which in turn could reduce length of hospital stay and prevent re-hospitalisation. They are:

1. ***Initiate discharge planning at the earliest possible time*** in admission, possibly within the first 24-48 hours of admission.
2. ***Provide each patient with two highly skilled and knowledgeable coordinators*** – an in-patient coordinator AND a community care coordinator – who will visit the patient regularly, discuss with families to identify their next-level care supports and expectations (both during in-patient stay and after discharge), work with and across multiple system to advocate for the patient and resolve issues as they arise.
3. ***Request NDIS and other funding as soon as possible.***
4. ***Improve communication, collaboration and coordination*** between medical staff, allied hospital staff, patient, family members, community services and key stakeholders; keeping in mind a ‘person-centred’ approach so that the person with disability is placed at the centre of decision making regarding supports and services.
5. ***Engage external advocacy services, neuropsychology supports and communication experts*** that consult with the patient and the carers about their housing and support preferences, while addressing expert medical advice. Continue providing this support post-discharge so that they can all cope with the new way of living, together.
6. ***Provide family and carers training and support*** in preparation for their post discharge roles.
7. ***Identify local (i.e. West Australian) interface challenges*** around the roles and responsibilities of the NDIS, WA Health mainstream health providers, disability service providers and people with disabilities and their families.
8. ***Develop and maintain an up-to-date database of resources from public and non-governmental sector,*** including mainstream health sector staff and hospital sector staff and general practitioners who are skilled and capable of working with people with disabilities, so that there is a continuum of care upon discharge.
9. ***Develop and maintain an up-to-date database of skilled community care coordinators*** who are familiar with local processes and practices of the various

mainstream health services, disability and assistive supports, so as to facilitate interface collaboration and negotiation of funding and support plans.

10. ***Develop and maintain an up-to-date inclusive housing register*** so people can be offered, or themselves find the most appropriate accommodation more easily.

The third key finding was that even with the best hospital discharge and cross-sector system processes, many people with disabilities will be forced to reside in unsuitable residential environments (e.g., an impractical dwelling, an impractical neighbourhood, a group home with strict routines, or a RAC), or in housing that is not their preferred option, simply due to the broader and persistent issues relating to housing availability and housing suitability.

Despite the recent emphasis in Australian political, academic and legislative narratives to more actively promote real housing choice for people with disabilities, there is a lack of understanding regarding the specific housing features that might constitute better housing solutions for this population. While the Livable Housing Design Initiative is being championed across all new homes in Australia, there appears to be no minimum standards of housing design and development (or redevelopment) for Australians with complex disability *that purposefully and equally consider* all the important physical, psychological and social aspects of wellness and quality of life.

The fourth, and last key finding of this literature review was that there exists some highly innovative and conceptual academic research in disability specific inclusive housing. By highlighting these, the 'Ready To Go Home' project team now has the opportunity to use this evidence to engage advocacy for bold and new forms of inclusive housing that embraces the concepts of good design and holistic features such as a homely atmosphere, privacy, comfort, efficiency of care, convenience of local amenities, nearby social networks, good proximity to local services, adequacy of community services and resources, and appropriate community support.

5 Appendix 1: Summary of recent and relevant studies

Social work and complex care systems: The case of people hospitalised with a disability.

Redfern et al., 2015 published the findings from a practice improvement research project undertaken in Queensland and focused their findings on people with new or pre-existing disabilities who require time to maximize functional independence. They looked at discharge planning challenges by analysing a dataset of 80 patients with new or pre-existing disabilities, and through interviewing five hospital social workers.

They acknowledged that social workers have historically played a major role in facilitating patient discharge from hospital, aiding transition and community support for patients and their families. The social workers mentioned the constraints on their role especially when discharge delays stem from lack of community support, prolonged waiting times for appropriate funding, or availability of inclusive housing.

They suggested strategies that could assist in reducing length of hospital stay once an individual with disability is medically ready to be discharged. This included:

- Initiating interventions and referrals to disability services at the earliest possible time in the patient's admission.
- Discussing with families to identify their care and expectations, for example how they could physically and realistically look after the patient at home.
- Engaging external advocacy services that would regularly visit the patient, 'stick with them' and work with, and across, multiple systems to solve their issues and enhance care options.
- Improving communication between health staff, patient and their carer and community services and key stakeholders.

The impact of living in a care home on the health and wellbeing of spinal cord injured people.

Smith & Caddick, 2015 sought to understand the impact of health and wellbeing in people with spinal cord injury living in RAC facilities in the UK, and interviewed 20 individuals.

Their research found that living in a RAC facility severely damages quality of life, physical health and psychological wellbeing in the short and long-term. Reasons included: a lack of freedom, control, and flexibility; inability to participate in community life; inability to sustain relationships; safety problems; restricted participation in work and leisure time physical activity; lack of meaning, self-expression, and a future; loneliness; difficulties with the re-housing process; depression; and suicidal thoughts and actions.

The two main reasons why these people ended up in a RAC were lack of knowledge about all the alternative accommodation options during hospital discharge; and lack of available, safe and accessible accommodation options in the community, particularly in rural locations. The authors concluded that:

- People should be discharged into adapted property that meets their housing needs and supports their right to independent living. This should ideally be close to their initial home, or in a location of their choosing.
- Maintain an up-to-date accessible housing register so people can be offered, or themselves find, truly accessible social housing more easily.
- Increase awareness with home-builders and developers about accessibility and liveability standards.

Best practice discussion paper: A comprehensive evidence-base for innovative design methods that can improve accommodation outcomes for TBI and SCI residents.

Bertram et al, 2015 conducted a study to understand the impacts of best practice case study innovations in retrofits and new builds for clients and carers, and argued that there is a need to move the discussion beyond what are known as 'universal design

principles and to recognise that whilst critical, physical accessibility and functionality are only part of the issue.

Design principles in housing for people with complex physical and cognitive disability: towards an integrated framework of practice.

Wright et al., 2016 highlighted that people with disabilities and high care needs spend more time indoors, and therefore have greater potential to be excluded, rather than included, by the very homes and communities they live in. To understand the necessary and imperative residential environments that optimise physical, psychological, social, symbolic, and emotional well-being; they applied evidence-based design principles to the inclusive housing context and produced a theoretically-based environmental conceptual framework. They conclude that an:

- Integrated housing and development framework coupled with physical, social, natural, symbolic and care environment factors in relation to the intrinsic design, location and neighbourhood housing domains should be set as minimum standard to guide residential design and (re)development for people with complex disabilities.

What housing features should inform the development of housing solutions for adults with neurological disability? A systematic review of the literature.

Wright et al., 2017 conducted a systematic review of the literature to determine what housing features (inclusive of design, location, and neighbourhood) ought to (or should not) inform housing design and development for adults with neurological disability. The authors summarised their review with preliminary guiding principles relating to housing design, location and the neighbourhood context for inclusive housing solutions, which included:

- Housing design: housing for adults with neurological disability ought to: (a) facilitate physical access (e.g., physical accessibility; ease of access to household items and resources; technological features) inside and outside the person's home; (b) encompass a homely environment; (c) enhance the person's safety, security, and privacy (while not compromising the homely

environment); (d) improve the comfort of users, client and carer workplace health and safety, and the availability and efficiency of the care provided; and (e) provide access to rehabilitation and exercise facilities.

- Location: housing for adults with neurological disability ought to be located within good proximity to local amenities, the person's social networks, and local services.
- Neighbourhood: housing for adults with neurological disability ought to be constructed in neighbourhoods that: (a) promote physical access to public places and spaces; (b) provide suitable community services and resources for adults with neurological disability; and (c) enable the development of positive social networks, thereby facilitating social support.

The review findings also provide example housing features so that stakeholders involved in housing design and development (e.g., architects, designers, builders, developers, funding agencies) have access to practical information to inform housing decisions.

Experiences of adults with high-care needs and their family members with housing and support pathways in Australia.

McIntyre et al., 2017 conducted qualitative semi-structured interviews with 21 people with progressive and non-progressive acquired disabilities to understand transition pathways and choices regarding housing and support in South East Queensland. To understand each perspective, they interviewed people living in different housing models including: (1) residential aged care facilities; (2) institutional facilities designed to provide care to adults; (3) group homes, clustered housing or shared living facilities; and (4) private residences including living alone or in the family home with or without the use of respite services and other formal supports.

Through very structured and detailed analysis, they found that there were distinct and diverse needs of adults with high-care needs. There was no one-size-fits-all in housing support because each individual had varying needs, expectations and preferences to meet their rehabilitation, equipment needs, carer support and community engagement. Carers and family members used the terms 'fight, battle and war'

constantly when describing their frustration in negotiating appropriate housing and support pathways.

The authors concluded that current disability policy is not satisfying the housing and support requirements of adults with high-care needs and their families. They concluded that:

- Individual preferences are an important consideration in housing and support arrangements, alongside needs-based solutions.
- Individualised funding approaches may provide flexibility of care and choice in housing and support for people with disability.
- Family members willingly provide substantial informal care, support and advocacy for younger people with high needs but perceive their role as a constant 'battle'.
- Payment of family members in recognition of caring work was perceived as a solution to relieve family hardship and ensure optimal care.

Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: A qualitative study.

Abrahamson et al., 2017 explored the experiences of individuals who have had a severe traumatic brain injury and their carers in the first month post-discharge from in-patient to living in the community in the UK. They conducted qualitative semi-structured interviews with 10 patients and 9 carers and found that health professionals underestimate the change in abilities and impact on daily life once patients return home.

Both the patient and carer felt there was lack of communication from the hospital team while in hospital and during discharge. They felt that while the actual discharge processes were relatively smooth, they identified some barriers in the discharge planning process. For example, the patients and the carers mentioned poor communication between clinicians and patients/carers plus lack of co-ordination between services. Furthermore, the carers said they felt overwhelmed and underinformed because they were not fully involved in the discharge and rehabilitation

decisions, yet the responsibility to organise on-going care, rehabilitation, appointments once home, fell upon them.

On a different note, the patients and carers highlighted that they particularly valued the in-hospital neuropsychology support, but mentioned that the support stopped post-discharge. They requested more emotional support, during and after transitioning to home. Therefore, the authors recommend:

- Provide ongoing and long-term emotional/psychological support for patient and the carer, so that both of them can deal with the new way of living, together.
- Conduct comprehensive needs assessment and goal setting as part of discharge planning, considering their carers' needs.
- Appoint a care coordinator as the first and ongoing point of contact, who would be ideally placed to facilitate integrated care and ensure patient and carer are at the forefront of decisions from inpatient admission onwards.

Cross Sector Discharge Planners Forum Summary 2015-2016 Summer Foundation.

Larwill, 2017 reported the findings from five stakeholder forums facilitated by the Summer Foundation. They attempted to understand perspectives of a range of participants regarding their experiences of discharge planning and processes for adults with disabilities and at risk of entering residential aged care. The primary themes to emerge from their stakeholder forums were:

- Lack of collaboration across sectors (health, disability, aged care) characterised by a lack of agreement around respective responsibilities, particularly in regard to funding, and compounded by a lack of knowledge sharing.
- Poor communication between health professionals and those involved in making discharge decisions, resulting in delays in accessing funding for post-discharge disability supports. There is also a need for improved communication between the health professionals, the patient and their family.
- Slow processes and limited staff resources resulting in delays and frustration which can lead to pressure to compromise or accept inferior options.

- Limited knowledge and awareness of issues among relevant staff and systems.

Towards a holistic home modification design process; 3 case studies

Bertram et al., 2017 conducted a study to look at how holistic and analytic design-led strategies can inform the home modification process for people who have sustained a spinal cord injury or an acquired brain injury. They proposed holistic design strategies and a set of 8 recommendations.

Opportunities for a meaningful life for working-aged adults with neurological conditions living in residential aged care facilities: A review of qualitative research.

Levack & Thornton, 2018 conducted a review of the literature to identify and synthesise findings from all the qualitative research investigating experiences of adults with neurological conditions living in RAC facilities. We included this paper in our analysis because one of the key themes the authors investigated was 'reasons for being in RAC facilities'. The three main reasons why many adults with disability under the age of 65 years end up in RAC facilities were:

- Lack of knowledge about all the alternative accommodation options during hospital discharge;
- Lack of available, safe and accessible accommodation options in the community, particularly in rural locations; and
- Lack of knowledge about how to access funds for house modifications and assistive technologies that would be necessary for them to live in the community.

Hospital discharge planning for young people with severe disability: Literature Review.

Knox et al., 2017, through the Summer Foundation, conducted a literature review on discharge planning interventions from the non-disability sector and made recommendations in relation to discharge planning for adults (under the age of 65

years) with disability and complex needs. They identified four elements from the literature associated with effective discharge planning including: (1) adopting a comprehensive discharge planning process; (2) engaging a dedicated discharge planning and community liaison officer; (3) using technological solutions to enhance education and improve information handover; and (4) actively engaging the person and their family in all stages of the discharge planning process. They concluded with 'suggested discharge planning principles':

- Early start discharge planning should commence within 24-48 hours of admission.
- Expertly coordinated health and disability knowledge.
- Person-centred engagement in discussions and decisions.
- Family-focussed active involvement.
- Communication of clear and timely information.
- Education of person, family, health and support workers is key.
- Outcome-oriented finishes when person has housing and support to live an ordinary life

A scoping review of the nature and outcomes of extended rehabilitation programmes after very severe brain injury.

Knox & Douglas, 2018 conducted a literature review to map the nature and outcomes of rehabilitation programmes for adults experiencing prolonged recovery after very severe brain injury. They reviewed 13 studies into service delivery at the severe end of the recovery continuum, and found that extended rehabilitation contributed to positive long-term outcomes and supported their right to live in the community, by enhancing their independence. Specifically, adults who participated in extended rehabilitation programmes required fewer hours of care, had lower costs and were more likely to live in their own home, with family, or in a disability-specific accommodation and not a RAC.

Housing for People with an Acquired Brain or Spinal Injury: Mapping the Australian Funding Landscape

Wright et al., 2019 conducted a structured and systematic literature review to synthesise housing supports funded by 20 major insurance-based schemes for Australians with an acquired brain injury or spinal cord injury.

Their findings highlighted several interactions and inconsistencies that complicate the funding provided by major insurance schemes. The gaps and opportunities revealed in their study can be useful for policy and advocacy to empower individuals and their families to pursue information about housing supports they may be entitled to, in order to improve their housing situation.

Exploring the efficacy of housing alternatives for adults with an acquired brain or spinal injury: A systematic review

Wright et al., 2019 undertook a systematic review of the literature to identify and critically evaluate the current research evidence regarding the efficacy of housing alternatives for adults with an acquired brain or spinal injury in relation to four principal outcomes of interest, namely: the person's (1) community integration/ participation, (2) independence (including physical/cognitive functional recovery), (3) psychosocial well-being (including satisfaction, choice and control in decision-making, adjustment) and (4) quality of life

All of the 10 included studies focused on housing for adults with acute brain injury, and none focused on spinal cord injury. The three studies from Australia included in the review were from 2010 and 2012. They therefore reported on housing models that have now transitioned into the NDIS and/or reflect models that may not be funded in the same structure as reported by the research.

Regardless, the authors concluded that that 'home-like' environments (i.e., private homes where the person either lives alone, with parents, with other family, with friends or in a detached residence on private property), and 'disability-specific' settings (i.e., shared supported accommodation, group homes, foster care homes, cluster units) to a lesser degree, provide a suitable alternative to RAC.

Understand disability through the lens of Aboriginal and Torres Strait Islander people - challenges and opportunities.

Ferdinand et al., 2019 conducted a study to understand the implementation of the NDIS Aboriginal and Torres Strait Islander Engagement Strategy, the interaction between National Disability Insurance Agency staff, local area co-ordinators and Aboriginal Community Controlled Health Services and non-governmental organisations; experiences of Aboriginal and Torres Strait Islander people in accessing the NDIS, planning, and receiving disability supports through the scheme. In doing so, a set of 13 recommendations were made.

Care coordination experiences of people with traumatic brain injury and their family members in the 4-years after injury: A qualitative analysis.

Braaf et al., 2019 conducted qualitative research to explore experiences of care coordination in the first 4-years after severe traumatic brain injury. They conducted 18 semi-structured interviews 48-months post-injury with six adults living with severe traumatic brain injury, and the family members of 12 other adults with severe traumatic brain injury in Victoria.

They found that most individuals used a number of health and allied health services in community yet none of them had a dedicated care coordinator. Family members ended up advocating for the person with TBI, but they felt they had little success as they struggled to navigate the complex systems of health, disability and compensation. They voiced their frustrations around lack of accountability of ineffective services, and said they were frustrated with frequency of staff change, for it made communication about the care, and the rehabilitation, difficult.

The authors mentioned that effective care coordination post discharge is not only important for people with traumatic brain injury to receive quality and planned care that meets their needs and goals, it is also important for preventing re-hospitalisation, and preventing extra stress on family carers. Consequently, they suggested:

- All patients with long-term or complex disability should have an independent care coordinator.

- The care coordinator needs to be funded and be knowledgeable about the health conditions and rehabilitation processes.

From Hospital to Home with NDIS Funded Support: Examining Participant Pathway Timeframes Against Discharge Expectations

Houston et al., 2020 conducted a retrospective analysis of data regarding inpatients with spinal cord injury or acute brain injury to examine impact of NDIS on timing of discharge, and to determine factors contributing to delay and complications in discharge planning. They analysed data from 54 patients from Metro South Hospital and Health Service, Queensland.

They found that 41 patients were eligible for NDIS funding and the legislated 21-day NDIS access request was achieved in patients with acute brain injury, but not in spinal cord injury. This was because of the complex clinical needs and prognosis of more traumatic or severe individuals. They highlighted critical points in the NDIS pathway where interface challenges such as requesting NDIS funding, receiving outcome of NDIS funding, planning processes and implementation of plans may have contributed to longer hospital stays. They also identified that discharge delays occurred because patients were waiting for assistive technology and home modifications. Consequently, they suggested that hospital discharge processes could be improved by:

- Requesting NDIS funding as soon as possible.
- Supporting local coordinators to become familiar with local processes and practices so as to facilitate interface working and negotiation of plans.
- Monitoring implementation of NDIS to understand and avert interface problems that impede timely discharge and access.

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