

2024

Dual Diagnosis Alternate Level of Care

Vignette Series



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Dual Diagnosis

Alternate Level of Care

Vignette Series

The journey from hospital to home can be a significant challenge, especially for individuals with a dual diagnosis, which means they have both a developmental disability and a psychiatric condition. This group faces a higher risk of being designated as Alternate Level of Care (ALC). An ALC designation is given when patients no longer require hospital-level care but remain there, sometimes for extended stays, due to a lack of appropriate community settings and support. This situation not only adversely affects the ALC patient but also results in delays for other patients in need of hospital resources.

The Azrieli Adult Neurodevelopmental Centre's H-CARDD team, in partnership with CAMH's Provincial System Support Program, developed practice guidance on how to support ALC patients with a dual diagnosis to successfully transition out of hospital and into the community. As part of the process, we spoke with individuals with a dual diagnosis and their families who have experienced an ALC hospitalization.

In this document, you will find the stories of six of these individuals. Through their experiences and those of their families, we can understand some of the obstacles they faced and the strategies that paved the way to a successful transition. While the experiences of these individuals were far from perfect, they were guided by some key elements that made their transition smoother. Each story concludes by highlighting how these key elements align with the core components detailed in *[Supporting alternate level of care \(ALC\) patients with a dual diagnosis to transition from hospital to home: Practice guidance](#)*.

The team wishes to express sincere appreciation to the individuals, their family members, and service providers, who generously shared their stories with us. In most of the following vignettes, pseudonyms have been used to safeguard the identities and privacy of the individuals involved. You can also view all the vignettes online at EENet.ca.



Amanda's Story

"It took more than a year for Amanda to finally move into her apartment. The barriers we faced included insufficient expertise in developmental disabilities within the hospital staff, lack of a centralized process to find housing, and delays getting the budget approved."

- Sarah, Amanda's stepmom

Amanda and her parents Robert and Sarah

“They should respect people.”

– Amanda

Who is Amanda?

Amanda, a sociable young woman in her 30's, has an intellectual disability, a physical disability and a number of physical health concerns related to her genetic condition. She sometimes has trouble understanding time and money concepts, organizing her belongings, and detecting when people are taking advantage of her. Quiet-spoken and easy-going, she always wants to please the people around her. She loves arts and crafts, conversing with friends, cooking, watching movies, and playing wheelchair basketball. After her mother died in 2016, Amanda was diagnosed with depression, for which she received medication and psychotherapy. Then in 2019, she started having seizures. These episodes became progressively more severe which required her to be hospitalized several times. In May 2021, Amanda, who was living with her father and stepmother, Robert and Sarah, suffered a series of particularly severe and prolonged seizures. After a number of brief hospitalizations and unsuccessful discharges, Amanda was ultimately hospitalized for 16 months.

What led to Amanda's hospitalization?

At first, Amanda was admitted to the neurology unit of the hospital, where a video EEG determined that her seizures were non-epileptic. The hospital discharged her multiple times, but with no success - some of these discharges lasted only a few hours before she had another severe seizure and was readmitted. Prior to her final hospitalization, her father incurred an injury that required surgery while trying to prevent Amanda from falling during a seizure. After Amanda was readmitted, the neurologists indicated that they could not treat her and transferred her to the psychiatry unit.

How did things change for the better for Amanda?

The psychiatry team tried different medications to treat Amanda, but the seizures continued. After a month, the doctors asked her family to take her home. Robert and Sarah contacted their local home and community care centre to inquire about getting emergency on-call or in-house 24/7 support for Amanda. However, the centre could only offer one hour of support per day, which was not enough help to keep her safe. In spite of persistent requests from the psychiatry team to bring Amanda home, due to the combination of insufficient support and Robert's injury, Robert and Sarah refused. After three months in the psychiatry unit, and with no suitable supportive housing options available, she was moved to a reactivation centre affiliated with the hospital. Reactivation centres are facilities that provide care for patients who no longer need acute care but are waiting for an appropriate community placement. These settings are not designed for people with developmental disabilities. Amanda only received medication management and was not given any non-pharmacological treatment such as IV rehydration for her seizures, physiotherapy, speech and language therapy or a specialized diet for her diabetes. Social workers from the hospital, reactivation centre and local home and community care centre tried to convince Robert and Sarah to accept inadequate housing options such as boarding houses and shelters. However, Amanda's parents, horrified at the idea of her living in settings that were not able to meet her needs and keep her safe, refused these placements threatening to contact politicians and the media if she were discharged to one of them.

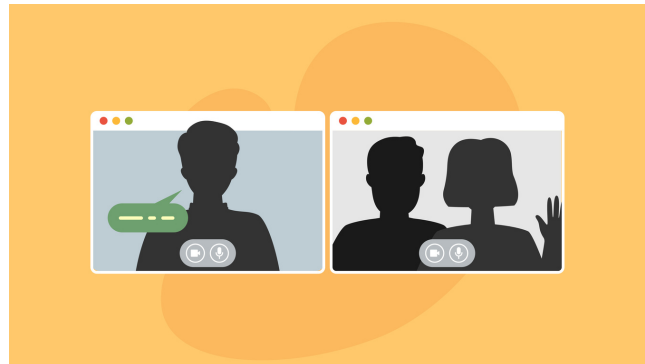
"It took more than a year for Amanda to finally move into her apartment. The barriers we faced included insufficient expertise in developmental disabilities within the hospital staff, lack of a centralized process to find housing, and delays getting the budget approved."

- Sarah, Amanda's stepmom

What were the challenges hindering Amanda's return to the community?

Thankfully, Sarah was an experienced advocate. She consulted a professional who had previously worked with Amanda and obtained a referral to a Complex Care Coordinator with the Community Networks of Specialized Care (CNSC).

The coordinator convened a team from multiple agencies to determine the type of support Amanda would need and to search for suitable housing options. The coordinator also chaired regular inter-agency planning meetings in which Robert and Sarah participated. Although Amanda was invited to join as well, she typically chose not to.



Due to the COVID-19 pandemic, the meetings were conducted virtually, which made it easier for everyone to participate. After a three-month search, the coordinator found an accessible apartment for Amanda. Over the next nine months, a budget was developed and approved and staff were hired and trained. Amanda and her parents visited the apartment before she moved in and the coordinator worked with agency staff to facilitate and support the transition of her care. Following an extensive 16 month stay in the hospital and reactivation centre, Amanda was finally able to move into her new home.

How is Amanda doing post-transition?

Amanda now lives in a fully accessible high-rise apartment building, located fairly close to her parents' home. Her housing is considered "intensive support", which means that Amanda receives individualized and flexible support 24/7 and can make choices about most aspects of daily living and recreation. She has a team of agency support workers who help her with adaptive skills and who care for her when she has a seizure. Throughout this process, Amanda has received support from her family physician and psychologist, who have diligently evaluated and updated her medications while offering psychotherapy sessions. In addition, after considerable advocacy by Sarah and Robert, the local home and community care centre provides a nurse to give intravenous hydration when seizures last for 36 hours or more, and paramedics have special permission to bring Amanda home instead of the hospital if she has a seizure while in the community.

Amanda likes her apartment and, since moving in, has established a good routine. She and her family are very satisfied with the quality of the support that she receives, which allows her to live in the community and do the activities she enjoys. Her mental health has also improved and she has a great relationship with her roommate. She goes out for walks and lunch in her neighborhood, meets with friends, and attends multiple programs doing things that she loves.



Notwithstanding these successes, Robert and Sarah have ongoing concerns for Amanda's physical health – she continues to have frequent and severe seizures, and the gastrointestinal problems associated with her genetic syndrome have worsened. Although getting the health care she needs will continue to be challenging, Amanda's support team actively advocates for better health care on her behalf.

What key components helped with Amanda's hospital-to-community transition?

Amanda's successful transition from hospital to community was facilitated by several crucial elements. These elements align with some of the 10 core components identified in the practice guidance document.

Component 1 - Ongoing information sharing - Although hospital and reactivation centre staff were not always able to participate, biweekly meetings were held with Robert, Sarah and the community health and developmental service providers involved in Amanda's transition to share clinical updates and explore possible placement options.

Component 3 - Patient and family involvement in transition planning - The family was routinely involved in transition planning meetings and Amanda was invited to join, though she typically chose not to. Additionally, her parents tirelessly advocated to obtain the best care and housing options for their daughter. The family firmly believes that their active involvement and advocacy played a crucial role in aiding Amanda's successful transition from the hospital to the community.

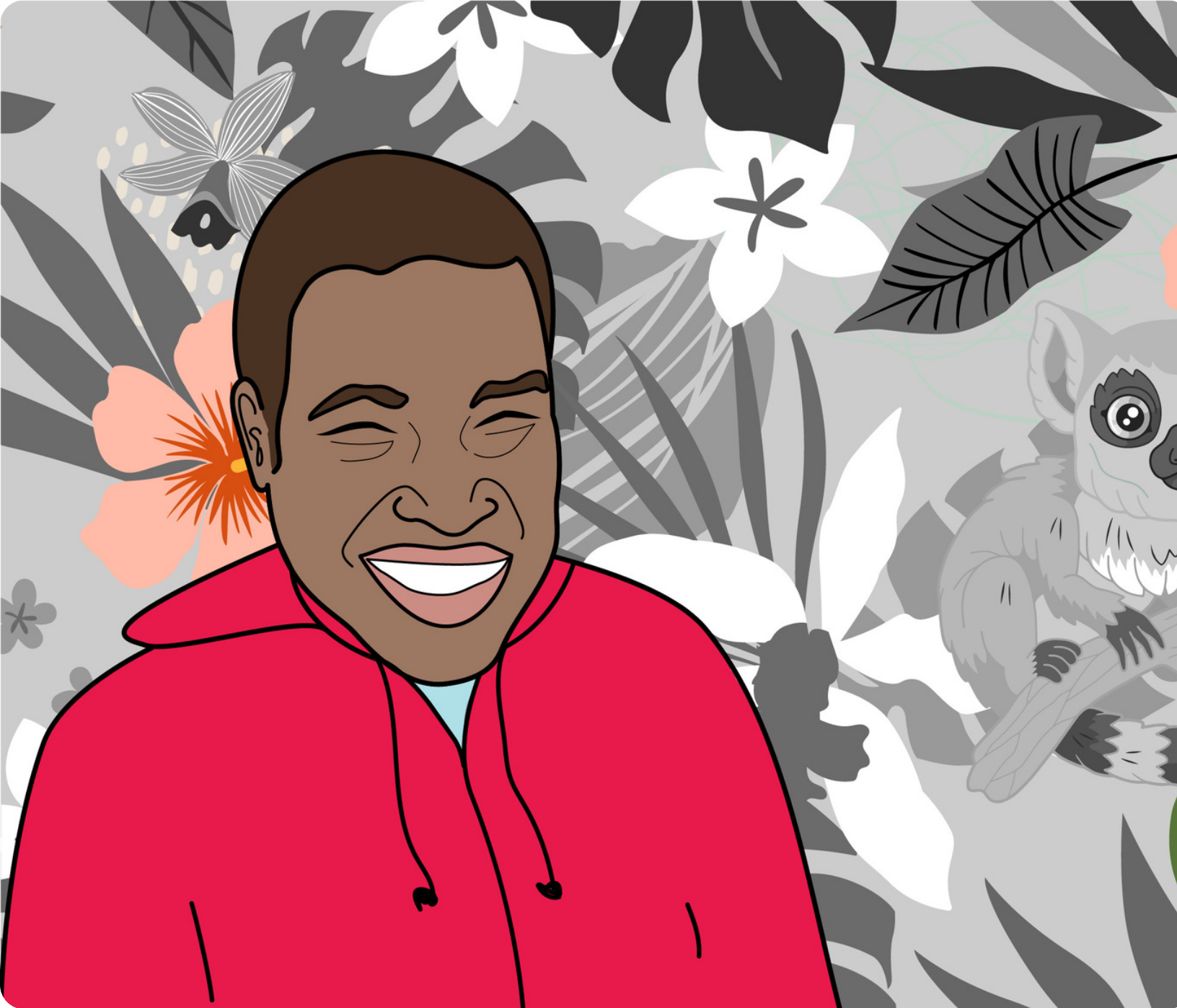
Component 4 - Patient, family and community provider education, training and support - The support staff at Amanda's apartment building received training on safely managing her seizures at home, instead of sending her to the hospital.

Component 6 - Gradual, overlapping and coordinated transitions - The involvement of a range of specialized staff, including a Complex Care Coordinator with the CNSC and the developmental services agency providers, were instrumental in driving the planning process forward. These individuals knew who to contact to make things happen. They met with Amanda at the reactivation centre, supported her in visiting her apartment before moving in and provided ongoing support after the move. In addition, an outpatient psychiatrist from the hospital followed Amanda for a few months after she moved from the hospital to the reactivation centre.

Component 8 - Coordinated follow-up medical and clinical care - Amanda has a number of health care providers who ensure she receives the care she needs in the community. This includes a family physician and a psychologist who have worked with Amanda for 15 years and local home and community care centre nurses who can provide intravenous rehydration in cases where Amanda's seizures last for three or more days. A senior member of Amanda's support team is active in ensuring that medical care is provided.

Component 9 - Appropriate and timely housing and community support - Though it took some time to get in place, Amanda's current housing and supports are excellent. Her home environment provides her with access to continuous, individualized support, as well as programs to engage her in a meaningful and fulfilling way.

Component 10 - Sufficient and flexible funding - Based on Amanda's health and community support needs, the transition team put together a budget proposal, which was approved by the government. This allowed Amanda to have the right kind of home with the right level of support to allow her to live safely in the community.



Taydon's Story

"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."

- Denise, Taydon's mother

Taydon and his mother Denise

Who is Taydon?

Taydon is a very outgoing young man in his early thirties who enjoys spending time with his family and friends. Taydon's life is full of simple pleasures, such as the joy of shopping, watching movies and going for walks. His favourite movie is "Madagascar" and the iconic tune "I Like To Move It" is his ultimate favourite song that gets people dancing while Taydon claps his hands with joy!

Taydon's favourite day of the week is Sunday when his mother, Denise, and younger brother, Anderson, often come to visit. Taydon has a developmental disability and is a man of few words. Despite this, he can communicate by pointing to symbols and pictures. Prior to being in the hospital, Taydon lived with Denise and Anderson, supported by caregivers who would visit his home.



Unfortunately, in 2016 medication changes led to heightened aggression and seizures that became unsafe for Taydon and his family. This ultimately led to a 12-month stay in a large urban hospital.

What led to Taydon's hospitalization?

In 2016, Taydon experienced seizures that sent him to the emergency room for three weekends in a row. The medical team tried changing his medications to stop the seizures, but Taydon's condition kept worsening. He was experiencing toxicity to his medication, which caused additional seizures and made him unable to control his movements. When he returned home, Denise became increasingly worried. Nobody in the family could manage his seizures, which were happening more frequently, and his behaviors were posing a danger to himself and Anderson.

These incidents were traumatic for Taydon and his family. At some point, Taydon became so lethargic that Denise called an ambulance for him. Ultimately, Taydon was admitted to the hospital.

What were the challenges hindering Taydon's return to the community?

It took a long time for the medical team to diagnose Taydon's condition and stabilize him with a new medication regimen. The repeated seizures and medications had left him so weak that he started using a wheelchair and wearing a helmet to keep him safe. During this period, his individualized funding (Passport funding) was used to bring support workers into the hospital. However, the funding wasn't enough to meet Taydon's needs, and Denise ended up paying out of pocket to ensure Taydon had the support he needed.



Following a six-month stay in hospital, Taydon was stabilized. However, given her son's fragile state, Denise knew that Taydon returning home was not an option. The hospital tried to secure different placement options for him, but due to lack of funding none of them could provide the types of support that he needed. As a result, he remained in hospital for another six months.

“More essential services and funding is needed. Not less! It's never enough!”

– Denise, Taydon's mother

How did things change for the better for Taydon?

After some strong collaborative advocacy, a team was assembled that included the hospital and different agencies from the developmental sector. This team took the time to get to know Taydon and understand his community support needs in order to develop a transition plan.

Taydon and his mother were always included in the meetings. Meanwhile, a worker from a developmental service provider helped Taydon join a day program so he could receive stimulation and begin re-engaging with the community while he was in hospital. In January 2017, the team secured a temporary placement for Taydon. Denise organized and painted her son's room to prepare for his move and Taydon had an opportunity to visit and become familiar with his new home before moving in. This transitional home allowed Taydon to experience living in a community setting while his team and family continued to search for a permanent placement. The hospital staff as well as workers from the developmental service provider went to see him regularly to ensure that he was adapting well to his new home. In summer 2022, Taydon finally was able to move to his forever home, a 2-bedroom unit in a large urban centre not far from his family.

“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.”

– Denise, Taydon's mother

How is Taydon doing post-transition?

Taydon is extremely happy with his current living situation, and Denise is equally thrilled and happy for him. Taydon is healthy and thriving. He gets along well with his roommate, who is only a few years older than he is and they share many of the same interests. He has access to two support staff at all times who have worked with him to build back his physical strength. He continues to attend his day program and his individualized funding (Passport funding) allows him to be out in the community with one-on-one support. In addition, he has a fantastic team of providers supporting his physical and mental health. Taydon continues to have regular appointments with the hospital neurologist and receives excellent support from his longtime family health team (a primary care model where a family physician works together with a multidisciplinary team).

What key components helped with Taydon's hospital-to-community transition?

Taydon's successful transition from hospital to community was facilitated by several crucial elements. These elements align with some of the 10 core components identified in the practice guidance document.

Component 3 - Patient and family involvement in transition planning - All transition planning meetings included Taydon and his mother Denise. Denise played a key role in ensuring her son received the care and supports he needed. She strongly advocated for her son to attend a day program while he was hospitalized, which he still attends today.

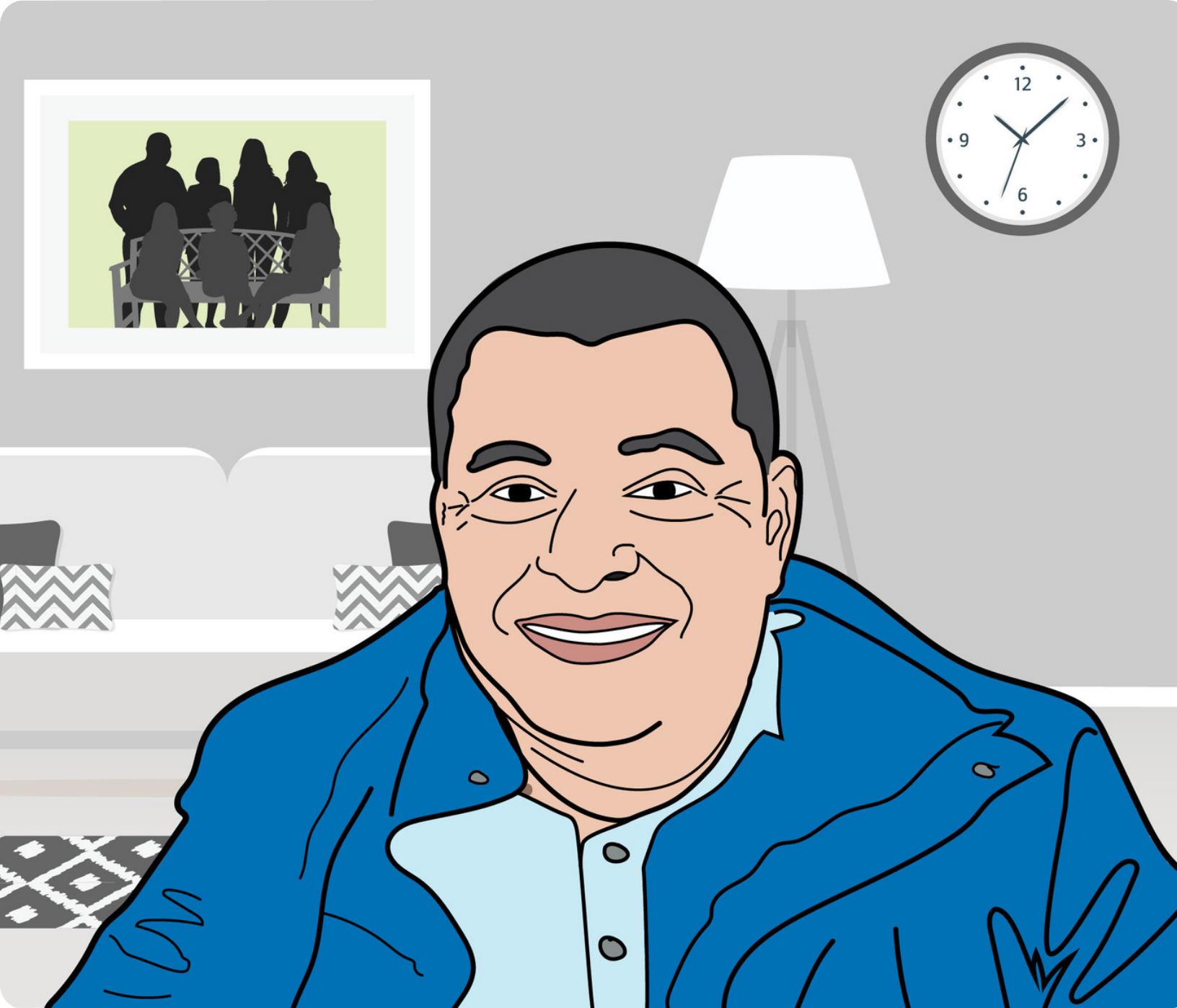
Component 5 - Transition and Community Support Plan - A multidisciplinary team including hospital and community representatives worked together to develop a comprehensive transition plan and secure a housing situation that matched Taydon's medical and community support needs.

Component 6 - Graduated, overlapping and coordinated transition - Taydon's transition was supported by a strong collaborative team including partners from the hospital and different agencies from the developmental sector. This team facilitated a graduated and overlapping transition, including opportunities for Taydon to visit his new home before moving in and ongoing support from the hospital team after Taydon moved to ensure he was adjusting well to his new home.

Component 8 - Coordinated follow-up medical and clinical care - Even after Taydon transitioned out of hospital, his medical team stayed the same. He continues to see the hospital's neurologist and his longtime family doctor, who works within a family health team. Family health teams include interdisciplinary providers (e.g. nurses, dietitians, social workers) that work together with family doctors to provide comprehensive primary care.

Component 9 - Appropriate and timely housing and community support - Although it took some time to get there, Taydon ultimately ended up in a home that is right for him. Taydon's permanent placement allows him to have access to continuous support from staff and day programs. He has a roommate he gets along with and he is only a 20-minute drive away from his family, allowing for weekly visits with his mom and leisurely drives through the neighborhood.

Component 10 - Sufficient and flexible funding - Funding was essential in finding Taydon a transition placement and then a permanent home. Passport funding was also important to cover some of the cost of the additional staff supports Taydon required while hospitalized, though it fell short of covering the full cost.



John's Story

“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.”

- Isabelle, John's sister

John and the Acosta family

Who is John?

The Acosta family forms a tight-knit clan. They have always looked out for each other, especially for their younger brother, John. John, 50 years old, is autistic and has an intellectual disability. He is incredibly outgoing, sociable and full of love for his three siblings. John has a great sense of humor and often has everyone around him laughing. He is respectful, kind and compassionate. In his free time, you can find John enjoying the company of family and friends, watching sports, bowling, going to the movies and playing soccer. John was living at home with his mother in a large city in Ontario before he was hospitalized in September 2022 and became an ALC patient. He spent two months in hospital before moving to a private transition home paid for by his family.

What led to John's hospitalization?

When the COVID-19 pandemic started, John's regular day program was shut down, and that affected him tremendously. His mental state started to deteriorate. In March 2022, John's father passed away, which led to a rapid decline in his mental health. He started to experience intense fear, phobias and anxiety, and his behaviour at home became increasingly aggressive. This situation became unsafe for both John and his mother. By September 2022, things became so challenging that John ended up in the emergency department though he was sent home without being admitted. One week later, because things were no better, he returned to the emergency department and was subsequently admitted to a mental health unit for two months.

What were the challenges hindering John's return to the community?

John was seen by the inpatient psychiatrist who made adjustments to his medication, but his distress and aggression continued. After being hospitalized for two months, the hospital determined that John no longer needed treatment.

John's family was told that he needed to leave the hospital and that if they couldn't take him home, they would discharge him to a shelter. The family was shocked at the thought of John being placed in a shelter without appropriate care. Moving back home with his elderly mother was not a viable option so they scrambled to find an alternative solution. A couple of meetings were held with the hospital social worker, in-patient psychiatrist, family doctor and his developmental services caseworkers.



With the assistance of John's developmental caseworkers, the family managed to find a temporary placement at a private transition home. However, this home was located an hour away from where the family lived and they had to pay an exorbitant cost of \$18,000/month. John stayed there for three months.

“With no outpatient plan in place, no transition team from the hospital and no funding available to support him in transitioning into a home, we were trying to find ways to survive through instability and fear.”

– Susan, John's sister

How did things change for the better for John?

The Acosta family was determined to find the right forever home for John. They wrote letters to their government representatives and to the Ontario Ombudsman, the organization responsible for investigating complaints about government and public sector bodies. In these letters, they explained what had happened to their brother and advocated for increased support not only for John but also for other people like him who are stuck in hospital with no safe and affordable home to transition to.

They asked for help from two local specialized developmental services organizations to find him a permanent, affordable placement. Both organizations were very supportive in actively searching for housing options for John. Finally, after three months in the private transition home and with collaborative effort from the family and the two community organizations, they were able to secure a permanent placement.

How is John doing post-transition?

John now lives in a publicly funded group home located close to his family, with five housemates who are also autistic and have intellectual disabilities. Since moving into his home, John is happy and progressing well. His phobias and obsessions have decreased and he is able to focus and redirect his thoughts with help from staff. He has resumed his daily routines, including attending a new day program.



John is most happy about the wonderful friendships he has made with his housemates as well as all the great support staff. His family could not be more happy and relieved about his current living situation. John's transition was supported by a specialized developmental service provider team and they continue to provide support as needed. John's health and mental health are also supported by his family doctor and psychiatrist. The support from the incredible staff has ultimately been the most important factor in his successful transition. For the Acosta family, however, the fight is not over. Together with their extended family, they have established a charity with the goal of raising awareness about ALC care issues and empowering adults with autism and mental health challenges to overcome barriers and reach their full potential.

“Finding his forever home would not have been possible without the incredible support received from our caseworkers at the developmental service agencies. They were always there for us, every step of the way, providing insights, empowering and educating us. Together with the staff at the home, we collaborated and worked in partnership to find a suitable home for him. We shared the same goal and vision – for him to be settled in a home where he would be cared for and have the opportunity to lead a fulfilling life.”

– Maria, John's niece

What key components helped with John's hospital-to-community transition?

John's successful transition from hospital to community was facilitated by several crucial elements. These elements align with some of the 10 core components identified in the practice guidance document.

Component 1 - Ongoing information sharing - The Acosta family had regular meetings with the specialized developmental service provider teams, which accelerated the process of finding John a permanent home. Although there were several meetings with the hospital social worker and his community caseworkers, it was unfortunate that a more consistent process was not put in place while he was in the hospital. It was ultimately the caseworkers who diligently searched for and found a home for John.

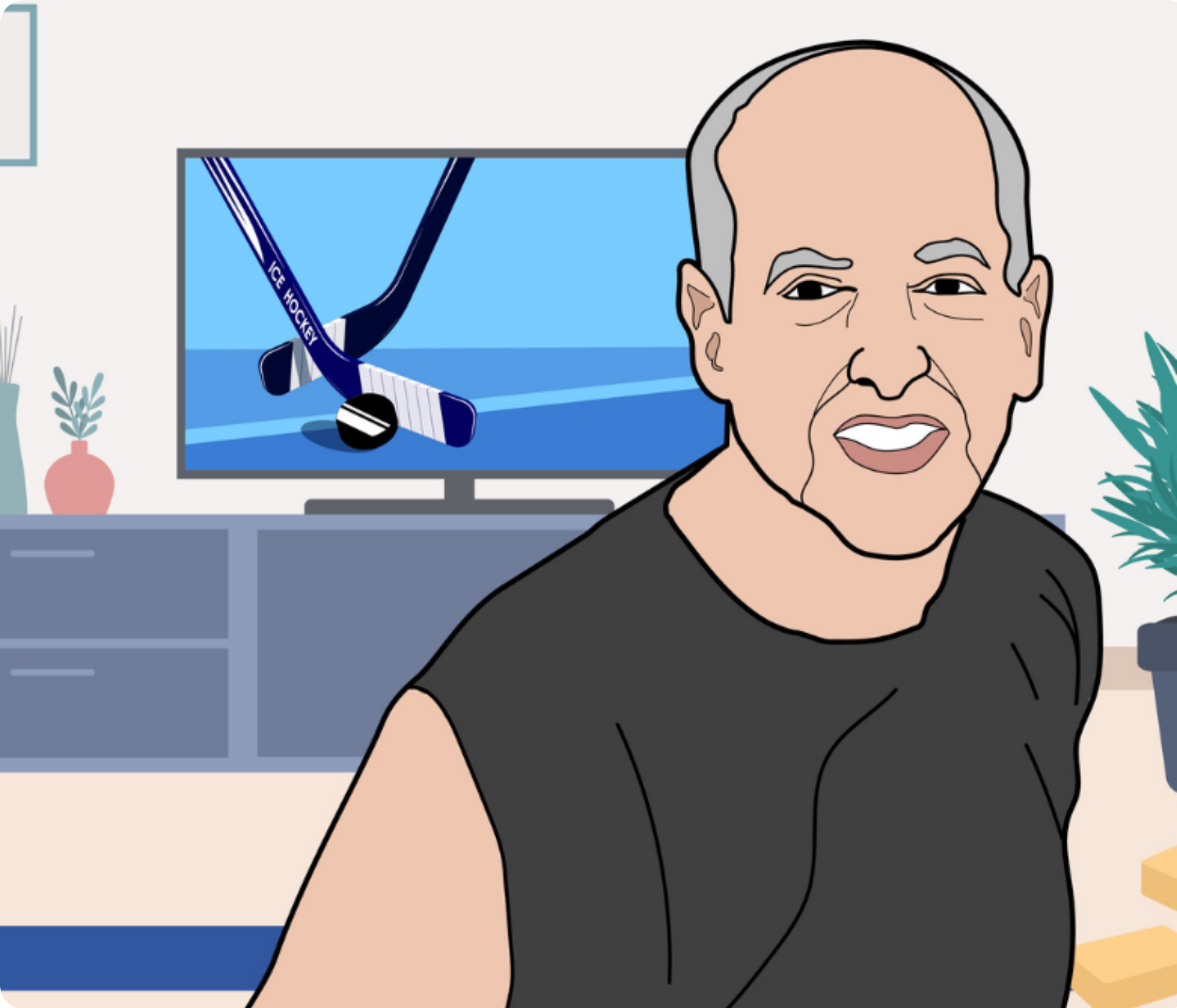
Component 3 - Patient and family involvement in transition planning - John's family was actively involved in John's care and in searching for and vetting housing options for him. This is important as he now lives close to his family so that they can continue to be very involved in his life.

Component 7 - Medication review and support - John has a family doctor and psychiatrist who, along with input from the specialized developmental service provider team, have been actively managing his medications while living in the community.

Component 8 - Coordinated follow-up medical and clinical care - John's long time family doctor continued to follow him and provide the family support throughout his hospitalization. Since moving into his new home, John is being seen by a new family doctor who supports everyone in the home and he also has a new psychiatrist supporting him in the community. Throughout the transition process, John was also supported by a specialized developmental service provider team and they continue to be available as needed to provide support.

Component 9 - Appropriate and timely housing and community support - Although it took some time to put in place, John now resides in a publicly funded group home, carefully selected to cater to his needs and preferences, and located in close proximity to his family. The environment, alongside his compatible housemates and dedicated staff, has helped to significantly reduce his phobias and obsessions, allowing him to regain a sense of belonging and comfort.

Component 10 - Sufficient and flexible funding - The cost of private housing was prohibitively expensive for his family and was not a sustainable option. Securing a publicly funded home that was appropriate to meet his needs was a critical factor in allowing John to continue living in the community.



Jordan's Story

“Everyone in his family is completely gone. He will say “don't leave me”. He believes if he acts a certain way he may be taken away, like he felt he was with his mother.”

- Residential supervisor

Jordan and his cousin Leo

Who is Jordan?

Jordan, a 54-year-old man with a developmental disability, has experienced a life journey characterized by love, loss and unwavering support. Though he is not very talkative, he is an outgoing, social and nurturing individual. During his free time, Jordan enjoys doing yoga, playing baseball, and indulging in his favourite pastime - watching hockey on television. Jordan and his older brother Stephen, who also had a developmental disability, lived together with their mother until she passed away in August 2021. Unable to care for themselves after her death and with no safe living alternative, they ended up in the hospital where Jordan remained for over a year.

What led to Jordan's hospitalization?

Jordan's mother, who did her best to raise and support her sons, also lived with her own mental health challenges. The three of them lived a fairly isolated life in subsidized housing, with little involvement from other family members or support services. In early 2021, Jordan's mother fell ill and was hospitalized for months, leaving the brothers to take care of themselves for the first time. Sadly, shortly after returning home, she passed away, leaving the brothers alone and bewildered. Social services became involved after a neighbour realized what had happened and emergency first responders were called. In August 2021, Jordan and Stephen were admitted to a hospital.

What were the challenges hindering Jordan's return to the community?

The hospital psychologist's assessment confirmed that the brothers had significant disabilities and were not capable of managing their own affairs. This assessment led to a referral for both brothers to their local DSO (Developmental Services Ontario, the central intake for developmental services) which confirmed the psychologist's conclusions.

Jordan's second cousin, Leo, who hadn't seen Jordan or his brother in 20 years, was contacted and stepped up to support them. In September 2021, after two months in hospital, the brothers were deemed ready for discharge but returning to their home alone was not an option. With nowhere else to go, the brothers were transferred to the hospital's reactivation centre, where people can stay when they no longer need acute care but there is no appropriate discharge option.



How did things change for the better for Jordan?

Once Leo became involved, one of the first things he did was reach out to a local developmental service provider to help find a home for Jordan and his brother. The developmental service provider, working closely with Leo and the hospital team, played a critical role in developing a transition plan and ultimately finding a home where the brothers could stay together, though it took some time to get there. While the hospital social worker tried their best to help, the agency's in-depth understanding of the developmental sector proved pivotal.

From September 2021 to April 2022, the reactivation care center became the brothers' new home. Though it was not the ideal environment, the reactivation center provided a sense of safety and the brothers had positive relationships with the staff. The nurse practitioner played a pivotal role in overseeing various aspects of his care and regularly communicated with Leo.

The brothers were placed on a waitlist for long-term care but because everyone agreed that it was important to keep the brothers together, a placement wasn't readily available. This gave the developmental service agency time to find emergency funding and the 24/7 staff needed to transition Jordan and his brother to a more appropriate setting.



In April 2022, Jordan and his brother were able to move to an apartment with 24-hour supervision supported by the local developmental service provider. Sadly, just a week after moving in, Jordan's brother was hospitalized for cardiac arrest and ultimately, passed away. In June 2022, Jordan moved into a supported three-bedroom apartment with two roommates and 24/7 support.

“The developmental service agency took us by the hand and led us through. Without them this would not have happened. They were able to guide us and streamline things. They would call and advocate for Jordan's special needs. They were like the case planner, hospital social worker, all in one.”

– Leo, Jordan's cousin

How is Jordan doing post-transition?

Jordan has transitioned successfully to his new home. Despite the tremendous grief he has experienced with the losses of both his mother and his brother, he remains socially engaged and maintains a happy disposition. He enjoys socializing with his peers, attending developmentally appropriate and stimulating programs, and interacting with staff.

His life is now much less isolated than before and he seems to be benefitting from new opportunities. The developmental service provider accompanies him to his medical appointments, and a nurse from the home care team conducts regular check-ups. While there have been a few bumps in the road and the need for continued care, he's been able to stay connected with his community.



Recently, Jordan's mental health deteriorated, which led to some distressed behaviours. Thankfully, his family doctor made sure he got the support he needed, which included a hospital visit, and he was able to return home quickly.

What key components helped with Jordan's hospital-to-community transition?

Jordan's successful transition from hospital to community was facilitated by several crucial elements. These elements align with some of the 10 core components identified in the practice guidance document.

Component 1 - Ongoing information sharing - The developmental service agency social worker and team were diligent and took the lead in consistently providing ongoing communication and updates to Jordan and his cousin Leo. The nurse practitioner at the reactivation center maintained regular contact with Leo to keep him informed of Jordan's condition.

Component 2 - Comprehensive assessment - Upon Jordan's admission to the hospital, he received a developmentally-informed assessment. This comprehensive assessment paved the way for a referral to the DSO, which corroborated the psychologist's findings. Ideally, this assessment process is started upon admission, as it was in Jordan's case, so this information can inform a customized transition plan and help optimize the transition process.

Component 3 - Patient and family involvement in transition planning - Staff from the reactivation center and the developmental service provider worked closely with Jordan and his cousin Leo to find a home that best suited Jordan's needs. They advocated on Jordan's behalf in rejecting inappropriate offers like nursing homes to make sure they found a place that would best fit Jordan's needs and his cultural values.

Component 6 - Graduated overlapping and coordinated transitions: The staff members from both the reactivation center and the developmental service provider went the extra mile to ensure that Jordan had a smooth transition into his new home. The staff who were going to be supporting Jordan in the community spent time with him while he was still in the hospital so they could get to know each other and help Jordan feel more comfortable after he moved home. Additionally, staff from the reactivation center went with Jordan to help him move into his new home and provide some familiarity during the transition.

Component 8 - Coordinated follow-up medical and clinical care - Now that Jordan is in the community, he continues to get the health care that he needs. The developmental service provider takes Jordan to all his medical appointments and he receives ongoing support from a home care nurse.

Component 9 - Appropriate and timely housing and community support - Though it took some time, Jordan ultimately was able to get a placement in a home that meets his needs. He is surrounded by a community that not only respects his cultural values, but also offers attentive staff who provide unwavering support.

Component 10 - Sufficient and flexible funding - Emergency funding secured by the developmental service provider allowed Jordan and his brother to move to a fully supported living arrangement with 24/7 supervision while awaiting access to a more permanent, funded residential opportunity.



Monique's Story

"You need to believe in yourself that you can do it. Have confidence in yourself. Because it is really hard."

- Monique

Monique and her mother Kathy

Who is Monique?

Monique is a young Francophone woman in her early 30's who has always kept herself busy with multiple hobbies and activities. She loves to swim, regularly walks the family dog in her neighborhood and enjoys going to the movies with her support staff. Monique has a great sense of humour, is very sociable, and is good at expressing herself in French and English. Monique, who has a moderate developmental disability and is in remission from an autoimmune neuromuscular disorder, used to live with her parents in the Eastern region of Ontario prior to her ALC experience. In 2021, after a series of emergency department visits and brief hospitalizations, she was admitted to a mental health unit where she stayed for eight months.

What led to Monique's hospitalization?

Though her family was unaware at the time, in January 2019, Monique experienced a distressing incident involving a support worker that greatly affected her emotionally. Following this, Monique's mental health rapidly deteriorated, leading to frequent meltdowns, self-harm, suicidal thoughts and attempts. In October 2019, Monique was finally able to share with her family and the police what had happened ten months prior, but no charges were filed, leaving Monique devastated. Despite having supports in place, including a specialized dual diagnosis mental health team and a Francophone psychotherapist, her mental health continued to deteriorate and Monique had multiple short-term hospitalizations. During the pandemic, support workers were unable to work due to public health restrictions, so Monique's sister quit her job to provide care. However, Monique's aggression and suicidal thoughts intensified and in May 2021, she was admitted to the mental health unit of an English-language regional hospital.

What were the challenges hindering Monique's return to the community?

Stepping into an English-only hospital environment, Monique and her family encountered a language barrier. Only two nurses on staff were able to communicate fluently in French.

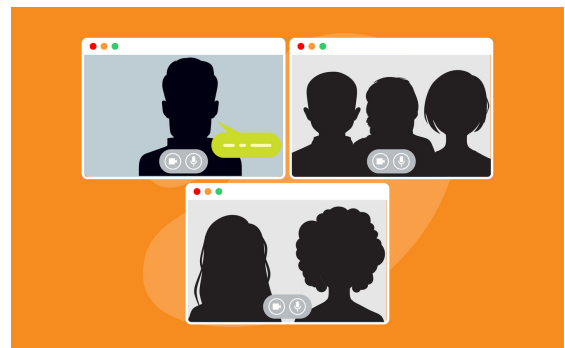
This led to challenges trying to manage communication between the hospital and the French-language developmental service agency involved in Monique’s care. With no other option, Monique’s family took on the role of translators, ensuring that she received the care and attention she needed. When the unit called Monique’s parents to pick her up three days after her hospitalization, they refused with great heartbreak. The hospital considered discharging her to a shelter, but her mother, Kathy, drawing from her experience in the social services sector, advocated for Monique’s unique needs. Fortunately, a psychiatric nurse on the dual diagnosis team helped prevent this inappropriate discharge. Monique remained in hospital and was designated as ALC.

How did things change for the better for Monique?

The ALC designation unlocked additional resources, due to a new initiative by the Ministry of Children, Community and Social Services (MCCSS) for ALC patients. This initiative provided emergency funding to the regional Francophone agency to support Monique’s transition to residential care.

Monthly transition planning meetings were held virtually with the family, the community mental health and developmental services agencies and the hospital psychiatric social worker. Monique attended at times as well. The social worker and the Francophone community agency supervisor who had been involved with Monique since August 2019, organically assumed the role of co-leads in this process.

After two months in the hospital, Monique and her family had the opportunity to visit a potential host family. Host families enable individuals with a developmental disability to live in the community by providing them a private home environment and the support of a caring family.



However, Monique did not feel comfortable there. The hospital and the developmental services agency respected Monique's decision. As no families were available within the agency, a new host family was vetted, a very time-consuming process made even lengthier by the pandemic. Finally, after eight months in the hospital, Monique was able to move in with her new host family in December 2021.

Unfortunately, the assigned hospital psychiatrist chose not to be involved in this process, nor did he contact Monique's community psychiatrist with the specialized mental health team. This lack of involvement led to repercussions after Monique's discharge, when it was discovered three days before Christmas that there were no repeats on her medications.

“Having both worked in developmental services followed by a thirty-year career each in social services, we still had difficulty navigating the obstacles of the health care and developmental services systems. We found it a heartbreaking process, whereupon we had to basically designate our child as homeless for her to receive the care we could no longer provide. It took two and a half years from the first agency involvement to a new home for Monique, during which time our family was in crisis. Persistent advocacy was key.”

- Monique's parents

How is Monique doing post-transition?

Unfortunately, Monique is once again looking for a new home. While her current placement appeared promising, both Monique's family and her host family had recurring concerns. In May 2023, a series of medical events led to Monique being hospitalized for another two weeks. Consequently, both the developmental services agency and her parents have decided that it would be best to find a new housing situation for Monique. Although kindhearted and caring, the host family recognized they cannot provide support for Monique over the long term. They offered their home once again, this time on a temporary basis, until a more permanent housing solution can be found. These shifts in housing, although initially extremely disheartening for Monique and her family, can happen. Thankfully, Monique has a strong support team who are providing additional interim supports so Monique can live safely with her current host family until they can find her a permanent home.

Despite these bumps in the road, Monique is, physically and psychologically, in a much better place. She frequently visits her parents who live nearby and she has begun attending a day program for Francophone individuals struggling with mental health issues, where she participates in activities such as arts and crafts, exercise and cooking.



She also has the opportunity to enjoy biweekly outings with a worker supported through individualized funding (Passport funding)

"Appeler la ligne de crise, c'est très important. Parler à quelqu'un d'autre et vider le cœur, ça peut t'aider. Je peux le faire en anglais ou en français, ça me dérange pas. Les autres personnes où tu restes sont capables d'appeler la ligne de crise aussi."

- Monique

Translated English - "Calling the crisis line is very important. Talking to someone else and getting it off your chest can help. I can do it in English or French, I don't mind. Other people wherever you live can call the crisis line too."

- Monique

What key components helped with Monique's hospital-to-community transition?

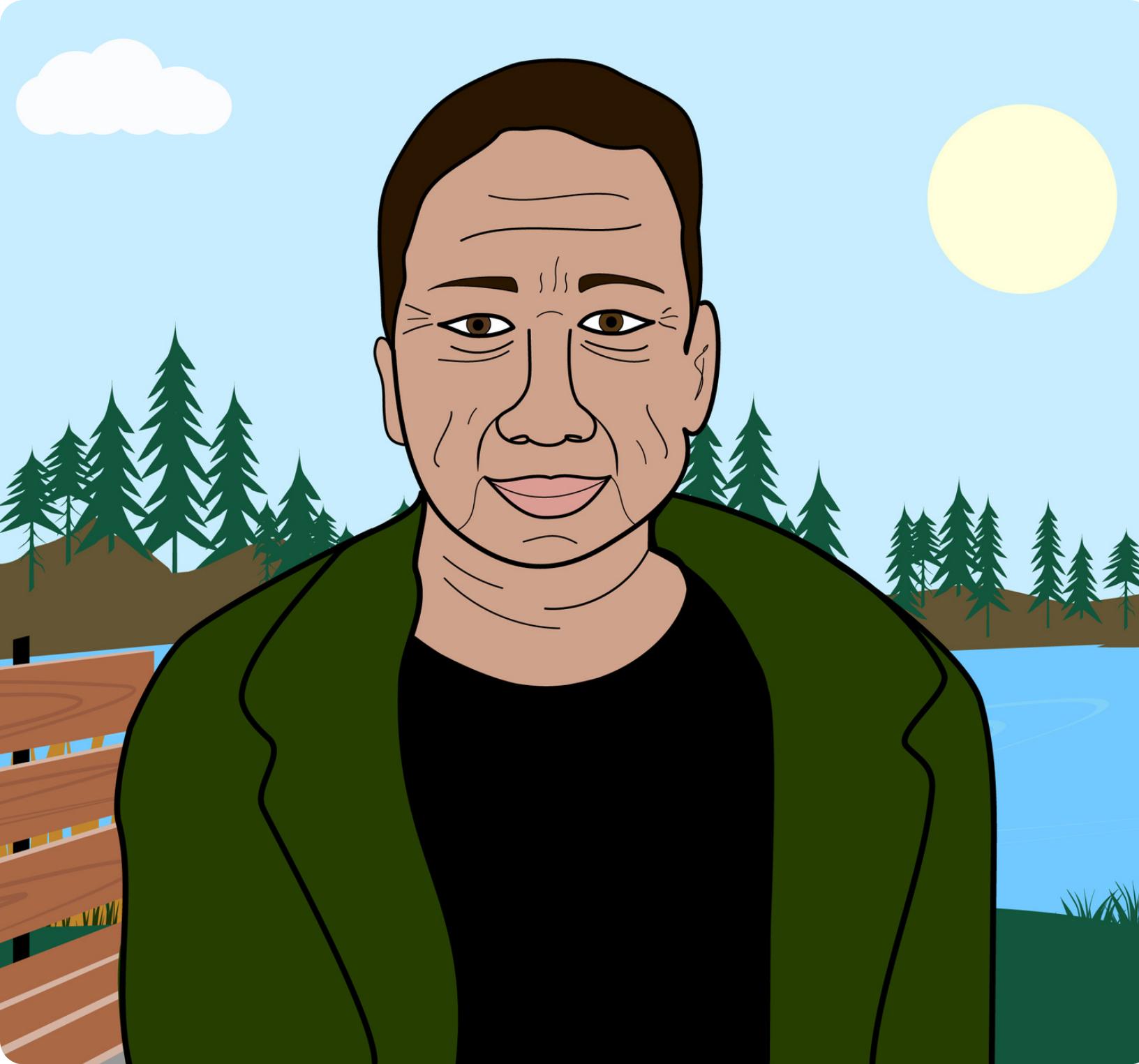
Monique's successful transition from hospital to community was facilitated by several crucial elements. These elements align with some of the 10 core components identified in the practice guidance document.

Component 3 - Patient and family involvement in transition planning - Monique's parents have been actively involved in Monique's transition from hospital to community including advocating for Monique to access appropriate housing. Monique and her parents were able to visit both potential homes before the final one was selected.

Component 5 - Transition and Community Support Plan - A lot of work went into finding the right home for Monique. Kathy and the psychiatric nurse advocated to stop the hospital from discharging Monique without safe and secure housing. Additionally, the developmental service provider was incredibly helpful in securing a host family that appeared to be the right fit for Monique.

Component 6 - Gradual, overlapping and coordinated transitions - The hospital social worker and the supervisor of the community agency functioned organically as co-leads for transition planning.

Component 10 - Sufficient and flexible funding - The MCCSS provided emergency funding to the regional Francophone agency working with Monique once she was hospitalized, which allowed the agency to secure residential care for her. Currently, the MCCSS is providing renewable funding for a 24 hour/week developmental service agency employee to work with Monique in her home and in the community.



Peter's Story

“Transition is key...There shouldn't be a timeline. It should be very flexible so that you can do it according to what the person needs and what staffing needs.”

- Peter's community services supervisor

Peter and his care team

Who is Peter?

Residing in the heart of a Northern Ontario community, Peter has lived a life that defies the odds. Peter likes to do things a certain way and at his own pace, which gives him a sense of safety and security. He enjoys drinking coffee, watching old Western movies, and spending time in his community. Not even the cold weather can keep him from taking his regular walks around the neighbourhood. Peter is an indigenous man in his seventies. He is able to make his own decisions and communicates both verbally and in writing when words fail to convey his thoughts. Diagnosed with a developmental disability and schizophrenia, Peter has faced a lot of adversity. Most recently, he spent nine years in the forensic unit of a mental health hospital, which is an inpatient mental health service for individuals involved with the legal system.

What led to Peter's hospitalization?

Peter's life has been marked by a history of institutionalization, beginning with a criminal offence at the age of 15. From the age of 18 onward, he lived in the community on and off until a violent incident led to his return to a forensic mental health hospital where he remained for the next nine years.

What were the challenges hindering Peter's return to the community?

Peter's journey back to the community was fraught with challenges, with one of the most significant being the lack of appropriate housing. However, the hurdles did not end there. Peter's schizophrenia diagnosis added another layer of uncertainty, leading the staff at a potential new home to question their ability to provide the necessary support and ensure the safety of both staff and other residents.

Peter's forensic status and history of institutionalization also contributed to staff concerns. Added to these challenges, Peter's family played a minimal role in his life, and his contact with the outside world had been limited during his stay in the forensic unit. The COVID-19 pandemic further complicated the transition process.

How did things change for the better for Peter?

Overcoming these challenges took time, hard work and collaboration between the hospital team and the staff at the supported group living residence but through their collective efforts, Peter was able to transition out of hospital successfully.

Peter's team worked together to develop a comprehensive transition plan, which included details related to Peter's likes and dislikes, funding considerations, medications, communication strategies, and a behaviour support plan. Importantly, the plan remained flexible, evolving throughout the transition process. Over a three-month period, staff members from both the forensic unit and Peter's new home met regularly to develop the plan and prepare for the transition.



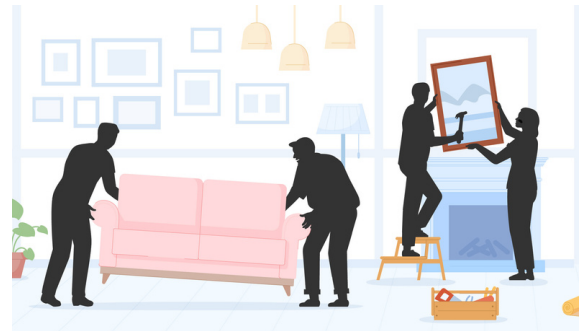
“Before he came into the home, we had quite a few meetings with the hospital. We put in place things he needed. [The transition plan] evolved over time. It was a learning curve for everyone. You can put whatever on paper, but most of the learning occurs when you are with the person. We all evolved together.”

- Supported group living residence staff

To help the supported group living residence staff understand Peter's diagnosis, they received both in-person training and access to training videos. While the staff appreciated this effort, they felt that more comprehensive training would have been helpful, given their limited experience in supporting people with mental health concerns. To help the staff communicate with Peter, the hospital team also created a list of phrases and their meanings that were familiar to Peter. Additionally, a behaviour analyst from the hospital worked closely with staff to collaboratively plan for the management of current and evolving behaviours and update Peter's medication plan.

The team also worked closely with Peter, making every effort to involve him in the planning process. Because of COVID restrictions, Peter was unable to visit his new home before the transition, but he was driven by the house and staff came out to warmly greet him.

The behaviour analyst met with Peter multiple times to show him pictures of the staff and his new home. The behaviour analyst also created some visual aids and supported Peter to choose the décor for his room, including the paint colour, curtains, and furniture to ensure it was exactly how he wanted it. Throughout the transition period, Peter was invited to join the larger team planning meetings, though he wasn't always interested in attending. In March 2021, Peter successfully moved into his new home.



How is Peter doing post-transition?

Peter now lives in a supported group living residence with five other individuals. Though his housemates are younger, Peter has found a way to make it work by creating a space for himself where he feels at ease. He affectionately refers to it as "Peter's restaurant," where his preferences take centre stage. He enjoys weekly excursions into the community, such as trips to the mall or neighbourhood walks, accompanied by a staff member.

Since Peter's move into his new home, he has been able to accomplish things that didn't seem possible during his hospital stay. He is communicating both verbally and in writing much more than he did in the hospital and now navigates the community without relying on his wheelchair. The initial phase of the transition was challenging as everyone adjusted, but with patience, flexibility and an adaptable plan, the process became smoother over time.



In the first few months following Peter's transition to the home, staff were able to call the forensic unit nurses 24/7 to address any of their questions or concerns, which was tremendously helpful. Peter also has a robust support network for his mental and physical health, including a family doctor, as well as ongoing support from the behaviour analyst, the nurse and the psychiatrist from the forensic unit.

To alleviate concerns about bringing Peter back to the hospital for ongoing care, his psychiatrist comes to the home for Peter's appointments and has been amazed by Peter's progress. Peter's successful transition is a testament to the dedicated and supportive team surrounding him, as well as his own resilience, empowering him to thrive in his new home.

"We were not just "dropping him off" but providing support after the transition."

- Developmental service provider

What key components helped with Peter's hospital-to-community transition?

Peter's successful transition from hospital to community was facilitated by several crucial elements. These elements align with some of the 10 core components identified in the practice guidance document.

Component 1 - Ongoing information sharing - Throughout the transition process and continuing post-transition, the hospital staff (including nurses, social worker, behaviour analyst, and psychiatrist) maintained regular communication with the supported group living residence staff. This ensured that any questions about how to best support Peter's needs were promptly addressed. The behaviour analyst checked in regularly with staff to help modify and update strategies as needed to address changing behaviours, which helped both staff and Peter feel heard and supported.

Component 3 - Patient and family involvement in transition planning - The transition team worked hard to include Peter as much as possible in the planning process. While he wasn't always interested in joining team meetings, he actively worked with the social worker and the behaviour analyst to design and furnish his room and make sure everything was just how he liked it. Unfortunately, Peter's family was not involved.

Component 4 - Patient, family and community provider education, training and support - Before Peter's transition to his new home, the hospital nurses, social worker and behaviour analyst provided training to the supported group living residence staff to support a smooth transition. This included both in-person training and access to training videos aimed at educating staff about Peter's diagnosis. After Peter moved into his new home, staff continued to have access to the hospital team to address questions and help modify the plan to address changing behaviours.

Component 5 - Transition and Community Support Plan - Peter's team worked together to develop an extensive transition plan, which included details related to Peter's preferences, funding considerations, communication strategies, and his medical and behavioural support needs. Importantly, the plan was flexible, incorporated visuals, remained adaptable, and evolved throughout the transition process to meet Peter's changing needs.

Component 6 - Graduated, overlapping and coordinated transitions - The residence staff and the hospital team worked closely together to support Peter's transition. Before Peter moved into his new home, he met with the staff over videoconferencing, viewed pictures of his new home, accompanied by a social script, and had a virtual tour. Peter even had a chance to drive by and wave to his new staff. After Peter's move into his new home, staff from the developmental service agency had 24/7 access to the hospital nurses if they had any concerns. They also had full-time access to the behaviour analyst, who works in both the hospital and community and is a resource that is still available to them.

Component 7 - Medication review and support - Peter's medications continue to be managed by the hospital psychiatrist. As part of a unique arrangement to accommodate Peter's needs, the psychiatrist provides home visits. The behaviour analyst also tracks Peter's PRN (as needed medication) use and updates his plan as needed.

Component 8 - Coordinated follow-up medical and clinical care - Peter's physical and mental health are well supported by a multidisciplinary team including a family doctor, dentist, behaviour analyst, psychiatrist, transitional nurse, and outpatient nurse.

Conclusion

This collection of vignettes highlights the complex journey often required to transition from hospital to home for individuals with a dual diagnosis. The stories highlight many obstacles currently preventing people from transitioning out of hospital but they also show what is possible when passionate and committed providers, individuals and families work together. In each story, there were key steps in the journey that helped contribute to a successful transition. These successful strategies are reflected in the [Supporting alternate level of care \(ALC\) patients with a dual diagnosis to transition from hospital to home: Practice guidance](#). By implementing the practice guidance, we can avoid some of the challenges experienced in these stories and improve the quality of life of individuals who are still in hospital waiting to transition. While each journey is unique, the practice guidance provides a roadmap for navigating the complexities of transitions, fostering hope, and building a more compassionate and supportive health care system for all.

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A sincere recognition of the exceptional contributions from our illustrators, **Tirzah Tward and Mary Plasterer**, in giving life to these stories.

About the organizations

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