RESEARCH PAPER

Innovative Programs with Multi-Service Integration for Children and Youth with High Functional Health Needs

Programmes novateurs avec intégration de services multiples pour les enfants et les jeunes ayant des besoins élevés en matière de santé fonctionnelle

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Abstract

The integration of care services and providers across the health–social–community continuum has helped improve the lives of many children and youth living with complex health conditions. Using environmental scan data, 16 promising multi-service programs were selected and analyzed qualitatively through a deliberative conversation approach. Descriptive data of analyzed programs are presented, as well as the thematic analysis results. An important program strength is its clear founding principles and engagement of patients and families. However, the scale-up of these initiatives remains a challenge unless such programs can be better financed and supported.

Résumé

L'intégration des services et des fournisseurs de soins dans l'ensemble du continuum « services de santé–services sociaux–services communautaires » contribue à améliorer la vie de nombreux enfants et jeunes aux prises avec des problèmes de santé complexes. À l'aide de données d'analyse du contexte, 16 programmes multiservices prometteurs ont été sélectionnés et analysés qualitativement au moyen d'une approche de conversation délibérative. Les données descriptives des programmes analysés sont présentées ainsi que les résultats de l'analyse thématique. Une des forces importantes du programme consiste en ses principes fondateurs clairs et en l'engagement des patients et des familles. Cependant, l'intensification de ces initiatives demeurera un défi, à moins que de tels programmes puissent être mieux financés et soutenus.

Introduction

Children and youth aged 0 to 25 years who have high functional health needs account for about 15–18% of North American children (Berry et al. 2011; Haggerty et al. 2023; Kaufman et al. 2007). Advances in neonatal, medical and nutritional care have significantly improved the survival rate of vulnerable children who can now live into adulthood despite complex health conditions (here understood as one or more chronic physical, emotional, developmental, neurological or behavioural conditions). Such children require care from a wide range of health, social and community services (Burns et al. 2010), and it has long been understood that their well-being can be optimized when a diverse team of care professionals work together to address the needs of these children (Cohen et al. 2011, 2012). Innovative programs and initiatives that seek to integrate multiple services across the health, social and community continuum can prove to be a key source of information to help us understand what care providers and organizations are doing to respond to the needs of these children and their families. It is in this context that we undertook a qualitative analysis of a small sample of these innovative programs from across all 10 Canadian provinces. Our research aims to identify and analyze promising provincially based multi-service integration programs to distill dominant trends in multi-service integration, document their strengths and weaknesses and formulate policy recommendations on how to better support local integration initiatives to increase spread and scale.

Methodology

To achieve our aim, 16 promising programs were identified from an innovative programs database containing approximately 100 programs across all Canadian provinces, which was created in an earlier phase of the larger study (Haggerty et al. 2023). The following five criteria were used to create our program sample: (1) the programs should be province-based and publicly supported; (2) the programs should show an innovative approach to multi-service integration; (3) the programs should show potential for scalability; (4) the programs should provide useful lessons regarding key ingredients of success or failure of multi-service care integration; and (5) all 10 provinces should be represented. To meet criteria 2 to 4, three independent co-investigators applied an "Innovativeness Scale" that was adapted from the "Innovative Practices Evaluation Framework" (Health Quality Ontario 2016).

Once programs were selected, the research team collected descriptive program data from readily available sources (e.g., program websites and publications, as well as informal conversations with key program informants) using a rating tool adapted from the literature to assign an integration score to each program. The tool reflects the achievement of 10 principles of care integration (Suter et al. 2009) and nine implementation facilitators (Damschroder et al. 2009). These data were then used to create program narratives, which were validated by both key program informants and the research leads. Using the descriptive program data and the narrative summaries, 14 co-investigators from the larger study representing each of the 10 provinces and having complementary knowledge and expertise (e.g., children/youth health clinicians, researchers, social and health service integrators, educators) participated in a three-hour virtual deliberative conversation led by a professional facilitator who guided the discussion using four reflective questions: (1) What are identifiable trends, across Canada, in provincially based integrated service programs that address the needs of children and youth with complex care needs? (2) What are the strengths and weaknesses of the programs? (3) Is there anything missing from the programs in terms of best approaches or models to services integration for this population group? (4) What would the policy recommendations be, based on this review? The conversations were audio-recorded and transcribed, and all the data were imported into NVivo 12 (QSR, 2018) and then analyzed thematically using codes agreed upon by members of the research team. Themes and sub-themes were identified by the main author using a thematic analysis approach (Clarke et al. 2015; Terry et al. 2017) and then synthesized and shared with the research team members and participants in the deliberative forum. Feedback to clarify or add nuance to the themes and sub-themes was provided and incorporated to produce a final report of thematic analysis, which was validated by participants and co-authors. Their feedback was used to reflect on policy implications and formulate recommendations.

Results

Our findings are presented as both (1) synthesized descriptive program data and (2) findings from thematic analysis of the deliberative conversations. Data excerpts are taken from the programs' narratives.

Descriptions of programs

Table 1 (available online at www.longwoods.com/content/27178) provides descriptive data of the programs selected, including the program's name, a brief description and the province in which the program is located; it also includes information regarding components of successful integration as per our theoretical conceptualization (Haggerty et al. 2023). Fourteen of the 16 programs included community organizations in their purview, and 13 of the 16 programs included mental health and substance use services in their design and also provided training or support for providers, specifically in a multi-service integration perspective. Twelve of the 16 programs served the entire province and included social services. The presence of individual intervention plans, patient and family centred-care, use of electronic medical records and use of telehealth follow-up, as well as implementation within existing clinics (e.g., family health teams, family group medicine), were the components least often included in the programs. Information about the role of family physicians in integrating or connecting services was not explicitly discussed, but we could usually ascertain their intended role through other information provided (e.g., Quebec [QC] programs; Prince Edward Island-[PEI]-BestStart.

Deliberative conversations: Thematic analysis

Our thematic analysis yielded four overlapping program themes to be considered when making policy recommendations for multi-service integration programs: (1) program philosophy, (2) governance, (3) engagement and (4) infrastructure, as well as sub-themes for each. Table 2 presents an overview of each theme and its corresponding sub-themes. Table 3 (available online at www.longwoods.com/content/27178) presents quotes and excerpts for each sub-theme, taken from the programs' narratives and the deliberative conversations.

PROGRAM PHILOSOPHY

Program philosophy refers to the foundational principles, theories, concepts and/or values that guide the program's creation and/or operation. We found that all programs had a "foundational story" that articulated its philosophy and served as both a catalyst and a guide to implementation. This philosophy was often presented in the form of a program's mission statement that articulated its objectives. These stories provided the most information for our program data analysis.

Six sub-themes of program philosophy emerged from our analyses (see Tables 2–4).

TABLE 2. Results from the thematic analysis: Key emerging themes and sub-themes

Program philosophy	Governance	Engagement	Infrastructure
1. Engagement (mainly patients and family members) 2. Prevention and early intervention 3. Local flexibility and adaptation 4. Primary care continuity 5. Incentives for providers 6. Sub-population stratification	1. Governance structure 2. Shared decision-making processes 3. Standardized processes 4. Definition of multi-service integration	**Who?** 1. Patients and family members 2. Providers 3. Larger community 4. Cultural diversity **How?** 1. On decision/advisory boards 2. By seeking experiential knowledge 3. In various types of meetings 4. In program planning 5. Through patient satisfaction evaluation methods	1. Role and presence of a care coordinator (or case manager or patient navigator) 2. Colocation of services 3. Data-sharing processes or structures 4. Evaluation and monitoring processes 5. Financial resources

Engagement was most often referred to as "person-centred care" and was used by programs to emphasize the central role patients and family members play, especially in the program's creation.

> Person and family engagement has been paramount throughout the stages of planning for Specialized Services for Children and Youth (SSCY). SSCY currently has a Family Advisory Council that helps to inform the direction of current and future priorities of the Centre (Manitoba-Specialized Services for Children and Youth [MB]-SSCY).

Prevention and early intervention emerged as an important theme and driver of programs, with particular attention given to mental health, emotional well-being and social support. Attention to social determinants of health was also noted here.

> Program promotes upstream approaches and early intervention services to facilitate positive childhood development (New Brunswick-Integrated Service Delivery [NB-ISD]).

Local flexibility and adaptation speaks to how the programs allowed for regional adaptation. This appeared to support implementation and program sustainability.

> There is a large degree of flexibility for PCNs to adapt to the needs of their region in Alberta, in consultation with the regional health authorities and the priorities of the family physicians. (Alberta-Primary Care Networks [AB-PCNs]).

Primary continuity refers to whether or not a program followed the federal primary healthcare renewal initiative and adhered to the renewed conception of primary care as primary healthcare (Dionne et al. 2023).

> Primary care renewal is a trend with an emphasis on care continuity and interprofessional practice (primary care/medical home) (Ontario-Family Health Teams [ON-FHTs]).

Incentives for providers refers to whether or not programs relied on incentivization (financial or otherwise) to increase providers' buy-in and participation in the program.

> [There is] capitation, as well as specific financial incentives for enrolling patients (ON-FHTs).

Subpopulation stratification refers to whether or not the program was designed for a specific subgroup of the target population, e.g., young adults transitioning to adult care.

> [The target population includes] children and youth up to age 18 inclusively, and up to the age of 21 for those within the public school system, who have identified multiple needs as defined by core areas of development, including physical health and wellness, emotional and behavioural functioning, family relationships, educational development and mental health (NB-ISD).

Table 4 shows which programs displayed which sub-themes.

GOVERNANCE

Our second theme, governance, refers to the structure and mechanisms used to enable and ensure efficacious management and deployment of a program. Four sub-themes emerged to facilitate the successful implementation of governance: (1) governance structure, (2) shared decision-making processes, (3) standardized processes and (4) definition of multi-service integration (see also Table 2). For each sub-theme, we provided a short definition; indicated whether or not it was well represented across all programs; and, if so represented, whether its representation was strong or weak. We also indicated which individual programs represented which sub-themes and whether or not this representation appeared strong or weak.

Governance structure refers to the various mechanisms of the program used to support its implementation and sustainability. When present, we found that the governance structure most often reflected the program's stated philosophy and principles (see theme #1). For example, programs that presented themselves as "person-centred" would most often also show a shared governance structure or shared accountability mechanisms with providers and patients/family members. In some cases, programs favoured accountability mechanisms

TABLE 4. Programs and sub-themes

Province	Program name	Engagement	Prevention and early intervention	Local flexibility and adaptation	Primary care continuity	Incentives for providers	Sub-population stratification
British Columbia	ON TRAC			X			X
Alberta	Primary Care Networks			X	X	X	
	Regional Collaborative Service Delivery			X		X	X
Saskatchewan	Cognitive Disability Strategy (CDS)		X	X			
Manitoba	Specialized Services for Children and Youth	X					X
	United Referral and Intake System						X
Ontario	Family Health Teams		X	X	X	X	
	Good 2 Go Transition Programs						X
Quebec	Community Social Pediatric Centres	X		X		X	X
	Programme d'aide personnelle, familiale et communautaire	X		X			X
New Brunswick	NaviCare	X					X
	Integrated Service Delivery		X		X		X
Nova Scotia	SchoolsPlus			X		X	X
Prince Edward Island	Best Start						X

established through institutional or governmental structures (e.g., universities or ministries). Overall, however, most programs did not provide sufficient information to assess this sub-theme (e.g., MB-SSCY, NB-ISD, Saskatchewan-Cognitive Disability Strategy [SK-CDS]) (see also Stewart et al. 2023).

Our second sub-theme pertains to the presence, absence and strength of *shared decision-making processes* of the design and the implementation of the programs. Our deliberative exchange suggested that such mechanisms are particularly effective and innovative in how they include patients and family members in meaningful ways. However, we found that most programs either lacked such mechanisms or the information to assess them. This was a recurrent weakness of programs analyzed (e.g., AB-Regional Collaborative Service Delivery [AB-RCSD], MB-United Referral and Intake System [MB-URIS], NB-ISD, Nova Scotia [NS]-SchoolsPlus, ON-FHTs, ON-Good 2 Go, PEI-BestStart, QC-Community Social Pediatric Centres [QC-CSPCs], SK-CDS).

Standardized processes refers to the presence of processes, materials or mechanisms to ensure a certain level of standardization throughout the program, which is viewed as important to the success of a program. An example is the standardization of service delivery protocols for multi-service delivery integration. We found that many programs displayed this component and that from the available information, these protocols were used by healthcare providers (e.g., Alberta-Primary Care Networks [AB-PCNs], BC-ON TRAC, MB-URIS, QC-CSPCs).

Definition of multi-service integration refers to whether or not programs provided a definition of multi-service integration. Generally, we found little information and a lack of clarity in this regard. None of the programs presented a clear conceptualization of integration, and some programs lacked a connection with primary care. Finally, some programs focused on social needs (e.g., community or educational needs), yet did not have any formal agreements or concrete connections with healthcare organizations or providers (e.g., MB-SSCY, NS-SchoolsPlus).

ENGAGEMENT

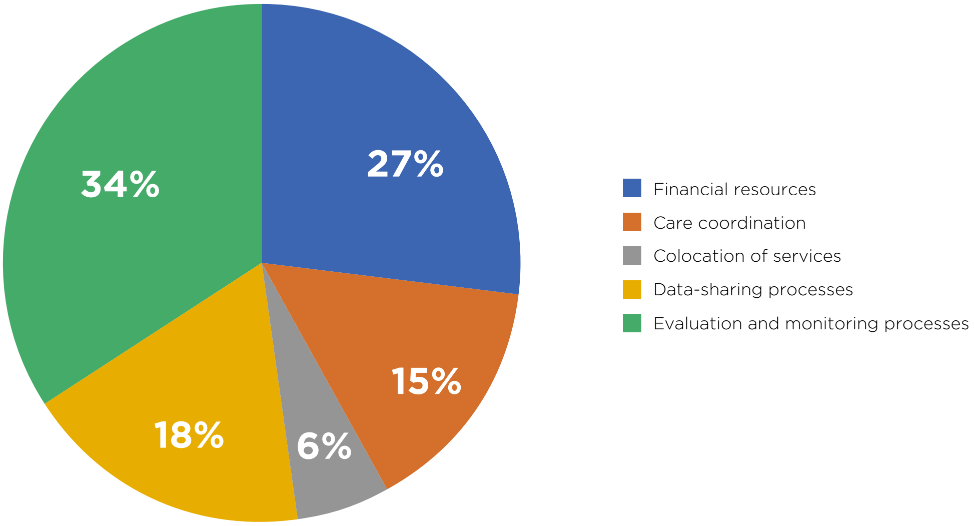
Engagement is described as how well programs engaged various stakeholders, such as patients and their family members, providers and local organizations. Here, we were also interested in how well programs integrated the principles of *equity, diversity and inclusion* (EDI), specifically in Indigenous and culturally diverse communities.

We found that only a handful of programs had a clear commitment to engaging patients and family members, and for those that did, the methods used varied greatly (e.g., inclusion on decision/advisory boards, of experiential knowledge, in a variety of meeting types; engagement in program planning; use of patient satisfaction evaluation methods) (e.g., MB-SSCY, QC-CSPCs, QC-Programme d'aide personnelle, familiale et communautaire [QC-PAPFC], NB-NaviCare). Most programs did not provide sufficient information to assess provider engagement. Only four programs that explicitly stated that they engaged providers also provided information on the engagement methods used (e.g., AB-RCSD, BC-ON TRAC, QC-PAPFC, NB-NaviCare). Only five programs explicitly stated that they regularly engaged local organizations to obtain early buy-in (e.g., in pilot programs; e.g., MC-SSCY, NB-ISD, NB-NaviCare, QC-CSPC, SK-CDS). Finally, most programs lacked cultural components or information on how they integrated EDI principles. None of the programs mentioned the involvement of Indigenous communities.

INFRASTRUCTURE

Infrastructure, the final dimension, describes the more concrete elements used to support the implementation of the program and the conduct of its activities. Five sub-dimensions emerged: (1) role and presence of a care coordinator or case manager or patient navigator, (2) colocation of services, (3) data-sharing processes or structures, (4) evaluation and monitoring processes and (5) financial resources. Figure 1 presents the distribution of these sub-themes per program. Evaluation and monitoring were the elements most present, with colocation of services the least.

FIGURE 1. Representation of infrastructure elements in all programs



Care coordinators, patient navigators and case managers emerged as key elements for achieving integrated care. These roles were viewed as an important support for patients with complex care needs (e.g., MB-SSCY, NB-NaviCare, NS-SchoolsPlus, ON-FHTs, QC-PAPFC). Interprofessional collaboration was a dominant theme across programs. Some programs clearly prioritized this approach (see Figure 1) to better support patients and families, minimizing the requirement to move across service organizations to access all services needed. For example, NS-SchoolsPlus emphasized colocation by delivering services in schools where children spent a large amount of their time. Colocation is also highlighted as helping providers to learn from and about other providers and services through working together in a more holistic and ecological approach (e.g., MB-SSCY, NS-SchoolsPlus). Data sharing was highlighted as an essential component to support multi-service integration by our diverse stakeholders (deliberative forum). However, most programs either lacked such infrastructure or information about it was missing. The deliberative exchange, however, suggested that some programs have inspiring approaches that could serve as useful examples in this regard (e.g., AB-PCNs, BC-ON TRAC, MC-SSCY, MB-URIS, NS-SchoolsPlus, ON-FHTs). Such approaches included facilitating communication to share knowledge and skills between providers or with patients and family members. At least one program specified doing data sharing informally as more robust structures had yet to be implemented (e.g., AB-RCSD). Overall, programs lacked adequate infrastructure to share records, which underscores the need for better resourcing (e.g., AB-RCSD, BC-ON TRAC, NB-ISD, ON-Good 2 Go, PEI-BestStart, QC-PAPFC).

Most programs explicitly stated that they collected data to evaluate and/or monitor their services (e.g., AB-PCNs, BC-ON TRAC, MB-SSCY, NB-ISD, NB-NaviCare, NS-SchoolsPlus, ON-FHTs, PEI-BestStart, QC-CSPCs, QC-PAPFC, SK-CDS).

Measures, however, were often very narrow insofar as they were predominantly quantitative and lacked evaluation of stakeholder satisfaction. There is also a lack of program data on implementation mechanisms, yet this information is critical to support the scale and spread of promising initiatives (e.g., AB-RCSD, BC-ON TRAC, MB-URIS, ON-Good 2 Go, PEI-BestStart, QC-CSPC). Finally, when information was available, there was a general lack of consistency in approaches used to evaluate programs. We also found little information on the integration theory driving the programs.

A common weakness of programs was their limited access to sufficient resources to support evaluation and monitoring processes. While this information was not readily available in publications, through conversations with key informants – who confirmed that there was a lack of implementation of a data-sharing system and/or electronic patient records, a lack of awareness about the programs and weak evaluation and monitoring practices – we concluded that programs did not have access to adequate resources to support these activities. When available, we noted that funding appeared to be provided on a short-term basis at best. This can negatively impact the sustainability programs, as well as their ability to innovate (e.g., AB-RCSD, BC-ON TRAC, MB-SSCY, NB-ISD, NB-NaviCare, NS-SchoolsPlus, ON-Good 2 Go, PEI-BestStart, QC-PAPFC, SK-CDS). Limited funds can also negatively affect the reach of programs and the ability to promote local awareness (e.g., AB-RCSD, BC-ON TRAC, MB-SSCY, NB-NaviCare, NS-SchoolsPlus, PEI-BestStart, QC-PAPFC).

Discussion

Several elements from our findings warrant further discussion. When considering recent literature regarding the recommendations on care adaptation for this patient group, we found some similarities but also differences. Some of our themes echo recommendations made in the current literature, notably regarding how to best provide and organize care across the health and social continuum for children and youth with complex care needs and their families. For example, Kuo et al. (2022) remind readers of a 1987 US Surgeon General's report that states key principles for the care of this patient population group (which were proposed for the design of the medical home hub) that remain timely. These were access to services, ensuring that all children and youth have a medical home (comprehensive care), community support, transitions in care, health information technology and quality improvement (Kuo et al. 2022). All but quality improvement were reflected particularly well in our analysis.

However, other principles of integrated care that appear essential for this population were largely absent from the program information available to us. Various authors emphasize the following principles as absolutely needed when caring for children and youth with complex care needs and their families: (1) the importance of the medical home as the "hub" for various professionals or services, (2) an emphasis on *family-centred care* and the role of family members (Kuo et al. 2012, 2022), (3) the adoption of a *life course perspective* (Bethell et al. 2014) and (4) the role and training of interdisciplinary teams (Coller et al. 2020). The second and third principles are importantly missing. We found no mention of them.

Policy recommendations

In light of the current literature and our analysis of the data that we collected, there are three policy recommendations to consider. First, there is a dire need to equip local programs with the resources needed to enable program evaluation and assessment that can be used to support the spread and scale of the program and thus avoid duplication that leads to a waste of resources. Our recommendation is that these tasks be done locally – for example, by the program coordinator. However, the resources required to do this well – which include program evaluation, engagement of relevant stakeholders, communication strategies and knowledge of the best implementation practices available – should be made available at a more centralized level – for example, by federal or provincial governmental bodies, who would be responsible for managing an easily available online platform. The value of such a platform will enable programs to better share their innovations. An example of such a platform is the Children and Youth with Special Health Care Needs National Research Network, created in the US in 2017 by the Health Resources and Services Administration Maternal and Child Health Bureau (see CYSHCNET.org; Coller et al. 2020).

Our second recommendation is to increase the engagement of relevant stakeholders, specifically that of patients and family members. Most programs indicated that they engage various stakeholders and take engagement at heart, particularly that of users and family members. However, our assessment of existing program data suggests that the methods used to engage participants are often limited to a posteriori quantitative satisfaction questionnaire, which we hypothesize reflects how local initiatives lack resources or expertise (to support robust scientific program evaluation).

Our final recommendation pertains to the need to equip local teams with adequate resources, notably digital (infrastructure, capacity, expertise), to develop and sustain robust integrated services solutions. Data and information sharing are highlighted both in the scientific literature and by our diverse stakeholders as an essential component to support multi-service integration. This requires resources to ensure that programs use confidential information-sharing platforms; have electronic medical records; and provide data access to patients, family members and other providers to benefit from involvement in nationally managed digital solutions platforms. Our study indicates that little innovation is done at this level and that most programs do not meet the digital turn. It is likely that many organizations, notably those that rely on public funding, do not have the resources, training or infrastructure to innovate digitally. However, it is hard to conceive of an integrated multi-service approach that would not also have a strong digital component and tools (e.g., electronic medical files). If we want to support local innovations and integrate care, such capacity needs to be developed and well supported through funding and investment by provincial and federal governmental bodies.

Limitations

There are a number of limitations to this study. To begin with, this study was conducted five years ago. Some of the conclusions we draw may no longer reflect the state of innovation in multi-service integration for this patient population and their families (e.g., the number of programs that have followed the digital turn due to the pandemic; greater consideration for mental health and youth protection in policy priorities). Also, to select programs, we relied on a database of innovative programs that were created at an earlier phase of the study, which relied on contributions from the Canadian Primary Care Research Network. This method, however, was not exhaustive and was time bound. Finally, of the programs selected for in-depth analysis, some revealed themselves to be insufficiently documented to support the level of analysis desired. Due to limited resources, including a limited amount of time, going back and selecting other programs was not feasible. With more funding, we would have been able to identify all current and past programs throughout Canada in order to support a more exhaustive analysis. Nevertheless, the insights obtained in this study were sufficient to support the policy recommendations outlined.

Conclusion

Our study provided an in-depth analysis, based on publicly available data, of innovative programs across Canadian provinces that aim to integrate health and social care to better support children and youth with complex care needs. These innovative programs could be a rich source of information and inspiration for other provinces or regions that are looking to create similar solutions, but without appropriate documentation we are losing such capacity to learn and grow.

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