Evidence Brief

Creating a Pan-Canadian Learning Health System for Neurodevelopmental Disorders

14 and 15 December 2020

McMaster University | HEALTH FORUM

EVIDENCE >> INSIGHT >> ACTION

Evidence Brief:
Creating a Pan-Canadian Learning Health System for Neurodevelopmental Disorders

14 & 15 December 2020

McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

Authors

Kaelan A. Moat, PhD, Managing Director, McMaster Health Forum

Paula Voorheis, M.Sc., Lead, Co-Lead Evidence Synthesis, McMaster Health Forum

Aunima R. Bhuiya, M.Sc. Candidate, Co-Lead Evidence Synthesis, McMaster Health Forum

Abeer Ahmad, B.H.Sc. Candidate, Forum Fellow, McMaster Health Forum

John N. Lavis, MD PhD, Director, McMaster Health Forum, and Professor, McMaster University

Funding

The evidence brief and the stakeholder dialogue it was prepared to inform were funded by the Azrieli Foundation in partnership with McMaster University. The McMaster Health Forum receives both financial and in-kind support from McMaster University. The views expressed in the evidence brief are the views of the authors and should not be taken to represent the views of the Azrieli Foundation or its partners at McMaster University.

Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the evidence brief. The funders played no role in the identification, selection, assessment, synthesis, or presentation of the research evidence profiled in the evidence brief.

Merit review

The evidence brief was reviewed by a small number of policymakers, stakeholders and researchers in order to ensure its scientific rigour and system relevance.

Acknowledgments

The authors wish to thank Grace Zhou. We are grateful to Steering Committee members (Karen Bopp, Stelios Georgiades, Jan Willem Gorter, Mira Puri, Roberto Sassi and Karun Singh) and merit reviewers (Michelle Craig, Frank Gavin and David Nicholas) for providing feedback on previous drafts of the brief. The views expressed in the evidence brief should not be taken to represent the views of these individuals.

Citation

Moat KA, Voorheis P, Bhuiya AR, Ahmad A, Lavis JN. Evidence brief: Creating a pan-Canadian learning health system for neurodevelopmental disorders. Hamilton: McMaster Health Forum, 14 & 15 December 2020.

Product registration numbers

ISSN 1925-2250 (online)

Table of Contents

KEY MESSAGES

What's the problem?

Policymakers, healthcare workers, stakeholders and researchers across Canada are increasingly aware of the importance of ensuring comprehensive and integrated care and supports are available to individuals with neurodevelopmental disorders (and their families) across the lifespan. However, there is a gap between what is being learned and achieved in the research community and the actions being taken to improve patient care and experiences. This current problem can best be understood in relation to five underlying challenges: 1) many Canadians are affected by neurodevelopmental disorders over their lifespan; 2) neurodevelopmental disorders are not easy to consider in isolation; 3) without appropriate integrated programs and services, neurodevelopmental disorders can place significant burden on individuals, their families, health systems, and society; 4) health-system arrangements are not conducive to optimizing services for neurodevelopmental disorders; and 5) health and research systems are not aligned to enable a rapid-learning and improvement approach. The COVID-19 pandemic has exacerbated some of these challenges, while creating additional issues that need to be considered.

What do we know (from systematic reviews) about three elements of a potentially comprehensive approach to addressing the problem?

Element 1 – Prioritize service needs and design a rapid-learning and improvement approach to meet them

- This element could include efforts to: 1) identify and segment the population of individuals with neurodevelopmental disorders into groups with shared needs; 2) design appropriate 'in-reach' and 'out-reach' services; 3) stratify these services to support their reach to prioritized population segments; 4) identify, prioritize, measure and publicly report on quadruple-aim metrics; and 5) continue to rapidly learn and improve on defined goals and assets. We identified six systematic reviews relevant to this element; however, most focused on the contextual factors to consider when designing and implementing services generally (rather than rapid learning and improvement specifically).

Element 2 – Strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada

- This element could include efforts to: 1) use established frameworks to identify rapid-learning assets and gaps at the provincial/territorial and national levels; 2) take steps to ensure assets are 'joined up' and strengthen areas where there are gaps in rapid-learning characteristics; and 3) strengthen technical supports that draw on networks of expertise across the country. We identified five systematic reviews pertaining to element 2, but only one review directly explored rapid-learning health systems, and none addressed neurodevelopmental disorders specifically. Some reviews provided insights about key factors that can support the implementation of this element.

Element 3 – Establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action

- This element could include efforts to: 1) identify and engage people at all levels who can advocate for and lead the work related to establishing rapid-learning health systems for neurodevelopmental disorders; 2) set up an administrative home to drive efforts; and 3) define the range of activities required to continuously build and strengthen the network. We identified 11 systematic reviews related to this element, but only three discussed the concept of 'champions' explicitly, and none addressed neurodevelopmental disorders. Champion partners with a shared mission, access to common resources, and clear outcomes were identified as key facilitators.

Additional key informant interviews suggested that the COVID-19 pandemic has strengthened demand for data and evidence to inform decision-making, which creates an ideal climate for pursuing these elements.

What implementation considerations need to be kept in mind?

Ensuring there is 'buy-in' among all necessary stakeholders for adopting a rapid-learning and improvement approach and all that it entails was identified as a key barrier. Windows of opportunity identified included the growing traction surrounding rapid-learning health system-related concepts, the added importance placed on the use of data and evidence as a result of the COVID-19 pandemic, and government investments to support projects and new approaches related to neurodevelopmental disorders.

REPORT

Neurodevelopmental disorders are a group of disorders – including Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Intellectual Disability (ID) and Obsessive Compulsive Disorder (OCD), among others – that affect the development of the nervous system, leading to abnormal brain function which may affect emotion, learning ability, self-control and memory. The effects of these disorders tend to last for a person's entire lifetime, which can make it a challenge to plan and deliver comprehensive, integrated and patient-centred care and supports.

To address this challenge, the research and knowledge-to-action landscape related to neurodevelopmental disorders in Canada has evolved greatly over the last two decades, with a growing number of initiatives focused on strengthening research-translation pipelines and service-capacity building. These initiatives include:

- the CHILD-BRIGHT Network, supported through Canada's Strategy for Patient-Oriented Research (SPOR);
- the Kids Brain Health Network (KBHN, formerly NeuroDevNet), supported through the Networks of Centres of Excellence (NCE) initiative;
- the Autism & Intellectual-Developmental Disabilities Knowledge Exchange Network (AIDE), supported by the Public Health Agency of Canada;
- the federal government's announcement in 2019 of an investment of $9.1 million over five years to support the development of community projects that can improve services for individuals living with ASD and their families, through the Autism Spectrum Disorder Strategic Fund;(1) and
- initiatives in the non-profit sector that also seek to support the advancement of research related to neurodevelopmental disorders, such as Autism Speaks Canada.

At the provincial level, there have also been several initiatives established to improve the translation of the best available data and research evidence into service delivery improvements for individuals with neurodevelopmental disorders and their families. In particular, there are now a range of organizations and networks working to this end, such as the Human Early Learning Partnership in B.C., and the Ontario Brain Institute and the Province of Ontario Neurodevelopmental Disorders network (POND) in Ontario. Additionally, provincial governments across the country are developing and adopting frameworks, or

Box 1: Background to the evidence brief

This evidence brief mobilizes both global and local research evidence about a problem, three approach elements for addressing the problem, and key implementation considerations. Whenever possible, the evidence brief summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The evidence brief does not contain recommendations, which would have required the authors of the brief to make judgments based on their personal values and preferences, and which could pre-empt important deliberations about whose values and preferences matter in making such judgments.

The preparation of the evidence brief involved six steps:
1) convening a Steering Committee comprised of representatives from the partner organizations (and/or key stakeholder groups) and the McMaster Health Forum;
2) developing and refining the terms of reference for an evidence brief, particularly the framing of the problem and three viable approach elements for addressing it, in consultation with the Steering Committee and a number of key informants, and with the aid of several conceptual frameworks that organize thinking about ways to approach the issue;
3) identifying, selecting, appraising and synthesizing relevant research evidence about the problem, approach elements and implementation considerations;
4) drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence;
5) conducting a second round of key informant interviews to understand how the framing of the problem, elements for addressing it and implementation considerations may need to be adjusted in light of the COVID-19 pandemic; and
6) finalizing the evidence brief based on the input of several merit reviewers.

The three approach elements for addressing the problem were not designed to be mutually exclusive. They could be pursued simultaneously or in a sequenced way, and each approach element could be given greater or lesser attention relative to the others.

The evidence brief was prepared to inform a stakeholder dialogue at which research evidence is one of many considerations. Participants' views and experiences and the tacit knowledge they bring to the issues at hand are also important inputs to the dialogue. One goal of the stakeholder dialogue is to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. A second goal of the stakeholder dialogue is to generate action by those who participate in the dialogue and by those who review the dialogue summary and the video interviews with dialogue participants.

introducing new programs related to care and support services for individuals with neurodevelopmental disorders and their families. In B.C., the Ministry of Children and Family Development is in the process of developing a service framework to better support children and youth with special needs; in Saskatchewan, the government introduced a Framework and Action Plan for Autism Spectrum Disorder Services, and the Government of Ontario has introduced and is in the process of revising the Ontario Autism Program.

Alongside these national and provincial initiatives, issues related to neurodevelopmental disorders are increasingly gaining prominence on the agendas of key policymakers across the country, with Prime Minister Justin Trudeau's recent inclusion of the need to "work collaboratively with provinces, territories, families and stakeholders toward the creation of a national autism strategy" in the federal Minister of Health's mandate letter as a clear illustration of this.(2) While the COVID-19 pandemic will continue to dominate policy discourse for the foreseeable future, the visible position of a neurodevelopmental disorder on policy agendas nationally has the potential to further facilitate collaboration in the area of ASD specifically, while opening up conversations and opportunities related to strengthening care and supports for individuals living with the full spectrum of neurodevelopmental disorders – many of which have traditionally been less of a focus for health- (and social) system policymakers, healthcare workers, stakeholders and researchers.

Despite the range of initiatives and increased attention paid to neurodevelopmental disorders, there is still a gap between what is being learned and achieved in the research community and the actions being taken to improve patient care and experiences in health systems across Canada. This is particularly important as policymakers, healthcare workers, stakeholders and researchers increasingly approach neurodevelopmental disorders through a 'lifespan' lens, acknowledging that while many disorders begin in early life, they have an impact throughout childhood, adolescence and adulthood, which requires system planners to account for the many transitions in support individuals and families will face.

Aim of this evidence brief

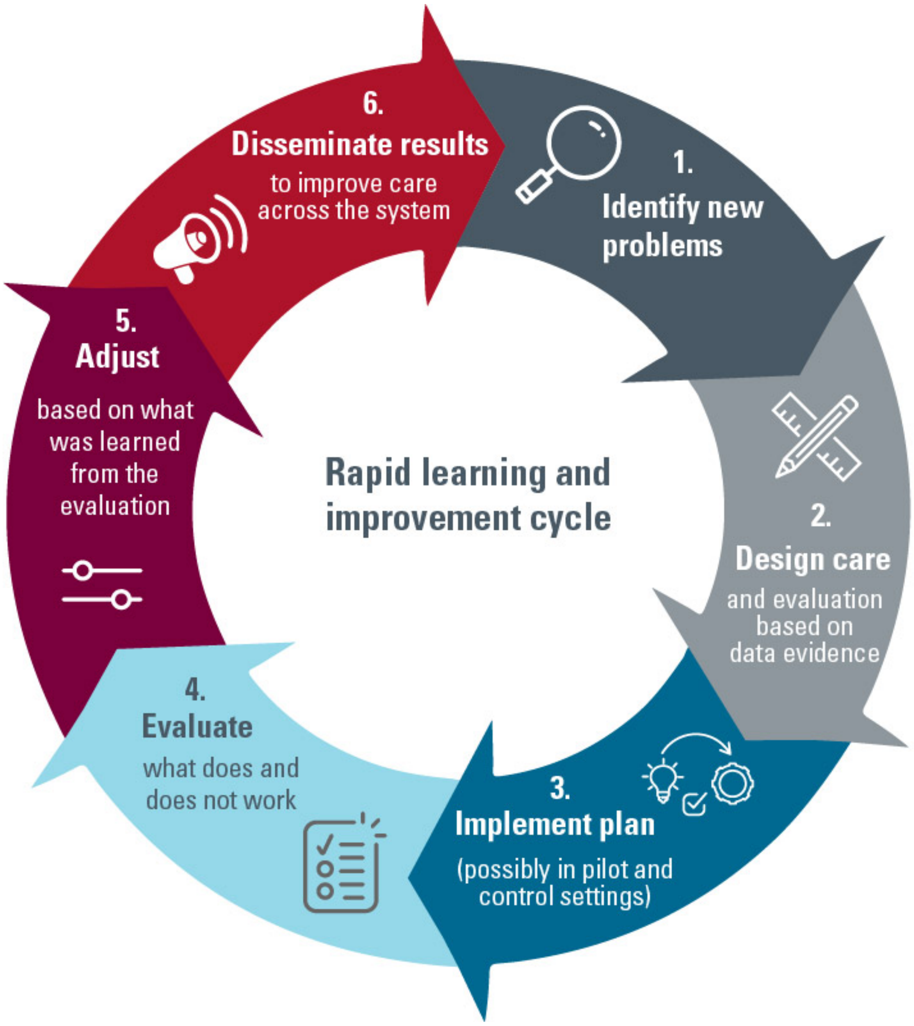
This evidence brief considers how a rapid-learning and improvement approach can be adopted to strengthen health (and social) systems, ensure optimal support for those with neurodevelopmental disorders and their families across the lifespan, and achieve the 'quadruple aim' (i.e., improving patient care experiences, improving health (and social) outcomes, keeping costs manageable, and supporting positive provider experiences). This approach offers the potential to better align health and research systems to:

- 'move the needle' for patients in their care experiences and outcomes in rapid-improvement cycles;
- enable data- and evidence-informed transformations;
- motivate greater collaboration among, and enable greater impacts of (and returns on investments in) all elements of the research system; and
- better leverage quality-improvement and other learning and improvement infrastructures operating at the interface between the health and research systems.

The seven key characteristics of a rapid-learning health system are listed in Table 1 alongside detailed examples of the types of efforts required to establish each characteristic as an 'asset' for supporting the approach. These assets are then used in ongoing cycles of rapid learning and improvement that draw on the full range of inputs made available through each characteristic (e.g., citizens' values and insights, data and evidence) to incrementally improve patient care and experiences in real time. Six steps can be considered in this process (represented in Figure 1):

1) identifying a problem (or goal) through an internal and external review (drawing on the best available data and evidence and with inputs from citizens and stakeholders);
2) designing a solution based on data and evidence generated locally and elsewhere;
3) implementing the plan (possibly in pilot and control settings);
4) evaluating to identify what does and does not work;
5) adjusting, with continuous improvement based on what was learned from the evaluation; and
6) disseminating the results to improve the coverage of effective solutions across the health system.(3)

Figure 1: Rapid-learning and improvement cycle



This approach is currently being rolled out in different forms across provincial health systems. In B.C., the Academic Health Science Network is adopting it to enable a scientific and learning approach to continuous improvement and strategic transformation in the health system. In Alberta, 16 Strategic Clinical Networks focused on prioritized health issues have been established to rapidly learn about and improve care, and in Ontario the development of Ontario Health Teams and the provision of support through a partnered program with the McMaster Health Forum – Rapid Improvement Support and Exchange – seeks to support rapid-learning and improvement cycles to improve care pathways for defined patient populations. These examples serve as helpful illustrations of how the concepts related to rapid learning and improvement can be operationalized in very practical ways, and could serve as inspiration for similar efforts focused on neurodevelopmental disorders in the country.

The aim of adopting this lens throughout the brief is to provide evidence-informed insights that will be used as a jumping-off point for health-system policymakers, healthcare workers, stakeholders (e.g., professionals and professional/organizational associations, organizational leaders, regulatory colleges, patient-advocacy groups and other non-governmental actors), and researchers focused on neurodevelopmental disorders to engage in off-the-record deliberations about the problem, elements of a comprehensive approach for addressing it, and implementation considerations. The goals of the deliberation will be to collectively determine how policymakers, healthcare workers, stakeholders and researchers across the country can:

1) operationalize the concept of rapid learning when applied in the context of neurodevelopmental disorders across the lifespan;
2) identify and 'join up' rapid-learning assets across the seven characteristics included in Table 1 (including capitalizing on the progress being made across the full range of existing initiatives outlined in the previous section);
3) address gaps that exist for neurodevelopmental disorders across the seven characteristics included in Table 1; and
4) capitalize on windows of opportunity to stimulate the development and consolidation of rapid-learning and improvement approaches to improve care and experiences for individuals with neurodevelopmental disorders and their families across the lifespan.

Finally, it is important to clarify two additional points. First, this brief will aim to discuss neurodevelopmental disorders broadly without a focus on any particular disorder (unless there are helpful illustrative examples that can be drawn from one or more disorders). The rationale for this approach is to establish common denominators that can inform the efforts of decision-makers across the spectrum of neurodevelopmental disorders. Second, throughout the brief, 'patients' is used to refer to:

- patients in the usual sense of those receiving care in the health system;
- potential patients who need care, whether or not they are receiving it now;
- families of and caregivers to these patients;
- citizens, by which we mean all Canadians – whether as taxpayers or voters or in other roles, and regardless of their formal citizenship status and whether they may also currently be considered a patient – who should have a voice in the rapid learning about and improvement of the health system; and
- communities, by which we mean groups of citizens – whether defined by geography, lived experience with particular conditions or treatments (or health determinants), ethnocultural group or other factors – who should also have a voice in the rapid learning about and improvement of the health system.

Table 1: Key characteristics of a rapid-learning health system

Category	Characteristic	Examples
Patient-centred	**Engaged patients:** Systems are anchored on patient needs, perspectives and aspirations (at all levels), and focused on improving their care experiences and health at manageable per capita costs and with positive provider experiences	1) Set and regularly adjust patient-relevant targets for rapid learning and improvement (e.g., improvements to a particular type of patient experience or in a particular health outcome) 2) Engage patients, families and citizens in: a. their own health (e.g., goal setting; self-management and living well with conditions; access to personal-health information, including test results) b. their own care (e.g., shared decision-making; use of patient-decision aids) c. the organizations that deliver care (e.g., patient-experience surveys; co-design of programs and services; membership of quality-improvement committees and advisory councils) d. the organizations that oversee the professionals and other organizations in the system (e.g., professional regulatory bodies; quality-improvement bodies; ombudsman; and complaint processes) e. policymaking (e.g., committees making decisions about which services and drugs are covered; government advisory councils that set direction for (parts of) the system; patient storytelling to kick off key meetings; citizen panels to elicit citizen values) f. research (e.g., engaging patients as research partners; eliciting patients' input on research priorities) 3) Build patient/citizen capacity to engage in all of the above
Data and evidence driven	**Digital capture, linkage and timely sharing of relevant data**: Systems capture, link and share (with individuals at all levels) data (from real-life, not ideal conditions) about patient experiences (with services, transitions and longitudinally) and provider engagement alongside data about other process indicators (e.g., clinical encounters and costs) and outcome indicators (e.g., health status)	1) Data infrastructure (e.g., interoperable electronic health records; immunization or condition-specific registries; privacy policies that enable data sharing) 2) Capacity to capture patient-reported experiences (for both services and transitions), clinical encounters, outcomes and costs 3) Capacity to capture longitudinal data across time and settings 4) Capacity to link data about health, healthcare, social care and the social determinants of health 5) Capacity to analyze data (e.g., staff and resources) 6) Capacity to share 'local' data (alone and against relevant comparators) – in both patient- and provider-friendly formats and in a timely way – at the point of care, for providers and practices (e.g., audit and feedback), and through a centralized platform (to support patient decision-making and provider, organization and system-wide rapid learning and improvement)
	Timely production of research evidence: Systems produce, synthesize, curate and share (with individuals at all levels) research about problems, improvement options and implementation considerations	1) Distributed capacity to produce and share research (including evaluations) in a timely way 2) Distributed research ethics infrastructure that can support rapid-cycle evaluations 3) Capacity to synthesize research evidence in a timely way 4) One-stop shops for local evaluations and pre-appraised syntheses 5) Capacity to access, adapt and apply research evidence 6) Incentives and requirements for research groups to collaborate with one another, with patients, and with decision-makers *Note that for Indigenous peoples, this row would ideally be re-conceptualized to include traditional knowledge, however, more broadly the entire framework would need to be assessed by Indigenous leaders to determine if it adds value to Indigenous peoples-led approaches*
System supported	**Appropriate decision supports**: Systems support informed decision-making	1) Decision supports at all levels – self-management, clinical encounter, program, organization, local health authority and government – such as: a) patient-targeted evidence-based resources

Category	Characteristic	Examples
	at all levels with appropriate data, evidence and decision-making frameworks	b) patient decision aids c) patient goal-setting supports d) clinical practice guidelines e) clinical decision support systems (including those embedded in electronic health records) f) quality standards g) care pathways h) health technology assessments i) descriptions of how the health system works
	Aligned governance, financial and delivery arrangements: Systems adjust who can make what decisions (e.g., about joint learning priorities), how money flows and how the systems are organized and aligned to support rapid learning and improvement at all levels	1) Centralized coordination of efforts to adapt a RLHS approach, incrementally join up assets and fill gaps, and periodically update the status of assets and gaps 2) Mandates for preparing, sharing and reporting on quality-improvement plans 3) Mandates for accreditation 4) Funding and remuneration models that have the potential to incentivize rapid learning and improvement (e.g., focused on patient-reported outcome measures, some bundled-care funding models) 5) Value-based innovation-procurement model 6) Funding and active support to spread effective practices across sites 7) Standards for provincial expert groups to involve patients, a methodologist, use existing data and evidence to inform and justify their recommendations 8) Mechanisms to jointly set rapid-learning and improvement priorities 9) Mechanisms to identify and share the 'reproducible building blocks' of a rapid-learning health system
Culture and competencies enabled	**Culture of rapid learning and improvement**: Systems are stewarded at all levels by leaders committed to a culture of teamwork, collaboration and adaptability	1) Explicit mechanisms to develop a culture of teamwork, collaboration and adaptability in all operations, to develop and maintain trusted relationships with the full range of partners needed to support rapid learning and improvement, and to acknowledge, learn from and move on from 'failure'
	Competencies for rapid learning and improvement: Systems are rapidly improved by teams at all levels who have the competencies needed to identify and characterize problems, design data- and evidence-informed approaches (and learn from other comparable programs, organizations, local areas about proven approaches), implement these approaches, monitor their implementation, evaluate their impact, make further adjustments as needed, sustain proven approaches locally, and support their spread widely	1) Public reporting on rapid learning and improvement 2) Distributed competencies for rapid learning and improvement (e.g., data and research literacy, co-design, scaling up, leadership) 3) In-house capacity for supporting rapid learning and improvement 4) Centralized specialized expertise in supporting rapid learning and improvement 5) Rapid-learning infrastructure (e.g., learning collaboratives)

THE PROBLEM

As the previous section outlined, policymakers, healthcare workers, stakeholders, and researchers across Canada are increasingly aware of the importance of ensuring comprehensive and integrated care and supports are available to individuals with neurodevelopmental disorders (and their families) across the lifespan. Yet, despite significant developments in the research-to-action landscape at both national and provincial levels, and the prioritization of improving services for some neurodevelopmental disorders among politicians, there is still a gap between what is being learned and achieved in the research community and the actions being taken to improve patient care and experiences in health systems across Canada. While a rapid-learning and improvement approach – characterized by the full range of efforts detailed in Table 1 – has the potential to create opportunities for better alignment between health and research systems and, ultimately improvements in patient care and experiences for those with neurodevelopmental disorders, too few steps have been taken to support rapid-learning in health systems across Canada. This current problem can best be understood in relation to five underlying challenges, which were identified in consultation with the Steering Committee and key informants who we interviewed for this evidence brief. The five challenges are:

1) many Canadians are affected by neurodevelopmental disorders over their lifespan;
2) neurodevelopmental disorders are not easy to consider in isolation or characterize;
3) without appropriate and integrated programs and services, neurodevelopmental disorders can place a significant burden on individuals, their families, health systems and society;
4) health-system arrangements are not conducive to optimizing services and supports for neurodevelopmental disorders; and
5) health and research systems are not aligned to enable a rapid-learning and improvement approach.

Below, we describe these underlying challenges in greater detail.

Many Canadians are affected by neurodevelopmental disorders over their lifespan

In the last 50 years, there has been an increase in the number of people described as living with neurodevelopmental disorders such as ASD, cerebral palsy, developmental coordination disorder, Down syndrome, fetal alcohol spectrum disorder or spina bifida.(4)Some estimates suggest that children with neurodevelopmental disorders now account for between 7-14% of all children in developed countries, making them the most readily identified sub-population of

Box 2: Equity considerations

A problem may disproportionately affect some groups in society. The benefits, harms and costs of approach elements to address the problem may vary across groups. Implementation considerations may also vary across groups.

One way to identify groups warranting particular attention is to use "PROGRESS," which is an acronym formed by the first letters of the following eight ways that can be used to describe groups†:

- place of residence (e.g., rural and remote populations);
- race/ethnicity/culture (e.g., First Nations and Inuit populations, immigrant populations and linguistic minority populations);
- occupation or labour-market experiences more generally (e.g., those in "precarious work" arrangements);
- gender;
- religion;
- educational level (e.g., health literacy);
- socio-economic status (e.g., economically disadvantaged populations); and
- social capital/social exclusion.

The evidence brief strives to address all Canadians, but (where possible) it also gives particular attention to three groups:

- individuals living in rural or remote areas;
- individuals with limited coverage of products and services not currently paid for by provincial publicly funded insurance plans (including recent immigrants to Canada); and
- individuals from particular ethnocultural groups with unique needs (e.g., Indigenous populations).

Many other groups warrant serious consideration as well, and a similar approach could be adopted for any of them.

† The PROGRESS framework was developed by Tim Evans and Hilary Brown (Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. *Injury Control and Safety Promotion* 2003;10(1-2): 11–12). It is being tested by the Cochrane Collaboration Health Equity Field as a means of evaluating the impact of interventions on health equity.

children with disabilities.(5) In Canada, recent analyses have found that of the approximately 5% of children with a disability, 74% of them are classified as a neurodevelopmental disability.(4; 6) In Ontario, Canada's largest province, more than 300,000 children and youth are living with a neurodevelopmental condition.(7) These children may be limited in their ability to participate in age-appropriate activities, which can hamper their social, emotional, cognitive and physical development.(6) However, it should be noted the exact burden faced by patients and their families is often challenging to measure, especially in relation to the functional impacts experienced and how multi-sector services are used.

While there are likely many factors contributing to the rise of neurodevelopmental disorders – including a change in how these conditions are identified and reported – the increase has been linked to the growing prevalence of preterm birth, infertility treatments, and challenges accessing health services.(8) Overall, while the range of neurodevelopmental disorders aren't always top priorities in health systems, unlike a number of other conditions, they often require support across the entire lifespan. In a recent Cochrane systematic review, the importance of considering a lifespan approach was emphasized, as it found the transition from pediatric to adult care for children with chronic conditions is frequently associated with a deterioration in health, as services fail to adequately meet evolving patient needs.(9)

Neurodevelopmental disorders are not easy to consider in isolation or characterize

Planning for and providing the best available care for patients with neurodevelopmental disorders is challenging given the nature of the conditions that fall into this category. Neurodevelopmental disorders are seldom able to be considered in isolation, given many individuals are living with several of them.(7) Neurodevelopmental disorders are also not easy to characterize because there is considerable variability in how these disorders are expressed. Therefore, diagnoses may neglect to account for the individual patient's functional and behavioural needs. For example, ADHD and ASD frequently occur together, and although they both have a prognosis of social impairment, the specific features that are impaired are not always the same, therefore having an impact on how patients are cared for.(10) Tailored health and social-care services are required to address an individual's needs, which poses a challenge to health-system strategies such as developing care pathways that aim to provide common approaches for specific populations.

This interconnectedness across the range of neurodevelopmental disorders poses challenges for at least two reasons. First, it means that most patients with neurodevelopmental disorders will require ongoing and complex packages of health and social care to address their full range of needs across different stages of life. Second, challenges in isolating and/or characterizing which particular disorder an individual has and requires support for means that the care they receive is likely to change and evolve throughout their life alongside ongoing changes in how their disorders are understood (by themselves, and by the clinicians caring for them). The challenges experienced in adult care are often very different, and patients and their families may not know what to expect when transitioning from youth to adult care. Taken together, these issues create an extremely complicated context within which to design health (and social) systems that are set up to get the right programs and services to individuals with neurodevelopmental disorders.

Without appropriate and integrated programs and services, neurodevelopmental disorders can place significant burden on individuals, their families, health systems, and society

Without appropriate and integrated programs and services across different stages of life and different sectors, neurodevelopmental disorders can place significant burden on individuals, their families, health systems, and society.(11) For example, in the absence of the right supports, individual symptoms of neurodevelopmental disorders such as anxiety, depression, compulsive activity, social isolation, and other physical concerns can take an emotional, physical and social toll on patients and their families. Caregivers can experience higher rates of chronic health problems themselves, such as asthma, arthritis and back problems, migraine headaches, and limitations in other activities.(12) They also exhibit higher depression scores, more problematic family functioning, and challenges with social support.(12) Additionally, programs and services are often organized for specific age groups, with more focus put on supports before the age of 18 rather than on transitional needs into adulthood. These issues can be further exasperated by a lack of early diagnosis and by a lack of surveillance systems to help understand how services are being used, where it could potentially decrease health-utilization costs, and improve quality of life

In addition to these concerns, neurodevelopmental disorders are also associated with a range of financial costs including medical and healthcare service costs, therapeutic costs, cost for education, costs of production loss for adults with a condition, costs of informal care, lost productivity for family/caregivers, and costs of accommodation, respite care and out-of-pocket expenses.(11) One recent systematic review found that families with children with ASD had higher costs compared to families that did not have a child with the condition, with education being the major additional cost for these families.(11) An Ontario-based retrospective cohort study published in 2019 estimated healthcare costs of adults with intellectual and developmental disabilities (IDD). The study found that adults with IDD are four times more likely to incur high annual healthcare costs than those without IDD. The highest incurred costs came from hospitalizations, continuing care and medications.(13) At the societal level, there is an association between neurodevelopmental disorders and lost overall productivity, with many health and social systems not having adequate resources to ensure comprehensive integrated programs throughout an individual's lifespan given care costs can be high.(7) A 2019 report by the Institute for Clinical Evaluative Sciences explored gaps in healthcare services for adults with developmental disabilities in Ontario. The researchers found that adults with developmental disabilities compared to adults with no developmental disabilities were two times more likely to have repeat emergency-department visits, three times more likely to be re-hospitalized, 6.5 times more likely to remain in alternate level of care, and 17.5 times more likely to live in a long-term care facility.(14)

Health-system arrangements are not conducive to optimizing services and supports for neurodevelopmental disorders

Health system delivery arrangements to support individuals with neurodevelopmental disorders and their families have not been adequately designed to ensure access to comprehensive and integrated services that adopt a 'lifespan' perspective. Many patients with neurodevelopmental disorders require services that span health and social systems, delivered by multiple agencies, care sectors (e.g., home and community care, primary care and specialty care), and government ministries (e.g., health, children and youth services, social services, etc.).(15) Given the many types of programs and supports needed – particularly among patients with dual diagnoses – it may be challenging for health- and social-system planners to design and deliver appropriate care. The current lack of technology use that focuses on delivery arrangements (e.g., wearable technology that could detect neurological triggers) may also contribute to these challenges.

There are four specific challenges related to the nature of delivery arrangements as they relate to neurodevelopmental disorders that warrant attention. First, providers often lack the specialized training required to meet the holistic needs of individuals with neurodevelopmental disorders. Second, there is a lack of collaboration and communication among the full range of program and service providers working in numerous sectors and settings – which can be compounded by the fragmentation of government ministries overseeing these programs and services. Specifically, the role of the community-care sector in providing this holistic care is often overlooked, despite its deep engagement across the spectrum of care. Third, even when a full range of programs and services is offered to patients in need, they may not be widely accessed or accessible – which is particularly the case for specialized services. For instance, one study in B.C. found that specialized mental health services for individuals with a dual diagnosis of neurodevelopmental disorder and psychiatric disorders were difficult to access and not available for many children and families.(16) Fourth, pediatric transitions and adult services for neurodevelopmental disorders have not been planned together, resulting in missed opportunities to establish integrated, developmentally appropriate care, which would ultimately benefit patients and their families throughout the lifespan. Although there are few examples of how a lifespan perspective is being used in practice, Newfoundland and Labrador's three-year Autism Action Plan is a notable exception, which focuses on coordinating services across the lifespan using a whole-government approach.(17) Many organizations involved in neurodevelopmental disorders across Canadian provinces have put out calls for the implementation of a lifespan approach, including the Autism Management Advisory Team in Nova Scotia and the Canadian Autism Spectrum Disorder Alliance at the federal level.(18) Despite these calls for action, there is significant research missing to inform the development and delivery of a lifespan approach to care. For example, a 2014 review published in CMAJ concluded that there was a lack of evidence-based practices for autism among older children and adults, let alone for other neurodevelopmental disorders more broadly.(19) One notable effort to address this gap has been through the Ontario Brain Institute, which has prioritized determining how system navigations can be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families.(7)

In addition to the challenges associated with the delivery arrangements outlined above, health-system financial arrangements are also problematic in the context of neurodevelopmental disorders. Specifically, public funding for programs and services needed by patients and their families is often inconsistent and inadequate within and across Canadian health systems. Certain types of services may not be covered at all (e.g., outpatient mental health services) and the decision authority over these supports is fragmented across many ministries and levels of decision-making.(16) Coverage can also be dependent on specific diagnoses, leaving some patients without access to the services they require. For example, diagnoses based on disease classification systems – which may fail to account for the complexity of individual patient needs – often drive the eligibility criteria for public funding of both health and social services. This means that many with needs based on their functional characteristics, regardless of diagnoses, may go unsupported.(5) Furthermore, clinicians often report similarities in the functional needs of children diagnosed with different neurodevelopmental disorders, which suggests relying on diagnoses to determine access to services may create inequities in care.(5)

Health and research systems are not aligned to enable a rapid-learning and improvement approach

As detailed in Table 1, rapid learning and improvement requires assets that facilitate patient-centred care and data- and evidence-informed decision-making, supportive system characteristics (e.g., decision supports and aligned governance, financial and delivery arrangements), a conducive culture, and individuals at all levels of the system with the right competencies. In the context of neurodevelopmental disorders, not all assets are in place, and those that are in place are not always well connected to align health and research systems, making it difficult to enable cycles of rapid learning and improvement.

In Canada, opportunities for rapid learning and improvement to address the challenges associated with providing comprehensive wrap-around care for neurodevelopmental disorders may have been overlooked to date. For example, there are many centres of excellence in research and specialized care that exist but aren't linked up in ways to ensure effective approaches for improving patient care and experiences. These assets include networks focused on research and patient engagement such as SPOR (including CHILD-BRIGHT), and those that focus on investments in the timely production of research and competencies for rapid learning based on data and research (e.g., KBHN and CHILD-BRIGHT). In addition, a range of provincial disabilities policies also exist, although they are not aligned between jurisdictions or between health and social systems.

Despite these assets, there are gaps in current initiatives that would make it a challenge to 'link up' assets and create rapid-learning systems. For example, there may be little proactive engagement of patients and families in the design of care across Canada, as well as few attempts to engage them in setting targets for improving care and experiences. It should also be recognized that patients may not know about the features of the system that they are trying to navigate, the research that is being conducted, or how they can engage with each other. The experiences of patients and their level of engagement may also differ across the range of neurodevelopmental disorders. For example, Autism Spectrum Disorder is recognized to have a more consolidated voice compared to other non-developmental disorders, and this dynamic is something that will need to be addressed if broad representation is desired.

Furthermore, data and research systems for neurodevelopmental disorders are not well-resourced despite requiring the integration of diverse types of data across a variety of sources. These features inhibit the timely production of neurodevelopmental research, and particularly the type of research that can help to inform how health and social systems are arranged to ensure cost-effective programs and services get to those who need them most. For example, compared to other 'high-profile' conditions such as cancer and heart disease, investments in research focused on neurodevelopmental disorders are comparatively smaller, with 13,136 projects totalling $4.3 billion spent on cancer according to the CIHR Funded Research Database, in comparison to 397 projects totaling $129 million for neurodevelopmental disorders.(20)

In addition to these broader issues, there is also uncertainty around the unique needs of front-line service providers engaged in the delivery of services for those with neurodevelopmental disorders, particularly related to the decision supports needed to make better use of evidence and engage in rapid learning (e.g., practice guidelines and tools). Given the diversity of service providers across sectors engaged in care for individuals with neurodevelopmental disorders, it may also be difficult to understand the incentives that drive providers to act, and facilitating 'buy-in' to achieve a collective impact may be challenging. Furthermore, discrepancies also remain in understanding the functional challenges and needs of different sub-groups of children with neurodevelopmental disorders.(6) For example, patients with certain physical/motor conditions (e.g., cerebral palsy and autism) often receive more focus than others (e.g., neurosensory, communication/cognitive, social interaction and psychological impairments).(6)

Overall, better-established connections among existing assets could help to consolidate efforts in a way that could improve long-term sustainability, provide opportunities to better define the roles of each individual group, and ensure the strengths of each group are acknowledged and used to complement the strengths of others. It would also help to clarify where gaps exist across the characteristics of a rapid-learning health system.

Additional equity-related observations about the problem

As noted in box 2, the problems outlined above may disproportionately affect certain groups in society. Although many groups warrant consideration, this evidence brief gives particular attention to individuals living in rural or remote areas, individuals with limited coverage of products and services not currently paid for by publicly funded provincial insurance plans (including recent immigrants to Canada), and individuals from particular ethnocultural groups with unique needs (e.g., Indigenous populations).

As mentioned above, children with neurodevelopmental disabilities may be limited in their ability to participate in age-appropriate activities, which can hamper their social, emotional and physical development.(6) Although alternative options may be available in places where more children are affected by neurodevelopmental disorders, families who live in rural settings may have relatively limited options. Furthermore, we know that many individuals often have several neurodevelopmental disorders and require complex packages of health and social care that need to evolve throughout their life.(7) Ensuring access to a full range of programs and services to meet complex needs is challenging regardless of location, but may be particularly burdening for those who live in remote places. It is known that in the absence of access to supports, further issues can arise among patients and their caregivers.(12) Families who are forced to take on more care needs because of decreased access to services may experience further financial costs (especially if they aren't able to work) and healthcare costs (in compromised ability to attend to their own health needs).

In addition to barriers to accessing health services associated with geographic locations, many people, such as recent immigrants to Canada, may face limited coverage of services that are not currently paid for by provincial publicly funded insurance plans. A qualitative study among immigrant mothers of children with autism in Toronto, Canada found that barriers to service access included delays in diagnosis, fragmentation of services, loss of social ties, increased stigma, a lack of support from family partners, and negative perceptions of services that are available.(21) Overall, there is a limited range of work that aims to explore how to increase understanding and collaboration among the immigrant population and healthcare practitioners to address some of these barriers.(22)

Individuals from specific ethnocultural groups, such as Indigenous populations, also experience inequities in overcoming the problems mentioned above. It has been established that far less research about neurodevelopmental disorders exists with a focus on First Nations people, Métis and Inuit compared to research about these disorders that focuses on the general population in Canada.(23) In light of increased discrimination, historic oppression and trauma (which are tied to social and health inequalities in Indigenous peoples), research on access to disability services among this group would be especially relevant.(23) Although disability rates have been found to be higher among First Nations people living off reserve and Métis, these figures may be under-reported due to cultural bias in diagnostic instruments, stereotyping and stigma.(23) Furthermore, the research that does exist often fails to acknowledge community involvement in research decisions or dissemination of results that would benefit the communities involved.(24)

The impact of COVID-19 on the problem

Globally, the COVID-19 pandemic has forced profound changes in how health and social systems organize themselves to respond to societal needs. As the pandemic response in Canada transitions from the 'sprint' phase (i.e., addressing the acute infection-prevention and control needs that emerged in the early days of the pandemic) to the 'marathon' phase (i.e., maintaining the public-health gains made in controlling Canada's epidemic while continuing to ensure the full range of Canadians' health and social needs are met), understanding these changes in the context of neurodevelopmental disorders is key.

To take stock of the most important issues arising as a result of the pandemic, we conducted additional key informant interviews with policymakers, stakeholders and researchers to gain additional insights about supporting the needs of individuals with neurodevelopmental disorders during the pandemic. Important challenges were identified at the level of individuals with neurodevelopmental disorders and their families, as well as at the system level.

At the level of individuals (and their families), key informants highlighted a number of emergent challenges (which in some cases were worsening problems) being linked to the COVID-19 pandemic, which include:
1) disruptions in care (e.g., closure of in-person services, lack of availability of providers, clinic and home visits, or limited access to technology for virtual care), which have led to setbacks, loss in progress, and potential long-term negative consequences related to an individual's condition;
2) emotional distress due to feelings of isolation and fear among individuals (and their families) due to safety concerns related to accessing services and receiving care during the pandemic; and
3) lack of self-management supports for individuals (and their families) during situations when services and programs are inaccessible over the course of COVID-19.

At the system level, key informants highlighted the following challenges emerging as a result of the pandemic:
1) uncertainty and a lack of coordination among policymakers and care providers on the best approach to structure services and programs, such as how to utilize novel approaches (e.g., virtual care and telehealth) with usual care in an effective and cost-effective manner as the pandemic progresses over time;
2) an exacerbation of the extent to which there are 'silos' across the health- and social-systems players involved in providing services to individuals with neurodevelopmental disorders; and
3) a fragmented evidence ecosystem, which has created challenges to ensuring local, provincial and federal policymakers have access to the best available evidence syntheses to inform their decisions.

THREE ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH FOR ADDRESSING THE PROBLEM

Many approaches could be selected as a starting point for deliberations about an approach for creating a pan-Canadian learning health system for neurodevelopmental disorders. To promote discussion about the pros and cons of potentially viable approaches, we have selected three elements of a potentially comprehensive approach to addressing the problem. The three elements were developed and refined through consultation with the Steering Committee and key informants who we interviewed during the development of this evidence brief. The elements are:

1) prioritize service needs and design a rapid-learning and improvement approach to meet them;
2) strengthen and link the assets required to operationalize the rapid learning and improvement; and
3) establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action.

The elements could be pursued separately or simultaneously, or components could be drawn from each element to create a new (fourth) element. They are presented separately to foster deliberations about their respective components, the relative importance or priority of each, their interconnectedness and potential of or need for sequencing, and their feasibility. However, it is important that they are understood as interrelated and mutually reinforcing over the short, medium, and long term as efforts are pursued and scaled up to create a rapid-learning health system for neurodevelopmental disorders. For example, element 1 (prioritizing service needs and designing an approach) is essential for helping to establish what the focus should be in element 2 (strengthening and linking assets that are necessary to address those prioritized service needs), with both elements 1 and 2 having direct implications for how to approach engaging the right policymakers, healthcare workers, stakeholders and researchers in the short term (for addressing priority needs), as well as over the medium or long term (for addressing all needs related to neurodevelopmental disorders). to help move forward with element 3. These connections are illustrated in Figure 2.

Box 4: Mobilizing research evidence about the elements of a potentially comprehensive approach to addressing the problem

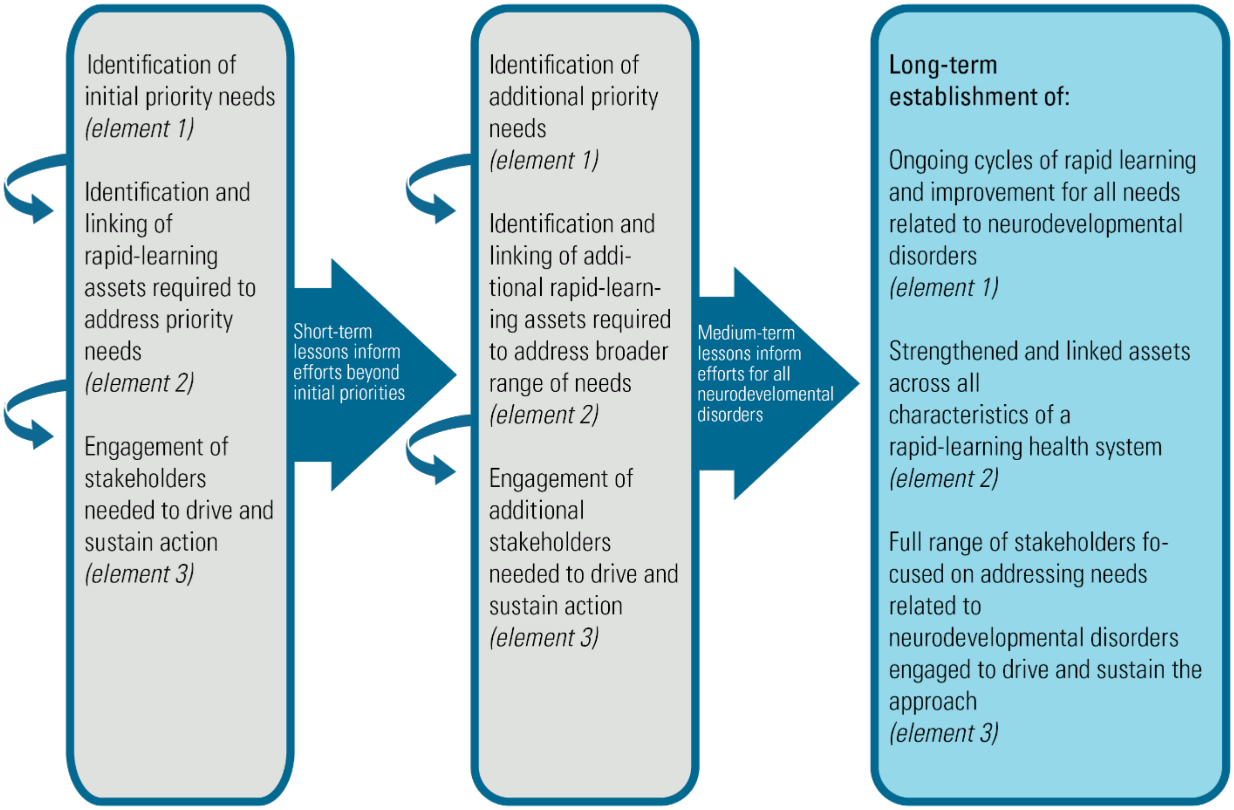
The available research evidence about elements of a potentially comprehensive approach for addressing the problem was sought primarily from Health Systems Evidence (www.healthsystemsevidence.org), which is a continuously updated database containing more than 8,000 systematic reviews and more than 2,800 economic evaluations of delivery, financial and governance arrangements within health systems. The reviews and economic evaluations were identified by searching the database for reviews addressing features of each of the elements. Searches to gain insights about the social dimensions of the issue were conducted in Social Systems Evidence (www.socialsystemsevidnece.org) which is a continuously updated database containing more than 3,500 systematic reviews and nearly 500 economic evaluations about social systems.

The authors' conclusions were extracted from the reviews whenever possible. Some reviews contained no studies despite an exhaustive search (i.e., they were 'empty' reviews), while others concluded that there was substantial uncertainty about the element based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the reviews' quality, the local applicability of the reviews' findings, equity considerations, and relevance to the issue. (See the appendices for a complete description of these assessments.)

Being aware of what is not known can be as important as being aware of what is known. When faced with an empty review, substantial uncertainty, or concerns about quality and local applicability or lack of attention to equity considerations, primary research could be commissioned, or an element could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a review that was published many years ago, an updating of the review could be commissioned if time allows.

No additional research evidence was sought beyond what was included in the systematic review. Those interested in pursuing a particular element may want to search for a more detailed description of the option approach elements or for additional research evidence about the elements.

Figure 2: Relationship between elements over short, medium and long term



The principal focus in the remaining parts of this section is on what is known about these elements based on findings from systematic reviews. We present the findings from systematic reviews along with an appraisal of whether their methodological quality (using the AMSTAR tool)(9) is high (scores of 8 or higher out of a possible 11), medium (scores of 4-7) or low (scores less than 4) (see the appendix for more details about the quality-appraisal process). We also highlight whether they were conducted recently, which we define as the search being conducted within the last five years. In the next section, the focus turns to the barriers to adopting and implementing these elements, and to possible implementation strategies to address the barriers.

Element 1 – Prioritize service needs and design a rapid-learning and improvement approach to meet them

This element focuses on the steps required to prioritize, design, and incrementally implement programs and services for neurodevelopmental disorders. Examples of this approach could involve an initial pilot project in various settings and then scaling up effective interventions across settings (or scaling out promising approaches to additional priority populations). Sub-elements could include:

- segment the population of individuals with developmental disorders into groups (or population segments) with shared needs and identify priority populations if applicable;
- design ‘in-reach’ and ‘out-reach’ services appropriate to each group (or for a prioritized population segment);
- stratify these services to support their delivery in a manner that reaches and is appropriate to sub-groups (or prioritized population segments);
- identify, prioritize, measure and publicly report on quadruple-aim metrics for which the solutions are expected to ‘move the needle’; and

- continue to rapidly learn and improve on defined goals, taking stock of how particular assets have been sustained or strengthened and gaps addressed.

We identified six systematic reviews relevant to identifying goals and establishing accountability to achieving them; however, these reviews did not directly focus on rapid learning and improvement or neurodevelopmental disorders. Additionally, we identified one primary study that focused on lessons learned from a learning-health-system approach for an autism pediatric research network. We discuss findings for sub-elements two and four, as no reviews were identified for the other sub-elements.

Design 'in-reach' and 'out-reach' services appropriate to each group (or for a prioritized population segment)

While a recent medium-quality review did not focus on neurodevelopmental disorders but on rehabilitative services, the authors identified specific factors to consider when designing services such as: involving individuals with a specific health condition in policy processes; capturing relevant data; explicitly recognizing other contextual factors that may have an impact on a health condition (e.g., access to services); and integrating new services into existing infrastructure and programs to help support sustainability.(25)

A primary study that focused on transforming an autism pediatric research network into a learning health system reported key considerations when redesigning current processes and services, including:
- conceptualize changes based on the program's strengths in order to leverage existing resources and enable smoother transitions;
- expand the rapid learning and improvement as the program grows, and incorporate patient partners and clinicians during the development stage; and
- recognize there will be complexities and challenges when redesigning current processes and data infrastructures.(26)

Identify, prioritize, measure, and publicly report on quadruple-aim metrics for which the solutions are expected to 'move the needle"

Five of the six the reviews could be tied to the fourth sub-element, which involves identifying, prioritizing, measuring, and publicly reporting on quadruple-aim metrics. One recent and one older low-quality reviews described factors and drivers when developing an evaluation process, including involving stakeholders, iterating processes, using evidence, incorporating community values, accountability, and linking data to relevant benchmarks.(27; 28) With regards to public reporting and providing opportunities for the public to engage with service providers, one recent high-quality review reported increased access to services, improved delivery of care, and increased citizen engagement.(29) Additionally, a review described public reporting in the U.K., where the authors indicated an increased provider reluctance to accept high-risk patients and closure of some practices, and the largest effect being among low-performing providers. The author explained how these findings could be transferred to other settings once other contextual factors of the health system are considered.(30) Finally, a recent medium-quality review identified studies that used the quadruple-aim metrics to evaluate the effectiveness of clinical networks, which found some improvements in patient outcomes and cost-effectiveness.(31)

A summary of the key findings from the synthesized research evidence is provided in Table 2. For those who want to know more about the systematic reviews contained in Table 2 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 3. Additional information of the primary study is provided in Appendix 4.

Table 2: Summary of key findings from systematic reviews relevant to Element 1 – Prioritize service needs and design a rapid-learning and improvement approach to meet them

Category of finding	Summary of key findings
Benefits	• **Design ‘in-reach’ and ‘out-reach’ services appropriate to each group (or for a prioritized population segment)** o One recent medium-quality review described factors about strong leadership and governance for rehabilitation services, including: the involvement of persons with a specified condition in policy processes; data on the condition; recognition in policies of other contributing factors related to the condition; and integration of existing services and programs to support sustainability. While specific to rehabilitation, the authors concluded that these factors could be applied in other contexts and settings within a health system.(25) • **Identify, prioritize, measure, and publicly report on quadruple-aim metrics for which the solutions are expected to ‘move the needle’** o One recent low-quality review described components to consider when developing an evaluation protocol for priority setting in macro- and meso level health systems, including stakeholder involvement, empowerment, revisions, use of evidence, enforcement, and incorporation of community values.(27) o An older low-quality review identified linking data to relevant benchmarks and the involvement of stakeholders as two main drivers in the uptake and use of performance measures. Stakeholder engagement ensured accountability and that relevant indicators were considered by utilizing their tacit knowledge to provide meaning to the data. The authors identified contributing factors such as effective leadership and the capacity to build an organizational culture that fosters dialogue and clear objectives.(28) o A recent high-quality review reported increased access to services, improved delivery of care, and increased engagement among citizens when programs provided opportunities to directly engage with service providers and citizens.(29) o A recent medium-quality review found some evidence to suggest that the establishment of clinical networks can improve patient outcomes related to the quadruple-aim metrics and goals. The authors noted that the methodological quality of studies was low.(31)
Potential harms	• No reviews found
Costs and/or cost-effectiveness in relation to the status quo	• **Identify, prioritize, measure, and publicly report on quadruple-aim metrics for which the solutions are expected to ‘move the needle’** o A recent medium-quality review reported reduction in total per-capita expenditures after implementing a clinical network.(31)
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	o Uncertainty because no systematic reviews were identified ▪ No reviews found o Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review ▪ No reviews found • No clear message from studies included in a systematic review o **Identify, prioritize, measure, and publicly report on quadruple-aim metrics for which the solutions are expected to ‘move the needle’** ▪ One recent low-quality review that focused on developing an evaluation protocol for healthcare priority setting in macro- and meso-level health systems reported that the disconnect between the evaluation theories and

	the literature on evaluating priority setting may limit the effectiveness of the evaluation protocol for priority setting.(25)
Key elements of the policy option if it was tried elsewhere	• **Identify, prioritize, measure, and publicly report on quadruple-aim metrics for which the solutions are expected to 'move the needle'** o One recent medium-quality review examined the effects of public reporting of providers to improve quality of care in the U.K. The authors found that public reporting was associated with increased provider reluctance to accept high-risk patients and closure of some practices, and the largest effect was among low-performing providers. Additionally, the authors concluded that these findings may be transferred to other settings, but must consider contextual factors such as an understanding of the health system (e.g., providers, access to data, patients, and organizations).(30)
Stakeholders' views and experience	• No reviews found

Element 2 – Strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada

With the insights gained from element 1 about prioritizing service needs and designing a rapid-learning approach to meet them, this element focuses on identifying and pooling assets to advance rapid-learning health systems for neurodevelopmental disorders. This could help to: 1) understand which assets are required to operationalize the approach; 2) determine where more support is required for strengthening and linking assets; and 3) identify system gaps that need to be filled to operationalize the approach. To facilitate these facets, sub-elements could include efforts to:

- use established frameworks to identify rapid-learning assets and gaps at the provincial/territorial and national levels;
- take steps to ensure assets are 'joined up', and strengthening areas where there are gaps in rapid-learning characteristics; and
- strengthen technical supports that draw on provincial and national networks of expertise across the country to ensure patient and family partners, providers, organizations, and system leaders interested in building their competencies for rapid learning and improvement are enabled to do so.

We identified five reviews and two primary studies pertaining to element 2 and its sub-elements. Most of the reviews identified were medium quality and primarily addressed the first sub-element of using established frameworks to identify rapid-learning assets and gaps at the provincial/territorial and national levels. While these findings provide valuable insights broadly applicable to mapping and linking up rapid-learning assets, only one review and two primary studies directly explored rapid-learning health systems.(32) We summarize the evidence identified in relation to each sub-element below.

Using established frameworks to identify rapid-learning assets and gaps at the provincial/territorial and national levels

We found three systematic reviews that provided relevant considerations and insights for sub-element one, although they did not explicitly focus on utilizing existing frameworks.

Two systematic reviews explored frameworks for recognizing assets and gaps through an asset-based approach. One systematic review proposed a framework comprised of four key stages: defining scope and size of asset-mapping process; identifying assets; mapping assets; and consulting and implementing findings.(1) Another review additionally pinpointed the following framework: identifying and prioritizing assets; planning which assets should be mobilized; and evaluating outcomes.(33) This review further highlighted several avenues by which to find assets, including asset-mapping, community engagement, needs assessments, appreciative inquiry and interviews.(33)

Most of the retrieved literature identified collaboration across multiple sectors as critical to implementing an asset-mapping approach.(34; 35) Several factors were identified as crucial to the success of the core team, including identifying a core-team leader, frequent core-team meetings, and pre-existing partnerships between core-team members.(34) Other key considerations in the development and implementation of an asset-based approach framework include identifying a target population, setting geographical boundaries, creating a plan for data collection, and determining how data will be utilized.(34)

Authors of the review propose utilizing a systematic approach such that any individual can easily and readily participate in asset-mapping. Defining a clear goal for asset-mapping and gearing an asset-mapping process towards this objective was also identified as another approach.(34) Authors of another systematic review further emphasized the need to use collaborative approaches which include individuals and their communities.(35)

The same reviews further identified several barriers to the implementation of an assets-based approach.(1; 5) One systematic review reported a lack of consistency in definitions of what constitutes a "health asset" and further pinpointed the limited operationalization of these existing definitions in sectors beyond health policy.(35) Another systematic review suggests that while asset-mapping may not require large upfront financial investments, updating asset maps consistently over time may require the continuous investment of human and financial resources.(34) This may pose a challenge to resource-strained settings and it is critical to acknowledge these considerations in undertaking an asset-based approach.

Most of the reviews identified revealed a paucity of high-quality research evidence pertaining to the implementation of asset-based approaches.(34; 35) As a result, there is uncertainty surrounding the benefits and impact of identifying assets and gaps.(34; 35)

Taking steps to ensure assets are 'joined up' and strengthening areas where there are gaps in rapid-learning characteristics

Two recent medium-quality systematic reviews addressed sub-element two.(33; 36) Though not directly applicable to this sub-element, both systematic reviews explore performance-assessment strategies which may be relevant in evaluating whether rapid-learning assets are 'linked' and in identifying gaps.

One systematic review emphasized evaluating the outcomes of asset-based approaches at an individual, community and organizational level through qualitative, quantitative, and mixed methods.(33) Another review suggested measuring the impact of existing assets by evaluating effective coverage, including measuring the utilization and quality of such assets, as well as their ability to address health needs at a community level.(36) Authors of this review further proposed utilizing complementary strategies, in addition to using administrative data, could be an approach to avoid bias in performance assessments.(36) Both reviews identified a lack of consistency in indicators and measures being used to evaluate the effectiveness of asset-based approaches and interventions across research evidence.(33; 36)

Additionally, a primary study that focused on transforming an autism pediatric research network into a learning health system reported that a self-evaluation would be beneficial, and could ensure a shared understanding of strengths and gaps with the research team (e.g., network's mission, activities, governance and decision-making authorities, data infrastructure).(26)

Establish a program of technical supports that draws on a network of expertise across the country to ensure patient and family partners, providers, organizations and systems leaders interested in building their competencies for rapid learning and improvement are enabled to do so

We identified one recent low-quality systematic review relevant to implementing a learning health system; however, this review offers limited insights applicable to the establishment of a program of technical supports.(32)

A primary study that explored stakeholders' views of developing and implementing a registry-based learning health system reported that a partnership between patients and clinicians allows for co-production to be foundational. Technology infrastructure that is capable of data-sharing would be beneficial to both patients and clinicians for joint decision-making and collaboration.(37)

A summary of the key findings from the synthesized research evidence is provided in Table 3. For those who want to know more about systematic reviews contained in Table 3 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 2. Additional information on the primary studies can be found in Appendix 5.

Table 3: Summary of key findings from systematic reviews relevant to Element 2 – Strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada

Category of finding	Summary of key findings
Benefits	• **Use established frameworks to identify rapid-learning assets and gaps at the provincial/territorial and national levels** ○ Three recent medium quality reviews aimed to explore mechanisms by which to identify health assets.(33-35) ▪ One systematic review proposed the following framework for asset-mapping: identifying the scope and size of asset-mapping, identifying assets, and consulting and implementing.(34) ▪ This review additionally identified the following factors as important considerations for asset-mapping: identifying a team lead, defining a target population and setting geographical boundaries, creating a data collection plan, deciding how the information will be used, and considering limitations in human and financial resources.(34) ▪ Another systematic review proposed the following as initial stages in an asset-based approach framework: identifying and prioritizing, planning; and outcomes and evaluation.(33) ▪ A third review found that health assets were most commonly defined as factors which reduce health disparities and improve an individual, population or system's ability to achieve optimal health and well-being.(35) The aforementioned review identified several types of health assets, including those which exist at the community, individual and organizational levels.(35) ○ Two recent medium-quality systematic reviews emphasized the value of interdisciplinary collaboration in mapping health assets.(34; 35) ▪ One review identified the selection of an interprofessional core team to drive asset mapping as a critical step. Anecdotal evidence suggests that the development of a core team may additionally foster collaboration across multiple sectors which may improve the coordination in the delivery of services.(34) ▪ This review found several facilitators crucial to the success of the core team, including identifying a core -eam leader, frequent meeting times and the presence of pre-existing partnerships between core-team members.(1) ▪ Another review underlined the inclusion of all crucial stakeholders in the implementation of an asset-based approach in health programming. Avenues by which to include stakeholders in asset-mapping may include toolkits which introduce individuals to this field and to local asset maps being developed in their communities.(35)

Category of finding	Summary of key findings
	o Two medium-quality systematic reviews suggested that undertaking an asset-based approach to health programming may be a successful strategy in that it reflects and addresses the complexity of communities and their health needs.(33) ▪ One review suggested that health-promotion programs which act at multiple levels may create more long-lasting behavioural changes.(35) • **Take steps to ensure assets are 'joined up' and strengthening areas where there are gaps in rapid-learning characteristics** o One recent medium-quality review proposed a three-step approach to mobilizing assets: linking existing resources; increasing awareness about existing assets; and enabling assets to thrive.(33) o Two recent medium-quality systematic reviews explored performance-assessment strategies for health programming. ▪ One review proposed that asset-based approaches should be evaluated through qualitative, quantitative and mixed approaches. Outcomes should be assessed at the individual, community and organizational levels.(33) ▪ Another review stated that the need for, use of, and quality of an intervention should be measured in order to determine effective coverage. Biomarkers, self-reported data from surveys, administrative records from disease-management programs, and statistical methods were commonly used to evaluate the utilization and quality of interventions.(36) ▪ The same review suggests that effective coverage should only be measured for specific interventions. Considerations for selecting interventions for performance assessments include: whether the intervention addresses a population's priority health needs; provides data which can be extrapolated to other interventions; is affordable; and is impactful on the burden of disease.(36) ▪ The review further emphasized the need to define quality indicators beforehand to ensure the adequate collection and availability of data for effective coverage.(36) • **Establish a program of technical supports that draws on a network of expertise across the country to ensure patient and family partners, providers, organizations, and system leaders interested in building their competencies for rapid learning and improvement are enabled to do so** o One recent low-quality review identified selecting an appropriate scale of implementation as critical to the success of learning health systems.(32)
Potential harms	• **Use established frameworks to identify rapid-learning assets and gaps at the provincial/territorial and national levels** o One recent medium-quality systematic review identified updating asset maps consistently and continuously as a significant challenge, especially if there were limitations in human and financial resources.(34) The review proposes that undertaking a systematic approach to asset-mapping, such as by keeping detailed records of assets, and aiming towards a clear objective, may be potential avenues to overcome this issue.(34) o Another recent medium-quality systematic review identified a lack of consistency surrounding the definition of 'health assets' across disciplines as a barrier.(35) • **Take steps to ensure assets are 'joined up' and strengthening areas where there are gaps in rapid-learning characteristics** o One recent medium-quality systematic review stated that measuring use and intervention coverage over time may be subject to bias. The review proposes avoiding relying primarily on administrative data and undertaking complementary strategies as a potential solution.(36) • **Establish a program of technical supports that draws on a network of**

Category of finding	Summary of key findings
	expertise across the country to ensure patient and family partners, providers, organizations, and system leaders interested in building their competencies for rapid learning and improvement are enabled to do so o One recent low-quality review suggests that selecting a larger scale by which to implement a learning health system may serve as a barrier in evaluating its impact. Implementing learning health systems on a smaller scale may enable more immediate assessments of its impact, and may also motivate efforts to implement on a larger scale.(32)
Costs and/or cost-effectiveness in relation to the status quo	• **Take steps to ensure assets are 'joined up' and strengthening areas where there are gaps in rapid-learning characteristics** o One recent medium-quality review suggests that there may be limited costs associated with collecting data necessary for evaluating effective coverage. • **Establish a program of technical supports that draws on a network of expertise across the country to ensure patient and family partners, providers, organizations, and system leaders interested in building their competencies for rapid learning and improvement are enabled to do so** o One recent low-quality review found that the implementation of a learning health system as a mechanism to support collaborative learning and train novices in surgical settings contributed to significant savings. In cost comparisons with and without learning health systems, $67.3 million was estimated to have been saved.(32) However, the cost of investment is unclear.
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	• No clear message from studies included in a systematic review o **Use established frameworks to identify rapid-learning assets and gaps at the provincial/territorial and national levels** ▪ One recent medium-quality review reported the availability of quality research evidence as a limitation to quantifying the benefits of asset-mapping. This review primarily explored the mapping of services in nursing and suggests that its findings may not be applicable to other sectors of health.(34) ▪ Another recent medium-quality review identified the need for a higher-quality and larger evidence base in evaluating the impact of asset-based approaches to programming on health outcomes.(35) o **Take steps to ensure assets are 'joined up' and strengthening areas where there are gaps in rapid-learning characteristics** ▪ One recent medium-quality review found that the large variance between studies in the types of indicators used to measure the outcomes of asset-based approaches served as a barrier in synthesizing evidence and evaluating the impact of this strategy.(33) ▪ Another medium-quality systematic review identified strengthening and 'linking' quality measures as a critical step in evaluating effective coverage.(36) o **Establish a program of technical supports that draws on a network of expertise across the country to ensure patient and family partners, providers, organizations, and system leaders interested in building their competencies for rapid learning and improvement are enabled to do so** ▪ One recent low-quality review reported a lack of empirical evidence on the impact of implementing a learning health-systems approach on health-service delivery.(32)
Stakeholders' views and experience	• No reviews found

Element 3 – Establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action

This element focuses on fostering a collaborative network of key individuals ('rapid-learning champions') who can foster rapid learning and improvement for neurodevelopmental disorders. These key individuals could help identify strengths and efficiencies to existing networks. This approach is about ensuring the sustained spread and scale across Canada, drawing on lessons learned from Elements 1 and 2.

The sub-elements include:
- identify and engage patients and family partners, knowledge brokers, providers, and organizational and system leaders who can advocate for and lead the work related to establishing rapid-learning health systems for neurodevelopmental disorders;
- set up an administrative home for efforts to support the development of rapid-learning health systems for neurodevelopmental disorders (could be an existing organization or research network); and
- define the range of activities required to continuously build and strengthen the network (e.g., through capacity-building workshops, webinars, and supports for a community of practice).

We identified 11 systematic reviews related to the element. The reviews ranged in quality and only three discussed the concept of 'champions' explicitly. We also identified two primary studies that were especially applicable to building a network of rapid-learning champions, and one primary study that described considerations when developing a learning health system. Below, we summarize the evidence identified in relation to each of the sub-elements listed above.

Identify and engage patients and family partners, providers, and organizational and system leaders who can advocate for and lead the work related to establishing rapid-learning health systems for neurodevelopmental disorders

There was a consensus in the literature that the evidence on identifying key champion partners was limited. A low-quality review indicated that a majority of studies simply stated whether champions existed or not, giving little detail on how they were selected or evaluated.(38) Another low-quality review agreed that there was little evidence on this topic, but concluded that selecting partners with a common culture, a complementary knowledge base and aligned strategic objectives was important.(39) That being said, it was also suggested by a different low-quality review that creating a universal framework for selecting champion partners may be unsuitable, as different contexts of innovation may require diverse approaches.(40)

While there was little evidence on how to select champion partners, there was indication that the number of champions selected and their strategic placement within organizations were fundamental considerations. For example, coordinating the placement of multiple champions to counter the influence of opponents at the executive, managerial and clinical levels was suggested to make subsequent uptake more likely.(38; 40) Two primary studies also stressed the importance of placing champions at different strategic levels. The first study emphasized the importance of inner-context championing (focusing on front-line practical support) and outer-context championing (focusing on system-level collaboration).(41) The second study suggested that practices which implemented project champions (focusing on implementation of the elements of a specific project) and organizational champions (focusing on leading change for the entire organization) were best at implementing and sustaining improvements.(42)

Further evidence was provided in terms of engaging champion partners. One medium-quality review that examined engagement with community-based organizations suggested that in order for engagement to happen, there must be a relevant community need, a shared mission among partners, common resources available, and clearly defined outcomes of the partnership.(43) A different medium-quality review that assessed citizen engagement found several obstacles that prevented successful engagement, but also highlighted their potential mitigators. These mitigators focused on long-term collaboration, shared research efforts, institutionalizing participatory processes, employing multiple engagement techniques, defining both immediate and long-term goals, and clarifying common language and terminology.(44) Two other reviews, one focused on joint working between health and social-care sectors and one focused on effective citizen engagement, both suggested that direct partnerships established at the point of care were an effective way of fostering engagement of stakeholders.(29; 45) For example, multidisciplinary teams of service providers and cross-service placements both helped promote joint working between sectors in practice. Furthermore, direct patient-provider engagement helped increase citizen participation, service access and quality service provision.

Set up an administrative home for efforts to support the development of rapid-learning health systems for neurodevelopmental disorders (could be an existing organization or research network)

Three reviews were identified as being relevant to addressing how to set up an administrative home to support rapid learning for neurodevelopmental disorders. One high-quality review worked to identify specific features of organizations that successfully implemented evidence-based practices, something that may be relevant for setting up a home to lead efforts for rapid-learning. The review concluded that having a principal organization with a culture open to innovation, effective leadership that can foster buy-in, communication supports to insure information clarity, access to required resources such as finances, staff, time and education, feedback mechanisms to ensure sustainability, and champions who can use their experience and availability to troubleshoot and support, were all crucial components.(46) Similarly, a primary study that focused on transforming an autism pediatric research network into a learning health system reported that it would be beneficial to integrate education and communication, broader participation and involvement, and negotiation from network leaders before or during the developmental phase of a learning health system.(26)

A different review focused specifically on the financial mechanisms that could be used to promote intersectoral collaboration for health promotion. The review found that earmarked funding for intersectoral health promotion, delegated financing to independent health-promotion organizations, and joint budgeting to share resources for specific projects were three key methods to support collaboration efforts.(47) These mechanisms tended to function at the local level rather than the national level, and their success depended on legal considerations, organizational structures, cultural understanding, and trust.(47)

A final low-quality review suggested that while structural governance was often able to establish the boundaries of collaboration, the presence of contracts and the trust between partners tended to guide behaviour.(39) The review added that collaboration boundaries often need to be carefully considered, as it may be challenging to handle too many partners or partners who are not fully committed for the allotted period of time. That being said, the review suggested that a certain amount of flexibility is also needed to accommodate for collaborations that may extend across the innovation period or that provide expertise on one specific component.(39)

Define the range of activities required to continuously build and strengthen the network (e.g., through capacity-building workshops, webinars, and supports for a community of practice)

Although there was little evidence on the specific activities that would support a network of rapid learning champions, several reviews aimed to identify the particular features of champions that facilitated innovation. For example, an integrative review on the role of champions in healthcare identified the key activities that champions did and the key characteristics that champions possessed.(38) Although the list was thorough and can be referred to in the references, key activities included being an organizational advocate, a team leader, an activity planner, an educator, a relationship builder, a cross-service worker, a visible point of contact, a recruiter and a troubleshooter.(38) Effective characteristics included negotiation skills, communication, enthusiasm, local knowledge, initiative understanding, commitment, respect, leadership, visibility, and the ability to set goals and give feedback.

A different high-quality review similarly found that the features of successful champions related to their ability to troubleshoot, train and provide a consistent point of contact, but also included their expertise on the intervention itself.(46) That being said a low-quality review found that champions gave autonomy to the actual innovators, acting as buffers to ensure monitoring and feedback would be implemented.(40)

A summary of the key findings from the synthesized systematic reviews are provided in Table 4. For those who want to know more about the systematic reviews contained in Table 4 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 1. Additional information of the primary study is provided in Appendix 6.

Table 4: Summary of key findings from systematic reviews relevant to Element 3 – Establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action

Category of finding	Summary of key findings
Benefits	• **Identify and engage patients and family partners, providers, and organizational and system leaders who can advocate for and lead the work related to establishing rapid-learning health systems for neurodevelopmental disorders** o Three reviews addressed the identification of key partners, concluding that there was limited evidence on how this might be operationalized. ▪ One lower-quality review found that the majority of studies simply stated whether or not champions were present, giving little detail on how they were chosen or their effectiveness.(38) ▪ Another lower-quality review suggested that although limited evidence currently exists, it would be unlikely that an all-encompassing framework for selecting and engaging partners could be developed independent of the context and nature of the innovation at hand.(40) ▪ A final lower-quality review concluded that although no blueprint was available for selecting partners, having a common culture, a complementary knowledge base and aligned strategic objectives were important features. Members of partnerships were able to pool resources and provide rewards or collective benefits for carrying out innovations.(39) o Five reviews addressed engaging key partners in collaborative efforts. ▪ A medium-quality review identified four key components to community-based organization engagement:(43) • a community need must be present and established; • the partnership must be founded on a shared mission; • all partners must have the resources available to contribute; and • the outcomes of the partnership must be clearly defined. ▪ Another medium-quality review aimed to identify the barriers, and potential mitigators, to engaging citizens. The review found that information asymmetries, negative pre-existing perceptions of the partnership, difficulty agreeing on group representation, challenges in designing the engagement process, and ensuring adequate quality in collaboration were all concerns.(44) These were combatted by a commitment to long-term collaboration, shared research efforts, institutionalizing participatory processes, employing multiple engagement techniques, defining immediate and long-term goals, and clarifying common language and terminology. ▪ A lower-quality review added that when considering collaboration policies, voucher programs, consortium initiatives and cluster policies could help achieve joint objectives. These policies should focus on formation as well as growth and maturity.(39) ▪ One medium-quality review found that engagement in joint working between health and social-care sectors focused mainly on front-line services, where multidisciplinary teams and cross-sector placements were commonly employed.(45) ▪ Similarly, a high-quality review found that the direct engagement of citizens with service providers at the front line was more effective in increasing citizen engagement, access to services and the quality of service provision compared to engagement at the political level.(29) • **Set up an administrative home for efforts to support the development of rapid-learning health systems for neurodevelopmental disorders (could be an existing organization or research network)**

Category of finding	Summary of key findings
	○ Three reviews addressed issues related to setting up an administrative home to support development. ▪ One low-quality review focused on financial and budgeting considerations during intersectoral partnership and concluded that earmarked funding for intersectoral health promotion, delegated financing to independent health-promotion organizations, and joint budgeting to share resources for specific projects were three key mechanisms that supported collaboration efforts.(47) ▪ This same review also noted that these mechanisms tended to work at the local level, and their success often depended on factors such as legal considerations, organizational structures, differences in culture, and trust.(47) ▪ Finally, this review noted that combining financial mechanisms with regulatory procedures, clear accountabilities, realistic timing, legislative safeguards, quantifying benefits and costs, and building foundational trust were key considerations for future policy.(47) ▪ A high-quality review which examined the features of organizations that have an impact on uptake of evidence-based practices found that organizational culture, effective leadership, supportive communication, access to resources, feedback mechanisms and identifying champions were key components that facilitated implementation.(46) ▪ A final low-quality review suggested that while structural governance was often able to establish the boundaries of collaboration, the contracts put in place and relational trust between partners tended to guide behaviour.(39) • **Define the range of activities required to continuously build and strengthen the network (e.g., through capacity-building workshops, webinars, and supports for a community of practice)** ○ Although there was little description of specific activities done to build and strengthen champion networks, several reviews identified key characteristics of champions that allow them to succeed. ▪ A low-quality review noted that several studies which assessed effective championing found that multiple champions working simultaneously on a project aided implementation compared to single champions.(38) This same review also noted that champions had several characteristics, including being organization advocates, team leaders, activity planners, educators, relationship builders, recruiters, and troubleshooters. ▪ A high-quality review found that the features of successful champions related to their knowledge of the intervention, their availability to troubleshoot and train, and their consistency in providing familiarity to the organization.(46) ▪ A low-quality review found that champions were a key factor in the adoption of innovations and that their roles included giving autonomy to the innovators while acting as buffers to ensure monitoring and feedback, as well as harnessing support across the organization to facilitate collaborative networks.(40) This same review suggested that if champions could be strategically placed to outweigh the influence of any opponents to the intervention, subsequent innovation uptake would be more likely.
Potential harms	• **Identify and engage patients and family partners, providers, organizational and system leaders who can advocate for and lead the work related to establishing rapid-learning health systems for neurodevelopmental disorders** ○ One medium-quality review suggested that although citizen participation has been regarded for its ability to allow citizens to participate in the decisions that affect them, concerns remain about its potential downfalls and costs.(44) This review highlighted several concerns: information asymmetries could lead to poor focus and unrealistic expectation; unwillingness to engage could result in unsuccessful partnerships; deciding on representation and the engagement process could be challenging; and negative group dynamics could deteriorate outputs.(44)
Costs and/or cost-effectiveness in relation to the status quo	• **Identify and engage patients and family partners, providers, organizational and system leaders who can advocate for and lead the work related to establishing rapid-learning health systems for neurodevelopmental disorders**

Category of finding	Summary of key findings
	o One medium-quality review on joint working between health and social-care sectors suggested that in terms of costs, places which had integrated mental health and social services were no costlier than places which had independent services.(45) o Another medium-quality review found a decrease in per capita cost with the establishment of clinical networks in three of four studies that analyzed efficiency. ▪ One study from this review specifically focused on linking primary care, hospital and voluntary-sector services for patients with personality disorders, and found a reduction in total per capita expenditure after implementation, specifically due to cost reductions in medication, general practitioner appointments, secondary care and mental health services. However, the review noted that this study didn't account for the costs of implementing the clinical network.
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	• No clear message from the studies included in a systematic review o **Identify and engage patients and family partners, providers, organizational and system leaders who can advocate for and lead the work related to establishing rapid-learning health systems for neurodevelopmental disorders** ▪ A medium-quality review that assessed engagement with community-based organizations concluded that although they were able to describe the components of engagement, evidence on the impact of engagement on health-related outcomes was unclear and warrants further research.(43) ▪ Similarly, a different medium-quality review on citizen engagement concluded that although citizen participation was found to broaden alternative solutions and foster local accountability, little evidence was found on whether or how it had an impact on decision-making effectiveness or efficiency.(44) ▪ Finally, a medium-quality review on joint working between health and social-care sectors concluded that, overall, the evidence base on joint working is underdeveloped.(45) o **Set up an administrative home for efforts to support the development of rapid-learning health systems for neurodevelopmental disorders (could be an existing organization or research network)** ▪ A low-quality review that aimed to examine promoting intersectoral collaboration through financial mechanisms, concluded that despite its findings, the literature remains sparse, with few publications explicitly looking at the effectiveness of such mechanisms.(47) ▪ A high-quality review that focused on the organizational features that influenced the implementation of evidence-based interventions concluded that each of the organizational features it identified appeared to be interrelated and did not influence implementation independently from other features. Future research should focus on how these features interact in implementation effectiveness.(46) o **Define the range of activities required to continuously build and strengthen the network (e.g., through capacity-building workshops, webinars, and supports for a community of practice)** ▪ A low-quality review focused on the role of champions in healthcare intervention implementation found that despite identifying many relevant studies, the review likely missed articles because of the variation in the terms used to refer to a 'champion'.(38) ▪ A high-quality review that identified champions as an important feature of organizations that implemented evidence-based interventions concluded that it was unclear whether the conceptual or operational definitions of these features were consistent across studies.(46)
Key elements of the policy option if it was tried elsewhere	• No reviews found
Stakeholders' views and experience	• No reviews found

Additional equity-related observations about the elements

The research evidence identified for each of the three elements did not provide specific equity-related observations about individuals living in rural or remote areas, individuals with limited coverage of products and services not currently paid for by provincial publicly funded insurance plans (including recent immigrants to Canada), and individuals from particular ethnocultural groups with unique needs (e.g., Indigenous populations). The evidence included in the elements tended to focus on different approaches to advance problem-focused rapid learning and improvement. Some general challenges identified in the evidence may disproportionally affect the groups mentioned above.

Regarding Element 2, (strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada), one medium-quality review found that updating asset maps consistently and continuously may be a significant challenge if there are limitations in human and financial resources.(34) Furthermore, a different review added that selecting a larger scale by which to implement a learning health system may serve as a barrier in evaluating its impact over time.(32) Overcoming these barriers to successfully linking up assets may be particularly challenging when engaging those living in remote locations, for example, as they may not have systems in place to be continuously updating data, nor have the financial capacity to make relevant changes. Regarding Element 3 (establishing a pan-Canadian network of 'rapid-learning champions'), one medium-quality review suggested that engaging patient-partners may lead to unrealistic expectations, that an unwillingness to engage could result in unsuccessful partnerships, and that deciding on appropriate representation may be a significant barrier.(19) In groups such as Indigenous peoples who experience inequities in research and have faced historic discrimination tied to health and social inequality, these issues with engagement will need to be carefully considered.

Additional COVID-19 related observations about the elements

As highlighted in the problem section, we conducted additional key informant interviews with policymakers, stakeholders and researchers focused on supporting the needs of individuals with neurodevelopmental disorders to determine how our conceptualization of the issues addressed in this brief – including which approaches are best positioned to address new and emergent challenges – have been influenced as a result of the COVID-19 pandemic. Overall, key informants acknowledged that there is a need for nimble and flexible approaches to help address issues within health and social systems. Specific to neurodevelopmental conditions, health and social supports have had to adjust and respond in real-time due to closures of diagnostic services and other in-person care, with a major transition being the shift of some services to virtual formats. The pandemic highlights that novel approaches such as virtual care and telehealth are promising; however, there are different needs from different population groups and settings (e.g., individuals at developmental and/or functional stages, or at different life stages, underserved communities with varied technology infrastructure) that require a mix of different programs, services and modalities. Some of the key informants described a supportive senior management (e.g., fast-track approval and trust between providers and management) and the availability of technology infrastructure as facilitators for successfully transitioning to virtual care.

Additional insights also emerged about the role that data and evidence need to play in driving these approaches. In particular, several key informants suggested that there has been an increased appetite for data and evidence to inform decision-making. Challenges in supporting this approach notwithstanding, the increased emphasis on data and evidence-informed decision-making aligns closely with the ethos of creating rapid-learning health and social systems, which can help to ensure all stages in the planning, implementation and monitoring, and evaluation of new programs and services are closely aligned with the best data and evidence.

In short, these insights suggest that the current climate created by the pandemic presents an ideal opportunity for helping to identify key priority needs related to neurodevelopmental disorders (element 1), to identify and 'link up' the key assets available for supporting a rapid-learning and improvement approach in addressing these priority needs (element 2), and ultimately lay the groundwork for a broader network of patients, providers and organizations across health and social systems in Canada to support ongoing cycles of rapid learning and improvement for the full range of needs among those with neurodevelopmental disorders.

IMPLEMENTATION CONSIDERATIONS

Several barriers might hinder implementation of the three elements of a potentially comprehensive approach to supporting rapid learning and improvement for select conditions (Table 4). While potential barriers exist at the levels of providers, organizations and systems (if not patients/citizens, who are unlikely to be aware of or particularly interested in the specifics of these approach elements), perhaps the biggest barrier lies in ensuring there is 'buy-in' among patients, providers, organizations and across the system, but also among elected officials who, by adopting a rapid-learning and improvement approach, are collectively committing to identifying, acknowledging and working to address the full range of problems that people with neurodevelopmental disorders face.

There are also several potential windows of opportunity that should be considered, despite these barriers (Table 5). The most important is likely the fact that the rapid-learning health system-related concepts, especially pertaining to neurodevelopmental disorders, are gaining traction across Canada. Further, there may be an opportunity to adopt new approaches at the pan-Canadian level in the wake of the federal government's recent investment of $9.1 million to support projects that can improve services for individuals living with ASD and their families.

Table 5: Potential barriers to implementing the elements

Levels	Element 1 – Prioritize service needs and design a rapid-learning and improvement approach to meet them	Element 2 – Strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada	Element 3 – Establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action
Patient/Individual	• Patients and families may not want to engage in service design if the services prioritized aren't perceived to be addressing their own particular needs • Patients and families may be hesitant to engage in the absence of understandable data and evidence (or tailored decision supports) • Patients and families may not feel they have the additional time required to engage in efforts to prioritize service needs and design approaches to address them	• Patients and families may not want to engage in strengthening and linking assets if the services prioritized aren't perceived to be addressing their own particular needs • Patients and families may not feel they have the additional time required to engage in efforts to strengthen and link assets for rapid learning and improvement	• Patients and families may not be willing to champion an approach if not focused on improving services related to their particular needs • Patients and families may not feel they have the additional time required to engage in efforts to champion rapid learning and improvement
Care provider	• Providers may oppose the prioritization of services that aren't within their remit to provide patients and families,	• Providers may be hesitant to embrace the rapid-learning and improvement model if it demonstrates	• Providers may not be willing to champion a rapid-learning and improvement approach if

Levels	Element 1 – Prioritize service needs and design a rapid-learning and improvement approach to meet them	Element 2 – Strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada	Element 3 – Establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action
	or that could redirect services to other providers	underperformance in their provision of care • Providers may be hesitant to engage in efforts to operationalize a rapid-learning and improvement approach if it requires a fundamental shift to how they are expected to engage patients, use data and evidence, and work with other providers and organizations across the system	not focused on improving services within their remit to provide to patients • Providers may not be willing to champion a rapid-learning and improvement approach if they perceive these efforts to come at the expense of their own ability to provide patients with high-quality care
Organization	• Organizations may oppose the prioritization of services that aren't within their remit to provide patients and families, or that could redirect services to other organizations	• Organizations may be hesitant to embrace the rapid-learning and improvement model if it demonstrates underperformance in their provision of care • Organizations may be hesitant to engage in efforts to operationalize a rapid-learning and improvement approach if it requires a fundamental shift to how they are expected to engage patients, use data and evidence, and work with other providers and organizations across the system	• Organizations may not be willing to champion a rapid-learning and improvement approach if not focused on improving services within their remit to provide to patients • Organizations may not be willing to champion a rapid-learning and improvement approach if they perceive these efforts to come at the expense of their own ability to provide patients with high-quality care
System	• Systems may not be able to easily adjust governance, financial and delivery arrangements to align with new prioritized services and care pathways • Systems may not have all of the assets in place to support rapid-learning and improvement approaches for prioritized services	• Systems may not be able to easily adjust governance, financial and delivery arrangements to support strengthening or linking of required assets • Systems may not be able to quickly shift how they approach prioritizing services, setting performance targets and evaluating progress towards achieving 'quadruple-aim' metrics	• Systems may have already established strategic directions that are not entirely supportive of or consistent with a rapid-learning and improvement approach

Table 5: Potential windows of opportunity for implementing the elements

Type	Element 1 – Prioritize service needs and design a rapid-learning and improvement approach to meet them	Element 2 – Strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada	Element 3 – Establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action
General	• Across Canada, there have been several initiatives focused on strengthening research-translation pipelines and service-capacity building for neurodevelopmental disorders (e.g., CHILD-BRIGHT, KBHN, and the AIDE network), as well as initiatives in the non-profit sector, such as Autism Speaks Canada, which can all be leveraged to move forward with the approach. • Existing disability policies that have health-policy elements could be an opportunity to legislate linkages between health and social systems, health policies, and family and child policies (e.g., existing disability policies in Ontario, Manitoba, British Columbia, Alberta). • The federal government's announcement in 2019 of an investment of $9.1 million over five years to support individuals living with ASD and their families shows commitment and support for pan-Canadian efforts (which could include efforts to support rapid-learning health systems). • Strong assets exist at the provincial level, which can serve as jumping-off points for the creation of broader pan-Canadian rapid-learning and improvement networks. • There is growing awareness of the importance of embracing the rapid-learning health system approach, and it has been gaining support across Canada (e.g., among CIHR's Institute of Health Services and Policy Research (IHSPR), the Canadian Health Services and Policy Research Alliance) as well as provincially in Ontario (e.g., through the Rapid Support and Improvement Exchange (RISE) for Ontario Health Teams (OHTs), SPOR SUPPORT network) and in B.C. (e.g., through the Academic Health Sciences Network). • The COVID-19 pandemic demonstrates opportunities for rapid-learning and novel approaches to neurodevelopmental services and care (e.g., virtual care and telehealth), and in particular in approaches that leverage insights from the best available data and research evidence to address priority needs.		
Option-specific	• Some provinces have moved forward with operationalizing rapid learning and improvement approaches, such as Alberta's Strategic Clinical Networks, which may provide insights about how to operationalize a rapid-learning health system for neurodevelopmental disorders.	• The approach for mapping assets and gaps in the characteristics of rapid-learning health systems has been developed and piloted across Canada for a regional focus, as well as in specific sectors such as primary care, providing relevant approaches that can be adopted for neurodevelopmental disabilities.	• Autism Speaks Canada developed a network called "CONNECT" which is a virtual platform for individuals in the autism community to engage, promote solutions, enhance resources and services, increase understanding, and advance research. They provide a commonly accessible national database of information, supports, resources and interactive groups.

REFERENCES

1. Government of Canada. Backgrounder: New Projects under Autism Spectrum Disorder Strategic Fund. 2019. https://www.canada.ca/en/public-health/news/2019/08/backgrounder-new-projects-under-autism-spectrum-disorder-strategic-fund.html (accessed March 16, 2020 2020).
2. Government of Canada. Minister of Health Mandate Letter. Ottawa: Office of the Prime Minister; 2019.
3. Lavis J, Gauvin F, Mattison C. Rapid synthesis: Creating rapid-learning health systems in Canada. Hamilton, Canada: McMaster Health Forum; 2018.
4. Raouafi SA, Achiche SA, Raison MA. Socioeconomic disparities and difficulties to access to healthcare services among Canadian children with neurodevelopmental disorders and disabilities. 2018; (2092-7193 (Electronic).
5. Statistics Canada. Child functional characteristics explain child and family outcomes better than diagnosis: Population-based study of children with autism or other neurodevelopmental disorders/disabilities. June 15, 2016.
6. Masse LC, Miller A, Schiariti V, Roxborough L. Patterns of participation across a range of activities among Canadian children with neurodevelopmental disorders and disabilities. 2013; (1469-8749 (Electronic)).
7. Ontario Brain Institute. Neurodevelopmental Disorders. 2019.
8. Boyle CA, Boulet S, Schieve LA, Cohen RA. Trends in the prevalence of developmental disabilities in US children, 1997-2008. 2011; (1098-4275 (Electronic).
9. Campbell F, Biggs K, Aldiss SK, et al. Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews* 2016; (4).
10. Mikami AY, Miller M, Lerner MD. Social functioning in youth with attention-deficit/hyperactivity disorder and autism spectrum disorder: transdiagnostic commonalities and differences. 2019; (1873-7811 (Electronic).
11. Rogge N, Janssen J. The Economic Costs of Autism Spectrum Disorder: A Literature Review. *Journal of Autism and Developmental Disorders* 2019; **49**(7): 2873-900.
12. Lach LM, Kohen D, Garner RE, Brehaut JC. The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. 2009; (0963-8288 (Print)).
13. Lunsky Y, De Oliveira C, Wilton A, Wodchis W. High health care costs among adults with intellectual and developmental disabilities: a populationbased study. *Journal of Intellectual Disability Research* 2019; **63**(2): 124-37.
14. Lin E. Addressing gaps in the health care services used by adults with developmental disabilities in Ontario: Institute for Clinical Evaluative Sciences; 2019.
15. Klassen A, Miller A, Anderson N, Shen J, Schiariti V, O'Donnell M. Performance measurement and improvement frameworks in health, education and social services systems: a systematic review. 2010; (1464-3677 (Electronic).
16. Ono E, Friedlander R, Salih T. Falling through the cracks: How service gaps leave children with neurodevelopmental disorders and mental health difficulties without the care they need. *British Columbia Medical Journal* 2019; **61**(3).
17. Government of Newfoundland and Labrador. Autism Action Plan 2019-2022: The Way Forward Government of Newfoundland and Labrador; 2019.
18. Government of Nova Scotia. Autism Spectrum Disorder Action Plan Nova Scotia: Government of Nova Scotia.

19. Anagnostou E, Zwaigenbaum L, Szatmari P, et al. Autism spectrum disorder: advances in evidence-based practice. *Canadian Medical Association Journal* 2014; **186**(7): 509-19.
20. Moat K, Bhuiya A, Wadell K, Lavis J. Evidence brief: Supporting rapid learning and improvement for select conditions in Canada. Hamilton, ON: McMaster Health Forum; 2020.
21. Khanlou N, Haque N, Mustafa N, Vazquez LM, Mantini A, Weiss J. Access Barriers to Services by Immigrant Mothers of Children with Autism in Canada. *International Journal of Mental Health and Addiction* 2017; **15**(2): 239-59.
22. Sritharan B, Koola MM. Barriers faced by immigrant families of children with autism: A program to address the challenges. *Asian Journal of Psychiatry* 2019; **39**: 53-7.
23. Hahmann T, Badets N, Hughes J. Indigenous people with disabilities in Canada: First Nations people living off reserve, Métis and Inuit aged 15 years and older. *Statistics Canada*; 2019.
24. Di Pietro NC, Illes J. Disparities in Canadian indigenous health research on neurodevelopmental disorders. *Journal of Developmental Behavioral Pediatrics* 2014; **35**(1): 74-81.
25. McVeigh J, MacLachlan M, Gilmore B, et al. Promoting good policy for leadership and governance of health related rehabilitation: a realist synthesis. *Globalization and health* 2016; **12**(1): 49.
26. Murray DS, Anixt JS, Coury DL, et al. Transforming an autism pediatric research network into a learning health system: Lessons learned. *Pediatric Quality & Safety* 2019; **4**(2).
27. Barasa E, Molyneux S, English M, Cleary S. Setting Healthcare Priorities at the Macro and Meso Levels: A Framework for Evaluation. *International Journal of Health Policy and Management (IJHPM)* 2015; **2015**: 719-32.
28. Kroll A. Drivers of Performance Information Use: Systematic Literature Review and Directions for Future Research. *Public Performance & Management Review* 2015; **38**: 459-86.
29. John D, Stevenson J. Does incorporating participation and accountability improve development outcomes? Meta-analysis and framework synthesis. *International Intiative for Impact Evaluation* 2019.
30. Behrendt K, Groene O. Mechanisms and effects of public reporting of surgeon outcomes: A systematic review of the literature. *Health Policy* 2016; **120**(10): 1151-61.
31. D'Alleva A, Leigheb F, Rinaldi C, et al. Achieving quadruple aim goals through clinical networks: A systematic review. *Journal of Healthcare Quality Research* 2019; **34**(1): 29-39.
32. Budrionis A, Bellika JG. The Learning Healthcare System: Where are we now? A systematic review. *Journal of biomedical informatics* 2016; (1532-0480 (Electronic).
33. Cassetti V, Powell K, Barnes A, Sanders T. A systematic scoping review of asset-based approaches to promote health in communities: development of a framework. *Global Health Promotion* 2019: 1757975919848925.
34. Green A, Luckett T, Abbott P, et al. A framework for an asset-informed approach to service mapping. *Nurse researcher* 2017.
35. Van Bortel T, Wickramasinghe N, Morgan A, Martin S. Health assets in a global context: A systematic review of the literature. *BMJ Open* 2019; **9**: bmjopen-2018.
36. Jannati A, Sadeghi V, Imani A, Saadati M. Effective coverage as a new approach to health system performance assessment: a scoping review. *BMC Halth Services Research* 2018; **18**(1): 1-13.
37. Dixon-Woods M, Campbell A, Chang T, et al. A qualitative study of design stakeholders' views of developing and implementing a registry-based learning health system. *Implementation Science* 2020; **15**(1): 1-11.
38. Miech EJ, Rattray NA, Flanagan ME, Damschroder L, Schmid AA, Damush TM. Inside help: An integrative review of champions in healthcare-related implementation. *SAGE Open Med* 2018; **6**: 2050312118773261.

39. Coletti M, Landoni P. Collaborations for innovation: a meta-study of relevant typologies, governance and policies. *Economics of Innovation and New Technology* 2018; **27**(5-6): 493-509.
40. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion Of Innovations In Service Organizations: Systematic Review And Recommendations. *The Milbank quarterly* 2004; **82**: 581-629.
41. Aarons GA, Green AE, Trott E, et al. The Roles of System and Organizational Leadership in System-Wide Evidence-Based Intervention Sustainment: A Mixed-Method Study. *Administration and Policy in Mental Health* 2016; **43**(6): 991-1008.
42. Shaw EK, Howard J, West DR, et al. The role of the champion in primary care change efforts: from the State Networks of Colorado Ambulatory Practices and Partners (SNOCAP). *Journal of the American Board of Family Medicine* 2012; **25**(5): 676-85.
43. Adebayo O, Salerno J, Francillon V, Williams J. A systematic review of components of community-based organisation engagement. *Health & Social Care in the Community* 2018; **26**: 1-11.
44. Ianniello M, Iacuzzi S, Fedele P, Brusati L. Obstacles and solutions on the ladder of citizen participation: a systematic review. *Public Management Review* 2019; **21**(1): 21-46.
45. Cameron A, Lart R Bostock L, Coomber C. Factors that promote and hinder joint and integrated working between health and social care services: a review of research literature. 2014; (1365-2524 (Electronic).
46. Li S-A, Jeffs L, Barwick M, Stevens B. Organizational contextual features that influence the implementation of evidence-based practices across healthcare settings: a systematic integrative review. *Systematic Reviews* 2018; **7**(1): 72.
47. McDaid D, Park AL. Evidence on financing and budgeting mechanisms to support intersectoral actions between health, education, social welfare and labour sectors. WHO Regional Office for Europe; 2016.
48. De Vries H, Bekkers V, Tummers L. Innovation in the public sector: A systematic review and future research agenda. *Public Administration* 2016; **94**(1): 146-66.

APPENDICES

The following tables provide detailed information about the systematic reviews identified for each option. Each row in a table corresponds to a particular systematic review and the reviews are organized by element (first column). The focus of the review is described in the second column. Key findings from the review that relate to the option are listed in the third column, while the fourth column records the last year the literature was searched as part of the review.

The fifth column presents a rating of the overall quality of the review. The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial, or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered "high scores." A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8.

The last three columns convey information about the utility of the review in terms of local applicability, applicability concerning prioritized groups, and issue applicability. The second-from-last column notes the proportion of studies that were conducted in Canada, while the last column shows the proportion of studies included in the review that deal explicitly with one of the prioritized groups.

All of the information provided in the appendix tables was taken into account by the evidence brief's authors in compiling Tables 2-4 in the main text of the brief.

Appendix 1: **Systematic reviews relevant to Element 1 – Prioritize service needs and design a rapid-learning and improvement approach to meet them**

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
Prioritize service needs and design a rapid-learning and improvement approach to meet them	Developing an evaluation protocol for healthcare priority setting in macro- and meso-level health systems (27)	This systematic review focused on two sets of literature: 1) studies on priority setting in health systems; and 2) theoretical studies on related topics. A total of 31 papers from the first set of literature were investigated. The authors advocated for frameworks of evaluation that draw from both consequentialist and proceduralist thought, which focus on the outcome and procedural aspects respectively. Commonly appraised outcomes using the consequential framework include stakeholder satisfaction, stakeholder understanding, allocation of resources, and implementation. Procedural approaches emphasize deliberative democracy, public argument, and incorporation of community values, amongst other elements. The authors suggest seven procedural conditions that are suitable for evaluation: stakeholder involvement, empowerment, transparency, revisions, use of evidence, enforcement, and incorporation of community values. In distributing scarce resources, the authors also emphasize efficiency should be balanced with equity considerations. The disconnect between evaluation theory and the literature on evaluating priority setting in health systems may limit the effectiveness of the authors' proposed framework.	2015	2/9 (AMSTAR rating from McMaster Health Forum)	17/31	0/31
	Providing scientific evidence on policies that promote good leadership and governance of health rehabilitation services in low-	This systematic review used two methods of information synthesis. First, the authors conducted a realist synthesis to identify context mechanism outcome pattern configurations (CMOCs) from the literature. Subsequently, the authors conducted a Delphi survey to convene recommendations made by expert stakeholders, which built on the CMOCs identified from the realist synthesis. Delphi survey participants held work experience from different regions of the world and were comprised of service users, service providers, and policy decision-makers. Several important principles of good leadership and governance on health rehabilitation included: "participation of persons with disabilities in policy	2016	5/9 (AMSTAR rating from McMaster Health Forum)	0/36	0/36

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
	resource settings (25)	processes," "collection of disaggregated disability statistics," "explicit recognition in policies that disability may interact with other vulnerability factors," "robust inter-sectoral coordination," and "'institutionalizing rehabilitation programmes by aligning programmes with… pre-existing Ministerial models of healthcare… to support programme sustainability." Since governance is not concerned with government alone but involves multiple actors in society with distinct roles, the above recommendations are relevant for many stakeholders across different domains, and careful collaboration amongst these stakeholders throughout policy and research processes are vital to good governance. The authors acknowledge that recommendations on leadership and governance on health-related rehabilitation merit from being flexible enough to fit in different health-system contexts. A potential limitation of this study is that the Delphi survey may have suffered from sampling bias as panel invitees were sourced from the researchers' own networks.				
	Assessing whether public reporting of surgeon outcomes can improve care quality or cause adverse consequences, and to determine how the evidence on public reporting of surgeon outcomes from other countries can predict	This review examined 25 studies in order to understand how the evidence on public reporting may be used to implement cross-country transferability of this strategy. Public reporting has been a widely used tool to measure the quality of healthcare providers and facilities, especially in the United States. The authors limited their search to primary reviews, but also searched articles that were referenced in those studies. The majority of the studies found that public reporting was associated with greater reluctance of surgeons to accept high-risk patients. Some evidence suggested patients from non-white backgrounds may also experience reduced access to quality surgery. However, the evidence from literature is mixed regarding the strength of these associations. The largest effects of public reporting were observed amongst the lowest-performing providers, some of whom decided to cease their practice. To	2016	6/10 (AMSTAR rating from McMaster Health Forum)	0/25	0/25

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
	outcomes of implementing this system (30)	assess the transferability of evidence across different settings, such as in cross-country learning, many factors must be considered including those regarding the health system, surgeons, data, patients and organizations. Certain studies included in this review may have suffered from responder bias, evidenced from their low reported response rates. Social acceptability bias may have also masked some surgeons' true attitudes towards high-risk patients. Additionally, many studies did not provide control groups or suffered from missing data.				
	Examining the factors that facilitate the use of performance information by managers in public administration (28)	This review examined 25 papers on the drivers of performance-information use by managers in public administration. The review suggested that although a growing number of initiatives have been implemented to hold public administration accountable through providing performance information, subsequent improvements in performance are not automatic. Understanding the determinants of performance-information use was the objective. This review identified that the two most prominent drivers were measurement-system maturity and stakeholder involvement. These were followed by leadership, support capacity, innovative culture and goal clarity. Regarding measurement-system maturity, systems that go beyond the raw data to actually link information to relevant goals and benchmarks are more likely to be used. Involving external stakeholders was also described to ensure accountability, help identify applicable indicators and give meaning to the data. Leadership and support capacity related to the management, resources, capabilities and technology that were available to make performance measurement work. Finally, building an organizational culture that fosters dialogue and is clear about its objectives is also prominent. The review concluded that its findings were focused on the direct effects of specific drivers on data use, not accounting for more indirect mechanisms and mediators. It also suggested that very little is known	2014	2/11 (AMSTAR rating from McMaster Health Forum)	0/25	Not available

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		about drivers at the individual level or the type of information that is actually used.				
	Assessing whether programs which aimed to support citizen engagement in public services had an impact on the quality, accessibility and quality-of-life outcomes of those services (29)	This systematic review examined 35 citizen-engagement programs in low- and middle-income countries which aimed to promote citizen engagement in the planning and management of public services. The review aimed to understand whether engaging citizens in these services, which were critical to development, actually had an impact on the quality of services, their accessibility and their subsequent impact on citizens' lives. It assessed this question through four avenues which are referred to as the PITA Mechanisms; participation in priority setting and decision-making, inclusion of marginalized groups, transparency of information provision and rights, and accountability through feedback and monitoring. Regarding outcomes, the review only included studies that described the immediate outcomes of citizen engagement, such as participation in meetings or public-service responses. These were only eligible if these studies also measured the subsequent impacts on the accessibility of services, service use or final outcomes such as health or nutrition. The review suggested that promoting direct citizen engagement between service users and service providers (termed the "short route") was more effective in increasing engagement itself, while also increasing access to services and the quality of provision. This was in contrast to the "long route" which focused on increasing citizen pressure on politicians. Regarding well-being targets, it was found that although direct engagement was important, interventions that also address the inefficiencies in service-provider supply chains would be necessary. The review did not draw conclusions for different socio-economic groups, geographic groups, or genders due to the small sample of studies.	2018	9/9 (AMSTAR rating from McMaster Health Forum)	0/9	Not available
	Examining the impact of establishing	This review examined 12 studies which focused on the impact clinical networks had on patient-health outcomes and network efficiency.	2018	6/10 (AMSTAR rating from	0/12	1/12

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
	clinical networks on the outcomes defined by the quadruple-aim goals (31)	The review suggested that establishing clinical networks in healthcare can enable providers to better coordinate work across care settings. This review aimed to evaluate whether clinical networks improved metrics related to the "quadruple-aim" goals; improving the health of populations, reducing the per capita cost, enhancing the patient experience of care, and improving the work life of healthcare clinicians and staff. The review found that nine studies focused on patient outcomes and four studies focused on increasing efficiency. Professionals' and patients' experiences were not considered. Although the review noted that the methodological quality of studies was generally low, there was some evidence that clinical networks could have a positive impact on patient outcomes. Although no studies assessing patient outcomes focused on neurodevelopmental conditions, it was specifically noted that the timeliness and appropriateness of patient care were important proxies. Three of the four studies which examined efficiency via a decrease in per capita cost found that improvements were seen with the establishment of clinical networks. One study focused on linking primary care, hospital and voluntary-sector services offered to patients with personality disorders, and found a significant reduction in total per capita expenditure after implementation, specifically due to medication, general practitioner, secondary care and mental health services costs. However, it should be noted that this study didn't account for the costs of implementing the clinical network. Overall, the review concluded that despite several study limitations, there was some evidence that clinical networks can improve metrics established in the quadruple aim. However, specific features of the networks, such as their governance, operations and information systems, may differentially influence outcomes and were not reported on here.		McMaster Health Forum)		

Appendix 2: Systematic reviews relevant to Element 2 - Invest in mapping and 'linking up' assets that can support rapid-learning health systems for neurodevelopmental conditions across Canada

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
Invest in mapping and 'linking up' assets that can support rapid-learning health systems for neurodevelopmental conditions across Canada	Identifying methods of asset-informed mapping and developing a framework for this method (34)	In order to identify methods of asset-informed mapping, a literature search was conducted, and 10 articles were examined. The process of how to conduct asset-informed service mapping began with formulating a core team to drive the process. The subsequent steps in this process include identifying a team leader, the target population, and geographical boundaries, developing a plan for data collection, and determining how the collected data will be used. However, limited details on the methods of asset-informed mapping were present in the studies. Furthermore, facilitators to the effectiveness of the core team included having a designated leader, ensuring frequent meetings, and establishing partnerships between members who have worked with one another previously. Ensuring that cultural considerations are taken into account when establishing a core team, and consistently tracking resources were also identified as facilitators within this process. No barriers were identified within the literature review. Informed by the review of the literature, a framework was developed for asset-informed mapping. This method was as follows: Stage 1 – Define the parameters of the service mapping process; Stage 2 – Identify services; Stage 3 – Map services; Stage 4 – Consultation and implementation. In conclusion, this review highlights the lack of rigorous methodological research on asset-informed mapping, and proposed a framework to assist in developing an evidence base.	Not reported	4/9 (AMSTAR rating from McMaster Health Forum)	Not available	Not available
	Examining the key elements and steps of assessing	This review examined 18 studies in order to examine the key elements and steps of assessing health-system performance through effective coverage metrics.	2017	5/9 (AMSTAR rating from	Not available	Not available

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
	health-system performance through effective coverage metrics (36)	The intervention areas included child health, prenatal and antenatal care and delivery, and chronic conditions (hypertension, diabetes, hypercholesterolemia, vision disorders and cancer). Only four studies contributed findings at the health-system level, and the remaining 14 studies were related to specific intervention assessments. The quality-assessment strategies in the included studies were heterogeneous, and included bio-markers, self-reported surveys, records of disease-management programs, and statistical methods. Due to the diversity in the findings, the included studies could not be combined, the overall quality of the review was low, and the ability to draw conclusions on the outcome of interest – effective coverage metrics – was hindered. This review identified that the first step in implementing effective coverage as a performance-assessment tool is the selection of interventions. Selecting specific interventions is known to be difficult and varies by setting, but it is recommended to consider burden of disease, affordable interventions and social priority when selecting interventions. Properly measuring intervention use and tracking intervention coverage over time to avoid biases was also identified to be a challenge. Avoiding relying primarily on administrative data, and integrating other complementary strategies was suggested as a strategy to improve measurement. Due to the variety and complexity of interventions in the health system, it is recommended that health outcomes are not measured using a single method. In conclusion, this study emphasizes that more studies are needed to contribute to the improvement of effective coverage efforts and strategies, and to improve the consistency of the findings. Further		McMaster Health Forum)		

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		efforts should be directed towards strategies and frameworks that better measure the connection between coverage rates and intervention effectiveness.				
	Examining attempts to adopt the Learning Health System paradigm, with an emphasis on implementations and evaluating the impact on current medical practices (32)	The review examined 32 documents, including 13 studies, in order to examine the attempts to adopt the Learning Health System paradigm. A learning healthcare system is driven to generate and apply the best evidence for collaborative healthcare, while focusing on innovation, quality, safety and value. Patients are a major factor in this model of health provision, given the emphasis on collaboration and collective decision-making. This review examines the attempts to implement this model of medicine. The results of this review indicate that there has been very little action in terms of implementing learning health systems, despite a great deal of interest. It is possible that there is great trust placed in the learning health system without proper assessment of impact. This may have contributed to the low number of studies qualifying for inclusion in the review. A major focus should be placed on assessment and reporting, considering that many attempts to adopt this system of health have been attempted and not reported. Existing frameworks for assessing medicine applications can be used to assess the efficacy of learning health systems. Further, reporting of the evaluation of these systems must be comprehensive. Lack of consistency across studies diminishes quality and effectiveness, and makes it difficult to assess outcomes. Taken together, the Learning Health System paradigm must be of central focus to researchers moving forward. While the central tenets of this approach are supported by researchers, there is a lack of assessment. The impact of such a system must be evaluated in order to boost adoption.	2015	3/10 (AMSTAR rating from McMaster Health Forum)	0/13	0/13

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
	Assessing how asset-based approaches are operationalized when adopted in interventions aimed to promote health and reduce inequalities in local communities (33)	This review examined 30 studies in order to assess how asset-based approaches are operationalized when adopted in interventions aimed to promote health and reduce inequalities in local communities. Within the included studies, 18 interventions were targeted at people living in communities as a whole, and the remainder were targeted at specific populations within the communities. This review proposed three main approaches to understand how assets are mobilized: connecting existing assets; raising awareness of assets; and enabling assets to thrive. Connecting existing assets refers to programs that recognize other organizations as assets and connect together to work and share resources. Raising awareness of assets refers to existing resources that are often underused, or which other community members are not aware of. Enabling assets to thrive refers to processes where potential assets need further support to develop their potential. Within this review, eight interventions used the connecting existing assets approach, seven used the raising awareness of assets approach, three used enabling assets to thrive approach, and 10 used more than one approach. Using the obtained data, a framework was developed to highlight the key characteristics of asset-based approaches. In summary, assets should be identified through mapping, community engagement, needs assessments, appreciative inquiry or interviews. Planning which assets to use should be done by examining interests, networks and settings. Assets should be applied in practice by connecting assets among themselves, raising awareness of available assets, or enabling assets to thrive. Outcomes of assets should be assessed at the individual, community or organizational level. Assets should be evaluated using qualitative approaches, or mixed-method approaches. This review is limited by the lack of inclusion of grey literature. It provided an overview of the key characteristics of interventions	2017	4/9 (AMSTAR rating from McMaster Health Forum)	Not available	Not available

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		adopting an asset-based approach. The proposed framework can be used as a foundation when designing assets. Further research is needed to better understand how asset-based approaches can support health promotion and reduce inequalities.				
	Examining health assets from a global context both from a theoretical and methodological perspective (35)	This review examined 478 publications to provide an overview of health assets in a global context both from a theoretical and methodological perspective, and its applications to address inequalities and achieve sustainable health. A broad variety of health assets were identified. Within the included publications, 316 were included in a health context, 23 were community assets, 28 were individual assets, 43 were religious health assets, 15 were organizational assets, 11 were resilience assets, 28 papers focused on asset mapping, three focused on co-production, and nine assets were not clearly defined. A wide variety of interventions and approaches were implemented within the included publications. The most common interventions were education, training, asset-mapping and asset approaches. Moreover, a large number of outcomes were also reported across the individual level, community level and organizational level. This review concluded that, globally, most authors referred to general health assets, assets, or community assets in relation to health. The idea of health assets focuses on health prevention and promotion, as opposed to curative approaches. However, due to the large variation in definitions, interventions and outcomes, future research should be directed towards defining and standardizing these assets, which will benefit policymakers and service commissioners.	2018	6/10 (AMSTAR rating from McMaster Health Forum)	11/478	Not available

Appendix 3: Systematic reviews relevant to Element 3 – Establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
Establish a pan-Canadian network of 'rapid-learning champions' to drive action in support of rapid learning and improvement	Examining attempts to adopt the Learning Health System paradigm, with an emphasis on implementations and evaluating the impact on current medical practices (32)	The review examined 32 documents, including 13 studies, in order to examine the attempts to adopt the Learning Health System paradigm. A learning healthcare system is driven to generate and apply the best evidence for collaborative healthcare, while focusing on innovation, quality, safety and value. Patients are a major factor in this model of health provision, given the emphasis on collaboration and collective decision-making. This review examines the attempts to implement this model of medicine. The results of this review indicate that there has been very little action in terms of implementing learning health systems, despite a great deal of interest. It is possible that there is great trust placed in the learning health system without proper assessment of impact. This may have contributed to the low number of studies qualifying for inclusion in the review. A major focus should be placed on assessment and reporting, considering that many attempts to adopt this system of health have been attempted and not reported. Existing frameworks for assessing medicine applications can be used to assess the efficacy of learning health systems. Further, reporting of the evaluation of these systems must be comprehensive. Lack of consistency across studies diminishes quality and effectiveness, and makes it difficult to assess outcomes. Taken together, the Learning Health System paradigm must be of central focus to researchers moving forward. While the central tenets of this approach are supported by researchers, there is a lack of assessment. The impact of such a system must be evaluated in order to boost adoption.	2015	3/10 (AMSTAR rating from McMaster Health Forum)	0/13	0/13
	Examining how different financial mechanisms promote intersectoral collaboration for	This review examined 51 documents in order to understand the financial mechanisms used to promote intersectoral collaboration for health promotion. Intersectoral collaboration between health and the social welfare, education or labour sectors can be conducive to addressing the social determinants of health. However, these sectors often have differing regulatory structures, incentives and goals. This review aimed to identify approaches to financing that may help to overcome these barriers.	2016	3/9 (AMSTAR rating from McMaster Health Forum)	Not available	Not available

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
	health promotion (47)	The results of this review indicate that dedicated earmarked funding for intersectoral health promotion, delegated financing for independent health-promotion organizations, and joint budgeting to share resources for a specific project are three major mechanisms used to support intersectoral collaboration. These mechanisms tended to take place at local or regional levels, and their success often depended on other factors such as legal considerations, organizational structures, differences in culture, and the level of trust. Although financial approaches may help stimulate collaboration, many other issues influence the success or failure of intersectoral activities, and they must be looked as well. The review suggests that combining financial and regulatory mechanisms, clear accountability, realistic timing, legislative safeguards, quantifying benefits and costs, and building foundational trust are key policy considerations.				
	Assessing the barriers and facilitators to citizen participation in public-sector decision-making (44)	This review examined 50 articles which focused on the barriers to implementation of citizen participation, while simultaneously identifying the facilitators to lessen them. Although citizen participation has been regarded for allowing citizens to participate in the decisions that affect them, there remain concerns about its downfalls and potential costs. This review aimed to identify these impact variables. Three sets of variables were identified as having an impact on effectiveness: contextual factors, organizational arrangements and process management patterns. Regarding contextual factors, the review found that information asymmetries among participants could lead to poor focus and unrealistic expectations, whereas long-term collaboration and shared research efforts could help mitigate this. Additionally, the pre-existing unwillingness of public officials to focus on bottom-up community empowerment often impeded successful partnership, however, this was sometimes mitigated by the institutionalization of participatory processes. For organizational arrangements, deciding on representation criteria as well as the engagement-process design were key considerations to be made in designing citizen-engagement programs. Specifically, using multiple engagement techniques to facilitate clear immediate	2014	5/9 (AMSTAR rating from McMaster Health Forum)	3/50	0/50

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		impacts embedded within a long-term strategy can help allow for citizen goals and agendas to be realized, while organizers are able to establish clear outcomes. Finally, for process management, negative group dynamics could often be a concern, but employing multiple different engagement techniques was helpful. The quality of collaboration also often affected outcomes, which was mitigated by a long-term commitment to collaboration, clarity in language and broader involvement. Overall, the review suggests that although citizen participation broadened alternative solutions, increased accountability, and localized decision-making, there was little evidence that it can improve the efficiency and effectiveness of decision-making.				
	Identifying the features, barriers and facilitators of joint working between health and social-care services during recent United Kingdom reforms (45)	This review examined 46 articles which describe various models of joint working, their effectiveness, and key barriers and facilitators. Twenty-two studies evaluated services for older people, six looked at mental health services, and two looked at both. The review suggests that an increasing demand for services and a pressure to reduce public expenditure has created an incentive for greater collaboration to address complex needs. In the U.K., recent reforms intended to facilitate joint working and integration, however, there is little known about whether these changes met the objectives of policymakers. The review found that most studies focused on joint working for front-line services, which included using multi-agency teams, placements of individual staff across agencies, single assessment processes, the provision of intermediate care, structurally integrated services, and use of pooled budgets. The most common model for collaboration was employing multidisciplinary teams, followed by cross-agency placement schemes. Although there was limited effectiveness data, it was generally demonstrated that joint working can lead to improvements in health and well-being while reducing inappropriate admissions to acute care. Measures generally focused on clinical outcomes, service provision and staff satisfaction. In terms of cost, there was some evidence of savings using intermediate care, but specifically, that integrated districts were no costlier. The barriers and facilitators to joint working were	2011	4/9 (AMSTAR rating from McMaster Health Forum)	Not available	0/46

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		related to organizational, cultural, professional and contextual issues. For organizational issues, these related to establishing shared purposes, clear roles and responsibilities, work flexibility, differing agendas, communication, management, history of collaboration and resource access. For cultural and professional issues, influencing factors tended to relate to professional philosophies, trust and joint working. For contextual issues, the relationship between agencies and the financial certainty of initiatives were influential. Overall, the review indicates that the evidence for joint working remains generally under-developed, but that there is some support for the benefits of integrated working between organizations, service-users and providers.				
	A meta-synthesis of the dimensions of collaboration that are conducive to innovation (39)	This paper is a meta-study that examined previous pieces of research conducted mostly by the same authors, with the aim to identify the commonalities in the different forms of collaboration that are conducive to innovation. This review examined three case studies submitted to different academic journals focusing on the following collaborations: project-based partnerships, small consortia for joint innovation and marketing, and technology and industrial clusters. The review suggests that the key dimensions of collaborations for innovation are their members, the forms of governance that ensure coordination, and control and the scope of the partnership. Regarding membership, collaboration partners pool resources, where either vouchers are awarded to carry out specific innovations or collective benefits are received during joint activities. No 'blueprint' on selecting partners was provided, but it appears that having common culture, a complementary knowledge base and aligned strategic objectives are fundamental. Regarding governance, the review suggests that while structural governance establishes the boundaries of the collaboration, internal spaces are usually governed by the dynamic interplay of contracts and relational trust. Finally, regarding collaboration policies, the review suggests that voucher programs, consortium initiatives and cluster policies help achieve joint	Not reported	3/9 (AMSTAR rating from McMaster Health Forum)	Not available	Not available

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		objectives. Policies should focus on formation as well as the stages of growing or maturity. The review was limited by a lack of clarity in its methodology, and it was difficult to abstract further information.				
	Identifying the components of engaging community-based organizations in partnerships with scientific research (43)	This review examined 32 studies about the components of community-based organization (CBO) engagement, with the aim to assist researchers in planning partnerships with CBOs. CBOs have been shown to serve as liaisons between researchers and the community, however, the features that define community-scientific engagement have received limited attention. This review sought to synthesize the literature on this topic in order to identify any consensus on key components. The review identified four key components of CBO engagement. First, in order for engagement to occur there needs to be an established community need, where the importance of a project and its proposed benefits are clearly defined. Second, the partnership dynamic must be founded on aligned values and missions that guide the work for the organization and scientific stakeholder. Third, partners must all have the resources available to contribute to success, including human resources, physical resources, money and expertise. Finally, the outcomes of the partnership should be clear and inform subsequent activity. The review concluded that the identification of these components of CBO engagement will assist researchers and CBOs in evaluating and improving their partnerships.	2017	5/9 (AMSTAR rating from McMaster Health Forum)	Not available	Not available
	Examining how innovations in health-service delivery are scaled and spread (40)	This review examines 495 sources (213 empirical) to assess how innovations in health-service delivery can be spread and sustained. This review aimed to create a conceptual model from its synthesis to describe the determinants of diffusion, dissemination and implementation of innovations. Although it considered many different aspects of these complex	2017	2/9 (AMSTAR rating from McMaster Health Forum)	Not available	Not available

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		determinants, a large emphasis was placed on assessing the role of champions in contributing to innovation diffusion. The review found that the adoption of an innovation by organizations was more likely if key individuals championed it. Champions took on a diverse range of roles, which included: giving autonomy to the innovators, but also acting as a buffer to ensure monitoring and feedback is properly employed; and harnessing support across the organization, facilitating collaborative networks. The review also suggested that champions have an important role in ensuring system readiness for innovation through creating strategic support and advocacy. If champions could be strategically placed to outweigh the influence of opponents, subsequent innovation uptake would be more likely. Although the review concludes that champions were often key determinants of organizational innovation, there remains limited evidence on how to actually identify and harness the influence of these leaders. Furthermore, the review suggests that that no amount of research may be able to elicit this information, as creating an all-encompassing framework for the identification and engagement of champions which is independent of the nature and context of the innovation is unlikely.				
	Identifying the types, goals and determinants of innovation in the public sector (48)	This review examines 181 sources on public-sector innovation in order to identify the definitions, types, goals, determinants and outcomes of innovation. This review suggests that innovation in the public sector can lead to improvements in the quality of public services and enhance the capacity of governmental organizations to deal with change. It aimed to understand the meaning and importance of public-sector innovation, while also identifying the underlying factors that contribute to or hinder success. Regarding innovation types, the most common innovation was process innovation, which was comprised of both administrative and technological processes. This was followed by service innovation, governance innovation and conceptual innovation. Regarding innovation goals, among sources that mentioned a goal, the most commonly cited goal was increasing performance, measured through either effectiveness or efficiency. This goal was followed by	2014	3/9 (AMSTAR rating from McMaster Health Forum)	Not available	Not available

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		tackling societal problems, increasing customer satisfaction, involving citizens, and involving private partners. Finally, regarding the factors influencing innovation, four general categories were described: environmental, organizational, individual and the innovation. Environmental factors related to pressures such as media and politics, inter-organizational networks, regulatory frameworks, compatibility of other organizations to adopt the innovation, and competition. Organizational factors included the availability of resources, leadership style, level of risk aversion, incentivization, conflicts, and organizational structure. Individual factors related to employee empowerment, individual position within the organization, job skills, room for creativity, demographics, job satisfaction, norms, and innovation acceptance. Finally, factors related to the type of innovation were its ease of use, relative advantage, compatibility and trialability. The article concludes by motioning that gaps remain in our understanding of the public-sector innovation process across different contexts, as there was a large U.K./U.S. focus in the studies.				
	Identifying the contextual features of organizations that have an impact on the uptake of evidence-based practices in healthcare (46)	This review examined 36 articles that explored the organizational context of implementation initiatives within healthcare settings. The review indicates that although contextual features at the level of the organization are recognized for their impact on the uptake of evidence-based practices in healthcare, there is little consensus on the features that are most important. This review aimed to identify these features. The six most reported organizational features that had an impact on implementation were culture, leadership, communication, resources, feedback and champions. Regarding culture, the organization's openness to trialing new innovations, and learning from their successes and failures, was imperative. For leadership, the people providing new knowledge were key influencers in facilitating staff morale and fostering buy-in for the new initiative. Communication supports such as collaborative teamwork and clear information provision during innovation implementation were also essential. Access to financial, staff, time and educational resources aided implementation, while inputting the appropriate mechanisms to feed information back helped	2017	7/10 (AMSTAR rating from McMaster Health Forum)	Not available	Not available

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		ensure sustainability. Finally, appointing a 'champion' was described as the most consistent and strongest feature related to the delivery of prevention services. Key attributes of successful champions included their expertise on the intervention, their availability to troubleshoot and train, and their consistency in providing a sense of familiarity to the organization. The review concluded that each of the organizational features it identified appeared to be interrelated and did not influence implementation independently from other features. Future research should focus on how these features interact in implementation effectiveness.				
	Reviewing the role of champions in healthcare interventions (38)	This review examined 199 articles to analyze the approaches for operationalizing "champions" in healthcare-related interventions. The most common method to define a champion across studies was the use of a dichotomous variable designating a champion's presence or absence, which was employed in over 90% of articles. Champions were also cited as key factors in implementation success, with more than 80% of articles identifying champions as an essential component. Regarding the efficacy of using solo champions versus multiple champions, several articles found that multiple champions working simultaneously was a key feature of implementation success. The article described the many characteristics of champions across articles which included: champions tenaciously advocating for an initiative within the work environment; facilitating reflection; serving as team leader; motivating staff; engaging in planning activities; educating and training staff about the initiative; making a business case to leadership; persuading staff that the initiative was important and worthwhile; developing pamphlets, stickers and posters; building relationships with key stakeholders; boundary-spanning across service lines; spending one-on-one time with staff; being visibly identified with the initiative; recruiting team members for implementation; using data to persuade peers; and troubleshooting problems that emerge during implementation.	2016	3/9 (AMSTAR rating from McMaster Health Forum)	Not available	Not available

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups
		Although the review found that champions were important influences on implementation effectiveness, only four studies implemented randomized designs.				
	Assessing whether programs aimed to support citizen engagement in public services had an impact on the quality, accessibility and quality-of-life outcomes of those services (29)	This systematic review examined 35 citizen-engagement programs in low- and middle-income countries which aimed to promote citizen engagement in the planning and management of public services. The review aimed to understand whether engaging citizens in these services, which were critical to development, actually had an impact on the quality of services, their accessibility, and their subsequent impact on citizens' lives. It assessed this question through four avenues which are referred to as the PITA Mechanisms: participation in priority setting and decision-making, inclusion of marginalized groups, transparency of information provision and rights, and accountability through feedback and monitoring. Regarding outcomes, the review only included studies that described the immediate outcomes of citizen engagement, such as participation in meetings or public-service responses. These were only eligible if these studies also measured the subsequent impacts on the accessibility of services, service use or final outcomes such as health or nutrition. The review suggested that promoting direct citizen engagement between service users and service providers (termed the "short route") was more effective in increasing engagement itself, while also increasing access to services and the quality of provision. This was in contrast to the "long route" which focused on increasing citizen pressure on politicians. Regarding well-being targets, it was found that although direct engagement was important, interventions that also address the inefficiencies in service-provider supply chains would be necessary. The review did not draw conclusions for different socio-economic groups, geographic groups, or genders due to the small sample of studies.	2018	9/9 (AMSTAR rating from McMaster Health Forum)	0/9	Not available

Appendix 4: Primary study relevant to Element 1 – Prioritize service needs and design a rapid-learning and improvement approach to meet them

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Examining lessons learned from the transition of an autism intervention and research network to an autism learning health network (26)	Date: 2019 Jurisdiction: U.S. Methods: Mixed methods	This study included results from 12 networks sites within the Autism Speaks Autism Treatment Network (ATN)/Autism Intervention Research Network on Physical Health (AIR-P) that joined the learning network transition initiative	The design process involved an organizational structure framework to help facilitate the preliminary stages of a network transition, which includes: 1) an alignment around a common goal; 2) development of standards and infrastructure; and 3) sharing information and resources to achieve the goal. The design process included a two-day design session with weekly calls with the design team (including ATN/AIR-P leadership, Anderson Center team, parents, clinicians, researchers, and data analysts/biostatisticians). During in-person two-day design sessions, the team identified outcomes that would be used to measure improvements, which were then collected through a technology-based platform.	The study reported key considerations when redesigning current processes and services, including: conceptualize changes based on the program's strengths in order to leverage existing resources and enable smoother transitions; expand the rapid learning and improvement as the program grows; incorporate patient partners and clinicians during the development stage; and recognize there will be complexities and challenges when redesigning current processes and data infrastructures. Additionally, a shared understanding and vision facilitated a cohesive approach to gathering evidence, implementation and dissemination of synthesized findings.

Appendix 5: Primary studies relevant to Element 2 – Strengthen and link the assets required to operationalize the rapid-learning and improvement approach for neurodevelopmental disorders in Canada

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Examining lessons learned from the transition of an autism intervention and research network to an autism learning health network (26)	Date: 2019 Jurisdiction: U.S. Methods: Mixed methods	This study included results from 12 networks sites within the Autism Speaks Autism Treatment Network (ATN)/Autism Intervention Research Network on Physical Health (AIR-P) that joined the learning network transition initiative	The design process involved an organizational structure framework to help facilitate the preliminary stages of a network transition, which includes: 1) an alignment around a common goal; 2) development of standards and infrastructure; and 3) sharing information and resources to achieve the goal. The design process included a two-day design session with weekly calls with the design team (including ATN/AIR-P leadership, Anderson Center team, parents, clinicians, researchers, and data analysts/biostatisticians). During in-person two-day design sessions, the team identified outcomes that would be used to measure improvements, which were then collected through a technology-based platform.	The study reported that a self-evaluation would be beneficial and could ensure a shared understanding of strengths and gaps with the research team to maintain buy-in (e.g., network's mission, activities, governance and decision-making authorities, data infrastructure). Aligning the network's existing strengths and missions could allow for an efficient way to use existing resources, thus expediting the transition and success.
Examining stakeholders' views on designing and implementing a learning system (37)	Date: 2020 Jurisdiction: U.S. Methods: Qualitative	This study included semi-structured interviews with 19 program planners, designers, and managers, and 11 additional follow-up interviews. These interviews were analyzed through a comparative method.	The creation of the registry-enabled care and learning system for cystic fibrosis (RCLS-CF) involved developing a conceptual model to help establish common goals, data platform that includes patient-reported and clinical data, and integration to existing healthcare-record systems.	The study reported that a partnership between patients and clinicians that allows for co-production to be foundational. Technology infrastructure that is capable of data-sharing would be beneficial to both patients and clinicians for joint decision-making and collaboration. The stakeholders cited a few practical challenges such as aligning systems and data to the overall vision and goal, culture shifts from the transitional clinician-patient relationship, and time and resource constraints.

Appendix 6: Primary studies relevant to Element 3 – Establish a pan-Canadian network of 'rapid-learning champions' to drive and sustain action

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Examining the determinants of effective leadership during the implementation and sustainment of an evidence-based intervention (41)	Date: 2016 Jurisdiction: U.S. Methods: Mixed methods	This study reviews the results from 11 service systems that implemented SafeCare, an evidence-based intervention to reduce child maltreatment. Both quantitative and qualitative data were used.	SafeCare aims to reduce child maltreatment through home-based skills training and education for caregivers at risk for child neglect. The program included home visitors who would deliver the intervention to caregivers, trainers who helped train new home visitors, and coaches who supported and monitored home visits. The study used the Exploration, Preparation, Implementation, Sustainment (EPIS) framework to assess outer-context and inner-context leadership in the SafeCare implementations.	The study concludes that there is evidence to support the importance of leadership in program implementation and sustainment. Quantitative results showed that effective outer-context leadership was comprised of clarifying the program mission and realistic planning for sustainment. Effective inner-context leadership was transformational at the front line, and specifically avoided passive and avoidant actions. Qualitative results found that effective outer-context leadership was characterized by ongoing championing of the program, incorporating the program into service systems, and collaborating across the system. Positive inner-context leadership also incorporated championing the program as well as providing front-line practical support for the service providers.
Assessing the role of champions in implementing quality-improvement efforts (42)	Date: 2013 Jurisdiction: U.S. Methods: Qualitative	This study included qualitative data from eight practices that implemented the program EPIC. Data on field notes, meetings and interviews were collected.	Enhancing Practice, Improving Care (EPIC) was a program launched to test three different approaches to improve diabetes and depression care. The arm that focused on the role of 'change champions' was looked at here. A champion of EPIC was the point-person in a diverse practice team who would lead on ensuring quality-improvement efforts were made. These teams regularly met over a six-month period.	The study specifically found that there was value in having two discrete types of change champions; the project champion who would focus on the specific project implementation elements, and the organizational champion who would focus on those leading change for the entire organization. Practices that had both types of champions, who complemented each other, were best able to implement and sustain improvements.

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Examining lessons learned from the transition of an autism intervention and research network to an autism learning health network (26)	Date: 2019 Jurisdiction: U.S. Methods: Mixed methods	This study included results from 12 network sites within the Autism Speaks Autism Treatment Network (ATN)/Autism Intervention Research Network on Physical Health (AIR-P) that joined the learning network transition initiative.	The design process involved an organizational structure framework to help facilitate the preliminary stages of a network transition, which includes: 1) an alignment around a common goal; 2) development of standards and infrastructure; and 3) sharing information and resources to achieve the goal. The design process included a two-day design session with weekly calls with the design team (including ATN/AIR-P leadership, Anderson Center team, parents, clinicians, researchers, and data analysts/biostatisticians). During in-person two-day design sessions, the team identified outcomes that would be used to measure improvements, which were then collected through a technology-based platform.	The study reported that it would be beneficial to integrate education and communication, broader participation and involvement, and negotiation from network leaders before or during the developmental phase of a learning health system. Co-production between clinicians and patient partners provided an opportunity for a deeper understanding of each other's needs and identify outcomes to measure that determined improved quality of life. Patients and family representatives were actively involved in the two-day session, leadership calls, monthly webinars, and development of the technology-based platform to collect relevant measures.

McMaster
University

HEALTH FORUM

>> Contact us

1280 Main St. West, MML-417
Hamilton, ON, Canada L8S 4L6
+1.905.525.9140 x 22121
forum@mcmaster.ca

>> Find and follow us

mcmasterforum.org
healthsystemsevidence.org
socialsystemsevidence.org
mcmasteroptimalaging.org
mcmasterforum