Supporting alternate level of care (ALC) patients with a dual diagnosis to transition from hospital to home

Practice guidance

September 6, 2023

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camh
mental health is health

HCARDD Health Care Access Research and Developmental Disabilities

"

You need to believe in yourself that you can do it. **Have confidence in yourself, because it can be really hard.**

- *Former ALC patient*

"

The quotes included in this report are from our consultations with key informants; to protect their privacy, we have removed identifiers and used pseudonyms in place of real names.

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H-CARDD Program

The Health Care Access Research and Developmental Disabilities Program (H-CARDD) focuses on identifying and addressing challenges that adults with developmental disabilities have accessing their health care through research and collaborative innovations.

Provincial System Support Program

The Provincial System Support Program (PSSP) works with communities, service providers, government and system partners, including Ontario Health's Mental Health and Addictions Centre of Excellence, to move evidence to action and create sustainable change in Ontario's mental health and addictions system. With expertise in implementation, knowledge mobilization, evaluation, equity, lived experience engagement and data management, PSSP is on the ground across the province, collaborating with a wide variety of health and social care partners, to build a stronger, more equitable and more accessible mental health and substance use care system.

Azrieli Adult Neurodevelopmental Centre

The Azrieli Adult Neurodevelopmental Centre is the first research and education centre in Canada dedicated to improving care for adults with neurodevelopmental disabilities and mental health challenges. The Centre includes several scientists who work closely with trainees, and patient and family advisors to study and develop ways to improve the mental health of this population. The Azrieli Centre is committed to improving outcomes for a population that has slipped through the cracks for far too long.

PSSP and the Azrieli Adult Neurodevelopmental Centre are located at the Centre for Addiction and Mental Health (CAMH), the largest mental health hospital in Canada and a world leader in mental health and addiction research.

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Expert Review Panel

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NOTE: This report has been revised as of February 2024 to incorporate newly available resources.

Contents

Transition principles

- **A hospital is not a person's home**. People should be transitioned out of hospital into an appropriate community setting as soon as they no longer need hospital care.
- Adults with a dual diagnosis have the same rights as other Ontarians to be **treated with dignity and respect and to receive high quality care** while in hospital, during the transition period and while living in the community.
- **A successful transition is a process not an event**. Transition planning should begin at (or before) admission and include a graduated transition to community with a period of coordinated, overlapping care provided by both the hospital and community teams.
- **Transition planning should be person-centred, culturally sensitive and trauma-informed**. It should begin by understanding what the person, and those who know them best, think is most important to support a successful life in the community and live as independently as possible.
- **A successful transition requires clear, consistent communication and coordination** among the patient, their family and their hospital, community health, mental health and developmental services providers.
- **Health equity, anti-racism and anti-oppression should be foundational to all aspects of care**, including transitions, with particular attention to ensuring equitable access, positive service experiences and optimal outcomes for diverse individuals living with a dual diagnosis.
- A successful transition should not rely on patient, family or staff advocacy. **A standardized process is needed to ensure equitable access for all patients**, particularly for individuals facing intersecting forms of marginalization.

Transition core components: Overview

1. Ongoing information sharing

There is a process in place to support ongoing communication and information sharing between everyone involved in planning and supporting the transition. Communication begins at (or before) admission and continues throughout the patient's hospital stay and the transition period.

2. Comprehensive assessment

Patients receive a developmentally informed comprehensive assessment of their health care and support needs by trained providers, which is used to inform the transition plan and optimize the transition process. Ideally, this assessment is started early upon admission, and updated regularly throughout the hospital stay and the transition period.

3. Patient and family involvement in transition planning

A person-centred, family-centred and culturally appropriate approach is used throughout the transition process. The person transitioning from hospital to community, together with those that support and know them best, are involved in planning the transition and developing a written transition plan. The patient and family are also provided support to address any anxieties, concerns or trauma related to the hospital stay and/or transition process.

4. Patient, family and community provider education, training and support

Before transitioning from hospital, the patient, their family, and the health care and developmental services providers who will be supporting them in the community are provided the information and training they need to manage the patient's physical and mental health care needs. This includes spending time with the clinical team and the patient in hospital to observe and learn these skills.

5. Transition and Community Support Plan

A written Transition and Community Support Plan is developed that identifies the most appropriate housing, developmental services and health care supports necessary for the person to live successfully in the community and outlines a graduated transition process. Transition planning begins when the person is admitted to hospital and the plan is updated regularly throughout their stay and the transition period.

6. Graduated, overlapping and coordinated transition

An identified lead from the hospital and an identified lead from the community work closely with the patient, their family, their hospital team and their community health and developmental service providers to support a graduated, coordinated transition which includes a period of overlapping care.

7. Medication review and support

Patients have medication reviews at admission, before discharge and once they are in the community which include information regarding medication reconciliation, adherence and optimization. There is a plan in place for accessing medications in the community, ongoing medication monitoring and supporting medication administration.

8. Coordinated follow-up medical and clinical care

Appropriate health care is provided throughout the transition period and, prior to discharge, all necessary health care providers are identified and prepared to provide follow-up care in the community. All patients require a primary care provider and some may also require other providers such as psychiatrists, psychologists, behaviour therapists, social workers, nurses, occupational therapists and speech-language pathologists, as well as case coordination. For people with complex needs, a team-based approach is required.

9. Appropriate and timely housing and community support

Housing and community services are identified that meet the patient’s needs and preferences, promote a sense of belonging, and support them to feel safe and comfortable. Considerations include proximity to family, services and community; the physical environment; other residents; cultural appropriateness; and staff supports.

10. Sufficient and flexible funding

Dedicated funding is in place to support the transition period and to provide the necessary community housing and services to help individuals thrive and prevent re-hospitalization. Funding packages have flexibility to adapt to the complex and evolving needs of the individual.

Introduction

Ontario is currently in the midst of a hospital crisis. Hospitals were already facing severe bed shortages prior to the COVID-19 pandemic[1], and a combination of factors, including staff shortages, delayed care due to COVID and access issues across the health system, has made it even more challenging to meet the need for hospital care.[2] Amid this crisis, there is renewed focus on addressing alternate level of care (ALC) patients. Patients are designated ALC when they no longer require the level of care provided in that setting.[3] Often this occurs because there is no appropriate setting with the necessary supports for them to be discharged to, and they end up staying in hospital beds that are not appropriate for them. These beds could be used to provide critical care to other patients.

People with developmental disabilities are particularly vulnerable to becoming ALC patients. A recent study found that inpatients with developmental disabilities are 6.5 times more likely to end up ALC, compared to inpatients without developmental disabilities (4.6% vs. 0.7%).[4] Almost half of people with developmental disabilities also have a psychiatric condition.[5] This is commonly referred to as a dual diagnosis. People with a dual diagnosis often have complex needs, including co-occurring physical disabilities and chronic health conditions,[6] and are even more likely to become ALC.[4] When compared to inpatients with a psychiatric condition only, inpatients with dual diagnosis are five times more likely to be designated ALC (6.1% vs 1.2%).[4] Having a dual diagnosis has also been found to be associated with having lengthy ALC stays (over 90 days).[7] In some cases, patients spend years stuck in the hospital.

Hospitals are intended to provide acute care to individuals who require medical attention. For people who are in medical, psychiatric or emotional distress, it is important that they can receive this intensive care. Once these challenges are resolved or stabilized, however, the hospital is not the appropriate place for people to live. Extended hospital stays can lead to various negative outcomes, including risks of hospital-acquired infections, physical deterioration, loss of skills and independence, and loss of important relationships.[8,9] Hospitals often lack privacy, opportunities for social engagement and the ability to exercise choice and autonomy.[8,9] They can also be noisy, chaotic and full of bright lights that can be distressing for patients with sensory sensitivities and lead to further deterioration.[10,11]

Keeping ALC patients in hospital reduces the number of beds available to other patients who need them. This leads to treatment delays, added burden on community resources, poor health outcomes for patients experiencing treatment delays, and contributes to staff workload and burnout.[8]

In Ontario, much of the discussion on ALC is focused on older adults who comprise a large portion of ALC patients.[12] While many of these same considerations are relevant for people with a dual diagnosis, there are some important differences. People with developmental disabilities are much more likely to become ALC patients at a younger age. Among adults under the age of 50, those with developmental disabilities are 12 times more likely to be ALC[4] and, because of their age, they may need different supports and considerations for discharge. For example, a long-term care home is less likely to be the appropriate destination for younger ALC patients. Additionally, finding appropriate community supports for people with developmental disabilities will most likely require the involvement of developmental services funded by the Ministry of Children, Community and Social Services (MCCSS).

The issue of people with developmental disabilities being inappropriately housed in hospital was highlighted in the 2016 Ontario Ombudsman report *Nowhere to Turn*.[13] Recently, the Ontario Ombudsman announced a new investigation focused specifically on this issue.[14]

Though many barriers still exist, in the process of writing this report we heard numerous examples of successful transitions. In these cases, dedicated and compassionate staff from hospitals and community settings came together to overcome hurdles and support people with a dual diagnosis to transition from living in a hospital to living in a home. We heard stories of people who had been living in hospital for many years and are now flourishing in the right environments with the right supports. Drawing from these experiences, as well as evidence from other jurisdictions, this report presents a set of principles and core components that outline how to support successful transitions for people with a dual diagnosis.

Purpose

This report identifies principles and core components that are necessary to successfully transition adults with a dual diagnosis out of hospital and into the community. We focused specifically on the needs of ALC patients with a dual diagnosis, a group that can be particularly difficult to successfully transition. However, many of these practices are also relevant for other populations, including adults with developmental disabilities who have complex medical needs or who present with distressed behaviours for other reasons unrelated to psychiatric issues.

Approach

This work was undertaken by a multi-disciplinary team with extensive experience working at the intersection of health and developmental services. Our team included a psychologist, occupational therapist, psychiatrist and social worker, as well as researchers and individuals with expertise in engagement and equity.

First, we conducted an environmental scan of the academic and grey literature on how to successfully transition ALC patients with a dual diagnosis out of hospital. Since the literature was limited, we also reviewed selected documents related to ALC more broadly. During the initial literature review, it became evident that many of the best practices for transitioning ALC patients with a dual diagnosis were already reflected in the Ontario Health Quality Standards on *Transitions Between Hospital and Home.*[15] Therefore, we used this document as the framework for our approach.

Based on key documents identified in our literature review (see **Appendix A**), our team developed preliminary transition principles and adapted the original Quality Standards into tailored core components specific to this patient population. For a comparison of the original Ontario Health Quality Standards and the adapted core components included in this report, see **Appendix B**.

Second, we conducted consultations with key stakeholders in Ontario to learn about their experiences with ALC transitions and to gather feedback on the preliminary transition principles and core components. During our consultation process, we spoke with over 100 people located across Ontario from diverse sectors, including specialty psychiatric hospitals, general hospitals, community health and developmental services. Within these sectors, we spoke with individuals in leadership, planning and managerial roles, direct service providers (e.g., social workers, registered nurses, physicians, care coordinators, direct support professionals), researchers and trainees. We also spoke with people who had experienced an ALC hospitalization and their families. See **Table 1** for a detailed overview of consultation participants.

In addition, we received input from several standing provincial committees at different phases of the consultation process. These included the *Health Strategy and Engagement Working Group* of the Provincial Network on Developmental Services who shared their key concerns and experiences as developmental services agency leaders, the *Azrieli Caregiver Advisory* who focused on the needs of family caregivers, the *Azrieli Easy Read Task Group* who provided input as self-advocates on how to simplify the guidance for people with a dual diagnosis, and the *DD ALC Cross Sector Committee*, who provided input as representatives from the Ministry of Health (MOH), MCCSS and Ontario Health tasked with operationalizing transitions for this population on a regional level.

Based on consultation feedback, our team revised and finalized the transition principles and core components and developed an initial draft report.

Table 1

Consultation Participants

Stakeholder groups	**Total sessions (N=50)**	**Total participants (N=106)**
Specialty psychiatric hospitals (including forensic, dual diagnosis and general psychiatric units)	12	23
General hospitals (including academic hospitals, community hospitals and reactivation centres)	4	7
Developmental sector (including Community Networks of Specialized Care, Developmental Services Ontario and developmental service agencies)	18	54
Community mental health agencies	2	3
Research groups	2	3
Adults with a dual diagnosis who have been ALC	4	4*
Family members of adults with a dual diagnosis who have been ALC	8	12
Regional representation		
GTA region	17	33
East region	15	30
Central region	4	9
West region	8	14
North region	6	20

*In three cases, the person was accompanied by a support person who helped facilitate the conversation.

Finally, we engaged a multi-sectoral expert review panel comprised of representatives from across the province, most of whom had also participated in our initial consultation process. This panel reviewed a draft version of this report to ensure accuracy, completeness, relevance and clarity. They provided written feedback, which our research team reviewed and collated. Subsequently, we conducted a meeting with panel members to discuss their recommendations and resolve any differing perspectives. Their feedback and insights were incorporated into the final version of the report.

This work was conducted between Fall 2022 and Spring 2023.

The final report contains seven transition principles and ten core components. For each core component, we provide:

- an overview of the practices that should be in place related to the component
- a rationale for why the component is important
- implications for patients and families, hospital teams, community health and developmental service providers, and community health and developmental service planners
- relevant existing tools and resources.

Important notes

Patients with a dual diagnosis may be ALC in various hospital settings, including dedicated dual diagnosis units, forensic mental health units, other units in specialty psychiatric hospitals, psychiatric or medical units in general hospitals, dedicated ALC units or reactivation centres. The type and level of resources available vary widely across different settings and regions in the province. The transition principles and core components identified in this report represent best practices that should be applied universally to all patients; however, we acknowledge that some settings may currently lack the necessary resources to fully implement all elements.

In alignment with the *Transitions Between Hospital and Home* Quality Standard, we use the term “transition” instead of “discharge” in this report to refer to the process by which a patient leaves the hospital. Discharge refers to a specific moment when the person physically leaves the hospital. It would be a mistake to focus on this moment alone. A successful move to the community requires a broader transition process, which includes the period of planning and preparation before discharge and the period after discharge when the person, and the people who support them, adjust to living in the community.

This report is focused on the ALC experiences of adults with a dual diagnosis. Although many of the components have relevance for children and youth, our consultations were centred on the adult patient population. Consequently, many of the Ontario-specific health and developmental services referenced in this report are only available to people aged 18 years and above. There are separate services and structures in place for children and youth and there are other sectors, such as education, that would be important to include in the planning process. Additionally, children’s health care services tend to involve families in a different way than adult-based health care services.

Key definitions

Alternate level of care (ALC) → This is a term used in hospitals to describe patients who no longer require the level of care provided in that setting.[3] Typically, patients are labelled as ALC because there is nowhere appropriate for them to be discharged to, so they remain in hospital. This term may be used in other settings to describe patients who are there inappropriately, such as a young person with Down syndrome living in a long-term care home or a person with a dual diagnosis who has completed treatment in a transitional treatment home. This report focuses on ALC patients in the hospital.

Capacity for decision-making and consent → Many people with developmental disabilities can have capacity for decision-making if provided with accommodations and supports. Decision-making capacity is not static but can change over time, based on the complexity of the decision or how the conversation is supported.[16,17] People might have capacity to consent for some decisions but not others. Health care providers should support patients to be included as much as possible in decision-making. This is sometimes called supported decision-making.[16,18] This may mean involving people who know the person well, using simple language and repetition, using pictures and visual aids, having the discussion at time or in a space where the person is comfortable, or involving a speech-language pathologist for additional communication strategies. For decisions where it is deemed the person does not have capacity to consent, consent must be provided by their substitute decision-maker. Consent to share information with other members of the person's health care team (i.e., their circle of care) may be implied.[19] **Throughout this document when it is recommended that information be shared with anyone outside the circle of care (e.g., family or developmental service providers), it is based on the assumption that explicit consent has been provided.**

Community health and developmental service provider → This refers to the people who will provide ongoing support in the community following discharge. It includes health care providers outside the hospital inpatient unit who offer in-home and community-based care (e.g., primary care providers, personal support workers, psychiatrists, other specialist physicians, psychologists, behaviour therapists, social workers, nurses, occupational therapists, speech-language pathologists) and developmental service providers (e.g., direct support professionals, day programs, vocational support programs) funded within the developmental sector.

Community Networks of Specialized Care (CNSC) → The CNSCs provide direct complex coordination to adults with developmental disabilities with high support and complex care needs, including linking specialized services and professionals to collaborate and develop complex support plans. The CNSCs have geographic teams throughout Ontario and are housed in local MCCSS-funded developmental service agencies. Their services are typically accessed via referral to Developmental Services Ontario (see below). CNSC services vary by region but generally include complex support coordination, health care facilitation, capacity building within local agencies and dual diagnosis justice case management.

Developmental Services Ontario (DSO) → DSO is the access point for all adult developmental services in Ontario that are funded by the MCCSS. To access developmental services in Ontario, a person must first demonstrate eligibility (confirmation of a developmental disability). If eligible, their support needs are assessed by the DSO and they are referred for services through one or more developmental service agencies which offer housing supports, specialized supports (e.g., case management, behavioural services, person-directed planning), community participation supports, caregiver respite supports and funding programs. There are long wait times for some services, so it is important to ensure patients are connected with the DSO as early as possible.

Developmental disabilities → According to Ontario legislation, developmental disabilities is defined as including people who have "significant limitations in cognitive functioning and adaptive functioning and those limitations, (a) originated before the person reached 18 years of age; (b) are likely to be life-long in nature; and (c) affect areas of major life activity, such as personal care, language skills or learning abilities, the capacity to live independently as an adult or any other prescribed activity."[20] This includes, for example, individuals with an intellectual disability, autism, Down syndrome and fetal alcohol spectrum disorder (FASD). There are some conditions, such as autism and FASD where a person may or may not meet the above criteria outlined in the provincial legislation, depending on the degree of limitations exhibited. Someone may meet criteria for a developmental disability according to the Ontario Disability Supports Program (ODSP) or child-based programs, but not to adult-based services supported by the DSO. This is because different sectors and programs have slightly different definitions.

Direct support professional (DSP) → DSPs are trained staff who work directly with people with developmental disabilities. Sometimes they are called direct support staff or developmental service workers (DSWs). They provide similar support to what is offered by personal support workers (PSWs) but there are important differences. The college-level DSW diploma is a two year program whereas college-level PSW training is typically less than one year. In DSW training, there is greater emphasis on developmental disabilities, as opposed to disability generally, and ways to support someone to be included in their community.

Dual diagnosis → According to the 2008 Dual Diagnosis Joint Policy Guidelines, this refers to individuals who have "both a developmental disability and mental health needs".[21] It is recognized that diagnosing psychiatric disorders in some people with developmental disabilities can be challenging, particularly when they have limited verbal communication.

Family → The term "family" is used broadly in this report to include family members, significant others, friends or other unpaid people who the patient defines as their family. Most of the patients addressed in this document rely on a support person and it is very important that whenever possible these individuals are included in transition planning. **In cases when the patient has capacity to provide consent concerning their health care, consent must be obtained before engaging with the family member. Throughout this document, the recommendation to include family is based on the assumption that the patient has provided consent.**

Family-centred care → Family-centred care recognizes the central role that families can play in supporting the patient. Family-centred care means ensuring that family members, as defined by the patient and with consent, are included in planning and decision-making related to the patient's care. It also means considering the care families need to support their own wellness and ongoing ability to support the patient (see also person-centred care).[22,23]

Forensic mental health system → There are ten designated hospitals in Ontario that include forensic inpatient mental health units. These units contain individuals, including people with a dual diagnosis, who have been charged with a crime but deemed unfit to stand trial or not criminally responsible. People who have been declared unfit to stand trial or not criminally responsible are under the authority of the Ontario Review Board (ORB). The ORB conducts regular reviews to determine if the person should remain in hospital or if they should receive a conditional or absolute discharge. Individuals in these hospital units can become ALC if they receive a conditional or absolute discharge but there is no appropriate discharge setting. A conditional discharge means that the person can live in the community, but they continue to be under the supervision of the designated hospital. This means that once they transition to the community, the forensic team continues to be responsible for providing care until an absolute discharge is granted by the ORB.

Health and developmental service planner ⟶ This refers to individuals in government and other system planning bodies who make decisions on how health and developmental services are organized and funded. Transitions from hospital to home for people with a dual diagnosis usually require involvement from multiple sectors. Key planning and/or funding bodies include the MOH, MCCSS, Ministry of Long-Term Care, Ontario Health and Ontario Health Teams.

Hospital team ⟶ This refers to the team of health care providers who provide support to the patient while they are on the inpatient unit. This may include nurses, social workers, psychiatrists, internist physicians, occupational therapists, speech-language pathologists, behaviour therapists, psychologists, neurologists, geriatricians and other health care providers.

Ontario Disability Support Program (ODSP) ⟶ ODSP provides an income source for eligible adults (age 18 years and above) with disabilities in Ontario.

Passport Program ⟶ The Passport Program provides reimbursement to eligible individuals up to a set limit for certain fee-based services (e.g., recreational programming, skill development, support worker or respite services). The program is funded by MCCSS and can be accessed through the DSO once eligibility is confirmed.

Person-centred care ⟶ Person-centred or patient-centred care means that planning and decisions regarding care are made collaboratively with the person based on consideration of their individual needs and preferences. Additional time and support may be required to ensure the person can be meaningfully included in the planning and decision-making process. For people with developmental disabilities, person-centred care often requires close collaboration with family members (see also family-centered care).[17,24]

Service Solutions ⟶ Accessed through the DSO, Service Solutions is a process for long-term support planning for individuals with complex needs. They are typically involved when existing resources are unable to provide services or are deemed inappropriate to mitigate risks, there are barriers to accessing the required support due to system gaps, and/or the individual is part of priority target group.

Substitute decision-maker ⟶ In cases when a person lacks capacity to provide consent for their health care decisions, a substitute decision-maker is required. This person is often a family member or when family is not available, this service may be through the Ontario Office of the Public Guardian and Trustee. The Ontario Health Care Consent Act[25] provides specific guidance about who can be the substitute decision-maker.

Transition period ⟶ This document uses the term “transition period” to include the periods before, during and after hospital discharge where additional planning and resources are needed to support the individual to live successfully in the community. The length of the transition period is unique to each individual.

Transition coordinator ⟶ The transition planning process should be led by clearly identified individuals from the hospital and from the community who have responsibility for planning and supporting the transition. In this document, these individuals are referred to as “transition coordinators”. Depending on the availability and expertise of local staff, different types of staff may occupy this role. The hospital lead may be a designated discharge planner, a social worker or another member of staff. The community lead may be from a CNSC or they may be from the community agency who will provide housing.

Acronyms used in this report

ACT → Assertive Community Treatment

ALC → Alternate level of care

CNSC → Community Networks of Specialized Care

CTO → Community Treatment Order

DSO → Developmental Services Ontario

DSP → Direct support professional

FACT → Flexible Assertive Community Treatment

HELP → Health, environment, lived experiences and psychiatric disorders

MCCSS → Ministry of Children, Community and Social Services

MOH → Ministry of Health

ODSP → Ontario Disability Support Program

ORB → Ontario Review Board

SHEDD → Successful Housing Elements & Developmental Disabilities

Transition core components: The details

1 Ongoing information sharing

> "Lines of communication are number one – you have to be able to communicate with every partner – agencies, community – with the patient at the top of it. **Don't leave him out because this is his life.** Everything branches out from him."
>
> *– Family member of a former ALC patient*

There is a process in place to support ongoing information sharing and communication between everyone involved in planning and supporting the transition. This includes the patient, their family, the hospital team, community health care providers and developmental service providers. Communication begins at (or before) admission and continues throughout the person's stay in hospital and the transition period.

The transition coordinators (**see Component 6**) are responsible for developing (or updating) a communication plan that identifies:

- all individuals who need to be kept updated and included in discussions related to transition planning
    - *This includes the patient, their family, their hospital team and any community health and developmental service providers who will provide care following discharge.*
- the frequency and mechanism by which communication will be supported for each person or group (e.g., email, phone, virtual meetings, or in-person meetings) and any accommodations that may be needed to support participation (e.g., translation services, meeting outside of 9–5 hours)

Key points

- Ongoing communication is needed with everyone involved in transition planning.
- Think beyond the usual hospital and community-based health care providers. Developmental services may already be involved or should become involved.
- Communication needs to be adapted to make sure patients, and the people who support them, can be included.

- how communication with the patient can best be supported
    - *Some patients prefer verbal communication, while others prefer written communication or visual images. Some patients use augmentative and assistive communication devices, sign language or communicate with the support of a caregiver. Some patients are comfortable in group meetings and some prefer to have individual conversations. Some patients may prefer to meet virtually while others may prefer to meet face-to-face.*
- a central contact person that family and care providers involved in the transition can reach in case of questions or concerns
- the person/people who are responsible for updating and executing the communication plan and documenting meetings.

This plan should be updated throughout the person's hospital stay as the people who need to be included will likely change over time. For example, at admission it is important to obtain information from any former providers and new providers may become involved as community resources are identified to support care post-discharge.

To support transition planning and prevent miscommunications, a combination of communication mechanisms may be required. Regular meetings with all stakeholders should be incorporated into the plan. Meetings should be documented to support transparency and information sharing with anyone unable to attend.

Rationale

An interdisciplinary and cross sector team is needed to support a successful transition, particularly in more complex situations. Poor communication within the hospital team and between hospital and community providers, can lead to ill-informed transition plans, tension within teams and partnerships, and inconsistent communication with patients and families leading to confusion and mistrust.[26] Good communication is important to establish transparency, trust and understanding between hospital and community partners. Regular transition planning meetings including hospital and community providers can improve collaboration, relationships and successful planning.[26]

Information sharing initiatives, when they exist, often focus on staff and do not include patients and families.[27] Consequently, patients who are ALC and their families can find the experience confusing and unclear, including uncertainty regarding care in hospital, the transition process and who they can go to for answers.[8,9] Patients with developmental disabilities can experience additional communication barriers if the necessary accommodations are not provided (e.g., access to communication devices, opportunities for written communication, or including a support person) and if information is not shared in a way they can understand (e.g., using visuals, simplified language).[28]

Our consultations revealed that in many situations there was inconsistent communication with family and community providers while the patient was in hospital. Successful transitions included designated individuals who supported ongoing inclusive communication. This approach led to a smoother transition planning process and helped patients and families feel included, respected and confident in the process.

Implications for patients and families

- Your care team will talk to you often to make sure you understand the care you are receiving and the plan to help you leave the hospital. You will have lots of opportunities to ask questions. Your care team will also ask you who the important people are in your life that they should also talk to.
- Your care team will ask you and your family questions to help make sure they are providing the right care in hospital and they are organizing the right supports in the community for when you leave the hospital.
- Your care team will ask you how you like to communicate and the best way to talk with you. You might like talking with your voice or you may like writing, typing, using sign language or using pictures or symbols to help you communicate. You might also like having a family member or someone else who knows you well be part of the conversations to provide support.

Implications for hospital teams

- At (or before) admission, notify any community health and developmental service providers who are already connected to the patient about their admission to the hospital and anticipated length of stay. Additionally, collect relevant histories and contextual information from these providers. Note that developmental service providers are not included in the patient's circle of care and explicit consent is required for the hospital and developmental service providers to communicate with each other.
- Support regular communication with relevant community providers throughout the patient's stay in hospital and the transition period to keep them apprised of the person's status and support transition planning. If the person is not already connected to necessary community providers, appropriate providers should be identified and engaged in the planning process as soon as possible (**see Component 8 and Component 9**).

- Identify the hospital provider who will lead the transition process (referred to in this document as the transition coordinator; **see Component 6**). Together with a community transition coordinator, they should provide leadership in coordinating the transition process, including developing and implementing the communication plan.
- Determine how to best support communication with the patient so they can be included in all aspects of transition planning. This process can be supported by people who know the patient well (e.g., family members, community providers) and in some cases it may be helpful to consult with a speech-language pathologist to identify strategies to support communication.

Implications for community health and developmental service providers

- When a person is admitted to hospital, share all relevant information including health, mental health, behavioural and/or social history with the hospital team. To facilitate this process, it is recommended that the DSO and developmental service agencies have a routine process in place to obtain and update consents from all individuals they support to share information with hospitals in the event that they are hospitalized.
- Provide support to the person and their family, as required, to communicate effectively with hospital staff. Community health and developmental service providers should also clarify with hospital staff their role during hospitalization and establish a plan regarding frequency and duration of visits with the individual, availability to provide support and/or training to hospital staff regarding effective approaches and communication, and attendance at planning meetings.
- Identify the community provider who will lead the transition process (referred to in this document as the transition coordinator; **see Component 6**). Together with a hospital transition coordinator, they should provide leadership in coordinating the transition process, including developing and implementing the communication plan.

Implications for health and developmental service planners

- Ensure hospital providers have the necessary training and resources to adapt communication to be accessible and inclusive of people with a dual diagnosis.
- Implement standardized tools to share health information in developmental service agencies and train hospital staff on how to use these tools to ensure the right information is communicated to the hospital team.

- Ensure there are clear processes to support community health care providers, developmental service agencies and hospitals to communicate and share information. Ideally, all providers should have interoperable electronic information systems.

Tools and resources

- **About My Health** → This is a tool that can be filled out by people with developmental disabilities and the people who support them. It captures basic information about the individual, their medical history, key contact information, medications and helpful communication strategies.[29,30]
- **One Idea Per Line: A Guide to Making Easy Read Resources** → This is a guide created by the Autistic Self Advocates Network on how to create easy read resources. These are accessible resources intended for people with disabilities that use pictures and easy-to-understand language.[31]

2 Comprehensive assessment

> “We really can’t plan a good positive outcome in transition if we haven’t actually figured out what’s going on in the first place… **So we have to understand what’s going on medically, psychiatrically and then we can plan for the transition out**.”
>
> *– Hospital provider*

Patients receive a comprehensive assessment of their health care and developmental support needs to inform the transition plan and optimize the transition process. The assessment should be conducted by providers with the necessary training and expertise in dual diagnosis and use a strengths-based, culturally relevant, developmentally-informed and trauma-informed approach. Family members, community health providers, developmental service providers and other individuals who know the person should be included in the assessment process.

This assessment is started at admission to identify whether the person has a dual diagnosis (if unclear), inform care delivery, start transition planning and flag risks for transition challenges (i.e., becoming ALC). The assessment should be updated regularly throughout the hospital stay and transition period. Assessments should be conducted in-person and not based solely on clinical chart reviews. The person may have previous psychological, behavioural or functional assessments that are important to review but if the person has been hospitalized for a long time or if their functioning has changed, they should be updated.

Key points

- A trauma-informed approach is needed.
- Work with the DSO to see if the patient is eligible for services.
- Providers (e.g., psychologist) with dual diagnosis expertise may be needed to conduct some assessments.
- Collateral input from family and community providers is typically required to fully understand the patient’s history and current needs.

A comprehensive assessment should include:

- the person’s history, including physical health, mental health, family, social and trauma history
- status with the DSO, including whether the person has already connected with their local DSO, whether they have been confirmed eligible, and if they are currently receiving any MCCSS-funded services

  - *If they have not already connected with the DSO, this is an important first step.*
- current physical and mental health, developmental and social concerns, as well as any caregiver concerns
  - *For people with developmental disabilities, medical concerns and pain can appear as "psychiatric or behavioural" (see HELP Framework[32,33]).*
  - *Other presentations of distressed behaviour can be misattributed to the person's disability, and not recognized as a manifestation of an underlying psychiatric issue, especially when the clinicians lack expertise in developmental disabilities.*
  - *This is sometimes referred to as "diagnostic overshadowing" and prevents people from getting the care they need.*
- level of intellectual functioning and autism screening/assessment, including genetic screening if warranted, identification of sensory sensitivities, communication assessment, behaviour assessment and any necessary accommodations
  - *Prior assessments may be available (conducted when the individual was in school or through the DSO) but it may be important that elements are updated.*
- assessment of patient capacity and decision-making capabilities
  - *Capacity is decision-specific, can change over time and can be supported (see Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities tool[18]).*
- the person's ability to manage activities of daily living (e.g., personal care, walking) and instrumental activities of daily living (e.g., housework, preparing meals, shopping, managing medications)
- the person's housing, support and caregiver needs
  - *Consider whether the person's housing and supports prior to hospitalization meet current needs or if other solutions are required (**see Component 9**; see SHEDD tool[34]).*
- medication review, including information regarding medication reconciliation, adherence and optimization
  - *Often people with a dual diagnosis have a lengthy history of polypharmacy, inadequate follow-up or inconsistent reviews (**see Component 7**).*
- assessment of safety and risk factors, considering safety planning while in the hospital and upon return to community
- assessment for geriatric syndromes, including falls, immobility, delirium or dementia, polypharmacy, incontinence and end-of-life care
  - *People with developmental disabilities are at risk for geriatric syndromes at younger ages.*[35]

- nutrition needs and special dietary requirements
- names and contact information for the person's substitute decision-maker, community caregivers and other people in their social support circle.

Rationale

Identifying whether a person has a dual diagnosis is an important first step to ensure appropriate treatment and transition planning. In some cases, it is clear when a patient has a developmental disability but in other cases, such as those involving mild intellectual disability or autism, the diagnosis can be missed. Additionally, mental health issues may be overlooked or assumed to be a function of the disability.[36]

In order to support a successful transition and ensure the right services are in place, it is important to understand the person, their previous life experiences, what they want from their life and what supports they need.[10,37] Best practice guidelines recommend a comprehensive assessment that includes bio-medical issues, psychiatric problems, neuro-developmental influences, speech/language skills, functional behaviours, and environmental, emotional and sensory modulation difficulties.[38] Without the right assessments, too much focus may be given to behaviours without understanding what is causing an individual distress or how their needs are not being met.[10,37] It should be noted that people with developmental disabilities are disproportionately more likely to experience various forms of trauma in their lives and hospitalization itself can be extremely traumatizing.[39] Assessments and treatment should always use a trauma-informed approach.

Many ALC patients have been in hospital for a long time and prior assessments may be incomplete or out of date. It is also important that the person be reassessed after transition to the community as the person's needs may look different when no longer in a hospital setting, especially individuals who have been in hospital for a long time. If family is involved, it is important to assess their capacity as well to see whether additional training and/or support is needed to facilitate their ongoing involvement.

We heard in our consultations that hospitals sometimes lack the training to identify patients who may have a dual diagnosis and they do not always have access to, or recognize the need for, trained professionals (e.g., psychologists) to conduct specialized assessments. In some regions, hospitals noted that the developmental service sector is unable to provide in-hospital consultations until a specific discharge location is identified. This can lead to misunderstanding the individual and their needs, delays in getting the right services and providers involved, and poor transition planning. In situations where there was a comprehensive understanding of the patient's needs, it improved the planning process and provided valuable information relevant to setting up the new home and training staff to support the transition.

Implications for patients and families

- Your care team will ask you a lot of questions. This is called a comprehensive assessment. The people taking care of you in the hospital want to know as much information as possible about your health, any special assessments that have been completed, information about your home life and what you do every day.
- Your care team will also want to talk to your family and anyone else who helps take care of you so they have all the information needed to make sure you receive the best possible care while you are in the hospital and after you leave the hospital. You can tell the hospital who you want them to talk to and who you don't want them to talk to.

Implications for hospital teams

- Ensure a comprehensive assessment is completed and updated regularly during the person's hospital stay. Efforts should be made to identify patients at admission who are at risk of becoming ALC (e.g., if current housing is no longer appropriate or caregivers are no longer able to provide support) to support early planning.
- Contact the local DSO office as soon as patients with developmental disabilities (or suspected developmental disabilities) are at risk of being designated as ALC, if not sooner. The DSO serves as the central access point for MCCSS-funded adult developmental services and supports. If the person is already registered with the DSO, they will support a new and updated assessment of the person's developmental service and support needs. If the person is new to the DSO, the DSO will work with the patient and the hospital to confirm the person's eligibility for services and complete the application assessment. The DSO can also make connections with other relevant service providers such as the local CNSC who can support the transition process. Not everyone receiving ODSP funding is connected to their DSO and not everyone who receives ODSP is eligible for DSO supports. It is important to obtain patient consent to communicate with the DSO as part of standard hospital processes.
- Consult with clinicians with specialized expertise in dual diagnosis as necessary to conduct assessments. The necessary expertise may exist within the hospital, or it may require consultation with an external provider. Some individuals may already be connected with relevant clinicians, or the local CNSC can help locate someone with the appropriate expertise. Virtual technologies can support remote consultations with

providers across the province. Some individuals may have had previous specialized assessments that can be accessed with consent.

- When a patient with a dual diagnosis is designated as ALC, ensure they are coded as having a developmental disability in the Ontario Health Wait Time Information System to support system planning and response. The current system does not have a clear way to do this but "developmental requirements" can be identified under the *Specialized Needs and Supports* category and "Supportive Housing/Group Homes/Assisted Living Accommodation" can be selected under the *Discharge Destination* category.
- Given the high rate of trauma in this patient group, it is critical that a trauma-informed approach is used throughout assessment and treatment.

Implications for community health and developmental service providers

- Provide the hospital team all relevant prior assessment information and contextual information to inform the comprehensive assessment.
- Hospital providers may have little knowledge or experience with dual diagnosis so, if necessary, community providers should provide information on the developmental sector, unique patient needs and necessary accommodations, and how to access clinicians with dual diagnosis expertise.
- Update the comprehensive assessment after discharge from hospital as the person's needs may change once they are living in the community.

Implications for health and developmental service planners

- Identify or develop a standardized package of assessments that are required to be completed for all patients with a dual diagnosis while in hospital.
- Establish consistent protocols and augment funding where needed to ensure equitable and timely access for hospitals across the province to clinicians with specialized dual diagnosis expertise (e.g., psychologists, behaviour therapists, occupational therapists, speech-language pathologists and psychiatrists). This may require training existing hospital staff, hiring new staff or consulting with external experts. Establishing a point person within each hospital with specific expertise and knowledge of developmental disabilities can facilitate these linkages. Due to the shortage of providers trained in dual diagnosis, it is also necessary to develop increased training opportunities within health professional education programs.

- All health care providers should receive general training on identifying dual diagnosis patients and how to access the necessary specialized health and developmental services resources to provide quality care.
- Ensure data systems, including the Ontario Health Wait Time Information System, are set up to clearly flag patients with a dual diagnosis and hospital staff are properly trained to ensure data quality. Key developmental service providers (e.g., DSO, CNSCs) should have access to real-time data so they can proactively identify ALC patients and support transition planning. Further refinement of the data system to more accurately identify patients with dual diagnosis and their needs would improve capacity to respond to current needs and plan for the future.

Tools and resources

- **HELP with Emotional and Behavioural Concerns in Adults with Intellectual and Developmental Disabilities** → This tool helps providers understand four areas relating to biopsychosocial circumstances that might underlie or be contributing to emotional distress and behaviours of concern: Health, environment, lived experiences and psychiatric disorders (HELP).[32,33]
- **Successful Housing Elements & Developmental Disabilities (SHEDD) tool** → The SHEDD tool can be used to help people with developmental disabilities, and the people who provide them care and support, to plan for a home that is personalized, promotes a sense of belonging and is comfortable and safe. It promotes discussion of personal preferences and choices and suggests design ideas for the physical space of a home.[34]
- **Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities** → This tool provides practical guidance to support health care providers to meet their obligation to respect the decision-making rights of people with developmental disabilities.[18]
- **Communicate CARE** → This tip sheet offers guidance to providers on conducting a person-centred assessment of adults with developmental disabilities.[40]
- **Brief Family Distress Scale** → The Brief Family Distress Scale is a single item measure of crisis experienced by caregivers of individuals with developmental disabilities. It is available in English, Arabic, Indonesian, Macedonian and Turkish.[41,42]

3

Patient and family involvement in transition planning

"They should **respect** people." – *Former ALC patient*

A person-centred, family-centred and culturally appropriate approach is used throughout the transition process. The patient and those that support and know them best are involved in transition planning, decision-making and developing a written transition plan. If the patient has capacity, they must provide consent before involving family or other support people in their care.

Key points:

- With appropriate accommodations and support, patients can be involved in planning and decision-making.
- Family and other support people are often central to the patient's care and should be included whenever possible.

Patient and family inclusion requires active steps to support participation such as:

- using appropriately adapted communication to seek the patient's input and feedback (**see Component 1**)
    - *Depending on the person, this may include the use of assistive communication devices, sign language, visual aids and having someone (e.g., a family member) who knows the patient well support communication.*
- developing easy read versions of documents that use simple language and pictures
    - *All patient facing tools and forms must be compliant with the Accessibility for Ontarians with Disabilities Act*[43] *and adhere to the Ontario Patient's Bill of Rights.*[44]
- facilitating family participation by accommodating their availability and communication preferences
    - *For example, this may involve scheduling meetings outside of regular business hours, offering virtual options for those unable to travel or holding in-person meetings for those who struggle with technology.*
- offering language interpretation and French language health care and community services as required
    - *Note that even people who speak some English may benefit from interpreters for health care discussions that include more complex or unfamiliar medical language.*
- using approaches grounded in cultural safety and anti-racism.

- *Consider how the patient and their family's cultural background, intersectional identities and past experiences of care may impact how they understand or participate in care, as well as the biases and expectations the provider is bringing into the interaction.*[45,46]

The patient and family are also provided support to address any anxieties, concerns or trauma related to the experience in hospital, and the transition process.

Rationale

Patients and families are often excluded or insufficiently included in the transition process, causing them to feel confused, uninformed and disempowered.[7,9] Especially when a patient has been in hospital a long time, the patient and their family can be apprehensive about the transition and may be reluctant to accept placements.[7] Additionally, lack of patient and caregiver involvement in transition planning can lead to poor quality or inappropriate transition plans that do not adequately meet the needs of patients and their families and may lead to unsuccessful transitions.[7]

Patients and families have the right to accessible communication when receiving health care services in Ontario. The Ontario Human Rights Code[47] and the Accessibility for Ontarians with Disabilities Act[43] protect the rights of patients with disabilities to receive communication supports that are appropriate for their needs. The recent *Helping People Thrive Report* from the UK highlighted that successful person-centred planning means: "We really listen to what people want and/or what they are telling us with their actions or behaviour, we involve their families and people who know and love them, and we take a positive, creative problem-solving approach so that we can help people to take more control of their lives."[37]

Ontario is a diverse province comprised of individuals, families and communities with a wide range of backgrounds, identities and experiences. Some patients and families may have different ways of understanding disability and illness. They may also have experiences of exclusion, oppression and discrimination within health care settings. Effective inclusion should start by understanding patients and families within the context of their culture, intersectional identities and experiences of structural marginalization. Approaches to care grounded in principles of cultural safety and anti-racism can help reduce miscommunication, negative interactions and alienation from services.[45,46]

In our consultations, families spoke about the importance of recognizing and respecting their expertise, as well as offering opportunities for both patient and family input. Successful transitions often included the active involvement of patients and families in the decision-making and transition planning process, leading to the development of trust, confidence and comfort with the community placement.

Implications for patients and families

- You and your family should be involved in all planning and decisions about moving from the hospital to a home.
- Your involvement will help make sure that you move into a home that you like, you have the right people in your life to support you and you can do the things that make you happy, healthy and safe.

Implications for hospital teams

- The transition coordinators are responsible for ensuring that patients and families are involved in transition planning and decision-making.
- A patient who does not have capacity to consent to treatment can and should still be involved in the transition planning and decision-making process.
- For patients returning to a family home, consideration and planning with family members regarding their willingness, capacity and ability to provide the needed support is necessary, as well as establishing a plan to support the family (e.g., respite services, home care or family support groups).

> "[The hospital social worker] was great at keeping us in the loop. **He was the glue**. A critical person on the team keeping us informed. Instrumental."
>
> *– Family member of a former ALC patient*

Implications for community health and developmental service providers

- The transition coordinators are responsible for ensuring that patients and families are involved in transition planning and decision-making.
- Some hospital teams may have little expertise working with this population, in which case community providers should provide education on the importance of patient and family inclusion, and strategies to support inclusion.

Implications for health and developmental service planners

- Patient and family inclusion in planning and decision-making should be identified as a standard and required component of high quality care.
- Training should be provided to health care providers on the importance of patient and family inclusion, and strategies to support inclusive decision-making with people who have a dual diagnosis.

Tools and resources

- **Communicate CARE** → This tip sheet offers guidance to providers for conducting a person-centred assessment of adults with developmental disabilities.[40]
- **Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities** → This tool provides practical guidance to support health care providers to meet their obligation to respect the decision-making rights of people with developmental disabilities.[18]
- **Adaptive Functioning and Communication for Adults with Intellectual and Developmental Disabilities: Fact Sheet** → This fact sheet explains the different levels of intellectual functioning and corresponding adaptive functioning and communication of people with developmental disabilities. It can help health care providers understand and accommodate for patients' conceptual, social, practical and communication skills.[48]

4 Patient, family and community provider education, training and support

"When it comes to transition, **it's vital to consider the whole person**, including any dual diagnoses and address developmental aspects. **Education is key, both for the individuals and their families.**"

– Family member of a former ALC patient

Before leaving the hospital, the patient and the people who will be supporting them in the community are provided the information and training they need to manage the patient's physical and mental health care needs. Key support people may include family members, DSPs who provide daily support, and community health care providers (e.g., primary care provider, psychiatrist, other specialist physicians, psychologist, behaviour therapist, social worker, nurse, occupational therapist, speech-language pathologist).

Training should be tailored to the individual needs of the patient, family, DSPs and community health care providers and offered in accessible formats. This includes consideration of the patient's cognitive ability and the ways in which they communicate, cultural appropriateness and the language best understood by the patient and those supporting them.

Training may be provided in-person, virtually (i.e., by phone or video), through written plain language and though visual tools as appropriate. It may include information sharing and hands on skill practice (e.g., wheelchair transfers or medication administration). DSPs and other key community providers should spend time with the patient in hospital to observe, practice

Key points

- Often patients are not returning to a family home and DSPs will support their day-to-day care.
- DSPs are not trained health care providers, yet they often play an important role in supporting the health of individuals in the community. They need training to make sure they are prepared to take on this role.
- Primary care and other community health care providers usually don't have expertise in caring for people with a dual diagnosis. They also need training to make sure they are prepared to support these patients.

recommended approaches and learn from the hospital team. It may also be important for the patient to have opportunities to practise skills outside of the hospital.

Training should be provided before discharge and there should be ongoing opportunities for support and guidance if needed after discharge. Members of the hospital team may provide training or it may be necessary to bring in dual diagnosis specialist consultants and/or community providers who have specific knowledge of the individual and their needs. Key information should be included as part of the Transition and Community Support Plan (**see Component 5**).

Information and training may include (as relevant):

- information about the patient's diagnosis/diagnoses and what they mean for long-term treatment, symptoms, functioning and needed supports
- an overview of the patient's medications, including how to administer them, possible side effects to be aware of and how to access these medications in the community
- medical warning signs and symptoms to watch out for, including which signs and symptoms should prompt a call to a health care professional and which require a visit to the emergency department
- how to use any necessary medical equipment and devices
- risk management, de-escalation strategies and causes of distressed behaviours and how to respond
- important components of the patient's routine at home, including diet and physical activity
- resources to support families including family support services or groups, system navigators, peer supports, mental health services and respite care
- names and contact information for the health care providers who will be providing ongoing support in the community, including information about scheduled follow-up appointments
- if relevant, the ongoing role for the Ontario Review Board (ORB) and forensic mental health team.

Rationale

When a person is in hospital, they often have a comprehensive care team supporting their needs. Once they leave the hospital, the person, their family and their community providers need to take over many of these activities. This may require knowledge and skills that they do not already have. Families and developmental service providers often have very little health care knowledge[30,49] and community health care providers often have little knowledge of developmental disabilities.[50–52]

The need for more frequent and ongoing training for community providers was highlighted repeatedly in our consultations. Finding health care providers, including psychiatrists, with the necessary expertise to provide ongoing care was often a challenge. Sometimes a lone primary care provider with no support or experience in dual diagnosis was responsible for supporting an individual with complex health care needs. Even when psychiatrists were involved, they did not always have the necessary knowledge or experience with this population. Community agencies also reported that they are seeing individuals with more complex behavioural, substance use and mental health needs, and identified a need to build staff capacity in these areas. Lack of preparation and support sometimes led to agencies being reluctant to accept people with more complex needs.

The transition period after leaving the hospital can be challenging while both the person and their providers adjust. During our consultations, we learned that in some cases the hospital team provided ongoing support to the community providers. Often this was for forensic patients where hospitals retain ongoing responsibility. One developmental services agency shared that they are excited when they receive a forensic patient because they know they will be supported. In other cases, hospital policy did not permit their staff to provide any ongoing support post-discharge. Both hospital and community providers identified this as a barrier to successful transitions.

Our consultations highlighted a number of successful examples of training and support. In one case, the hospital brought in outside behaviour therapists to help prepare a patient for a community placement. In another case, community support workers were provided with access to the inpatient nursing staff post-discharge to provide support and answer questions. Staff reported that this made them feel more confident and willing to accept the person. It is critical that the patient, their family and their community providers receive proper training so that they are prepared to manage the patient’s care in the community, as well as ongoing support as needed.

Implications for patients and families

- Before you leave the hospital, your care team should help you and the people who support you learn how to manage your care at home. This might include:
    - the medications you need, how to take them and what they are for
    - strategies to help you feel better when you get upset, scared or overwhelmed
    - who you can call for help if there is a problem and when you need to go to the emergency department

  - the type of daily routine that will work best for you.
- Your care team will share this information in ways that you and the people who support you can understand. If you have new equipment like a wheelchair or a walker, you will get to practise using it. You might also leave the hospital for short periods of time so you can practice new skills.
- Your care team will include everything in your Transition and Community Support Plan to help you remember. They can use words or pictures or both depending on what is most helpful for you.

Implications for hospital teams

- The transition coordinators are responsible for ensuring the necessary education and training are provided to patients, families, DSPs and community health care providers.
- In planning and providing education and training, hospital staff must recognize that care approaches used in hospitals may need to be adjusted to community environments. The hospital team should collaborate with the developmental sector to ensure the training provided is relevant for community settings and does not rely on practices that cannot be replicated in the community (e.g., calling security). In some cases, it may be beneficial for members of the hospital team to visit the home the patient will be transitioned into to ensure training is appropriate for the care environment.
- Where appropriate, training for DSPs should include the opportunity to spend time in hospital to observe the hospital team and to practise any new skills they may need (e.g., supporting physical transfers, use of medical devices, communication strategies).
- DSPs are not health care professionals. If DSPs will be expected to administer a controlled act under the Regulated Health Professions Act[53] (e.g., enemas, inhalants, insulin or catheterization), there are specific requirements for the circumstances under which it is permitted and they must receive training from a health care professional to do so.
- Patients should receive support as needed to acquire, retain and improve skills to prepare for transition into the community (e.g., use of medical devices, physical transfers, self-care, communication, car safety). Where appropriate, particularly in lengthy hospitalizations, the patient should be supported to engage in community activities while hospitalized. This can help maintain and develop skills, as well as identify challenges and supports required for transition.

- Key members of the hospital team should be available as needed to provide support and guidance to community health and developmental service providers for a defined period of time after the person is discharged while they adjust to their new environment. In some cases, the hospital team may continue to deliver clinical services and care beyond consultative support (**see Component 6**).

> "…**that education piece is huge and you can't just do it once because there's turnover in this population for staffing and resources**… education benefits not only our clients, but staff can use it to help other clients in the home…"
>
> *– Hospital provider*

Implications for community health and developmental service providers

- The transition coordinators are responsible for ensuring the necessary education and training are provided to patients, families, DSPs and community health care providers.
- Before discharge, DSPs, community health care providers and other key providers who will be supporting the person in the community should ensure they feel sufficiently knowledgeable and skilled to support the individual, including their physical health, mental health, and sensory and functional needs.
- Note that if DSPs will be expected to administer a controlled act under the Regulated Health Professions Act[53] (e.g., enemas, inhalants, insulin administration or catheterization), there are specific requirements for the circumstances under which it is permitted, and they must receive training from a health care professional. Training may be from a member of the hospital team, a home care nurse or from an agency that offers this service. If there are future staffing changes, any new staff caring for the individual will need to receive the same training (see Controlled Acts Tip Sheet[54]).
- Community providers should have opportunities to visit the person in the hospital to get to know them and develop rapport. They can also use these opportunities to observe their care in hospital, practice recommended approaches and consult with hospital staff regarding any necessary skills.
- Community agencies should also provide ongoing education and training for their staff on how to support the health care of people with dual diagnosis (e.g., ECHO Ontario Adult Intellectual & Developmental Disabilities,[55,56] Nuts and Bolts of Healthcare: A Toolkit for Direct Support Professionals[30,54]).

Implications for health and developmental service planners

- Ensure that hospitals have systems and resources in place to adapt education, training and support in response to the individual capacity and needs of patients, as well as those of their families and providers. Translation services should be universally available.
- Ensure policies are in place that allow community providers to visit the person in hospital and learn from the hospital team.
- Ensure hospital providers have the flexibility to provide ongoing support to families and community providers post-discharge when it is warranted.
- Across the system, improved training is needed for health care providers on how to care for people with developmental disabilities and dual diagnosis, and for developmental service providers on how to support the health and mental health needs of people with developmental disabilities. This includes opportunities for continuing education for established providers and improved training within professional education programs.

Tools and resources

- **ECHO Ontario Adult Intellectual & Developmental Disabilities** → This program is part of the CAMH ECHO Mental Health Program which provides virtual teaching and a community of practice for health and developmental service providers to learn together about supporting the mental health of adults with developmental disabilities. Course participants can bring cases forward to get input from the interprofessional clinical team, in addition to learning practical information about supporting this population.[55,56]
- **Patient Oriented Discharge Summary (PODS)** → PODS is a patient-centred discharge summary template that has been implemented in hospitals across Ontario and can be adapted to different settings and populations.[57]
- **Nuts and Bolts of Healthcare: A Toolkit for Direct Support Professionals** → This toolkit includes information and resources for DSPs to help them support the health care of people with developmental disabilities. It includes information on common health conditions, tip sheets on topics such as navigating the health care system and being an effective advocate, monitoring charts for health concerns, and easy read health resources that can be shared with individuals with developmental disabilities.[30,54]
- **Family Matters Toolkit** → This toolkit was adapted from the Nuts and Bolts of Healthcare Toolkit. It includes information and resources for families to help them support the health care of their family member with a developmental disability. It

includes information on common health conditions, tip sheets on topics such as navigating the health care system and being an effective advocate, monitoring charts for health concerns, and easy read health resources that can be shared with individuals with developmental disabilities.[58]

- **A Family Guide to Dual Diagnosis** → This guide provides families with information on dual diagnosis, service navigation and strategies for self-care.[59]
- **Developmental Disabilities Primary Care Program** → This program has primary care guidelines and tools to support the care of patients with developmental disabilities. The tools may also be helpful for other health care providers and include several patient-oriented resources and mental health related tools.[60]
- **Easy Health** → This is an online library of health information and videos designed for people with intellectual disabilities based in the UK. Note that some of the language may require adaptation to meet local cultures and lexicons.
- **Controlled Acts Tip Sheet** → This tip sheet was developed as part of the Nuts and Bolts toolkit for DSPs and provides information on what constitutes a controlled act and the circumstances under which DSPs are permitted to administer controlled acts.[54]

5 Transition and Community Support Plan

“**It was super helpful that we had…one document that was tracking the progress of this transition**. So we had accountability. We had a hard copy. It was a living document, it changed constantly. It was the tool we used at all the meetings to look at.”

– Hospital provider

A written Transition and Community Support Plan is developed that identifies the most appropriate housing, social and health care supports to allow the person to live successfully in the community, and the process by which a graduated transition in care will take place. The plan is started when the person is admitted to hospital (or beforehand when it is a planned admission) and is updated regularly throughout their stay and the transition period. The plan is flexible and responsive to the changing needs of the individual.

The plan is referred to as a Transition and Community Support Plan because of its emphasis on how a graduated transition will take place, and the details of who, what and how supports will be provided in the community. A discharge summary, in contrast, summarizes the care which occurred in hospital and ends with a series of recommendations for community care. The Transition and Community Support Plan may reside within the discharge summary or be a separate document.

Key points:

- A written plan should be developed and regularly updated.
- The plan should consider the transition process and supports needed in the community.
- The planning process should include the patient, family, hospital team, community health care providers and developmental service providers.
- Everyone should receive an accessible copy of the plan before discharge.

The planning process is led by the transition coordinators (one from the hospital and one from developmental services; **see Component 6**) and includes the patient, family, hospital team, community health and developmental service providers, and anyone else who provides support. Regular meetings are held with all stakeholders to inform and update the plan while the person is in hospital as well as after the move has occurred (**see Component 1**).

The planning process begins by understanding the patient's preferences and what is important to them to support a successful transition. Planning is informed by consideration of the additional unique experiences and service needs of individuals who have intersecting experiences of marginalization, including clients who identify as 2SLGBTQ+, Black, Indigenous and racialized.

Accessible versions of the transition plan are made available to all involved before transition is initiated. Consider use of social stories and easy read formats for creation of the patient version of the plan.

The plan includes the following details, where available and as relevant:

- **information about the patient**
  - ***Health profile***, including their diagnoses, physical and mental health needs, substance use history, medical devices and necessary physical accommodations. This should also include signs the person is decompensating and how to respond.
  - ***Personal profile,*** including their goals for community living, likes and dislikes, social and emotional well-being, communication strategies, sensory sensitivities, dietary requirements and food preferences, primary spoken language, cultural and religious affiliations and any related requirements, ability to accomplish activities of daily living and level of support needed.
  - ***Name and contact information*** of key people who provide support to the patient, including family members, substitute decision-makers and other people involved in their social support circle (as relevant).
- **community support plan**
  - ***Medication plan***, including medication names, dosage, administration instructions, possible side effects and how to respond, how the person will be supported to take their medications, how to address missed doses, the prescriber who will monitor medications, PRN protocols, and a plan for regular review (including blood work if relevant) after transition (**see Component 7**).
  - ***Housing plan***, including where the person will live and how they will be supported there (***see* Component 9**). If there is no housing provider identified at the time of discharge, documenting which agency is responsible or the point of contact to support the person where they live is important.
  - ***Community health care support plan***, including names and contact information for the team of providers who will provide health care in the community (e.g., primary care provider, psychiatrist, other specialist physicians, psychologist, behaviour therapist, social worker, nurse, occupational therapist, speech-language pathologist etc.) and scheduled follow-up visits (**see Component 8**). In

some cases, this may include a Community Treatment Order (CTO) which allows a physician to mandate supervised treatment after discharge from hospital.

  - ***Activity plan*** that will support the person be involved in activities they enjoy and to be engaged in their communities in ways that are meaningful to them (e.g., social and leisure activities, day programs, skill building programs, vocational programs etc.).
  - ***Behaviour support plan***, including approaches to de-escalation as indicated.
  - ***Crisis prevention/management plan*** that indicates what to do in the event of an escalating situation when there may be a need for police or hospital involvement and how the hospital visit can be supported. If the person is transitioning to a location with a different local hospital, they should be included in developing the plan and consideration given to when it would be appropriate to use the services of the local hospital versus returning to the hospital from which they were discharged. The plan should include a photo of the person, along with the physical description, in case the person goes missing.
  - ***Formal risk management plan*** for individuals with forensic involvement or with very high risk behaviours.
  - ***Plan to support family caregivers***, if relevant (e.g., family support services, mental health services, respite services, peer support).
  - ***Funding source*** to support transition and community care.
- **transition plan**
  - ***Training and education plan*** for the patient, family and community providers (**see Component 4**).
  - ***Plan to support graduated transition***. If appropriate, this may include opportunities to meet new providers, visit a new home and participate in community activities before discharge (**see Component 6**).
  - ***Plan for adjustment of treatment interventions*** prior to discharge to ones that are more suited for the home environment (e.g., shift from intramuscular to oral medication).
  - ***Plan for a period of overlapping care*** from both hospital and community providers, including clarity in roles, responsibilities and duration of involvement (**see Component 6**).
  - ***Plan for information transfer*** to all community providers, including developmental service providers, primary care and any other health care providers.

- ***Plan for how to proceed if the transition is unsuccessful.*** This plan should identify the roles and responsibilities of the receiving agency and the hospital if the transition is deemed unsuccessful and the circumstances under which the patient would return to the hospital.

Rationale

Many individuals who are ALC and have a dual diagnosis have complex needs. Research in Ontario has shown that people with developmental disabilities are more likely to be re-hospitalized within a month of discharge than people without disabilities.[4] A comprehensive Transition and Community Support Plan can help accommodate the person's specific needs and prepare for when things go wrong, preventing re-hospitalizations.[10,37,61] Failed transitions can be traumatizing for the individual and make future transition attempts even more challenging.[10]

Transition planning should begin at admission.[7,10,62] It can be time consuming to engage the right people to develop the plan and there can be long wait lists to get access to the right housing and community services, so it is important that transition planning starts as early as possible. The planning process should be collaborative and include all stakeholders, including the patient, family and community providers. This helps ensure everyone feels engaged in the process and comfortable with the plan, the right supports are in place to meet patient and family needs, and community providers are prepared and supported to provide those supports.[7,9]

Everyone involved in supporting the transition or ongoing care in the community should have access to an accessible written Transition and Community Support Plan to ensure they have all the information necessary. This includes adapted versions of the plan for people with developmental disabilities, considering the language, font size and images used.[63]

As a person adjusts to being out of hospital, there may be crises which necessitate a visit to the emergency department and possibly an inpatient hospital admission. This should be woven into planning to facilitate such occurrences. A UK report on successful transitions noted, "Planning for the worst case as well as the likely scenarios is the only way to manage and minimize risk."[37] It is important that the individual and team members receive support when this happens and that there continue to be supports available.

We heard in our consultations that there is often no cohesive written plan developed. The primary objective is to discharge the patient, with reliance on the hospital discharge summary, or plans developed by the housing provider post-discharge, rather than developing a fulsome and integrated plan. There is sometimes a misunderstanding that planning can only begin once a discharge location is identified and thus some community providers from the developmental sector will only attend meetings or provide clinical consultation once this is in place. We also heard that crisis planning is often not done or done well during the transition process. This left families and community agencies unsure about what would happen in the event of a crisis requiring a visit to the emergency department or a readmission.

A number of consultation participants stated that in order to ensure a successful transition, a clear plan must be developed early in the hospitalization and necessary services and supports must be in place prior to discharge. There were many innovative examples of people engaging in transition planning, even in the absence of a discharge location. This included enhancing a person's readiness for transition based on discharge goals and building daily living skills. Clear communication about the plan contributed to patient stability and readiness, which resulted in a smoother transition.

Implications for patients and families

- Your care team should include you and the people who support you in decisions about your transition from hospital to home. Your care team should ask what you want to have in your life to make you happy and include this in a written Transition and Community Support Plan. The plan also explains everything you need to know about leaving the hospital and your care at home, including:
    - your goals for living in the community
    - where you will be living and who will be supporting you
    - what medications to take, how to take them and what they are for
    - who will provide your health care, including your mental health care
    - how you will remain safe in the community.
- You and your family should get a written copy of the plan before you leave the hospital. The plan should be easy to read and understand, and your care team should explain it to you.
- Make sure to let your care team know if you have any questions or concerns or if it is hard for you to understand the plan.

Implications for hospital teams

- The transition coordinators are responsible for leading the process to develop and write the Transition and Community Support Plan. The transition coordinators should be familiar and well connected with the health and developmental service systems in order to support a successful plan.

- The hospital should provide support and guidance to the patient, family and transition coordinators to address challenging ethical situations that may arise during the process when there are differing perspectives, for example related to risk and safety issues. This may include arranging access to expert resources, such as an ethicist or a patient advocate.
- The plan should be provided in an accessible format that is easy for the person, their family and their providers to understand. Consider the language, font size and images used. It may be important to have electronic and paper versions of the plan depending on patient, family and community providers' preferences.

Implications for community health and developmental service providers

- The transition coordinators are responsible for leading the process to develop the Transition and Community Support Plan. The transition coordinators should be familiar and well connected with the health and developmental service systems in order to support a successful plan.
- Community health and developmental service providers who will be providing care after discharge should be involved in developing the Transition and Community Support Plan. Ideally, both managers/decision-makers and the front-line staff who will be providing direct care should be included.
- The person's needs may change once they transition out of hospital. It is therefore important that the person receive ongoing assessments and there is flexibility to adjust the plan as needed.

Implications for health and developmental service planners

- Support the development of a standardized Transition and Community Plan template to ensure all key elements are considered in the plan.
- Ensure that hospitals have a process and resources in place to develop accessible versions of the plan and ensure they are shared with everyone involved.
- Establish clear procedures for making decisions about the Transition and Community Support Plan, as well as, a formal appeals process if the hospital team, community providers, patient or family deem it inappropriate.

Tools and resources:

- **Patient Oriented Discharge Summary (PODS)** → PODS is a patient-centred discharge summary template that has been implemented in hospitals across Ontario and can be adapted to different settings and populations.[57]
- **Patient Orientated Medication Tools** → This is a set of tools to support communication and education on medications for patients and families being discharged from hospital to facilitate adherence in the community. People with developmental disabilities contributed to the design of these tools.[57]
- **Successful Housing Elements & Developmental Disabilities (SHEDD) tool** → The SHEDD tool can be used to help people with developmental disabilities, and the people who provide them care and support, to plan for a home that is personalized, promotes a sense of belonging and is comfortable and safe. It promotes discussion of personal preferences and choices and suggests design ideas for the physical space of a home.[34]
- **About My Health** → This is a tool that can be filled out by people with developmental disabilities and the people who support them. It captures basic information about the individual, their medical history, key contact information, medications and helpful communication strategies.[29,30]
- **My Hospital Form** → This form can be used to communicate essential information to hospital staff in the event that a person is hospitalized and their caregivers are not present. It includes medical information, substitute decision-maker contacts and information about support needs.[64]
- **My Coping Tool** → This tool helps people with developmental disabilities and the people who support them identify signs the person is feeling distressed or "in crisis" and strategies that can help them manage these difficult feelings.[65]
- **One Idea Per Line: A Guide to Making Easy Read Resources** → This is a guide created by the Autistic Self Advocates Network on how to create easy read resources. These are accessible resources intended for people with disabilities that use pictures and easy-to-understand language.[31]

6 Graduated, overlapping and coordinated transition

"It is more than just an identified lead that is needed. **You need ONE team of everyone involved in the transition, all paddling in the same direction.**"

– Community mental health provider

Key points:

- Clearly identified leads are needed from both the hospital and the community.
- They should work together to plan, support and coordinate the transition. It is a shared responsibility.
- Transitions for this population should be graduated and allow for a period of overlapping care from the hospital and community teams.

Successful transitions are the joint responsibility of the hospital and community sectors. To support the process, leads should be identified from the hospital and from the community (referred to here as "transition coordinators") who work together to plan, coordinate and support the transition. The transition coordinators have a shared responsibility for ensuring all the transition core components are accomplished, ensuring that everyone involved understands their roles and responsibilities (in some cases a memorandum of understanding can be helpful), and fostering a culture of trust, inclusion, respect and open communication.

Depending on the person's needs, circumstances and local available resources, the people who need to be involved in planning the transition may differ. This group includes:

- the patient and their family
- the providers caring for the patient in hospital
- health care providers who will provide care in the community (e.g., primary care provider, psychiatrist, other specialist physicians, psychologist, behaviour therapist, social worker, nurse, occupational therapist, speech-language pathologist)
- developmental services agencies that will provide housing and/or day supports, if relevant
- representatives from the developmental services system who can support access to funded resources and specialized services (e.g., regional DSO, CNSC), if needed.

The transition process and timeframe is tailored to the needs of the individual and can be adjusted as needed depending on how the patient responds. There are regularly scheduled check-ins with all stakeholders to assess the plan and adjust as needed. Updated plans and timelines are clearly communicated to everyone involved in the transition.

If appropriate, the process may include opportunities for the individual to visit and become comfortable with their new home, potentially including overnight stays, before they are discharged from the hospital. It may also include a period of overlapping care from members of the hospital and community teams. Community providers, in particular any new DSPs who will be providing daily support in the community, should meet the individual and develop rapport while they are still in hospital. Key hospital providers should be available to provide support, including training and guidance for new providers and clinical services for the patient as appropriate, for a defined period of time after discharge to support the individual to adjust to their new environment. A clear plan should be in place with all transition partners on how to address any challenges as they emerge and how to proceed if it is ultimately determined that the home is not the right fit.

Rationale

The lack of coordination and communication between the health and developmental sectors in Ontario has been highlighted as a barrier to successful transitions.[7,13] In alignment with previous work in Ontario,[7,26] our consultations identified that community agencies are not always effectively included in transition planning. Consultation participants noted that hospitals were sometimes unsure of how to include community agencies and in some cases hospitals reported receiving minimal support from the community. When community was included, the pathway to access support varied widely. Sometimes the starting point was the DSO, sometimes the CNSC and sometimes a direct service agency. Similar to previous work,[7,26] we also heard that poor communication and misalignment in procedures (e.g., how patient needs are assessed) could cause additional barriers.

Our consultations also included many examples of hospitals and communities working closely together to support transitions. Essential ingredients included clearly identified leadership from the hospital and community who have knowledge of the system and dedicated time to jointly oversee the transition process. This aligns with a review of successful transitions in the UK which similarly identified accountable named leadership, as well as multi-agency partnerships committed to shared responsibility, as key to successful transitions.[37] Identified transition coordinators can ensure the right people are engaged in the transition planning process, everyone is clear on their roles and responsibilities and ongoing clear communication channels are established. They can also provide a consistent point of contact for the patient, family and providers throughout the transition period.

Abrupt change can be very difficult for many people with a dual diagnosis and can result in significant anxiety and distress.[32] In some cases, this can lead to crises and hospital visits.[66] Many individuals designated as ALC have been hospitalized for months or years and would benefit from a graduated transition and period of overlapping care, including an opportunity to get to know and become comfortable with new providers and their new home before being discharged from hospital. This can also help identify and respond to unanticipated challenges while hospital supports are still available.[7,37,38,61]

During our consultations, we heard examples of successful graduated transitions which included community staff working with patients in hospital as well as providing opportunities for the individual to visit their new home and participate in community activities before transitioning. Participants noted that visiting the home was not appropriate for all patients, but it was important that this option be available. However, this was not always feasible as some hospital regulations did not permit patients to leave and there was pressure to discharge patients as soon as housing was secured. To address these challenges, there is a need for flexible and patient-centred policies that support graduated transition when appropriate.

> “**A slower transition allows for a more successful transition.** A quick transition allows for a lot more hiccups to arise. A gradual transition, for example, having day and overnight visits, is helpful. It is a big step to go from hospital to a large group home… it can be very overwhelming.”
>
> *– Community mental health provider*

Implications for patients and families

- Key members of your care team will be in charge of supporting your move from the hospital into your new home. They will work with you and your family to learn what you want your life to look like when you leave the hospital, make a plan for leaving the hospital and help support you to adjust to living in the community.
- Before you leave the hospital, you will get a chance to meet and get to know any new people who will be helping you after you move. If it is helpful, you might visit your new home so you can see what it looks like before you move in.

Implications for hospital teams

- A hospital staff member should be identified as the hospital transition coordinator. Ideally, this is done early in a person's hospital stay, particularly if they are identified as being at risk of becoming ALC (e.g., person has aging parents who can longer provide care at home). The transition coordinator may be a designated discharge planner, a social worker or another staff member. To the extent possible, it is important this person stay consistent to increase efficiency and clarity in the process. The hospital transition coordinator will work together with a community transition coordinator to support the transition.
- To identify a community co-lead, the hospital transition coordinator should begin by connecting with the local DSO who can facilitate further connections with key local and specialized resources, case coordination and transition planning support.
- The hospital transition coordinator should attend local Service Solutions and developmental services priority setting tables to develop ongoing relationships and a shared understanding of sector issues, as well as to provide up-to-date information regarding current and future ALC patient needs.
- Hospital leadership should support their team members to facilitate timely decision-making and problem-solving. A clear process should be in place for when and how to engage leadership to provide support for challenging barriers to transition. For cases where leadership involvement still does not lead to a resolution, there should be a mechanism to escalate to the ministry level.
- Despite the urgency to discharge ALC clients, hospitals should permit a graduated transition with flexible timeframes as appropriate to meet the needs of the individual and their community providers. This will increase the likelihood of a successful transition and reduce re-admissions, ultimately supporting the aim of making beds available for other patients.
- Hospitals should have a clear process for supporting community providers to meet and engage with the patient while they are still on the unit.
- Key hospital providers should be available to provide support as needed for a defined period of time after discharge while the individual adjusts to their new environment. It is important that hospital providers, the patient, the family and community providers all have clarity on the roles and responsibilities of different providers before, during and after discharge from the hospital. Depending on the patient's needs and circumstances (e.g., if they are under the ORB), the ongoing role for hospital providers may be different.

Implications for community health and developmental service providers

- A community provider should be identified as the community transition coordinator who will work together with the hospital transition coordinator to support the transition. If the individual is eligible for the DSO, the DSO should facilitate access to the appropriate providers or agencies who can take on this role (e.g., CNSC coordinator, organization who will be providing housing, service coordination).
- Key providers who will support the person once they transition to community should ensure they meet and engage with the person while they are still in hospital to support a smoother transition to the community. This also provides an opportunity to observe, practice recommended approaches and consult with hospital staff **(see Component 4).**
- Leadership from involved agencies should support their respective team members throughout the process to facilitate timely decision-making and problem-solving.
- Local Service Solutions and developmental services priority setting tables should establish consistent procedures for engaging with hospital staff to establish ongoing relationships and shared understanding of sector issues, as well as to provide up-to-date information regarding current and future ALC patient needs.

Implications for health and developmental service planners

- Establish a clear, consistent and streamlined approach throughout the province for identifying and accessing the necessary health and developmental services to support the person in the community. The DSO should have a clear process for facilitating connections with appropriate services in the developmental sector.
- Ensure alignment in community and hospital policy and procedures to avoid misunderstandings, barriers or delays (e.g., how information is shared, paperwork required, terminology, definitions of developmental disabilities/dual diagnosis, how levels of need are described and eligibility criteria for programs).
- Establish a consistent protocol across all developmental service regions to ensure that hospital staff representatives can attend developmental services sector committees, in particular priority-setting meetings where current and future ALC clients can be discussed proactively.
- Ensure hospital policies allow community providers to attend meetings.

- Ensure all hospitals have staff with sufficient training and knowledge of relevant health and developmental services to be the hospital transition coordinator. At a minimum, staff should be provided with lists of local services and contact information.
- Ensure hospital policies are in place that allow community providers to visit the patient while in hospital, allow for a graduated transition and allow hospital providers the flexibility to provide ongoing support post-discharge when it is warranted.
- The initiation of Home and Community Care Support Services starts only after discharge, which can cause delays in access and make it difficult to ensure appropriate training and transition of care. To ensure a seamless transition, policies should be implemented that allow for the initiation of Home Care Services prior to discharge, particularly for patients with more complex needs.
- To support hospitals with limited resources and expertise, consider developing dedicated health-based transition support teams as a system resource that is available to support local hospitals to transition ALC patients with a dual diagnosis.

"We transitioned one very complex individual. We had our staff working in the hospital for more than a month. **They were there along with the hospital staff, building rapport and understanding the individual's routine**… so extremely successful."

– Developmental service provider

Tools and resources

- **Making Positive Moves** → This UK based website includes resources and tips for people with developmental disabilities who are moving to a new home and their families.

7 Medication review and support

"We're incredibly fortunate to have an amazing family doctor who oversees John's medication. Together with the developmental service providers, **they have been pillars of support, actively aiding us in every step**."

– Family member of a former ALC patient

Patients have regular medication reviews, including on admission, before discharge and once they are in the community. Prior to discharge, a prescriber must be identified who can provide ongoing medication management in the community. Note that patients on certain medications (e.g., clozapine) may require additional consideration to identify a prescriber who is able and willing to provide ongoing management.

Medication reviews should include the following:

- medication reconciliation (i.e., identify all of the patient's current medications including the drug names, dosages and frequency of administration)
- assessment of medication adherence (i.e., whether a person uses their medications in the way agreed upon with their health care professionals) and development of a plan to improve adherence if necessary
- medication optimization (i.e., ensure all medications are indicated, effective, safe and convenient)
- consideration of medication cost and options for those unable to afford such costs
- packaging and instructions for those who may need assistance taking their medication (e.g., pre-prepared blister packs and pill boxes)
- the patient's medication schedule, particularly when caregiver support is needed to help administer medications throughout the day and night

Key points:

- This population is often on multiple medications, including psychotropic medications.
- Patients should receive regular medication reviews.
- A community prescriber must be in place with sufficient expertise in dual diagnosis (or receive training or consultation support) to provide ongoing medication monitoring and management after discharge.
- Medication needs may change during and after transition.

- caregiver capacity to support medication administration and monitoring (before transitioning to the community, medications may need to be adjusted to facilitate administration - e.g., shift from intramuscular to oral medication)
- training on how to manage complex medication regimens including any PRN medication protocols.

Accessible plain language information about the patient’s medication is included in the Transition and Community Support Plan and made available to the patient, family, staff who might support medication administration and the prescriber who will provide ongoing management (**see Component 5**). This includes medication names, administration instructions, possible side effects and how to respond, a plan for who will administer or support the person to take their medications (if relevant), a plan for accessing medications in the community, what to do if a medication dosage is missed and the prescriber who will provide ongoing medication monitoring.

Rationale

People with developmental disabilities are often prescribed multiple medications and have inadequate follow-up.[5,67] An Ontario study found that over 20% of adults with developmental disabilities receiving disability support were on five or more medications.[5] Many individuals with developmental disabilities are prescribed antipsychotic medications, as well as a range of other medications, to manage aggression toward themselves or others, despite limited evidence for their effectiveness.[68,69] Medications, especially multiple medications, carry risks of adverse reactions and negative medication interactions.[69,70] People with developmental disabilities may react differently to medications because of common comorbidities (e.g., epilepsy or metabolic disorders) and they may have more difficulty reporting side effects.[17]

Medications therefore require regular monitoring to review appropriateness and adverse reactions.[17] Medication needs may also change during the transition period and once the person is settled in the community. A recent study of ALC forensic patients with a dual diagnosis found significant reduction in the use of PRN medication after transition to the community.[71]

Whereas in hospitals medication administration is the responsibility of nursing staff, once in the community medication administration must be managed by the patient and the people who support them. Additionally, the community prescriber (e.g., psychiatrist, primary care physician, nurse practitioner) who will be responsible for ongoing medication management and monitoring may have little expertise in dual diagnosis.[50–52] These individuals may require training and a period of ongoing support to ensure medications are appropriately managed in the community.

In our consultations, we heard that there was sometimes no community psychiatrist or family physician in place to support medication review and monitoring following discharge. Additionally, delays in initiating Home Care Services after discharge resulted in medication errors, poor medication compliance and missed dosages. Having a community health care provider in place to manage medication-related issues prior to discharge was key to a successful transition. Medication issues were particularly well managed when the individual was discharged under ORB disposition, which ensured hospital psychiatric involvement, or when the individual was discharged under the care of a specialist dual diagnosis team.

"There should have been **a physician-to-physician conversation… to explain the medication she was on and why.** So that the doctor wasn't trying to flip through a file and figure it out on their own."

– Family member of a former ALC patient

Implications for patients and families

- You may be taking medications to help keep you well. Sometimes the kind of medication you need changes, so it is important to check-in regularly to make sure you are taking the right ones. Your care team should talk to you and the people who support you about your medications before you leave the hospital, and again after you leave the hospital.
- They will talk to you and the people who support you about:
    - how you are feeling and whether you are having any side effects from your medications
    - how and when to take your medications
    - any changes that need to be made to your medications and routines around when you take your medications and why
    - what to do if you forget to take your medications
    - options to help pay for your medications.

Implications for hospital teams

- Complete regular medication reviews, including on admission and before discharge. Include information regarding medication reconciliation, adherence and optimization.
- Engage in a discussion with the patient and the person who will support medication administration (this may be a family member or a DSP) about their ability and willingness to use their medications at home. Training and education should be provided and medication protocols may need to be adjusted. Note that there are specific training requirements in order for DSPs to administer any controlled act under the Regulated Health Professions Act[53] (**see Component 4**).
- The transition coordinators should ensure that a prescriber is identified and in place prior to discharge who can be responsible for monitoring medications in the community (e.g., psychiatrist, primary care physician, nurse practitioner). Note that patients on clozapine require more intensive monitoring (i.e., regular blood work), a physician who can prescribe the medication and a pharmacy that can dispense it.
- Community providers often have little experience with dual diagnosis. Training and education should be provided as needed to ensure they feel confident to provide ongoing medication management (**see Component 4**).
- The medication review should be communicated to all providers who will be supporting medication management in the community (e.g., primary care provider, psychiatrist, community pharmacist or home care nurse; **see Component 5**).
- Ensure patients have a sufficient supply of medication when they leave the hospital to last until a prescription can be filled.

Implications for community health and developmental service providers

- The transition coordinators should ensure a prescriber is identified and in place prior to discharge who can be responsible for monitoring medications in the community (e.g., psychiatrist, primary care physician, nurse practitioner). It may also be helpful to have a community pharmacist involved.
- Prescribers who are not experienced treating this patient population should seek additional training as needed from the hospital team to ensure they are prepared to provide ongoing care in the community (**see Component 4**). If primary monitoring is conducted by a primary care provider, ongoing consultation with specialists (e.g., psychiatry) should be available as needed.

- Ensure there is clarity on who will administer any necessary medications and they receive any necessary training. Administration may be done by the patient themselves, a family member, a DSPs or a home care nurse. If there will be a delay before home care can be accessed, an alternative must be in place before the patient leaves the hospital to ensure there are no medications errors or delays. Note that there are specific training requirements in order for DSPs to administer any controlled act under the Regulated Health Professions Act[53] (**see Component 4**).
- Ensure a medication review is completed by the prescriber responsible for community monitoring after the patient has transitioned to the community. The transition period may be stressful for individuals or they may have fewer challenges when living in the community. Medications may need to be adjusted accordingly and should be monitored closely during the transition period.

Implications for health and developmental service planners

- Ensure that hospitals and community providers have systems and processes in place to automatically flag when patients are due for a routine medication review.
- Support increased training for community prescribers on best practices related to medication management for people with dual diagnosis.

Tools and resources

- **Patient Oriented Medication Tools** → This is a set of tools to support communication and education on medications for patients and families transitioning out of hospital and can facilitate adherence in the community. People with developmental disabilities contributed to the design of these tools.
- **Stopping Over-Medication of People with a Learning Disability, Autism or Both (STOMP)** → STOMP is a project in the UK that aims to support providers to reduce or discontinue inappropriate psychotropic medications for people with developmental disabilities. It includes several resources about psychotropic medication monitoring for people with developmental disabilities, families, DSPs and health care providers.
- **Psychotropic Medication Review** → This tool assists health care providers in systematic and timely reviews of psychotropic medication prescribed to adults with developmental disabilities.[72]

8 Coordinated follow-up medical and clinical care

"You need to ensure hospitals do not make "cold referrals", that is send off a referral without confirming that it is accepted. **You need a completed referral, a warm hand-off, and a period of overlapping care.**"

– Developmental service provider

Appropriate health care is provided throughout the transition period and, prior to discharge, all necessary health care providers are identified and prepared to provide follow-up care in the community. All patients must have an identified primary care provider. Some patients may have an existing primary care provider who is willing to provide ongoing care. However, for other patients, especially those who have been in hospital for a long time, it may be necessary to seek a new primary care provider. In this situation, a primary care team (e.g., Family Health Team or Community Health Centre) is usually the best option to support the health, mental health and developmental complexity of many of these patients.

Some individuals may also require other health care providers such as a psychiatrist, other specialist physicians, a psychologist, a behaviour therapist, a social worker, a nurse, an occupational therapist, a speech-language pathologist or other health care providers. These health providers may be available through hospital outpatient programs, home and community care, community mental health care, or specialized developmental service agencies. If the necessary providers are not available locally, it may be possible to obtain access through telemedicine. Some patients with more complex needs may require a more intensive multi-disciplinary mental health team (e.g., Assertive Community Treatment [ACT], Flexible Assertive Community Treatment [FACT]). In some parts of the province there are formally funded specialist dual diagnosis teams. Alternatively, informal teams can be brought together around an individual, often led by a community coordinator, case manager or housing provider.

Key points

- It is not enough to have housing. It is also critical to have health care supports in place before discharge.
- Everyone needs primary care, and many will need a psychiatrist as well as other providers.
- For people with complex needs, care should be provided by multi-disciplinary teams.

Patients who are discharged under the ORB must be supported by a specialized forensic mental health team. Patients on clozapine require a physician who is able to prescribe and monitor the medication.

Health care providers must have the training and expertise needed to provide ongoing care to the patient, considering their mental health and physical health needs. The health care providers who cared for the patient while they were in hospital should continue to be available after discharge for a defined period of time to support new health care providers as they take over care. In some cases the inpatient provider may continue to deliver direct care for the patient as appropriate.

Family caregivers may also require ongoing health care services in the community (e.g., family support services, mental health services, peer support). These services should be identified prior to discharge to ensure the family will be supported and can in turn continue to provide support to their loved one.

Rationale

People with a dual diagnosis have mental illnesses and high rates of co-occurring chronic physical illnesses, such as congestive heart failure, chronic obstructive pulmonary disease, diabetes and asthma.[5,73] These health conditions require ongoing care while awaiting discharge in hospital and in the community after discharge.

Consultation feedback indicated that care provided to ALC patients in hospital varies widely. In some cases, patients with a dual diagnosis were transferred to ALC units or reactivation centres which are designed for different populations who comprise the majority of ALC patients. These units and centres may lack the providers (e.g., psychiatrists) needed to meet the needs of these patients. Some families and hospitals felt that patients were not provided adequate care in hospital leading to the deterioration of their physical and mental health.

Additionally, our consultations indicated that it is often difficult to find community health care providers, especially ones with dual diagnosis training. Community health care providers may be reluctant to take on patients with a dual diagnosis due to the provider's lack of expertise, concerns about inadequate access to specialist consultations and resources, and concerns of inadequate funding for the additional time required to coordinate such care.[74,75] Regional variation in resources can pose additional challenges to accessing health care.[76] Given the pressure to discharge patients as soon as a community space is available, patients are often discharged without health care supports in place. The community agency or family is left to seek access to necessary health care with no supports available in the interim.

Consultation feedback suggests that the most successful transitions occur when an individual is discharged to the community under the care of a familiar primary care provider or connected to a new provider or care team with the capacity and skills to support their needs. It is also helpful when home and community care services with specialized providers trained to support ALC patients are involved.

Individuals with more complex needs should be supported by a multi-disciplinary team. Currently, this population does not always meet inclusion criteria for general ACT or FACT teams and these teams may lack the skills and knowledge needed to care for this population. During our consultations, we heard about different team models that can be valuable for this patient population though they are currently in limited supply. These include specialized dual diagnosis mental health outpatient or community-based teams which can be funded through the health or developmental sectors (e.g., dual diagnosis FACT teams or forensic mental health teams) and informal teams brought together around a specific individual based on their needs. Key to this latter model is leadership, often provided by strong community coordinators, case managers or housing providers, to establish a coordinated team approach integrating clinical supports with community supports.

To prevent re-hospitalizations and ensure patient needs are met, appropriate mental and physical health care must be provided while in hospital and during and after transition. Community providers should be identified prior to discharge, patients with complex needs should be supported by teams, there should be opportunities for training, and there should be a period of overlapping care to support community providers.[7,38]

Implications for patients and families

- Before you leave the hospital, your care team will make sure that the right health care providers are in place to take care of you in the community.
- A list of these providers and their contact information will be included in your Transition and Community Support Plan (**see Component 5**).
- You might meet them while you are still in the hospital and follow-up appointments should be scheduled before you are discharged.

Implications for hospital teams

- Ensure the person continues to receive high quality care in hospital while awaiting a community placement.
- Ensure all necessary community health and clinical care providers are in place to support ongoing care in the community prior to discharge.
- Before leaving the hospital, appointments with follow-up medical and other dual diagnosis specialists should be in place, as well as a plan to support the patient to attend these appointments. Consider whether it will be most appropriate for these visits to take place in a provider's office, virtually or through a home visit.
- Where appropriate, provide community providers training and education to ensure they are prepared to provide ongoing care in the community. The hospital psychiatrist and other clinicians should be available, as necessary, for a defined period of time post-discharge to consult with and support the new community providers (**see Component 4)**.
- For patients under a conditional discharge from a forensic mental health unit, the forensic team is responsible for their care until they receive an absolute discharge.
- Relevant medical information should be included in the Transition and Community Support Plan and shared with community health care providers prior to discharge, in addition to the discharge summary (**see Component 5**).

"If you are going to transfer a person to a community physician, **that should be a verbal transition with an opportunity for the receiving physician to ask lots of questions and follow-up…** To just hand over a file and say "have at it" is disrespectful to the physician and to the client**.**"

– Family member of a former ALC patient

Implications for community health and developmental service providers

- Ensure all necessary community health and clinical care providers are in place to support ongoing care in the community prior to discharge.
- New health care providers should consider meeting the person while they are still in hospital (**see Component 6**).

- Ensure an appointment has been scheduled shortly after discharge to support a smooth transition and there is a plan to support the individual to attend these appointments.
- Health care providers should receive the necessary information, consultation, and/or training from the hospital team (or community specialists as indicated) to ensure they feel comfortable and confident providing ongoing care to the individual (**see Component 4**).
- Commitment to collaborative care and a team-based approach is required by community health and developmental service providers to effectively coordinate medical and clinical care.

Implications for health and developmental service planners

- Ensure that when ALC patients are transferred to ALC units or reactivation centres to await discharge, they have access to the providers necessary to deliver high quality care. This may require consideration of whether ALC units and reactivation centres are the appropriate settings this population and whether they require additional resources or training to care for these patients.
- Implement a mechanism to allow patients with complex needs to be prioritized for access to team-based primary health care and implement physician payment models that account for the additional time needed to support their care.
- Implement training to build capacity for health care providers to care for patients with a dual diagnosis. This can include general training for all providers and increasing availability of specialist consultation to support general providers (**see Component 4**).
- Establish consistent policies for hospital providers to provide follow-up care and support to new providers for a period post-discharge.
- Work collaboratively with providers, communities and people with lived experience to co-design community health and mental health services that meet the needs of all people with a dual diagnosis transitioning from hospital to home. Service models should be informed by local data on population needs and evidence on effective models. Some people with a dual diagnosis may require comprehensive, intensive team-based models. Facilitating access may require revisiting admission criteria for general mental health teams or implementing specialized dual diagnosis teams. Some examples of specialized teams currently exist in Ontario (e.g., Dual Diagnosis FACT Team at The Royal Ottawa Mental Health Centre), but they are limited.

Tools and resources

- **ECHO Ontario Adult Intellectual & Developmental Disabilities** → This program is part of the CAMH ECHO Mental Health Program which provides virtual teaching and a community of practice for health and developmental service providers to learn together about supporting the mental health of adults with developmental disabilities. Course participants can bring cases forward to get input from the interprofessional clinical team, in addition to learning practical information about supporting this population.[55,56]
- **Developmental Disabilities Primary Care Program** → This program has primary care guidelines and tools to support the care of patients with developmental disabilities. The tools may also be helpful for other health care providers and include several patient-oriented resources and mental health related tools.[60]

9 Appropriate and timely housing and community support

"A shelter is always thrown out there as an option, and this is absolutely not an option. So let's stop… and put our efforts into some other places."

– Hospital provider

Key points:

- Patients need a home in the community that is the right fit for them.
- They may also need community providers and programs that support their daily lives and community engagement.
- It can be important for patients to have opportunities to visit their new home and meet their new staff before discharge.

Housing and community supports are identified that meet the patient's needs and preferences, promote a sense of belonging, and support them to feel safe and comfortable. Many of these individuals have complex needs and require efforts to coordinate multiple services across sectors to develop individualized packages of support.

The best options for people moving out of hospital may be to live with their families, independently, in MCCSS-funded housing (see below), mental health supportive or supported housing, or in long-term care. Some individuals may benefit from integrative housing models which bring together mental health and developmental services expertise. In some regions there is transitional housing available which is intended to provide a time limited, high support setting (including clinical supports) to help the person adjust to living in the community before they transition to permanent housing. For example, the Dual Diagnosis Transitional Rehabilitation Housing Program is available in some regions for patients who are transitioning from a forensic unit and are still under an ORB disposition (note this unique program is not accessible through the DSO but is offered directly through participating hospitals). Other models include transitional housing offered through developmental sector transfer payment agencies and though Outside Paid Resources available in some regions of the province. Transitional housing may be appropriate for some individuals, while others may benefit from transitioning directly into permanent housing, thereby reducing potentially challenging transitions.

Regardless of where they live, individuals may also benefit from additional community services and supports (e.g., personal support services, homemaking support, transportation assistance, caregiver respite services, meal delivery etc.) which may be funded by MCCSS, MOH or privately. These services must be in place before people leave the hospital.

Additionally, an activity plan is developed which includes a daily schedule of programs and activities that will support the person to be involved in activities they enjoy and to be engaged in their communities in ways that are meaningful to them (e.g., social and recreational activities, adult day programs, skill building programs, vocational programs, volunteering etc.). This initial plan will likely need to evolve as it becomes clear which activities are the right fit and which are not.

Decisions related to housing should consider:

- the person's daily support needs (e.g., staff ratio and hours per day)
- the housing type that will best meet the person's sensory, social and functional needs (e.g., apartment, low rise, high rise or house; single vs. shared occupancy; congregate living with people you choose or within an agency)
- the persons' age (long-term care is usually not the appropriate setting for younger people)
- the location (e.g., proximity to family, friends, services, religious/cultural centres, parks, amenities and transportation)
- the physical environment (e.g., safety and accessibility features or medical equipment)
- the family's capacity to provide support
- cultural appropriateness (e.g., consider agencies who serve specific communities such as Indigenous, Black, French-speaking or faith-based communities).

There are several MCCSS-funded housing options:[77]

- *intensive support residences* → a staff-supported residence for one or two individuals who require intensive support
- *supported group living residences* → a staff-supported residence for three or more individuals (e.g., a group home)
- *host family residences* → a private family who receive funding to host an individual with a developmental disability who is not a family member
- *supported independent living residences* → a residence operated by a service agency where one or more individuals live without full-time staff support, though some level of support is available.

Rationale

There is insufficient housing available for adults with developmental disabilities in Ontario. The Developmental Services Housing Task Force (2018) noted that “there is a housing crisis confronting Ontarians with developmental disabilities — and it is a crisis that has been growing steadily more serious for at least twenty years.”[78] In our consultations, lengthy waitlists for housing with appropriate community services was one of the most consistently identified barriers to leaving the hospital.

Many patients with a dual diagnosis who are ALC have complex mental health and physical health challenges for which there is an even smaller number of housing options available. Lack of training, stigma, fear and lack of follow-up support from the hospital can make agencies reluctant to take on these individuals.[7] Additionally, many of the current housing options are group-living settings. While these are appropriate for many adults with developmental disabilities, they may not be safe or supportive for some of the patients designated as ALC who might do best in a purpose-built setting or a unit without roommates. A review of successful community transitions in the UK found that often single occupancy spaces were more successful as they grant individuals more control over their environments and reduce interpersonal and sensory distress.[37]

Hospitals are under enormous pressure to discharge patients and in our consultations, we heard accounts of families being pressured to agree to an inappropriate discharge setting, including returning to a family home with inadequate supports, requiring the family to pay exorbitant fees for a private placement, or being discharged to a shelter bed, custodial housing or a long-term care setting. These situations can result in re-hospitalizations and significant trauma for the individual, making future transitions even more challenging.[10]

Consultation participants suggested that obtaining appropriate housing was often facilitated by having family members or staff involved who were able to advocate for the individual or had personal relationships they could leverage. In some cases, movement happened only when there was an escalation, or the threat of escalation, to government officials or the media.

A clear process and guidelines are needed on how housing is selected to support equitable access to appropriate housing. Housing options are needed that are tailored to the needs of the individual and which can support them to thrive, live well and have a sense of belonging. They should be designed, retrofitted and renovated with universal design principles, including those focused on materials and spatial arrangements that can address distressed behaviours and support well-being.[79] In our consultations, we heard examples of patients being included in designing and decorating their new space while they were still in hospital (e.g., selecting paint colours and furniture). This helped them feel engaged, comfortable and excited about their new home. Opportunities to visit and even stay overnight in the new community home can also be helpful in some cases to ensure the right fit and help the person become comfortable in their new home.[7,37]

> "I sit at the local access table. I call it **my magic meeting**… and I get to work directly with the community and social services so they understand what patients we have here that are going to need placements. So it's not just a matter of sitting and waiting for a vacancy to come up**.**"
>
> *– Hospital provider*

Implications for patients and families

- Your care team will work with you and your family to find the right place for you to live and the right people to support you in the community.
- Your transition coordinators will make sure that you live in a space that is safe, comfortable and meets your needs. It should be close to the people you like to see and the things you like to do.
- New staff will come and meet you while you are still in the hospital so you have a chance to get to know each other.

Implications for hospital teams

- The hospital transition coordinator should be familiar with the range of community services available across the health and developmental services sectors or work closely with community partners who can provide this information.
- Ensure individuals have connected with the DSO as early as possible in the process. In order to be eligible for MCCSS-funded adult services, the person must be connected and confirmed eligible with the DSO and the process can be time consuming (individuals must be 18 years old or older to receive services but can start the application process at age 16).
- As soon as it has been identified that the person cannot return to their previous home, efforts should begin to seek appropriate housing as it can take a long time to find an available space.
- The transition coordinators work with the patient, their family, their hospital team and their community providers to understand the patient's needs, goals and preferences, and co-develop a plan for housing and community support (*see SHEDD tool*[34]).

- In some cases, it may be beneficial for members of the hospital team to visit the home the patient will be transitioned into so they can tailor the Transition and Community Support Plan for the environment. General familiarity with the different types of settings the hospital discharges patients to can also help support appropriate discharge decisions.
- The hospital team should provide any necessary training and support to the DSPs who will be providing daily support in the community (**see Component 4**).
- Before leaving the hospital, the patient should have the opportunity to visit and become familiar with their new community residence if appropriate (**see Component 6**).

Implications for community health and developmental service providers

- The community transition coordinator should be familiar with the range of community services available across the health care and developmental services sectors or work closely with hospital and community partners who can provide this information.
- The transition coordinators work with the patient, family, their hospital team and community providers to understand the patient's needs, goals and preferences and co-develop a plan for housing and community support (*see SHEDD tool*[34]).
- DSO should update individual profiles in a timely manner to ensure accurate and current information is available on ALC clients for priority setting meetings and potential housing providers.
- The DSPs who will provide primary support in the community should meet the patient while they are still in hospital to build a relationship and support a smooth transition (**see Component 6**).
- Efforts should be made to customize the person's home so that it is comfortable and familiar (e.g., allowing the person to choose the paint colours or furniture for their room) and ensure it has the necessary physical environment and equipment to meet their needs (e.g., accessible shower, grab bars, ramps, widened doorways).
- The person's needs may change over time and look different when they are no longer in a hospital setting. Once in the community, there should be flexibility to adjust the Community Support Plan and the home environment as needed.
- Agencies should provide general training and ongoing supervision to DSPs to ensure they have the knowledge and skills to provide support to individuals with developmental disabilities as well as complex behavioural, physical health and/or mental health needs.

- A plan should be in place to ensure that if the patient needs to be re-hospitalized, they will not lose their housing.

Implications for health and developmental service planners

- System planners in both health and developmental services (including MCCSS, MOH, the Ministry of Long-Term Care and Ontario Health) must work together to establish and adequately resource a minimum set of core services for people with dual diagnosis that are standardly available and accessible across the province. This should include a range of housing and community support options with appropriately trained staff. Decisions about housing models should be informed by data on population needs (e.g., shared vs. single occupancy) and evidence on effective models (e.g., transitional vs. permanent housing). Flexibility is needed to design or renovate settings when necessary to meet individual needs.
- Clear systems and protocols are needed to match ALC patients with appropriate housing options in the community. Currently the process varies widely and is often based on leveraging individual relationships which is both inefficient and inequitable. The process should be streamlined to reduce bureaucratic hurdles and support timely identification of housing and supports.
- Ontario Health Teams should engage with developmental service sector planners and providers to develop integrated pathways.
- Ensure that people who are ALC in hospital are prioritized for housing and community placements.

Tools and resources

- **Successful Housing Elements & Developmental Disabilities (SHEDD) tool** → The SHEDD tool can be used to help people with developmental disabilities, and the people who provide them care and support, to plan for a home that is personalized, promotes a sense of belonging, and is comfortable and safe. It promotes discussion of personal preferences and choices and suggests design ideas for the physical space of a home.[34]
- **Guidelines for Supporting Adults with a Developmental Disability When Applying to, Moving Into and Residing in a Long-Term Care Home** → These guidelines were developed by MCCSS and the Ministry of Long-Term Care and are focused on supporting adults with developmental disabilities to move into long-term care homes.

10 Sufficient and flexible funding

"If there is not funding for the physical space, I don't know where we're going to put people. **So while we can develop the best plans in the world, if there isn't a physical space to transition someone to we're out of luck…"**

– Developmental service provider

Dedicated funding is in place to support the transition period and the necessary community housing and services to help these individuals thrive and prevent re-hospitalization.

This includes capital and annualized funding for a minimum set of core services for people with dual diagnosis that are standardly available and accessible across the province including housing, health care and developmental services (**see Components 8 and 9**). Base funding should build in extra coverage to protect against staff turnover, prepare for unexpected needs and reduce staff burnout.

This also includes additional individualized funding packages (e.g., MCCSS's Multi-Year Supportive Living Planning) which are required for some individuals with complex needs to ensure the right basket of supports is in place. This funding may only be necessary for a limited time period to support transition, or it may be necessary to support ongoing community participation and required services. Funding packages have the flexibility to reflect the reality of the complex and evolving needs of the individual. Resources and/or funding from different sources or sectors may need to overlap during the transition period. Additional funding is readily available in case of emergencies or unanticipated needs. There is a clear, transparent and equitable process to access funding across the province.

Key points:

- Appropriate levels of funding are needed to support the transition period and ensure the right services in the community.
- Relevant funding and funded services are available through both health and developmental services.
- A clear, transparent and equitable process is needed for accessing funding.
- Extra flexible funding may be needed during the transition period to support overlapping care and in preparation for crises or unanticipated needs after discharge.

Patients and their families are supported to access all available and relevant funds needed to support community living. This includes individualized funding packages when necessary, as well as applying for ODSP and the Passport Program.

Rationale

Sufficient funds are needed to support a thoughtful, planned transition and to provide the appropriate housing and community care necessary to allow people to leave the hospital.[24] Typically people become ALC because their previous living situation is no longer an option and they require appropriate housing and supports to allow them to live in the community. Though the intensity of care proposed may be expensive, it is typically less expensive than the cost to remain in hospital or return to hospital.[10] Additionally, any economic analysis should consider the broader costs incurred due to delayed treatment for other patients while a bed continues to be occupied by a person who no longer requires it.[8]

In our consultations, we heard that it is not always clear what funding is available, how to access funding and who is eligible. As a result, access can be inconsistent based on advocacy, relationships, system knowledge and regional practices. In some cases, families ended up paying exorbitant fees for private homes, providers or staff. This can be devastating to family finances and leads to inequities in who can afford to access services. Urgently needed supports should not be reliant on family and friends who can privately support the individual. Funding can sometimes be delayed due to administrative hurdles and restrictions, which in one case resulted in a patient losing a potential housing placement.

> "**When there is an emergency, suddenly there's money.** There was emergency funding to make it possible for Celine to move back into the community… Poof, it happened. This is wonderful, but unfortunately it happens when there is an emergency and the family is no longer capable…Celine was at the top of the list [in two places] for two years**.**"
>
> *– Family member of a former ALC patient*

Experience here and in other jurisdictions has highlighted the importance of flexible funding.[7,37] We heard of examples where initial higher levels of funding could decrease over time as individual situations settled and programming adjustments were implemented. Additionally, unexpected challenges may arise during transition and the planned supports may be insufficient or inappropriate. Having immediate access to the funds needed to address these issues is critical and can prevent re-hospitalization.

Additionally, funding for additional DSPs, beyond the minimum estimate, can help ensure there is back up available, reduce burn out and protect against turnover.

Implications for patients and families

- Your care team should help you get a home that you can afford to live in. They will also make sure you have the health care and community services to support you in the community.
- Your care team should help you and your family learn about different funding that can help you pay for things and how to get those funds.

Implications for hospital teams

- The transition coordinators should ensure patients and families are supported to register for all eligible funding support programs (e.g., ODSP or Passport funding).
- When needed, the transition coordinators should apply for additional individualized funding to ensure the appropriate services are in place to meet the person’s needs during hospitalization and after discharge.

Implications for community health and developmental service providers

- The transition coordinators should ensure patients and families are supported to register for all eligible funding support programs (e.g., ODSP or Passport funding).
- When needed, the transition coordinators should apply for additional individualized funding to ensure the appropriate services are in place to meet the person’s needs during hospitalization and after discharge.

Implications for health and developmental service planners

- Adequately fund health and developmental services and systems (i.e., capital and annualized funding) so that people transitioning from hospital to home have timely and equitable access to appropriate housing, community supports and clinical care. It is important that services are developed intentionally and in proximity to each other where possible (e.g., housing is located close to the services the residents will require).

Data on current and projected needs should be used to drive funding decisions (e.g., types, quantities and locations of services).

- Evaluate funding models to determine the optimal models to support housing and community services (e.g., appropriate mix of program-based annualized funding, individualized funding and person-directed funding).
- Ensure there is dedicated funding to support the transition process, including transition coordination and planning, a period of overlapping care, and in-hospital supports to help prepare the person for life in the community.
- Ensure there is a clear, centralized, timely and transparent process to obtain additional individualized funding for individuals with complex needs (e.g., if funds are needed for high staff support ratio or renovations to physical spaces to make them safe and accessible). These funds may be time-limited or they may need to be ongoing. There should be flexibility in recognition that needs may change over time. Funds should be portable and attached to the person rather than the agency, in case one of the provider agencies becomes unable to provide further care.
- Establish consistent practices across Ontario regarding use of individualized funding while a patient is hospitalized (e.g., Passport funds for community participation) to support access to services and supports beginning when a person is in hospital.

Tools and resources:

- **Passport Funding** → The Passport Program is a reimbursement program for eligible individuals to access fee-based services in their community. Passport funds can be used to purchase recreational programming, skill development, to hire a support worker or to purchase respite services for a caregiver.
- **Getting Extra Money** → This tool provides simplified information for people with developmental disabilities about the different funding options that may be available to them including income support, respite services, tax credits and funding for equipment.[80]

Next steps

This report identifies transition principles and core practice components that can support adult ALC patients with a dual diagnosis to successfully transition from the hospital to home. Though some elements have relevance for children and youth, it would be important for future work to focus specifically on the needs of that population.

Currently, the necessary resources, policies and infrastructure may not always be in place to support the delivery of all core components in this report. To facilitate implementation and uptake, we recommend the following next steps:

1. High quality, real-time data

There is currently no way to consistently identify ALC patients with a dual diagnosis within existing datasets. Accurate data on ALC patients are important to inform system planning and resource allocation (e.g., types of housing and clinical supports needed). Real-time data could be used by the DSO to automatically identify ALC patients, and patients at risk of becoming ALC, and initiate proactive responses. Detailed data are currently collected through the Ontario Mental Health Reporting System (OMHRS), but this is limited to patients in psychiatric beds and would not reflect the needs of patients in other inpatient settings. One strategy could be to adjust the elements collected through the Ontario Health Wait Time Information System Data so they reflect this patient population more accurately and allow for greater detail on patient needs and barriers to discharge and ensure the DSO and system planners are provided real-time data. At a minimum, increased training for providers on how patients with dual diagnosis can be identified within the current systems would be beneficial. Data are also needed to evaluate and optimize the different housing, clinical service and funding models.

2. Clear, consistent processes and pathways

Accessing funding, resources and services in both the health and developmental service sectors can be confusing and inconsistent. Establishing clear, transparent, streamlined and consistent processes is crucial for improving efficiency and reducing inequity in how resources are approved and allocated.

3. Flexible policies to support shared/overlapping care

Our environmental scan and consultations consistently identified the importance of having a period of overlapping care between community and hospital providers. This includes opportunities, as appropriate, for community providers to get to know the patient while they are still in hospital, receive training and share knowledge with the hospital team. It can also be valuable for the patient to visit their new home and participate in community programs before discharge, and for the hospital team to provide a period of ongoing post-discharge support to the patient and their new providers. Currently, hospital and community agency policies do not always support or permit these activities.

4. Capacity and funding for housing and clinical services

Currently, there is a lack of appropriate housing available in Ontario and without appropriate housing, transitioning from hospital to community is impossible. There is also insufficient access to health care providers with the necessary training to support people with a dual diagnosis within both the hospital and community sectors. The developmental services and health care systems are facing a broader human resources crisis for which there is no easy solution. Nevertheless, important steps include providing increased training opportunities and funding for community mental health teams for patients with a dual diagnosis. Each hospital should have at least one staff member with familiarity with this population who can be a resource to other hospital staff and help identify other community resources who can provide support. Additionally, there should be a mechanism in place to prioritize this population for access to team-based primary care.

5. Training

Though not everyone can specialize in dual diagnosis, hospitals and community health care providers should at a minimum require training on how to identify patients with a dual diagnosis, provide appropriate care and access specialist consultation. Similarly, developmental service providers need training on how to support the health of people with a dual diagnosis. Training should include the transition core components in this report. There are evidence-informed training resources and models available[56] as well as lessons on mandated training that can be learned from other jurisdictions.

Patients with a dual diagnosis and their families also need accessible resources to help them understand their health conditions and how to access supports. Evidence suggests that providing them with training and support can improve their mental well-being.[81,82]

6. Tools and templates

Tools and templates need to be identified or developed to operationalize the transition core components. Key tools that would be helpful include a standardized Transition and Community Support Plan template, an easy read version of the Transition and Community Support Plan and a standard comprehensive assessment package. Some hospitals and agencies have developed versions of these tools that could potentially be used more widely. The SHEDD tool is a newly developed resource to support housing design that we recommend be adopted.

Ultimately, the problem of ALC patients in hospitals is a symptom of broader systemic issues. Addressing this problem requires not only focusing on existing ALC patients, but also preventing people from becoming ALC in the first place. Many of the transition principles and components described in this report, if made available to people prior to hospital admission as well as once hospitalized, could help avoid some unnecessary hospitalizations and prevent people who are hospitalized from becoming ALC. To achieve this, we need to focus on training health care and developmental service providers, investing in appropriate housing, creating collaborative partnerships and implementing systems to identify and flag people who are at risk of crisis to support proactive responses.

With the right resources and systems in place, it is possible to avoid many of the tragic stories we heard in the process of developing this report and support individuals to live safe, fulfilling lives in the community.

“

Until you are in that situation, you don’t realize there is not much out there. And you can’t plan for it. John being in a home was not part of our parents’ plan or the route we wanted to take but you have to be open to change your mind. We all wanted what was best for John to lead a self-fulfilling life.

- *Family member of a former ALC patient*

”

“

We were fortunate to have a lot of angels in our corner surrounding us with what I wanted to see for my son and setting him up for success. Not the norm, but it is his norm.

- *Family member of a former ALC patient*

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Appendix A

Key documents reviewed from environmental scan

Ontario

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Appendix B

Table B1

Alignment between original Ontario Health Quality Standards and adapted Dual Diagnosis ALC core components

Original HQ standards	DD ALC core components
1. Information sharing on admission	1. Ongoing information sharing
2. Comprehensive assessment	2. Comprehensive assessment
3. Patient, family and caregiver involvement in transition planning	3. Patient and family involvement in transition planning
4. Patient, family, and caregiver education, training and support	4. Patient, family, and community provider education, training and support
5. Transition plans	5. Transition and Community Support Plan
6. Coordinated transitions	6. Graduated, overlapping and coordinated transitions
7. Medication review and support	7. Medication review and support
8. Coordinated follow-up medical care	8. Coordinated follow-up medical and clinical care
9. Appropriate and timely support for home and community care	9. Appropriate and timely housing and community support
10. Out-of-pocket costs and limits of funded services	10. Sufficient and flexible funding