Implementation of Health Links coordinated care plans for adults with intellectual and developmental disabilities

Cross-sectoral pilot program

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Abstract

Problem addressed Adults with intellectual and developmental disabilities (IDD) are a complex population that could benefit from improved care coordination across health and social sectors, as they experience poorer health and have higher rates of emergency department use and hospitalization due to ambulatory care–sensitive conditions.

Objective of program To pilot a novel, enhanced model of care coordination for complex patients with IDD.

Program description Health Links is a provincial care-coordination program for patients with complex health care needs. This pilot program adapted Health Links to include a guide and training specific to adults with IDD to ensure that these patients' needs were met and high-quality, efficient care was provided.

Conclusion A tailored care-coordination approach for adults with IDD was able to identify complex patients in need and successfully bridge cross-sectoral care.

Editor's key points

- Patients with intellectual and developmental disabilities (IDD) require a high degree of health care services. These patients are 4 times more likely than the general adult population in Ontario to fall within the top 5% of health care expenditures and most of these patients remain in this category at the 1-year mark.
- A cross-sectoral, collaborative approach was able to identify and recruit patients with IDD from developmental service agencies. These patients demonstrated characteristics consistent with high-cost service users including challenging behaviour associated with caregiver burnout, transition to group home care, and high rates of both physical and mental health conditions.
- A tailored care-coordination approach was successful in bridging cross-sectoral care, engaging patients and their caregivers, and providing useful interventions aimed at strengthening community-based primary care and reducing unnecessary hospital admissions for adults with IDD.

Points de repère du rédacteur

- Les patients ayant une déficience intellectuelle et développementale (DID) ont besoin d'énormément de services de santé. Par rapport à la population générale adulte ontarienne, ces patients ont 4 fois plus de chances de s'inscrire dans les 5% des dépenses en santé les plus élevées, et la plupart sont toujours dans cette catégorie après 1 an.
- Une approche collaborative intersectorielle a permis d'identifier et de recruter des patients ayant une DID auprès des agences de services développementaux. Les patients présentaient des caractéristiques correspondant à celles des utilisateurs de services coûteux, y compris les comportements difficiles associés à l'épuisement des soignants, la transition dans un foyer de groupe, et un taux élevé de troubles physiques et de santé mentale.
- Une approche coordonnée et adaptée des soins a comblé l'écart entre les soins intersectoriels, a mobilisé les patients et leurs soignants, et a ouvert la porte à des interventions utiles visant à consolider les soins communautaires de première ligne et à réduire les hospitalisations inutiles chez les adultes ayant une DID.

Application des plans de soins coordonnés Maillons santé pour les adultes ayant une déficience intellectuelle et développementale

Programme pilote intersectoriel

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Résumé

Problème abordé Les adultes ayant une déficience intellectuelle et développementale (DID) sont une population complexe qui pourrait profiter d'une meilleure coordination des soins entre les secteurs des services sociaux et de la santé, puisque leur santé est moins bonne et qu'ils se rendent plus souvent au service des urgences ou qu'ils sont hospitalisés en raison d'affections propices au traitement ambulatoire.

Objectif du programme Mettre à l'essai un nouveau modèle amélioré de coordination des soins aux patients complexes ayant une DID.

Description du programme Maillons santé est un programme provincial de coordination des soins à l'intention des patients dont les besoins en santé sont complexes. Ce programme pilote a adapté Maillons santé pour inclure un guide et une formation propres aux adultes ayant une DID de manière à faire en sorte de répondre aux besoins de ces patients par des soins efficaces et de grande qualité.

Conclusion Une approche adaptée de la coordination des soins pour les adultes ayant une DID a permis d'identifier les patients complexes qui avaient des besoins et à combler l'écart entre les soins intersectoriels.

Adults with intellectual and developmental disabilities (IDD) have poorer health and access to health care compared with the general population.[1] The complex health needs of adults with IDD result in increased use of emergency departments and increased hospitalizations for ambulatory care–sensitive conditions.[2] Multiple factors contribute to the complexity of needs and barriers to accessing medical care for patients with IDD, including difficulties with communication, health literacy, system navigation, and coordination among health care providers[3] and across social and health services.[2,4] Additionally, adults with IDD experience frailty[5] and age-related health issues earlier than the general population does,[6-8] and the use of home care services[9] and long-term care admissions[10] are 3 and 9 times higher than in the general population, respectively.

Not surprisingly, a recent retrospective cohort study of Ontario's health care system users revealed that approximately 20% of adults with IDD fall into the top 5% of health care users in terms of health care spending.[11] Thirty-six percent had costs in the top 10%.[11] These individuals were more likely to be female, be older than age 35, live in group home settings, and have higher rates of physical and mental health conditions. It is important to note that most individuals whose health care costs placed them in the high-cost category remained in that category 1 year later.[11] With the proportion of older adults between 45 and 84 years of age with IDD expected to increase approximately 20% by 2020,[12] the already stressed Ontario health system must prepare for this influx in medically complex, aging adults with IDD.

One possible approach to managing this impending crisis is introducing patient-centred care coordination. Past research evaluating models of care coordination among frail, aging patients in the general population indicates a potential for cost savings; a number of studies have shown considerable savings when providing care coordination and supportive home care as a substitute for long-term care in hospitals and placement in long-term care homes in both Quebec[13-15] and Ontario.[16,17] Additionally, research from New Jersey supports cost savings related to decreased admissions and length of stay in hospital for adults with IDD who were linked with a coordinated care model.[18,19]

An existing model in Ontario is the Health Links program, an initiative of the Ontario Ministry of Health and Long-Term Care that is coordinated by Local Health Integration Networks. Health Links brings together local health care practitioners to provide patient-centred, enhanced care coordination and system navigation for the most complex patients, increasing communication between the primary care physician and others involved in care.[20] Care planning is also customary across other parts of Canada, including in British Columbia and Nova Scotia.[21] Upon its inception, Health Links was designed to target the most complex, resource-intensive, and costly group of individuals in Ontario; however, it was not anticipated that this group would include a higher-than-expected proportion of adults with IDD.

Objective of program

The objective of this pilot project was to examine the implementation of a program that brings the Health Links approach to care coordination, combined with the IDD expertise of the Ministry of Community and Social Services, to adults with IDD and complex health needs in Kingston, Ont. It is the first of its kind to target this population. An ongoing evaluation study is exploring the experience of participants relating to the clinical and social outcomes of participation, which is summarized in a logic model (**Figure 1**).

Program description

The tool used by Health Links is the coordinated care plan (CCP), which helps patients and their caregivers identify goals, document health information, and develop a coordinated plan that is tailored to fit each patient's unique needs for health and social support. Through the Ministry of Health and Long-Term Care Community Health Links program, eligible patients work with a Health Links care coordinator (HLCC) to complete the CCP.[20] The CCP is intended to be a living document that outlines patient goals and lists medical conditions and doctors and other professionals who are part of the patient's circle of care.

To help identify and recruit participants, a local crisis planning committee made up of regional representatives from developmental service agencies was engaged. In addition to a referral source, engaging this group provided the added benefit of bridging an important gap between the health and social sectors, as both ministries provide coordination services and support, yet have no formal linking process to connect existing Ministry of Community and Social Services developmental services case management with clients' family physicians, other specialists, or the local hospital system.

Next, the Health Links process was adapted to best suit adults with IDD, including the creation of a guide to completing CCPs for the HLCC. This guide highlights specific additional questions to include, focusing on communication and accommodations around sensory issues, challenging behaviour, and the requirement of engaging caregivers and substitute decision makers in care planning.

Participant characteristics. The pilot program began in January of 2017. To date, 15 clients have been referred to the pilot program. Eleven have consented to participate and 9 have had CCPs completed. Participants were younger than the general Health Links population, with most younger than 40 years of age (mean age has been reported to be 75.6 years[22] in the broader Health Links

Figure 1 HealthLinks CCP for Adults with IDD and Complex Needs

OVERALL GOAL: Increase the capacity of healthcare providers and social services workers to deliver coordinated, patient-centered care that improves the quality and continuity of care for adults with IDD and complex needs.

Resources	Activities	Outputs	Outcomes: Short-term	Outcomes: Medium -term	Outcomes: Long-term
Implementation Team Co-investigators CSPC Research Associate CSPC Research Manager	• Hire Health Links Care Coordinator (HLCC) • Oversee HLCC training • Define outcome measures • Develop relationships with key stakeholders, appoint key liaisons • Oversee recruitment of participants • Plan for long-term sustainability (grants etc)	• HLCC hired and trained • Outcome measures defined • Communication with stakeholders established and ongoing • Recruitment of patients organized • Plan for long-term funding finalized, grants prepared (if applicable)	• Tailored Care Coordination tools and processes refined • CCPs completed for patients • Evaluation data collected and analyzed • Study results disseminated among local and national colleagues • Connections and collaborations for future/ongoing programming in negotiation • Grant proposals written and submitted for additional (ongoing) funding, if appropriate	• Strong understanding of how the HL CCP process can be tailored to fit an IDD patient population • Strong understanding of utility of HL CCP process for adults with IDD and complexity • Increased knowledge of research team regarding which outcomes are measurable and important for future study • Funding structures in place for future/ongoing programming LHIN-wide • Roll out of program LHIN-wide OR Evaluation expanded to entire LHIN	✓ Ontario-wide adoption of program ✓ Appropriate, coordinated, integrated and interdisciplinary care across sectors for adults with IDD and complex needs ✓ Increased capacity for primary care to communicate with specialists, health and social care providers ✓ Reduced burden on health and social services (and resulting decrease in costs)
CSPC Evaluation Team Co-investigators CSPC Research Associate	• Obtain HSREB clearance • Define data source(s) for outcome measures • Develop consent forms • Develop data collection tools (surveys, interview scripts, databases) • Pilot tools for face validity • Consent patient, caregiver and healthcare provider participants • Oversee /conduct data collection • Analyze and present results	• HSREB application approved (study + tools) • Sources of data established and collection processes in place • Data collection tools developed and piloted • Participants consented to evaluation • Data collection completed • Results of evaluation completed and disseminated at local and national conferences			
SE Health Links HL Care Coordinator Linda Robb-Blenderman Laura Cassidy	• HLCC - Complete CCPs with patients • Provide ongoing follow up • Track client service usage and health info • LRB - Provide expertise for research team • Oversee orientation of HLCC • Provide expertise to HLCC, research team • LC – provide demographic and hospital usage data on CCP clients	• HLCC - CCPs completed and support provided • Service usage and client info documented • LRB - Expertise provided to research team • HLCC hired and trained in CCP and IDD lens • LC – demographic and hospital usage data reported quarterly	• Greater understanding among and between care sectors of problems and issues experienced • Greater understanding among and between sectors of resources available for clients • Effective sharing of information between partners • Increased interdisciplinary teamwork in community • Improved communication between care sectors	• Increased communication and collaboration between health and social sectors • Partners routinely share data and resources with patient outcomes in mind • Increased understanding of CCP process, outcomes and utility among community agencies. Primary care and health and social care sectors • Increased knowledge of primary care providers regarding how to best care for adults with IDD and complex needs	
Primary Care (PC) Physicians RNs Community Service Workers	• Communicate and collaborate with HLCC and research team • Take part in evaluation of CCP utility • P - Consent to use of patient data for health links and research	• Primary care aware of CCPs and actively involved in plans • Active involvement in evaluation of CCP utility (post-intervention interviews) Physicians consent to use of patient data			
Community Partners Richelle Uens (Community Networks of Specialized Care) Pressures and Priorities Committee SELHIN – Mike Spinks & Gina Johar KGH & HDH SECCAC	• RU – Orient HLCC re:IDD considerations • Provide oversight and expertise to HLCC, implementation and evaluation team • P&P - Identify patients who are complex and relay referral info to research team • Work with Research Associate to make contact and consent clients • SELHIN - Provide access to SHIIP data portal for research and CCP completion • Provide support and community engagement for long-term sustainability • KGH/HDH/CCAC - Provide usage data for clients for research purposes (if SHIIP not available)	• RU - HLCC oriented around IDD services and health/social considerations • Expertise and oversight provided to team • P&P - Pool of eligible patients identified • Patients/caregivers recruited and consented • SELHIN – SHIIP access in place for HLCC • Support and community engagement in place for long-term programming • KGH/HDH/CCAC – usage data shared with evaluation Team (if necessary)	• Enhanced support delivered to clients • Increased knowledge of clients. & caregivers re: o appropriate avenue for treatment • Perception of improved continuity of care • Increase in support provided by health, social and community programs/services	• Increased access to care in the community • Increased satisfaction of clients and families with care • Increased perception of support to deal with health needs for patients and caregivers • Increased continuity of care among and between sectors • Decreased inappropriate client visits to ED/primary care/hospital	
Clients Patient advisory group Intervention participants Evaluation participants	• Provide insight and feedback to implementation/evaluation teams to develop /validate tools, outcome measures • Consent to intervention (CCP) • Be available for evaluation activities such as surveys and interviews	• Data collection tools and outcome measure development informed and validated • Participants consented to CCP • 10 patients/caregivers consent and complete evaluation			

Assumptions: Stakeholder engagement; Ability to recruit participants

External Factors: Stakeholder priorities; Willingness of patients to participate in evaluation

CCP—coordinated care plan, CSPC—Centre for Studies in Primary Care, ED—emergency department, HDH—Hotel Dieu Hospital, HL—Health Links, HLCC—Health Links Care Coordinator, HSREB—Health Sciences Research Ethics Board, IDD—intellectual and developmental disabilities, KGH—Kingston General Hospital, LC—Laura Cassidy, LHIN—Local Health Integration Network, LRB—Linda Robb-Blenderman, P—physician, PC—primary care, P&P—Pressures and Priorities Committee, RN—registered nurse, RU—Richelle Uens, SE—south east, SECCAC—South East Community Care Access Centre, SELHIN—South East Local Health Integration Network, SHIIP—South East Health Integrated Information Portal.

population and 70 years in this Kingston area Health Links population specifically[23]), and most lived with their parents, who reported moderate levels of caregiver burnout and were on crisis waitlists for group home placement. Participants had a considerable number of physical and mental health issues and a large number of care providers identified as being in the circle of care (**Table 1**).

Common concerns and interventions. Common concerns identified and addressed on the CCP included end-of-life and advance care planning as well as caregiver burden and minimal respite service availability. Financial stress leading to food insecurity and trouble funding therapy and day programming were also common concerns. Life transitions, such as from pediatric care to adult health care or from living at home to living in a group home or long-term care home were also common themes and were a clear risk factor for health crises.

Table 1. Participant characteristics: *N=9.*

CHARACTERISTIC	VALUES
Sex, n	
• Female	7
• Male	2
Age, n	
• 21-30 y	3
• 31-40 y	3
• 41-50 y	2
• >50 y	1
Age range, y	21-62
Living arrangement, n	
• Lives with family	6
• Lives in group home	1
• Lives in long-term care	1
• Unstable housing	1
Substitute decision maker	
• Yes (parent)	6
• Yes (cousin)	1
• No	2
No. of individuals or organizations that are part of care team, range	5-23
Brief Family Distress Scale score	
• Range	3.5-9
• No. of scores ≥ 6*	3
No. of physical health issues identified, range	5-12
No. of mental health issues identified, range	0-2
No. of social health issues identified, range	0-2

*A score of ≥6 indicates that the family is approaching or is currently in crisis.

Supports and interventions. The HLCC facilitated system navigation and communication between health and social care sectors; referrals to care providers such as occupational and physical therapists, respiratory therapists, dietitians, community service workers, community pharmacists, and home and community care; and referrals to the Dual Diagnosis Consultation Outreach Team (a specialized mental health team targeting adults with IDD in the region). In some cases, the HLCC supported the completion of paperwork and applications to establish income security, respite funding, and day programming. Discussions about advanced care planning and long-term care placement were held with each individual, and procurement of assistive devices such as electric beds and lifts was facilitated to support aging at home.

Discussion

The emphasis on the patient voice was very important in adapting the CCP process to accommodate patients with IDD and their caregivers. This project was cross-sectoral "by design," with far-reaching collaborative capacity not only among primary care providers, hospitals, and emergency departments but also with developmental service agencies and other social service programs. A regional primary care council (with long-standing developmental disabilities stakeholder representation) had provided the leadership for early Health Links care-coordination initiatives, thus laying the foundation for special pilot programs like this that offer tailored solutions for managing the care of complex, vulnerable populations. The engagement of local hospitals was also very important for uptake to ensure that the CCPs developed through this study were shared within patient information systems.

Another facilitator was being able to draw on the expertise of an experienced HLCC who received training on the needs of patients with IDD. The HLCC was invaluable in navigating the Health Links process and providing real-time, practical adjustments to meet unique patient needs. As a result of her role, the HLCC was also in a position to advocate for changes to the provincially standardized CCP template that included sections important for this population (eg, substitute decision maker field, special communication and sensory integration needs, etc). The HLCC developed expertise in care coordination for individuals with IDD and is now well positioned to build capacity among other HLCCs in the region.

Limitations

Identifying and referring clients with IDD who fulfilled medical complexity criteria was more challenging than anticipated for crisis developmental service workers (whose training is in social not health services). Ongoing close collaboration with health professionals in the field as well as educational in-services on health issues faced by patients with IDD are potential means of building capacity and comfort with referrals.

A second challenge was engaging primary care teams in care coordination specifically for patients with IDD. Care coordination is a relatively new practice in primary care and patients with IDD have commonly been followed mainly by pediatricians and psychiatrists. A mentorship model where the IDD-focused HLCC is able to initiate the care plan and then ensure transfer of care to the primary care team in a way that fits with the comprehensive care model of family medicine is a potential solution.

A final challenge was finding creative and functional solutions to barriers in communication and coordination that occurred across different sectors. Special measures had to be taken to share information across separate "circles of care" and differences in case management (social service sector) versus care planning (health service sector) needed to be aligned to foster coordination. An essential next focus is moving toward models that are integrated, not just collaborative, where different professionals share a common knowledge base (in this case factors that lead patients with IDD to become high-cost users) and goals (patient- or client-centred care approach to optimizing community-based health and social services).

Conclusion

There are unique considerations for family physicians when caring for adults with IDD, including managing complex communication, health, and social factors. Care coordination is one approach to improving and assisting in management of these complex situations. Applying a tailored care-coordination approach specific to a patient's needs improves the potential for high-quality and efficient care, reducing gaps in care and the potential for unnecessary hospital admissions.

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Contributors

All authors made substantial contributions to this research from design, to data collection and analysis, to writing and revising the manuscript. Each author meets the authorship criteria of the International Committee of Medical Journal Editors.

Competing interests

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