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’affectations 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.
A
dults with intellectual and developmental disa
bilities (IDD) have poorer health and access to
health care compared with the general popu
lation. The complex health needs of adults with IDD
result in increased use of emergency departments and
increased hospitalizations for ambulatory care–se
nsitive conditions. Multiple factors contribute to the com
plexity of needs and barriers to accessing medical care for
patients with IDD, including difficulties with communi
cation, health literacy, system navigation, and coordina
tion among health care providers and across social and
health services. Additionally, adults with IDD experi
ence frailty and age-related health issues earlier than
the general population does and the use of home care
services and long-term care admissions 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 approx
imately 20% of adults with IDD fall into the top 5% of
health care users in terms of health care spending. Thirty-six percent had costs in the top 10%. These indi
viduals 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 impor
tant to note that most individuals whose health care
costs placed them in the high-cost category remained
in that category 1 year later. With the proportion of
older adults between 45 and 84 years of age with IDD
expected to increase approximately 20% by 2020, 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 stud
ies have shown considerable savings when provid
ing care coordination and supportive home care as a
substitute for long-term care in hospitals and place
ment in long-term care homes in both Quebec and Ontario. Additionally, research from New Jersey sup
ports cost savings related to decreased admissions and
length of stay in hospital for adults with IDD who were
linked with a coordinated care model.

An existing model in Ontario is the Health Links pro
gram, 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. Care planning is also customary across other
parts of Canada, including in British Columbia and Nova
Scotia. 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 caregiv
ers 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. 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 representa
tives from developmental service agencies was engaged.
In addition to a referral source, engaging this group pro
vided the added benefit of bridging an important gap
between the health and social sectors, as both minis
tries 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 partici
pate 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 in the broader Health Links
IMPLEMENTATION OF HEALTH LINKS COORDINATED CARE PLANS FOR ADULTS WITH IDD

OUTCOMES

Short-term

- HLCC hired and trained in CCP and IDD lens
- CSPC Research Associate
- Variables for face validity
- Data collection: observational, qualitative, quantitative, surveys and interviews
- Participants consented to evaluation

Medium-term

- Increased understanding of CCP process, outcomes and utility
- Strong understanding of CCP
- Increased knowledge of primary care and health/social care sectors
- Social sectors for adults with IDD are aware of CCP
- Integrated and clearly share data and issues experienced
- Increased understanding of CCP among and between partners
- Enhanced support delivered to patients/caregivers recruited and involved in plans
- Keep detailed health/social care service use information

Long-term

- Increased capacity of health care providers and social services workers to deliver coordinated, patient-centered care that improves the quality and continuity of care
- HLCC - Complete CCPs with patients and health and social sector participants consented
- RU - HLCC oriented around IDD services
- CSPC Research Associate
- Patients and their families are engaged for long-term sustainability
- Stakeholder engagement and ability to recruit patients/participants to be involved
- 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), 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.

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

*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

The Southeastern Ontario Academic Medical Organization (SEAMO), located in Kingston, Ont, granted a “SEAMO Innovation Fund” award to Drs Meg Gemmill and Ian Casson in March 2016 in the amount of $97,343 to carry out this research. The grant competition involved a peer review. No benefits have been received by any other authors.

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This article has been peer reviewed.

Cet article a fait l’objet d’une révision par des pairs.

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