

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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TABLE 1. Descriptive data about programs

Province	Program name	Program description	Provincial geographic reach	Inclusion of mental health and addictions services*	Inclusion of social services**	Inclusion of community	Individual intervention plans	Patient and family-centred	Electronic medical records	Telehealth for follow up	Training and support to providers	Family physician as the central role	Implementation within existing clinics (FHTs)
British Columbia (BC)	ON TRAC	A series of resources developed by staff at the BC Children's Hospital (n.d.) to improve transitions from pediatric to adult care.	X			X		X			X	X	

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Alberta (AB)	Primary Care Networks (PCNs)	Comprises 41 virtual networks, over 3,800 family doctors and 1,400 other healthcare providers providing primary care. Specific clinics have been set up, such as the Calgary Foothills PCN Youth Mental Health Clinic. Have the flexibility to adapt to local context within a framework provided by Alberta Health Services (AHS) and the Alberta Medical Association.	X	X	X	X			X			X	X
	Regional Collaborative Service Delivery (RCSD)	A partnership between Alberta Education, Alberta Health (and AHS), Children's Services and Community and Social Services to promote regional collaboration across partners. A result of the merger of several existing programs including in-school support programs and access to specialists. Comprises 17 RCSD regions.		X	X	X					X	X	

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Saskatchewan (SK)	Cognitive Disability Strategy (CDS)	A cross-ministerial initiative that involved ministries of health, social services, justice, education, advanced education, economy and Saskatchewan Liquor and Gaming Authority. Comprised a range of initiatives designed to meet the needs of children, youth and young adults with cognitive disabilities, and provides services and/or financial benefits for individuals with cognitive disabilities with significant behavioural and development challenges. Also comprised initiatives designed to improve the availability of assessment and diagnostic services; offer training and skills to people providing services to individuals with cognitive disabilities; and enhance prevention and intervention initiatives regarding fetal alcohol spectrum disorders.	X	x	X	X	X	X		X	X		

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Manitoba (MB)	Specialized Services for Children and Youth (SSCY)	Services integration for youth with disabilities and special needs. Alliance of families, community agencies, regional health authorities and the government providing specialized community-based services out of the SSCY Centre (e.g., homes, schools, daycares and communities) throughout the province.	X		X	X			X		X		
	United Referral and Intake System (URIS)	A program supporting children needing assistance while attending community programs, such as schools, licensed childcare facilities, respite services and accredited recreation programs.	X			X		X	X		X	Unclear	X

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Ontario (ON)	Family Health Teams (FHTs)	One of several primary care services, typically led by a family physician or nurse practitioner. Comprises an interdisciplinary team of nurses, social workers, dietitians and other healthcare workers. The setup is based on the needs of the local community through a collaborative process with the Ontario Ministry of Health and Long-Term Care.	X	X	X	X			X		X	X	X
	Good 2 Go Transition Programs	A program at The Hospital for Sick Children (Toronto) that aims to prepare youth with chronic health conditions to transition to adult care. Helps youth develop skills and knowledge to advocate for themselves (or through others), maintain health-promoting behaviours and utilize adult healthcare services appropriately and successfully.		X	X								

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Quebec (QC)	Community Social Pediatric Centres (CSPCs)	A program based on the integrated model of care developed by co-founders Gilles Julien and H��l��ne (Sioui) Trudel. It combines medicine, law and social work to support the development and well-being of children. Strengths-based and holistic, it incorporates child, family and community into the care plan. Identifies the needs of children in vulnerable situations, ensures rights are respected and reduces or eliminates negative stressors.		x	X	X	X	X			X	Assumed	

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Quebec (QC) (continued)	Programme d'aide personnelle, familiale et communautaire (PAPFC)	A program for children and their parents facing personal, relational and social difficulties relating to probable or actual neglect. Involves workshops, activities and groups offered in community organizations for parents and children. Addresses various factors and behaviours of an adult that could create an environment of neglect. Based on the ecosystemic and developmental theory of neglect.		x	X	X	X	X			X	Assumed	

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New Brunswick (NB)	NaviCare	Aims to support families of children and youth up to 25 years old with complex care needs through patient navigation services across the province. Patient navigators work to improve access to health, social and education services for children/youth and their caregivers. Families and the care team can contact the program directly (without a referral).	X	X	X	X	X	X	X	X			

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New Brunswick (NB) (continued)	Integrated Service Delivery (ISD)	Aims to improve coordination among departments (for patients considered to be “at risk” or with complex conditions). Designed to focus directly on providing services and programs to 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.	X	X	X	X		X			X		

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Nova Scotia (NS)	SchoolsPlus	Integrated service delivery model (not a program). Works with key government departments and agencies to create integrated service delivery and provide wraparound supports. Schools serve as a hub, promoting colocation of services directly in schools; existing services can expand and collaboration can happen. Offers and promotes an array of programs and services at school sites, including mentoring programs, homework clubs, health services (mental health clinicians, youth health coordinators, pediatricians), parenting support, youth groups and community policing.	X	X		X	X		X		X		

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Prince Edward Island (PEI)	BestStart	A voluntary in-home visiting program supported by the Department of Education, Early Learning and Culture and Health PEI. Identifies and provides services to families who face challenges and can benefit from additional support. Comprises two components: public health nurses screen all newborns and their families across the island within two weeks of their birth; and BestStart workers support families that are eligible.	X	x								Assumed	Assumed

The template was completed with the limited data publicly available. Some inferences were made. Absence of marks should not be assumed as absence of that characteristic in programs.

*: x = emotional development and well-being; X = mental health and/or emotional health.

** Mainly social workers.

TABLE 3. Excerpts and segments per sub-theme

Themes and sub-themes	Excerpts from the program data	Segments from the deliberative discussion
1: Program philosophy		
1.1 Engagement	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).	"They [programs] all seemed to have this focus (e.g., patient/family engagement). But they didn't necessarily have the data/evidence to support that this vision was achieved." "I think patient engagement (not only patient focus) is important". "Patient engagement in both design and focus; patient engagement, yes, in shared care, which is important, but not well defined from a planning [perspective]".
1.2 Prevention and early intervention	The program promotes upstream approaches and early intervention services to facilitate positive childhood development (New Brunswick-Integrated Service Delivery [NB-ISD]).	"We need to think more about programs that promote promotion and prevention. Some were missing from our selection (e.g., Agir tôt/QC; Kids First Program/SK." "Some programs appear to think outside the box in terms of services and professions – integrating with bus drivers, for example".
1.3 Local flexibility and adaptation	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]).	"A couple of programs described adapting program to context. It's important because most provide in urban setting vs. rural".
1.4 Primary continuity	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]).	"Some programs are not directly connected to primary care, community services/organizations. I also find it interesting that there were a few education programs and [they] did not have the connection to primary care."

Themes and sub-themes	Excerpts from the program data	Segments from the deliberative discussion
1.5 Incentives for providers	[There is] capitation, as well as specific financial incentives for enrolling patients (ON-FHTs).	"I think the financial incentive aspect was notable, especially as it often involved physicians; but this information was not as complete across all programs. Perhaps it was more important in the primary care models but less so when the ISD model focused more on other sectors".
1.6 Sub-population stratification	[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).	"The transition period seems important. There is anxiety around the transition period from a patient perspective: 'What would happen during that time?' There [are] worries about loss of services."
2: Governance		
2.1 Governance structure	Shared governance, or presence of mechanisms for shared accountability. Institutional or governmental-based accountability mechanisms (AB-Regional Collaborative Service Delivery-[RCSD]; NB-NaviCare). Formal agreements between professional organizations (e.g., AB-PCN).	"We need clear governance structures, particularly across sectors [of programs]. These are not mentioned; not part of the data available. Good integration requires good governance structure. It's also not clearly defined. It's challenging to work across sectors".
2.2 Shared decision-making processes	Throughout the initial appointment and subsequent interactions, the patient and their family are involved in shared decision making. The codification of [the] Community Social Pediatric Centres (CSPC) document extensively outlines the role of the child and the family in coming up with an action plan in collaboration with the professionals (QC-Community Social Pediatric Centres-[CSPC]).	"We need more patient and family involvement, in shared decision-making processes. These are not well described." "Reading about so many services that are integrated, I was nevertheless left with a sense that I wish the patient's family physicians were more integrated with these other services. Some already are, but for those programs/models not integrated with family practice, I wonder why that is."

Themes and sub-themes	Excerpts from the program data	Segments from the deliberative discussion
2.3 Standardized processes	The ON TRAC Transition Clinical Practice Guideline provides guidelines on roles and care coordination. Online modules and resources were developed to promote this standardized care protocol (BC-ON TRAC). To ensure a standardized delivery of care across all CSPCs, each CSPC adheres to a certification process developed by the Dr. Julien Foundation and the Bureau de normalisation du Québec (QC-CSPC).	"Seeing those programs, I would say that we need to move from interprofessional collaboration towards having services integrated, with shared agreements, organizational integration, formal integration".
2.4 Definition of multi-service integration	[Not seen in the data]	"None of the programs presented a clear conceptualization of integration. There is a lack of an integration approach between or with services [in] primary healthcare." "Some programs mention social needs, but there don't seem to be clear agreements".
3: Engagement		
3.1 Patients and family members	Person and family engagement has been paramount throughout the stages of planning for SSCY. SSCY currently has a Family Advisory Council that helps to inform the direction of current and future priorities of the Centre (MB-SSCY). There is an online feedback form on the BC Children's Hospital (BCCH) website for the ON TRAC program (BC-ON TRAC).	"The role of patients and families in shared decision making differs between sites. It's the focus of some programs, but it's limited [by the limited data]." "Patient advisory panel helps keep program/model of care on track. It's a reminder of "why we're there". This was missing in many [narratives]."
3.2 Providers	Only four programs explicitly stated engaging providers and professionals and provided methods used to engage them (AB-RCSD; BC-ON TRAC; QC-Programme d'aide personnelle, familiale et communautaire-[PAPFC]; NB-NaviCare).	"Providers could tell you what's going up." "If a program (or model of care) has been operating for 5+ years, it is time to evaluate".

Themes and sub-themes	Excerpts from the program data	Segments from the deliberative discussion
3.3 Local organizations	The program was well received by the public; this is due, in part, to a needs assessment (i.e., series of early learning and childcare consultations) conducted with parents by the Government of New Brunswick in 2007 (NB-ISD).	"There is limited uptake [of programs]. People could be aware and not using, or people not aware of programs. It could be that the program is not used by patients because it is not useful".
3.4 Equity, diversity and inclusion	[Not present in the program data]	"The cultural component (Indigenous especially) is not obviously present; the needs of Indigenous children and youth needs. A Manitoba program specifically mentioned the Jordan's principle as key, but this is missing from many programs."
4: Infrastructure		
4.1 Care coordinator or case manager or patient navigator	Little to no information was found on the formal goals of the FHT program. However, common themes of implicit goals include improving access and quality of primary care, improving chronic disease management, increasing health promotion and disease prevention, interdisciplinary teamwork, patient engagement and integration and coordination of care (ON-FHTs).	"Service navigation for children/youth with complex needs is certainly a trend. What I noted is the coordination of care for throughout transition. Another trend noted is the navigation through health, social and education services. Another trend – across service sectors."
4.2 Colocation of services	SchoolsPlus emphasizes colocation with delivery in schools where children spend a large amount of their time. Colocation is also highlighted as helping providers to learn from and about other providers and services and in working together, thus supporting the realization of a more holistic and ecological approach to health (e.g., MB-SSCY, NB-SchoolsPlus).	"Colocation seems to strengthen to integration; but it may not always be possible in some settings, such as rural settings, or with telehealth. We need to think creatively. Colocation can also be expensive. The technology is key; to use the technology to create virtual teams, especially for rural contexts."
4.3 Data-sharing processes or structures	[I]ncludes monitoring and exchanging patient data and sharing skills and knowledge (BC-ON TRAC). [T]he electronic medical record was in place and piloted by one agency, later with successive partners added both before and following the physical move. Electronic information systems (i.e., electronic medical records) are shared across all SSCY organizations (MB-SSCY).	"Generally there were no good ways of sharing information across, no shared record".

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4.4 Evaluation and monitoring processes	No information could be found on a formal evaluation of the program, except for two annual reports used for our data collection. These annual reports identified challenges, successes, and strategic actions (AB-RCSD). No information was found on any evaluations of the ON TRAC program, apart from a study to psychometrically validate the ON TRAC Youth Readiness tool (BC-ON TRAC).	“There was very little information on evaluation feedback around negative findings or lessons learned. The more likely case is that the programs that organizations wanted to present were only going to provide positive outcomes.”
4.5 Financial resources	The ON TRAC project received piecemeal funding from a variety of sources, including the BCCH and the BC Medical Association (BCMA) Shared Care and Specialist Services Committee. This funding mainly went to developing new tools and ensuring these tools, especially those for youth and their families, were available online. (...) No further information found. It is unclear if the program is still running (BC-ON TRAC).	“An important weakness of programs regards the limited access or lack of funding they face (we also report a lack of readily available information regarding this aspect).”