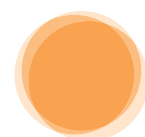


# HOSPITAL DISCHARGE PLANNING

FOR YOUNG PEOPLE WITH  
SEVERE DISABILITY AND  
COMPLEX NEEDS:

A REVIEW OF THE LITERATURE

JUNE 2018



SUMMER  
FOUNDATION

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## **CITATION GUIDE**

Knox, L., Symmons, M.A., Douglas, J., Hilton, G., & Winkler, D. (2017). *Hospital discharge planning for young people with complex disability: Literature review*. Melbourne, Australia: Summer Foundation.

## **ACKNOWLEDGEMENTS**

In 2017, the Summer Foundation received funding through a successful grant application from the William Buckland Foundation. The William Buckland Foundation is supporting the Summer Foundation over 3 years to develop a better pathway for young people with complex needs leaving hospital and returning to the community, with a focus on regional Victoria.

The Hospital Discharge Project aims to bring about better coordinated discharge planning processes that enable younger people to leave hospital earlier and move back into the community, ultimately leading to fewer young Victorians entering residential aged care (RAC).

Through this work, the Summer Foundation plans to work in direct partnership with hospital teams and the National Disability Insurance Agency (NDIA) to create a multi-sectorial approach for hospital discharge planning which will assist people with disability and their families to connect with the National Disability Insurance Scheme (NDIS), and improve health professionals' NDIS knowledge.

## **DISCLAIMERS**

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# EXECUTIVE SUMMARY

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The aim of the discharge planning process is to improve the coordination of a person's services post-discharge and reduce the likelihood of unplanned hospital re-admissions. This review sought to explore the current evidence base for hospital discharge planning for young adults (aged 18-64) with disability and complex support needs. Successful discharge planning for this group is complex and requires effective cooperation between health and disability services.

Historically, many patients in this group have found themselves in hospital beyond the time they are clinically ready to be discharged. Discharge delays may occur when processes necessary for their discharge have not been completed (such as referrals to community-based supports or funding approvals to enable commencement of these supports), when support and resources are not in place for them to be returned to their own home, or when there is nowhere suitable or available for them to be discharged to. Local evidence suggests that enduring difficulties remain in relation to access to suitable housing and community-based services and transition support. As a result, some young people with complex support needs continue to be discharged from hospital to residential aged care.

The importance of effective discharge planning has long been recognised. As such, it is not surprising that there is extensive literature documenting and evaluating discharge planning interventions. Despite this, this literature review found that young people with disability and complex support needs have not been the direct focus of any published discharge planning trials. However, there are some consistent findings across the discharge planning literature more generally regarding the likely nature and components of effective discharge planning interventions. Research evidence suggests that effective interventions centre on individualised discharge planning, commence early in a patient's admission, contain both pre and post-discharge elements, and focus on supporting individual empowerment. Further, the literature suggests the development of a discharge planning intervention for this group may involve a comprehensive discharge planning process, dedicated discharge planning officer, strategies to support the real-time handover of information, and actively engage the person and their family in all stages of the discharge planning process.

Based on the findings of this review, suggestions for change include both a set of guiding principles (how an initiative should be designed) and a complementary set of specific recommendations about possible discharge planning interventions that may be considered.

This literature review identified 7 principles for patients at risk of poor outcomes and/or delays in discharge:

- **Early start** discharge planning should commence within 24-48 hours of admission
- **Expertly coordinated** health and disability knowledge
- **Person-centred** engaged in discussions and decisions
- **Family-focussed** actively involved
- **Communication** 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

Based on the findings of this review, several possible interventions could be considered. If any of these interventions are adopted, it is recommended that a rigorous evaluation process be conducted and made publicly available to ensure that successes, failures and any lessons learnt can be shared and built on in future trials.

Possible interventions could include:

- **Early screening** tool to identify and assess risks of complex cohort
- **Early support** coordination starts in hospital and on-going
- **Tools** to support timely information exchange
- **Post-discharge follow-up** to measure outcomes and improve process
- **Discharge planning community of practice**

# CONTENTS

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- EXECUTIVE SUMMARY ..... 1**
- 1. INTRODUCTION ..... 4**
  - 1.1 Background..... 4
  - 1.2 Literature review structure ..... 5
  - 1.3 Scope and definitions..... 5
- 2.NEED FOR (EFFECTIVE) DISCHARGE PLANNING ..... 6**
  - 2.1 Discharge timing..... 6
  - 2.2 Explanations for discharge problems ..... 7
  - 2.3 Discharge issues specific to young people with complex support needs ..... 7
- 3.REVIEW OF DISCHARGE PLANNING REVIEWS..... 9**
- 4.LEARNING FROM OTHER DISCHARGE PLANNING INTERVENTIONS ..... 12**
  - 4.1 Adopting a comprehensive discharge planning process.....12
  - 4.2 Engaging a dedicated discharge planning officer to support transitions and ensure continuity of care..... 14
  - 4.3 Finding innovative solutions to improve the flow of information across the care continuum .....15
  - 4.4 Actively engaging the person and their family in all stages of the discharge planning process..... 16
- 5.PRINCIPLES AND POTENTIAL INTERVENTIONS .....17**
  - 5.1 Suggested discharge planning principles .....17
  - 5.2 Interventions for consideration..... 18
- REFERENCES ..... 19**

# 1. INTRODUCTION

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## 1.1 BACKGROUND

Discharge planning refers to the process of developing a discharge plan for a person before they leave hospital. The aim of this process is to improve the coordination of services post-discharge and reduce the likelihood of unplanned hospital re-admissions (Sheppard et al., 2004). Effective discharge planning processes may support health services to decrease the length of a person's hospital stay and reduce the number of delayed discharges, support individuals to increase their knowledge and capacity to manage their own condition, and improve patient satisfaction and outcomes.

Conversely, sub-optimal discharge processes have been associated with a range of negative social, health and economic consequences for the person and those around them, as well as for the health system and broader community. Such consequences may include significant financial costs associated with prolonged hospital admissions, poor health and behavioural outcomes for the person resulting from delays in access to specialist rehabilitation services, and increased levels of stress and strain for family members who may be provided with limited support during this period (Turner et al., 2011). Given the significant negative implications associated with sub-optimal discharge planning processes, both for individuals and institutions, there has been significant interest in investigating and evaluating discharge practices for individuals leaving hospital to identify the critical elements that are necessary to support an effective and client-centred discharge planning process.

The aim of this review is to explore the current evidence base for hospital discharge planning for young adults (aged 18-64) with disability and complex support needs. Individuals within this group are not homogeneous in terms of the nature of health conditions, support requirements and reasons for hospital admission. Some may be admitted to hospital with health conditions directly related to their disability (stroke, acquired brain injury). Others may be admitted to hospital with a pre-existing disability experiencing a secondary health condition related to their disability (e.g. pressure areas or chest infection). Regardless, many find that their pre-existing living arrangements are no longer suitable on discharge.

Successful discharge planning for this group is complex and requires effective cooperation between health and disability services. Historically, many patients in this group have found themselves in hospital beyond the time they are clinically ready to be discharged, or have been discharged to RAC (Winkler, Sloan, & Callaway, 2007). The negative consequences of admission to RAC for young people have been well documented, and include social isolation, restricted communication participation, and few opportunities to exercise choice and control in their lives (O'Reilly & Pryor, 2002; Persson & Ostwald, 2009; Rissanen et al., 2014; Smith, 2004).

The rollout of the NDIS provides an opportunity to improve the discharge experience of young people with disability and complex support needs. The scheme has the potential to facilitate more and greater appropriate housing and to expand the capacity of the disability services sector to meet the needs of these individuals living in the community. However, change will also be required at hospital level to ensure that the expectation of discharge planning is to support an individual to return to the community whenever possible. In line with this goal, the aim of this literature review is to identify those discharge practices that may minimise discharge delays and achieve a greater number of young people with complex support needs discharged to the community.

## 1.2 LITERATURE REVIEW STRUCTURE

Young people with disability and complex support needs are a small cohort for whom discharge planning is particularly challenging. People in this group are at higher risk of additional infection and complications while in hospital, longer hospital stays and an increased rate of hospital re-admission. As such, support to participate in a thorough, effective and evidence-based discharge planning process should be a priority for people within this group. Despite this, a survey of systematic reviews of discharge planning and a targeted literature search revealed no systematic published evaluations of discharge planning intervention for individuals within this cohort. However, there is agreement in the literature of the lack of attention to issues faced by adult patients in hospital with disability more generally, and the often-substandard experience they and their families endure during and after their hospital stay (Brown & Kalaitzidis, 2013; Iacono et al, 2014; Sharby, Martire & Iversen, 2015).

In the absence of a series of discharge planning interventions specific to the target cohort, this review will present a summary of the relevant existing literature against the following headings:

1. Need for (effective) discharge planning: Problems that arise from sub-optimal discharge
2. Review of discharge planning reviews
3. Learning from other discharge planning interventions
4. Suggested principle and potential interventions

## 1.3 SCOPE AND DEFINITIONS

The following are consistent concepts as they relate to the scope of this review:

- The population of interest is young adults (aged 18-64) who have severe disability and complex care needs. These support needs may relate to the person's physical, sensory and/or cognitive functioning and may include support with mobility, activities of daily living, communication and social interaction, memory and decision-making.
- The term *hospital* is used to refer to hospitals, hospital-based inpatient rehabilitation centres, and hospital-linked specialist care centres. These facilities are staffed by medical, nursing and allied health professionals, and patients receive services on an inpatient basis.
- For the purpose of this review, *discharge* refers to the process of a person being discharged from hospital to a location outside the health system. Any clinical handover from one care team to another within the health system (for example, from one ward to another, or from acute to sub-acute care) is not included as discharge for the purposes of this review.
- *Discharge planning* refers to the process of developing a discharge plan for a person before they leave hospital.
- *Primary care* refers to care provided by general practitioners, nurses and allied professionals in a community-based setting, and includes services such as health promotion, prevention and screening, early intervention, treatment and management.

## 2. NEED FOR (EFFECTIVE) DISCHARGE PLANNING

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Sub-optimal discharge processes have been associated with a range of negative consequences, both for the person being discharged and the broader community. This chapter provides an overview of the potential negative impacts of sub-optimal discharge.

### 2.1 DISCHARGE TIMING

Over recent decades, there has been a consistent trend towards shorter hospital stays. Two decades ago, Victoria's Department of Human Services (VicDHS, 1998) noted that length of hospital stay in Victoria's hospitals had declined markedly, and the number of same-day separations (i.e. discharged without an overnight hospital stay) had significantly increased. This trend has not abated, supported by more efficient health intervention practices, new technologies, and improvements in pharmacology which may reduce the amount of time patients require active treatment in hospital.

However, research demonstrates that there are a range of factors likely to influence the length of a person's hospital stay, including their diagnoses, age, number and type of health conditions and planned discharge destination (VAGO, 2016). In this context, hospital staff need to balance the potential negative implications of a premature discharge with the risks associated with a prolonged hospital stay. Premature discharge can impact on quality of care and health outcomes for patients, and discharge can result in a need for further re-admissions if the patient's condition is not managed effectively in the community.

Equally, a prolonged hospital admission increases the potential for complications and may negatively impact a person's quality of life. Health-related complications associated with lengthy hospital stays include delirium and "post-hospital syndrome" (Krumholz, 2013; Pearl, 2015). Post-hospital syndrome occurs when a patient is less healthy and resilient at discharge than they were at admission, and therefore at increased risk of being re-admitted to hospital with a new illness or injury. These complications have been associated with an increased risk of death in the year following hospitalisation in an elderly cohort (Pearl, 2015), and increased rates of re-admission in the month following discharge (Krumholz, 2013). These levels of risk may be similar for young people with disability and complex support needs, as it is a person's physical status and frailty (rather than their age) that increases risk (Pearl, 2015). Such risks also need to be considered in light of previous research which has demonstrated that young people with complex support needs are at increased risk given a general lack of attention to their needs in hospital (Iacono et al., 2014; Shakespeare, Iezzoni, & Groce, 2009; Sharby et al., 2015).

For young people with disability and complex support needs, discharge delays may occur when processes necessary for their discharge have not been completed (such as referrals to community-based supports or funding approvals to enable commencement of these supports), when support and resources are not in place for them to be returned to their own home, or when there is nowhere suitable or available for them to be discharged to. Statistics for such discharge delay range from 20% (McDonagh, Smith & Goddard, 2000) to 30% (Simonet et al., 2008), and up to 48% of patients (Hendy et al., 2012). For young people with complex support needs, while effective and timely discharge can support access to personalised and contextual-sensitive rehabilitation, evidence suggests that enduring difficulties remain in relation to access to suitable housing and community-based services and transition support (Cornwell et al., 2009; Turner et al., 2011; Piccenna et al., 2016).



## 2.2 EXPLANATIONS FOR DISCHARGE PROBLEMS

Several researchers have set out to better understand the factors that underpin poor hospital discharge outcomes. In 1999, Grimmer, Hedges and Moss undertook a large qualitative study exploring problems with discharge planning. The study involved 100 staff from three Australian hospitals, including nursing, allied health and specialist discharge planning personnel. Six key themes were identified from the data, which reflected common issues described by participants in their experience of discharge planning. These issues included:

1. *A lack of staff and patient education about discharge* reflecting a lack of shared understanding about effective discharge planning among medical and nursing staff, and limited provision of discharge-related education for patients and their families.
2. *Communication and coordination issues* including poor communication and poor coordination between staff, issues with documentation impacting on discharge, and lack of a formal discharge planning process.
3. *Availability of services and accommodation post-discharge*, such as a lack of appropriate community services and appropriate discharge accommodation.
4. *Patient-related complexities* which added to discharge delays (particularly patients who were frail, socially isolated or had a cognitive disability). Some health services reported that specialist case managers or discharge planning personnel had been employed to meet the needs of patients in these groups.
5. *A lack of early planning for discharge* and inadequate time to undertake activities to support successful discharge.
6. *Problems with the transition to community service provision*, including delays in providing appropriate post-discharge documentation to primary health care providers.

More recent studies have confirmed that the same issues continue to impact negatively on contemporary discharge planning processes. Researchers have continued to cite issues related to communication, patient and family education, and the availability of community resources as factors that may influence the success of a person's discharge. Communication issues include communication problems between teams (Okoniewska et al., 2015) and poor communication between the hospital and external providers of follow-up care (Gonçalves-Bradley et al., 2016), including delays in the provision of information to community-based providers (Guerin et al., 2012). The limited availability of community resources for post-discharge support is also frequently cited as an important factor that limits the success and effectiveness of a person's discharge in the context of adults with severe disability (Cornwell et al., 2009; Piccenna et al., 2016; Turner et al., 2008; Turner et al., 2011).

## 2.3 DISCHARGE ISSUES SPECIFIC TO YOUNG PEOPLE WITH COMPLEX SUPPORT NEEDS

While the literature summarised above outlines a number of issues related to successful discharge planning more generally, several authors have specifically explored the hospital experiences of adults with disability, including their experiences of discharge. This literature highlights that people in this group experience significant problems during their hospital stays (often related to their interactions and communication with healthcare professionals), may be discharged with limited planning, and report that their experience is shaped by a lack of collaboration among service sectors.

For adults with disability, the literature points to a number of issues relating to their interactions with healthcare professionals that are likely to impact discharge planning. These problems include negative attitudes from hospital staff, delays in diagnostic evaluations and treatment, and reliance on family and paid carers for both advocacy and care during hospital stays (Iacono et al., 2014). A systematic review undertaken by Brown and Kalaitzidis (2013) identified that nursing staff demonstrated deficits in their knowledge, skills, and communication with patients with disability. This included difficulties in their knowledge and ability to identify specialist needs for individual clients. Based on the results of a review of barriers to health care access, Sharby and colleagues (2015) reported that people with disability are more likely than other categories of patient to report that health professionals do not listen to them, do not explain things in a way they can understand, do not demonstrate respect for what they have to say, and do not spend enough time listening to them. As a result, patients with disability may have poorer follow-up after discharge, have greater risk of being misdiagnosed, and be less likely to have a longer-term relationship with a primary care provider.

In addition to problems with communication and interaction, research has indicated that people with disability report that their participation in discharge planning is limited and generally unsatisfactory. Buzio, Morgan and Blount (2002) interviewed adults with cerebral palsy about their recent hospital stay and discharge experiences. Only half (55%) of respondents reported any element of discharge planning. For those who did, this ranged from being asked how they would cope after returning home through to arranging a community nurse to make a follow-up visit. A study exploring the experiences of young people with complex support needs who had entered residential aged care suggested that decisions about discharge were made in the absence of time, knowledge of options or alternatives (Barry, Knox & Douglas, under review). Indeed, families have repeatedly identified a need for greater access to information, advocacy and counselling during discharge planning, particularly when considering RAC as a discharge option (Barry, Knox & Douglas, under review; Colantonio, Howse, & Patel, 2010; Leith, Phillips, & Sample, 2004; McIntyre et al., 2016).

Larwill (2017) reported the findings of a series of five fora facilitated by the Summer Foundation that engaged a range of stakeholders involved in the process of supporting young people making the transition from hospital to home. In the context of the NDIS rollout, the fora aimed to capture the perspectives of a range of participants regarding their experiences of discharge planning and processes for young people at risk of entering residential aged care. The primary themes to emerge from analysis of this data related to:

- *A lack of collaboration across sectors* (health, disability, aged care), characterised by a lack of agreement around respective responsibilities, particularly in regards 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.

# 3. REVIEW OF DISCHARGE PLANNING REVIEWS

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The importance of effective discharge planning has long been recognised. As such, it is not surprising that there is extensive literature documenting and evaluating discharge planning interventions. Given the extent of this literature, several authors have now undertaken systematic reviews of the discharge planning literature to be able to make recommendations about the efficacy of the interventions that have been documented. A summary of relevant reviews is presented in Table 1. As indicated in this table, none of the reviews included young people with disability and complex support needs as a specific patient cohort, either directly or in a related manner. However, the reviews provide some important evidence and information about (a) the likely impact of a comprehensive discharge planning process, and (b) the nature of discharge planning interventions documented in the literature.

Mistiaen, Francke and Poot (2007) conducted a systematic meta-review of studies published 1994-2004. They included 15 systematic reviews of discharge interventions for a mixed patient cohort. No studies specifically targeting young patients with disability were included. Based on their review, the authors concluded that interventions that combined both pre-discharge (discharge planning) and post-discharge interventions tended to result in the best outcomes.

McMartin (2013) conducted a systematic review of reviews, meta-analyses and randomised control trials (RCTs) examining discharge planning for people with chronic conditions who are likely to experience repeated hospitalisations. Eleven studies that compared discharge planning interventions to "usual care" were included. The author specifically sought studies that included discharge planning interventions that involved a "bundle" of services to support a patient's transition from hospital to the community (such as discharge planning, support services, follow-up activities and monitoring). The results of this review suggest that individualised discharge planning (with and without post-discharge support) can reduce re-admission rates for people with chronic health conditions compared to usual care.

Gonçalves-Bradley et al. (2016) published a Cochrane Review on discharge planning initiatives generally. The authors included 30 RCTs published between 1987 and 2011 (none specific to young people with disability and complex support needs). They concluded that length of stay and re-admissions were reduced for participants who had been involved in discharge planning, and that levels of satisfaction were also higher for these people.

Kumar and Grimmer-Somers' (2007) systematic review used a "best practice" lens to identify 48 studies that encompassed 57 interventions for a mixed patient cohort (including people with congestive heart failure, psychosocial disability and age-related frailty). The interventions were rated in terms of efficiency, effectiveness, patient-centredness, safety, timeliness, and equity. However, 20 studies exploring the evidence for early discharge programs (with associated community-based support and follow-up) compared to usual care demonstrated evidence for the increased effectiveness (60%), increased patient-centred outcomes (45%) and increased safety (35%) of these programs. Similarly, 14 studies reporting on the evidence for providing post-discharge programs following a usual length of stay demonstrated evidence for increased effectiveness (71%), increased patient-centred outcomes (50%) and increased safety (57%) associated with such interventions. In this context, post-discharge supports included nurse home visiting, telephone supports, and the provision of community supports. Overall, however, the authors reported equivocal findings for health outcomes, length of stay and re-admission rates associated with community-based care compared with hospital-based care, possibly due to the variable methodological quality of the included studies.

Hansen, Young, Hinami, Leung and Williams (2011) reviewed interventions designed to reduce the 30-day re-admission among paediatric, obstetric and psychiatric populations. Of the 43 studies included, the authors classified interventions into three categories: (1) pre-discharge interventions, which included patient education, discharge planning, medication

reconciliation and appointment scheduling; (2) post-discharge interventions, including timely follow-up, patient hotline, patient phone call and home visit; and (3) bridging interventions that started before discharge and continued afterward, including a transition coach, patient-centred discharge instructions and provider continuity. Based on their findings, the authors concluded that they were unable to identify a discrete intervention or group of interventions that reliably reduced re-admission rates. However, they noted that the bridging interventions tended to engage the patient in the discharge process, transforming it into an activity done with rather than to a patient.

Braet, Weltens and Sermeus (2016) conducted a meta-analysis of 47 RCTs to identify discharge interventions from hospital to home that reduce hospital re-admissions within three months. Findings indicate that interventions that begin before discharge and continue for some period after the patient has returned home are more effective than

**Table 1. Summary of discharge planning review studies**

<b>Authors (Year)</b>	<b>Study Type</b>	<b>Study Objective</b>
Braet et al., 2016	Systematic review & meta analysis (47 RCTs)	To identify discharge interventions from hospital to home that reduce hospital re-admissions within three months.
Gonçalves-Bradley et al., 2016	Systematic review & meta analysis (30 RCTs)	To assess the effectiveness of planning the discharge of individual patients moving from hospital.
Hansen et al., 2011	Systematic review (43 studies)	To describe interventions evaluated in studies aimed at reducing rehospitalisation within 30 days of discharge.
Kumar & Grimmer-Somers, 2007	Systematic review of reviews & grey literature (48 studies)	To synthesise secondary evidence for hospital avoidance and discharge programs compared with usual hospital care in terms of principles of best practice (safety, effectiveness, timeliness, equity, efficiency and patient-centredness).
McMartin, 2013	Systematic review (included 7 systematic reviews and 4 RCTs)	To determine if discharge planning bundles (e.g. support services, follow-up activities, and other interventions that span pre-hospital discharge to the home setting) are effective in reducing health resource utilisation and improving patient outcomes compared with usual care alone.
Mistiaen et al., 2007	Meta-review (included 15 systematic reviews)	To synthesise the evidence presented in literature on the effectiveness of interventions aimed to reduce post-discharge problems in adults discharged home from an acute general care hospital.

interventions that are confined to the period in hospital or the time post discharge. They also note that interventions to foster patient empowerment are more effective than those that do not.

Despite the presence of numerous reviews in relation to discharge planning, many authors raise concerns about the robustness and replicability of the interventions described and the methods used to evaluate their effectiveness. Further, none of the reviews included individual studies focussed specifically on the population of interest, with some authors specifically noting the absence of studies involving patients with cognitive disability (Naylor et al., 2011). Despite this, there are some consistent findings across this literature regarding the likely nature and components of effective discharge planning interventions. In particular, evidence suggests that effective interventions centre on individualised discharge planning, start early in a patient's admission, contain both pre and post-discharge elements, and focus on supporting individual empowerment.

Patient Type	Main findings
Adults discharged from a medical or surgical ward	<p>Interventions starting during hospital stay and continuing after discharge were more effective in reducing re-admissions compared to interventions starting after discharge.</p> <p>Interventions oriented towards patient empowerment were more effective compared to all other interventions.</p>
Hospital inpatients (including older adults, patients who have had medical/ surgical, psychiatric, general interventions)	<p>Hospital length of stay and re-admissions to hospital were reduced for participants admitted to hospital with a medical diagnosis and allocated to discharge planning.</p> <p>Discharge planning may lead to increased satisfaction for patients and healthcare professionals.</p> <p>It is uncertain whether there is any difference in the cost of care when discharge planning is implemented.</p>
Patients with a range of health conditions (aged, cardiac, general medicine, chronic obstructive pulmonary disease)	<p>No single intervention or bundle of interventions found to be effective. Patient-centred discharge information and post-discharge telephone call are promising intervention components.</p> <p>Results suggest bundled interventions more likely to be effective than single interventions.</p>
Patients with a range of health conditions (congestive heart failure, mental health, frail-aged, generic discharge)	<p>There is some evidence for improved patient-centred outcomes associated with hospital avoidance and discharge programs.</p>
Patients with chronic conditions (chronic obstructive pulmonary disease, cardiac disorders, stroke, diabetes, chronic wounds)	<p>One meta-analysis found a significant reduction in re-admissions favouring individualised discharge planning compared with usual care.</p> <p>A second meta-analysis compared comprehensive discharge planning with post-discharge support to usual care. There was a significant reduction in re-admissions favouring discharge planning with post-discharge support.</p>
Patients who are elderly or have experienced stroke, hip or femur fractures, heart failure	<p>There is some evidence that some interventions may have a positive impact, particularly those with educational components and those that combine pre-discharge and post-discharge interventions.</p> <p>There is limited evidence that interventions can positively impact status at discharge, discharge destination and costs.</p>

# 4. LEARNING FROM OTHER DISCHARGE PLANNING INTERVENTIONS

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Given the limited literature focusing specifically on the discharge planning needs of young people with disability and complex needs, this section of the review outlines recommendations in relation to discharge planning which may be tailored and implemented for this cohort. It also includes discussion of the likely efficacy of the intervention and considerations for their emulation in the current project. Four key elements from the literature associated with effective discharge planning will be discussed, 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.

## 4.1 ADOPTING A COMPREHENSIVE DISCHARGE PLANNING PROCESS

The literature highlights that successful and effective discharge occurs when a comprehensive process is followed. The core elements of such a process have been described by several authors in both local and international contexts.

In a local context, common understandings of discharge planning have been shaped by key policy documents, including as the background paper prepared by the Victorian Department of Human Services about effective discharge planning two decades ago (VicDHS, 1998). This document proposes that an effective discharge process will take place over four key phases:

1. *An initial screening process* to assess the patient's physiological, psychological, social and cultural needs, their access to resources, and impediments to their on-going improvement.
2. *Development of a discharge plan*, including identifying and documenting discharge strategies.
3. *Plan implementation*, including arranging for provision of services, educating the patient and family, arranging referrals, initiating conversation with the GP and other services, confirming transport and contacting the GP shortly before discharge.
4. *Post-discharge follow-up* with the patient to evaluate their progress and further needs, and to evaluate the effectiveness of the discharge strategy.

While the sequential logic of this approach is attractive, questions remain about the mechanics of the process (for example, how to screen, what information should be contained in a discharge plan, and who should undertake follow-up). However, many of the elements described in this process align with more recent studies recommending essential elements of the discharge planning process for young people with complex support needs.

On the basis of a forum dedicated to improving discharge planning and the hospital experience for patients with ABI, Bragge et al. (2013) made five primary recommendations:

1. *Conduct an initial screen and risk assessment* of social and care support, daily living function, falls history, mental state, medications, etc.
2. *Consider on-going clinical and functional assessment, medical health, and physical, psychological and social functioning* when planning for discharge.
3. *Discharge should be coordinated by a designated person taking a multidisciplinary approach*, incorporating case conferences, identification of discharge destination, referrals for support services, transfer to community providers, provision of equipment, education and training of carers, and medication management.
4. Discharge should *incorporate engagement and education of patients and carers, produce a discharge summary*, assemble information on suitable contacts to manage complex needs, arrange transport, and *complete a patient checklist to confirm the patient's understanding of the discharge plan*.
5. *Conduct a post discharge follow-up* with communication between institutions and individuals involved in the transfer of care responsibilities.

The Summer Foundation conducted a series of multidisciplinary forums to produce a set of recommendations for discharge planning for young people with disability in the context of the NDIS (Larwill, 2017). Several of these recommendations related to steps that should be undertaken as part of a comprehensive discharge process, including:

- *Early commencement of discharge planning*, ensuring that the person is supported to begin setting goals from the initial stages of their admission
- *Improved mechanisms to more quickly identify individuals likely to qualify for support from the NDIS*, and commencement of the relevant administrative processes as early as possible
- Ensuring that *family members and caregivers are supported to take part in discharge planning meetings*

Alongside this, forum participants also made a series of recommendations about actions to improve discharge experience for individuals in this group more generally. These recommendations included:

- The use of *interagency coordinators* (liaison) to build cooperation and communication between sectors
- *Targeted education and training for health and allied health personnel* and others about the post-discharge needs of people in this cohort, supported by the development of clear step-by-step manuals for on-going reference
- *Streamlined NDIA processes*
- *Increased access to temporary age-appropriate transition care programs* to allow additional time to complete processes for discharge location without a need to occupy a high-care hospital bed
- *Greater flexibility and increased emphasis on patient dignity* from hospital staff

Finally, in a Delphi study, Yam and colleagues (2012) described a new discharge planning process for trial in Hong Hong's health system. The core elements were a *screening test and care plan completed within 24 hours of admission*, followed by social support services. Next, equipment and transport were to be organised for a return to community on discharge. A *discharge summary* was to be provided to the patient and accommodation facilities within 48 hours of discharge, and to outpatient clinics within a week. No subsequent evaluation of the implementation of this process was identified.

## 4.2 ENGAGING A DEDICATED DISCHARGE PLANNING OFFICER TO SUPPORT TRANSITIONS AND ENSURE CONTINUITY OF CARE

Several relevant studies have described the potential role of a dedicated discharge planning officer to support the transition from hospital to community and improve discharge success, especially where individuals have more complex support needs (Burke et al., 2014; Houghton et al., 1996; Mennuni et al., 2017). The advantages of a dedicated discharge officer are many, and may include improved discharge planning processes, fewer problems experienced by patients after discharge, better communication with community-based services and improved patient satisfaction (Houghton et al., 1996; Mennuni et al., 2017; Tabanejad et al., 2014). Further, research suggests that patients prefer a transition process where responsibility is clear and unambiguous, regardless of who is formally allocated the responsibility (Hesselink et al., 2012). The discharge planning officer may have specialist knowledge and skills in discharge needs or community services and referrals, be a specialist in establishing linkages between the hospital and community-based providers, or have expertise as a case manager who focusses on the patient from admission to discharge, ensuring the earliest possible timely discharge (Yam et al., 2012).

Finn and colleagues (2011) reported on a randomised control trial in which a discharge facilitator was embedded in a clinical team for five months. This was compared with another team at the same hospital without a discharge facilitator. The discharge facilitator worked with the team to identify patients likely to be discharged within the next 1-3 days, scheduled follow-up tests and appointments, arranged their medication, contributed to discharge documentation, and acted as a contact for the patient following discharge. The intervention resulted in discharge documentation that was more complete and timely, and patients had a better understanding of their follow-up plans and reported greater satisfaction with the process.

Locally, two programs have trialled the use of a dedicated hospital-based discharge liaison officer to provide a direct link between the hospital and community following discharge for individuals with acquired brain disorders. The first of these programs is the BrainLink Community Liaison Program (BrainLink, 2018). Information about the program describes that the community liaison officer meets with the patient and their family, often over the course of several meetings during the person's inpatient stay, can link them with brain injury specific community-based services, and makes personal contact with the family after discharge. Unfortunately, there are no publicly available evaluations of the program.

Based on the BrainLink initiative, the Brain Injury Association of Tasmania trialled a 12-month Hospital Community Liaison Program primarily targeting the families of patients who had experienced a neurosurgery-related admission at Royal Hobart Hospital (BIAT, 2017). The liaison officer met with patients and family members face-to-face during their inpatient admission and followed up via telephone after discharge. As such, they aimed to provide a "single point of access" to support, information and education, as well as enable improved continuity of care (BIAT, 2017). The 10-month pilot involved 76 brain injury referrals (constituting 137 direct beneficiaries of the program when family members are included). An internal evaluation of the program suggested that the liaison officer provided a range of benefits for patients, families and health professionals. Qualitative data suggested that the continuing involvement of the liaison officer supported families to meet the new or changing needs of the person with brain injury, and reduce feelings of isolation and burden among caregivers. However, a rigorous external evaluation of the program was not completed and, despite its promising findings, the program did not continue beyond the pilot period.



## 4.3 FINDING INNOVATIVE SOLUTIONS TO IMPROVE THE FLOW OF INFORMATION ACROSS THE CARE CONTINUUM

The literature highlights several initiatives that have used innovative approaches to support the timely and effective flow of information across the discharge process. One specific example of an intervention targeted at people with disability is the A2D (Admission to Discharge: <http://a2d.healthcare/>) initiative (O'Connor et al., 2017). This intervention involves a folder in which a range of information about an individual with disability is recorded. The information is presented in a way that is easy to use by hospital staff, and contains medical information, contact details for carers, and information about the individual's personal likes and preferences, including their preferences around care. In doing so, this initiative helps to address the communication problems that people with disability are frequently reported to experience in hospital (see Iacono et al., 2014; Shakespeare et al., 2009; Sharby et al., 2015). This initiative is currently being evaluated in New South Wales. Preliminary analysis of 55 admissions shows a reduction in duplication of services, length of stay and in re-admissions (O'Connor et al., 2017). In the current context, if it was supported by an online element, A2D's potential may relate to its ability to provide a current record of care and reduce issues around the handover of information between providers. This aligns with recent recommendations that real-time communication between hospitals, post-acute and primary care providers gives the biggest opportunities to improve post-discharge support (NEJM, 2017; Rutherford et al, 2013).

In a related project that is currently underway, the Summer Foundation has developed a toolkit to assist people with disability to make their own videos to communicate their support needs and preferences to support workers engaged to support those needs (D'Cruz, Lawrence & Douglas, 2018). The impetus for this project is that cognitive and/or communication deficits can make providing instructions and feedback difficult and frustrating in the moment. A participant-led approach to video development has the potential to support initiatives such as the A2D, both to educate hospital staff and to assist the person to record their preferences around their transition back to home with support. This project will involve both process and outcome evaluations of this intervention, with the toolkit expected to be adapted in response to the findings.

## 4.4 ACTIVELY ENGAGING THE PERSON AND THEIR FAMILY IN ALL STAGES OF THE DISCHARGE PLANNING PROCESS

The following group of studies emphasises the need for discharge planning interventions to actively and continuously engage with people with disability and their caregivers. Research evidence suggests that involving families in the discharge planning process decreases rates of hospital re-admission, and results in shorter stays and greater patient satisfaction. Despite this, several studies highlight that patients and families could be better engaged in the process. For example, Luker and Grimmer-Somers (2009) investigated the post-discharge experiences of patients and their carers following stroke. Only 16% of participants reported that they had been involved in a formal family meeting to discuss discharge options, although 72% indicated they had been involved in informal discussions. In an Australian study, Bauer et al. (2011) focussed on the experiences of family members as carers of people with dementia after discharge. Respondents were generally negative in their views of the discharge planning process, which they found disorganised, ad hoc, and lacking in formality. They reported that discharge summaries were rare, as was communication in relation to the person's discharge timeline.

Paterson, Kieloch and Gmiterek (2001) interviewed eight individuals with TBI following discharge and members of their families about the information they received about post-discharge care and support for the person with TBI. All but one patient reported not receiving information about what to expect and were confused about prognosis, type and duration of services available following discharge. In contrast, staff insisted that all families and patients had participated in discussion while still in hospital, and all had been sent information to their homes. The authors suggest that hospital staff must consider the timing and complexity of the information they provide if they want it to be understood and retained. In their synthesis of qualitative studies exploring the experience of transition from the hospital to home setting following ABI, Piccenna and colleagues (2016) reported that every study they included reported criticism of the way information was provided to patients and families.

The literature also highlights that effective discharge process involves the person and their family members in the handover process as active participants (Philibert & Barach, 2012). Involving familial caregivers also increases satisfaction with discharge planning, improves continuity of care, and supports increased acceptance of the caregiving role (Bragstad et al., 2014). The discharge planning process should not just involve family members with respect to their role, but also give consideration to their needs as they relate to the patient – treating the patient as a system (Luxford et al., 2012) rather than an individual to surround with resources. For example, Grimmer and Moss (2001) found that anxiety at home spiked within the first week of discharge, but by two weeks after discharge concerns had decreased as health improved and strategies were developed and implemented to cope with changed living circumstances.

# 5. PRINCIPLES AND POTENTIAL INTERVENTIONS

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Discharge planning refers to the process of developing a discharge plan for a person before they leave hospital to improve the coordination of services post-discharge and reduce the likelihood of unplanned hospital re-admissions (Sheppard et al., 2004). Effective discharge planning processes may support health services to decrease the length of a person's hospital stay and reduce the number of delayed discharges, support individuals to increase their knowledge and capacity to manage their own condition/s, and improve patient satisfaction and outcomes. However, evidence for the effectiveness of discharge planning is mixed, despite hundreds of evaluative studies over several decades.

Compared to the general population, young adults with disability and complex care needs are more likely to be admitted to hospital more often, and more likely to have longer hospital stays. Yet, this cohort has not been the direct focus of any published discharge planning trials. As such, the discharge planning interventions considered in this review may not be directly applicable to the needs of this cohort. However, there are several common components of effective discharge planning processes evident in the literature, and these may inform the development of an intervention designed to improve the timeliness of discharge for young people with complex support needs and increase the likelihood of discharge to the community rather than to RAC.

The suggestions for change are organised here under a set of guiding principles – how an initiative should be designed – and a complementary set of specific recommendations – what should be done, or how the principles can be implemented.

## 5.1 SUGGESTED DISCHARGE PLANNING PRINCIPLES

Based on the findings of this review, it is recommended that the following principles underpin the development of any future discharge planning interventions for young people with severe disability at risk of poor outcomes and/or delays in discharge:

- **Early start** within 24-48 hours of admission
- **Expertly coordinated** health and disability knowledge
- **Person-centred** engaged in discussions and decisions
- **Family-focussed** actively involved
- **Communication** 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

## 5.2 INTERVENTIONS FOR CONSIDERATION

Based on the findings of this review, several possible interventions could be considered. If any of these interventions are adopted, it is recommended that a rigorous evaluation process be conducted and made publicly available to ensure that successes, failures and any lessons learnt can be shared and built on in future trials.

Possible intervention for consideration:

1. **Early screening tool to identify and assess risks of complex cohort:** Research evidence suggests that discharge planning should start as early as possible in a person's admission, ideally within 24-48 hours. For young people with complex support needs, it is arguably even more critical that potential issues around discharge are identified early, to ensure the maximum amount of time to make appropriate referrals, engage with funding agencies, and consider and develop innovative solutions. As such, one suggested intervention relates to the development and trial of an initial screening tool. Such a tool may include assessment of and risks associated with the person's social support network, likely discharge destination, need for complex/intensive discharge planning support, and likely eligibility for the NDIS.
2. **Early support coordination starting in hospital and on-going:** Across the literature, there is emerging evidence to support the role that specialist discharge planners can play in supporting a successful transition from hospital to home. Such a person would take a multidisciplinary approach and have expert knowledge of the health and disability interface. Their role could include tasks such as organising and facilitating patient-centred discharge planning meetings, identifying discharge destination, undertaking referrals for support services, supporting the person's transfer to community providers, and undertaking education and training for carers.
3. **Tools to support timely information exchange:** It is evident that the effective and timely handover of information over the course of a person's discharge continues to provide a significant pressure point. The development and evaluation of tools are needed to improve the real-time handover of care information and ensure that this information reflects the choices and preferences of the patient.
4. **Post-discharge follow-up to measure outcomes and improve processes:** The findings of this review indicate that a structured post-discharge follow-up involving communication between institutions and individuals involved in the process may support enhanced discharge outcomes. It is recommended that future interventions incorporate a structured post-transition follow-up program to ensure that the changing needs of the person are met, and post-discharge issues comprehensively documented.
5. **Discharge planning community of practice:** It is evident that while several local initiatives have been undertaken, their findings have not been widely disseminated. If further initiatives are planned, it is recommended that their details and findings are made available to others, for example via an open network clearing house. Such an initiative could be supported by semi-regular practice-focussed gatherings, which may also have the potential to support the dissemination of NDIS-related updates, trends and changes to processes and rules. Such a network also has the potential to encourage further collaboration and cooperation between interested sectors and the NDIA.

In conclusion, while this review has identified some interventions that may be useful in reducing the number of young people admitted to RAC, there is limited empirical evidence regarding their efficacy. Alongside these interventions, an improvement in the interface between health and the disability service systems and improved provision of timely supports, equipment and home modifications will enable some people to return home and avoid RAC. However, people with severe disability and complex support needs who do not have stable housing or social support are likely to continue to be admitted to RAC until there is a dramatic increase in the supply of affordable and accessible housing throughout Australia.

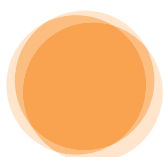
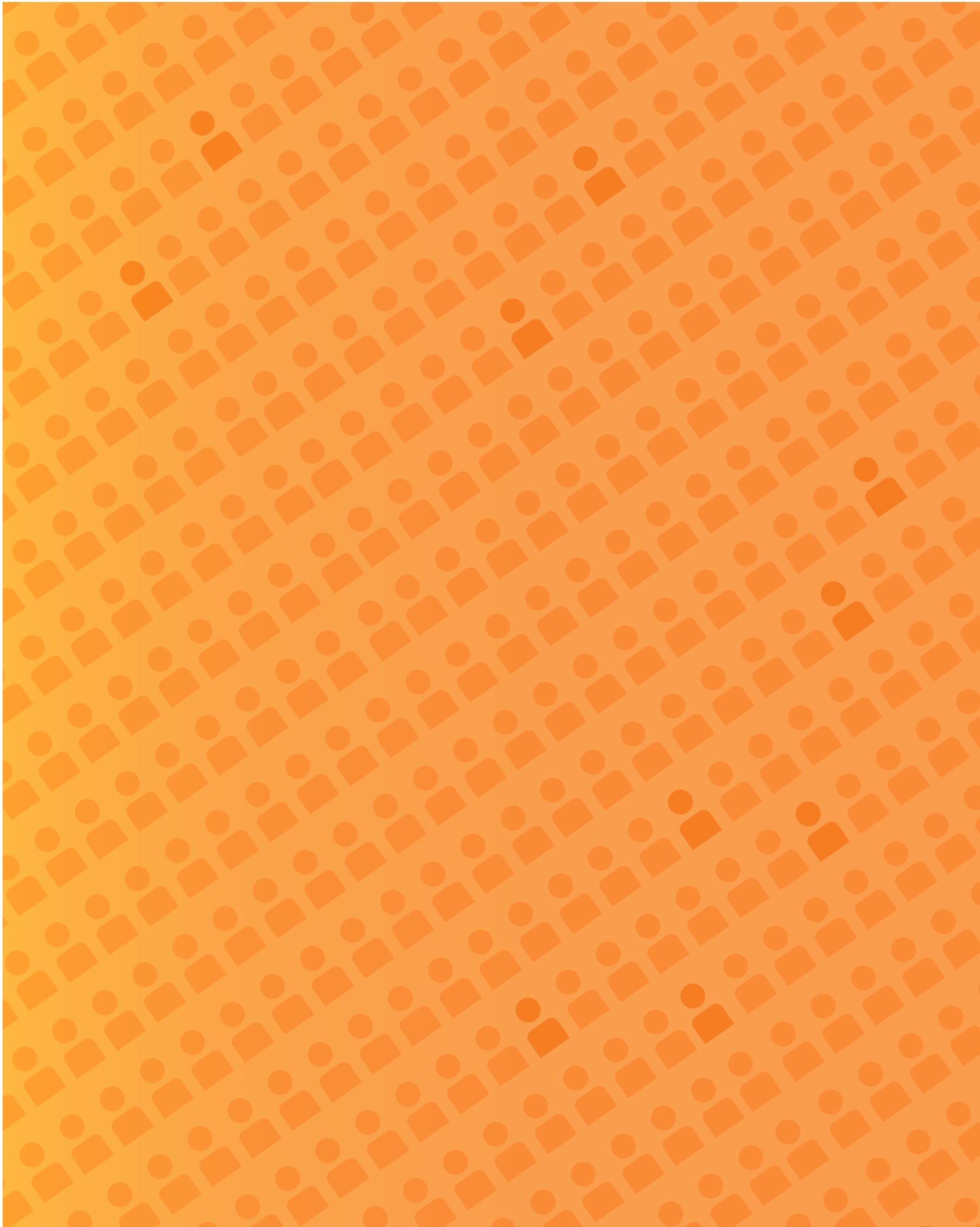
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