A Report of the Task Force on a
Centre of Excellence for Children and Youth
with Complex Needs

Bernard Richard
and
Shirley Smallwood
Task Force Co-Chairs

**Staying Connected:**
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**for Children and Youth with Complex Needs**

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# Staying Connected

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*It is the glory and the greatness of our tradition*
*To speak for those who have no voice,*
*To remember those who are forgotten.*

-John F. Kennedy

*Home is the place where, when you have to go there,*
*They have to take you in.*

-Robert Frost*, The Death of the Hired Man*

*The family is the natural and fundamental group unit of society and is entitled to protection.*

Article 16 – Universal Declaration of Human Rights
Article 23 – International Covenant of Civil and Political Rights

# Part I: Background

Families, for all their faults and foibles, are the people to whom we turn most frequently in times of need. Family members, especially parents and siblings, have a great capacity to give and love unconditionally. When our child, parent, brother or sister needs us, we'll often place ourselves in harm's way and do whatever it takes, regardless of costs, in order to support them.

When the State steps temporarily into the role of the family, as at times it must, it has the same goals as most parents: to be a good provider. However, the State cannot be an ideal parent; it acts not out of parental attachment or obligation, but in accordance with the law. While the law may impose fiduciary obligations upon the State, sometimes referring to the standard of a prudent administrator as that of a "Good Father," the law also places limits on the State: financial, legal and administrative. Therefore, despite the best of intentions, State services are usually a very poor surrogate for Mom or Dad.

Families are the basic building blocks of our society and the State must strive to support, nurture and protect them. When families are challenged by adversity, be it illness, poverty, violence, addictions or any other stress that fate may devise, they often need State supports.

However, all too often when dealing with children and youth[1], our approach in Canada has been for the State to step in and take over the parental role. In order to avoid perceived risks to a child, we apprehend them and place them in another's care. Often parents consent to these guardianship arrangements only in order to access services for their children. In some New Brunswick communities, the rate of placement outside the parental home is so high we have run out of safe alternatives within the community. At other times, when there is no basis whatsoever to take a youth into protective care, the youth may continue to tax his or her family and the mental health systems beyond their means until the youth commits some harm to themselves or someone else; he or she is then passed on to the criminal courts. These approaches have done little to build sustainable parental capacity, make our streets safer or help our children heal. They are contrary to the spirit of universal human rights norms and of our youth criminal justice laws, they harm and very often sever parental ties without rational justification and, what is more, they are financially unsustainable.

In fact, the interventions offered to children and youth with complex needs, in an age of deinstitutionalization and interventionist risk-based child protection services, are completely inadequate. We deprive youth of stable relationships, exacerbating their precarious health status, and yet fail to provide them with adequate or secure residential services or clinical supports. Too many youth are sent to jail as a place of safety when in fact they need clinical, educational and mental health supports. Exceptionally, a handful of children and youth have managed to obtain necessary residential and clinical supports outside of the province, but often at exorbitant public expense. In addition to the costs, expatriating children and youth outside the province may also have the negative effect of severing the child or youth from the positive relationships they have in their community. In any case, many other children are left without any comparable services. Parents of children and youth with complex needs live with the constant fear of not knowing who, if anyone, will care for their children and keep them safe when they are gone.

In July 2010, we were given a unique mandate to co-chair a provincial consultation process that would allow citizens (namely children, youth, parents, professionals and stakeholders) to help us define how a Centre of Excellence for Children and Youth with Complex Needs could help change this dynamic for New Brunswick families. We were asked to focus on what services the Centre should provide, what services should be accessible in communities across the province to support the work of the Centre, where the Centre should be located and how it should be

[1] Throughout this report we use the terms *children* and *youth* interchangeably. The *Family Services Act* defines a child as a person, including an unborn child, up to 19 years of age. Child welfare practice often distinguishes between children (under 12) and youth (aged 12 to 18 years).

governed. The consultation process has convinced us that such a Centre of Excellence will only succeed in its mission if conceived of as a part, albeit an important part, of a broader process of service delivery change. This change, which has already begun to occur in New Brunswick and which the Centre can help sustain, is a change towards child- and family-centric services; it is a move away from risk-based interventions towards relationship-based interventions. It is also evident in a change in philosophy, one which places less reliance on “doing for” approaches and tries instead to see what we can “do with” families in need. This approach places the child at the centre of family life and families at the heart of the solution. It recognizes that many public and private partners are involved and must work in an integrated, interdisciplinary fashion to support children and youth, particularly those with complex needs, by working with their families or therapeutic foster parents.

This approach is already evident in many programs and services recently announced by the Government of New Brunswick or which are now in the process of being developed. For families with children and youth with complex needs, the Centre of Excellence will provide much needed supports and peace of mind. We envision a Centre of Excellence which operates throughout the province through outreach at the family and local levels in both official languages, while offering step-up and step-down residential services in secure community-based settings. The Centre would monitor leading-edge research and make it available to New Brunswick families to offer children and youth here the benefit of the world’s best approaches and interventions. We believe the Centre should work in close collaboration with medical and university researchers here and across the country in order to attract to it the best minds and caregivers. Rather than expatriating our children for services in other provinces and even other countries, we believe that trained expert interveners could offer more services to our children at lower costs here at home. The Centre could capitalize on these investments by providing services to similarly situated families in the Atlantic region.

We see the Centre playing a crucial role in educating families and caregivers and developing tools and practices for information sharing and integrated service delivery. One of the Centre’s roles will be to deliver training for parents, caregivers and professionals in the school, government and community who are involved with the child or youth so that everyone involved in the young person’s life is provided with the tools to sustain the successes of the Centre’s interventions. Finally, we believe the Centre will achieve excellence through its early commitment to performance measurement and empirically-based programs and interventions.

Children and youth with complex needs are not necessarily complex. The complexity lies in coordinating all the services that have to adapt to the demands and needs of children and youth with behaviours that fall well outside the norm.  Normalizing our interventions with

these children and youth and providing their parents and caregivers with lots of training and support will often prove more effective and less costly than removing children from their environments and the relationships they know. Looking to extended family members for support and being more self-reliant may also be in order, keeping in mind that there must be other safe placements available, whether momentarily or for longer periods, when these family supports become exhausted. The government, for its part, has to invest more effectively as a partner of children and youth with complex needs and their families. If we commit as a society to seeing this change through, not only will children and youth with the greatest needs and their families benefit immensely, but all New Brunswickers will as well, as we will achieve a more equal and just society.

* * *

The following report sets out several key recommendations for the government to guide it in the establishment of the Centre of Excellence for Children and Youth with Complex Needs. It seeks to give voice to the many recommendations we heard from New Brunswickers of all stripes and to make sense of them in the context of the changes that are already afoot in our province.

While the responsibility for the recommendations set out below is ours alone as Co-Chairs of this Task Force, we are grateful for the advice and feedback received from many quarters and for the research and logistical support from the Office of the Child and Youth Advocate and from the New Brunswick Health Council. We also wish to express particular thanks to Dr. Simon Davidson, Dr. Tara Kennedy and Dr. Jacques Richard, who assisted our process as Advisory Committee members.

Our consultation process was designed in late August and early September 2010. With the support of the Departments of Health, Education, Public Safety and Social Development (which established our Task Force), we retained the services of Ascentum Consulting to help us design and deliver an important public consultation process. Our terms of reference limited us to the following four questions:

1) What services should be available at the Centre of Excellence?
2) What services should the Centre of Excellence support in other communities?
3) Where should the Centre of Excellence be located?
4) How should the Centre of Excellence be governed?

Many responses to these questions were received from public and private sector agencies and from individuals and families around the province. Some responded using an online choicebook that was posted on our consultation website between October 27$^{th}$ and November 24$^{th}$, 2010. Others participated in person at the provincial dialogue session that was held in Fredericton on

November 5th and 6th, 2010. Ascentum's report on the online choicebook responses and the provincial dialogue session is included as Appendix III. We also met individually with many other stakeholders throughout the fall and welcomed in particular the opportunity to hear directly from children and youth in various care settings and from their family members and caregivers. Finally, once our initial recommendations were mapped out, we asked staff at the Office of the Child and Youth Advocate to review them using a Child Impact Assessment tool to ensure that children's rights in our province would not be unfavourably impacted but could be materially advanced through the changes recommended. The Child Impact Assessment Report is included as Appendix II.

The recommendations outlined below are grouped in sections related to the four main aspects of our mandate. Before we turn to the recommendations themselves, we offer some brief contextual analysis: 1) A historical overview of the treatment of children and youth with complex needs in New Brunswick; 2) An explanation of how the idea for the Centre of Excellence came about; 3) A description of how the province is in the midst of an important paradigm shift of which the Centre of Excellence can form part; and 4) A review of our duties to children and the rights we have guaranteed them under the *United Nations Convention on the Rights of the Child*.

## 1. A Brief History of Treating Children and Youth with Complex Needs in New Brunswick

Until the late 1970s and early 1980s, New Brunswick's approach to the treatment of children and youth with complex needs was premised essentially on institutional care, primarily at the Dr. W. F. Roberts Hospital School in Saint John, but in other institutions as well. New Brunswick then embarked upon a fairly radical and forward-thinking program of deinstitutionalization and moved instead towards community-based care for developmentally challenged and behaviourally disordered children. Subsequently, the Dr. W.F. Roberts Hospital School and smaller institutions like it around the province were closed. This trend was reflected also in educational services with the move away from auxiliary classrooms to inclusive educational programs and eventually in correctional services as well, with a marked drop in reliance on closed custody sentencing.

The reasons for this are well-researched and amply justified by the literature. As one expert told us, "Prisons and residential institutions… are bad for kids and youth and to put young people in residential facilities, be they correctional or other, is quite simply to retard the resident's development, worsen their prognosis and improve their chances of becoming life-

long delinquents."[2] Despite the best program interventions in institutional settings, the peer-to-peer influences involved in aggregating several youth with complex needs in one residential setting proved to have negative impacts. New Brunswick's move was and continues to be regarded across Canada as a progressive best practice. The challenge, however, is that 30 years later, there is mounting evidence that while most developmentally challenged children and youth benefited greatly from community-based programming, a small number of children and youth with severe behavior disorders fared less well.

Over this same period, there has been a significant rise in the number of youth diagnosed with certain mental health disorders, such as Autism Spectrum Disorders, and a corresponding rise in those with co-morbid diagnoses who fail to cope despite the attempts of their families and multiple systems (educational, social, clinical and correctional). The children and youth with complex needs in New Brunswick often find their way back into institutional care, either at the Restigouche Hospital Center, the New Brunswick Youth Centre (NBYC) or in smaller specialized institutional settings in the province or outside our borders, often at significant costs to the province. These institutions are often not designed to meet the needs of youth with mental health issues and this only exacerbates the risks to their already precarious conditions. The reality is, however, that our community-based programs have also struggled to meet the needs of families with children and youth with very complex needs due to the lack of coordination between the programs and services that are offered. People in New Brunswick – families and service providers alike – are not aware of what is available, and there is no sharing of information between the various service providers necessary for effective collaboration. As the first generation of these children and youth are nearing midlife, the result of this incongruity is a large and potentially costly upswing in the number of youth requiring acute care interventions which are increasingly beyond the scope of our systems of care.

In 2006, the province reported that there were 78 children and youth in care with cost plans of more than $6,000 per month: a total yearly cost of $9.5 million. By January 2008, the number of such cases had risen to 117, with annualized costs of over $16 million. In 2010, seven cases alone accounted for over $3 million dollars in expenditure by the Departments of Social Development, Health, Education and Public Safety. Unfortunately, despite these rising costs, there are no standardized outcome measures to suggest we are investing effectively or even to permit the forecasting of future needs.

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[2] Dr. Charles Emmrys: "The Residential Care of Aggressive and Antisocial Children and Youth: A Plea to the Government of New Brunswick to Stop Using Residential Programs for Children and Youth that are Proven Not to Work" - Presentation to the N. B. Mental Health Commission, January 2009 and re-submitted to the Task Force Co-Chairs, July 2010.

Our consultation process was premised upon two certainties of which we have become even more convinced: 1) the status quo is failing the children with the most complex needs and is fiscally irresponsible; and 2) these children currently need more residential options but any move towards re-institutionalization of any kind would be detrimental and must be resisted.

## 2. Why a Centre of Excellence?

The recommendation to establish a Centre of Excellence for Youth with Complex Needs stems from a 2008 report by the Ombudsman and Child and Youth Advocate: *Connecting the Dots: A report on the condition of youth-at-risk and youth with very complex needs in New Brunswick.* This broad-ranging report outlined 48 recommendations to government in order to improve services to children and youth with complex needs. The report followed a lengthy investigation into the services offered to seven young New Brunswickers who were at the time at the very apex of the needs pyramid for youth in the province. The report's investigators visited three of these clients at the Spurwink Services treatment facility in Portland, Maine. One of the central recommendations in the report called for the establishment of a Centre of Excellence, based in part on the experiences of the Spurwink program. The passage from the report outlining the recommendation stated as follows:

> *14. A provincial centre of excellence for youths with highly complex needs*
> Gabriel, William and Jacob[3] are all receiving excellent service in an integrated community-based setting that is allowing them to make significant progress in their respective treatment plans. Each is placed in a home in a residential urban or rural setting with a staff model of care; each is the only resident of the home. Through Spurwink, they have access to specialized schools, to community-based work programs, to psychological, psychiatric, medical, dental and occupational therapy services, all of which are integrated and coordinated through program directors responsible for their care. Because Spurwink is an established treatment centre in the Portland, Maine, area, with nearly 50 years' experience of service to mental health clients, community-based services are well acquainted with the needs of such youth. Because most of the facility's residential-based programs are run out of homes in the Portland area, there is a critical mass of needs in this community that supports the establishment of specialized professional services.
>
> In a province the size of New Brunswick, it is not possible to roll out specialized educational, health and social services to all communities in the province. I recommend establishing a provincial centre of excellence for youth with highly complex needs. This centre of excellence could be located in a New Brunswick community and mandated to

[3] Gabriel, William and Jacob are pseudonyms used to mask the identities of the youth and families whose stories were told in the Advocate's report.

> recruit and retain expert services in child and adolescent psychiatry, developmental psychology, audiology, speech pathology and other support services in matters of child welfare. While it is important that this provincial centre of excellence be geographically accessible, and its services available to New Brunswick residents in both official languages, proposals for its location should come from interested communities themselves, and the final choice should be based in part on the basis of a demonstrated ability to integrate services to youth across a broad range of community-based interventions.

A few New Brunswick youth are still in Spurwink. The Human Rights Commission has since moved William's complaint to a Board of Inquiry to determine whether he should receive treatment nearer to his family in New Brunswick or whether his family could be compensated for the cost of travelling to visit him in Portland. The Province, however, argued successfully in the Court of Queen's Bench and then in the Court of Appeal that the case should not be heard. In February 2011, the Supreme Court of Canada refused the Commission's application for leave to appeal. The issues, of course, are mere points of law, relating to the definition of services under the Human Rights Code and what constitutes an appropriate comparator group within the meaning of Canadian Human Rights Law in a novel discrimination complaint like his.

It may not matter that the Court refused to hear the case. The legal issues mean very little to William or his family. His parents want what is best for William but would also very much like to have him nearer to home. In fact, the parents' view has always been that being nearer to home *would* be what is best for William. All the medical experts consulted over the past ten years share this opinion as well. William is a strong young man in his late twenties but is developmentally still a toddler with little to no language skills. However, those who have worked with him have a sense that William *knows* that he ought to be home, near his family. Despite the broad consensus on this point, William continues to receive services six hours away from his home across an international border separated from his family. He receives treatment at the cost of several millions of dollars to provincial taxpayers (without counting the legal fees and other administrative costs expended over the years by numerous public agencies). Recourse to our highest courts suggests that this is all perfectly sound. The judiciary has deftly lobbed this difficult ball squarely back into the court of our elected officials.

We need a Centre of Excellence in New Brunswick because families like William's currently have no options. We need services available to families like William's not in another country but here at home. We should not be training the best caregivers available so that they can be hired by institutions across the border and have their services charged back to our public purse. We need instead to retain our experts and build capacity at home by providing more direct and

timely interventions at the family level before emotional and behavioural issues escalate and spiral out of control. We need a place like Spurwink or something better that can direct interventions to the children with the greatest needs, so that we give them the best opportunity possible to lead happy and rewarding lives. It is cases like these that test the moral fibre of our society.

People in New Brunswick feel very strongly about this issue. In October 2010, we sent out invitations for a provincial dialogue session with only a few weeks' notice and filled the hall. Those attending had already organized themselves prior to the event through Facebook, e-mail and the media. Within a month from our event, they had increased their numbers tenfold and had convinced over 1,200 supporters from every walk of life to march through downtown Fredericton to deliver boxes of letters calling on government to establish this Centre of Excellence. The grassroots movement that was created to support the establishment of the Centre of Excellence is called DOTS NB, which stands for "Delivery of Treatment Services for children and youth's mental health in New Brunswick." As co-chairs of this Task Force, we were strongly impressed by the groundswell of public opinion we have heard in favour of the Centre. In our professional lives, we have both had many opportunities to observe public engagement processes up close and to direct and monitor them, and rarely have we seen any issue galvanize the public as strongly as this one has.

**On December 6, 2010, more than 1,200 New Brunswickers formed a line from the Victoria Health Centre to the Provincial Legislative Building in Fredericton to show their support for the establishment of a Centre of Excellence for Children and Youth with Complex Needs.**

In our view, this is a strong attestation to the fact that mental health services have been the orphan of Health Care for far too long and that child and adolescent mental health services have been the "orphan of that orphan." New Brunswickers want their government to put an end to this state of affairs - now. They don't want any more drawn out legal battles. They don't want a system that greases the squeaky wheels, throwing good money after bad, and leaving other children wanting. They want meaningful and sustained reform in our delivery of child and adolescent mental health services. And so do we.

In the three years since the *Connecting the Dots* report was released, the thinking about the Centre of Excellence and its operations and mandate has evolved significantly, but the need has not at all abated; in fact, it has become more urgent. The Centre of Excellence would be an independent monitoring agency on the progress of our most needy youth. Its independence would be guaranteed by an arm's length relationship with government, by a secure funding base, by institutional expertise and by the involvement in its governance of experts, business leaders and community representatives, including youth and former youth clients of the Centre's services. The Centre would of necessity maintain a close working relationship with Canadian academic and other national research centres in this area. In its day-to-day operations, the Centre would be responsible for coordinating services to children and youth with the most complex needs in the province. It could also dispense certain services to youth with complex needs from other parts of the country.

## 3. The Shift towards Integrated Child and Family Centric Services

New Brunswick is in the midst of a very powerful and positive paradigm shift. This shift constitutes a move from rigid rules, silo management and service delivery and a focus on reactionary, crisis-driven intervention to an interdisciplinary, collaborative, child-centric approach that focuses on outcomes, the provision of preventative interventions and services that are premised upon youth, family and community engagement.

Our view as Task Force Co-Chairs is that the Centre of Excellence has to lead this change as an independent expert dedicated to improving the lives of youth with complex needs. The Centre cannot, of course, carry out or deliver all the programs, services and initiatives that will help make this change possible. Four of the largest public sector departments are already heavily involved in this change process and they will continue to deliver on it. But the Centre of Excellence can be a centre of expertise to which the most problematic cases in our province and from around the region are referred for diagnosis and treatment. It can also be the expert centre that will provide guidance and advice to policy-makers on how to improve services based on leading practices and outcome measures.

All of the experts that we have consulted have been clear on the fact that overly intrusive interventions with children with complex needs can be just as damaging as a lack of intervention. We have also observed that early intervention, preventive and interdisciplinary approaches, particularly those which are family- and relationship-based, are far and away the most effective and the most economical.

In order to properly understand the context in which our recommendations are framed, we have to define more clearly the change process that we have already observed, and understand how the Centre of Excellence can help sustain these change processes. We also have to redefine in some ways how it is that we should best intervene with families and where to best situate them in all public services delivered to children. We have only a skeletal list of the numerous public programs and policies which impact families and services to children. Within that list, however, we have identified a number of promising initiatives based on leading practices, which we note here and some of which we further define below so that our recommendations can be read in context.

- Integrated Service Delivery;
- The Centre of Excellence for Children and Youth with Complex Needs;
- Family Enhancement Services;
- Family Group Conferencing;
- Youth Engagement Networks;
- Community Inclusions Networks;
- The NB Economic and Social Inclusion Plan;
- Community Schools in the Department of Education;
- Increased emphasis on early education;
- Patient portals, telehealth and electronic health records;
- Increased participation of provincial services in First Nations communities; and
- Community Youth Justice Committees

**Integrated Service Delivery (ISD)**

In 2009, the Government of New Brunswick committed to providing better services and programs for at-risk children and youth. The result of this commitment is a new strategy that enables departments to better work together to meet the needs of children and youth at risk. This approach is called the Integrated Service Delivery (ISD) Framework, and it intends to link all of the initiatives mentioned in the above list together in order to meet the needs of children, youth and their families in a more preventative, strengths-based collaborative approach and to keep children and youth within their families, schools and communities as much as possible.

The strategy was created in response to the Ombudsman and Child and Youth Advocate's recommendations as outlined in the reports *Connecting the Dots* and *The Ashley Smith Report;* the Department of Education's *MacKay Report;* and the Department of Health's *McKee Report*. All four reports clearly identified a strong need for better coordination among departments to increase support to children and youth with multiple needs.

The main goal of this strategy is to provide seamless services and programs for children, youth and their families. It is anticipated that this strategy will:

- Improve services and programs for at-risk children and youth. This also includes those who have complex behavioural, emotional, mental health, education and physical health/well-being needs. These needs are often the result of unsafe/unstable social circumstances such as homelessness, poverty, delinquency and fragile family relationships.

- Provide prevention and early intervention services, which are designed to promote positive conditions for a child's healthy development and to prevent the development of child abuse, emotional and behavioural problems, substance abuse and criminal behaviour.

- Provide relevant and timely services and programs to meet the needs of children and youth between the ages of 5 to 18 (and up to age 21 for those within the education system). This would include connections for early childhood intervention for the 0-5 age group and those making the transition to adult services.

- Establish an early care system with a clinical team that is focused on direct interventions within the school, community and family contexts.

- Make an inventory of regional and community-based programs and services available to families, youth and service providers.

In June 2010, the government selected two regional demonstration sites within New Brunswick: School Districts 9 and 10. The demonstration sites have been staffed, are expected to be operational later this spring and are in the initial phase of a provincial implementation plan. This staged implementation will allow assessment and adjustments to the program based on the experiences at the demonstration sites and help ensure a successful provincial rollout.

The core response to many of the parental concerns that we heard throughout our consultation process will be addressed through Integrated Service Delivery. A Centre of Excellence in and of itself is not the answer. However, the ISD Framework is still not well known and its change process, which is a cultural and strategic one, is just beginning to unfold. In our view, this is a critical development for which the Centre of Excellence can become an important change champion and which holds more promise than any provincial social program in many years. For this reason, we have asked the program leads to share a fuller program description which is included in Appendix I.

**The Centre of Excellence for Children and Youth with Complex Needs**

The Centre of Excellence for Children and Youth with Complex Needs is closely tied to the ISD Framework, since it would be the capstone tertiary care centre for youth with the most complex needs in the province. However, both programs, in our view, should have a primary focus on building caring capacity at the family, school and community levels and helping youth and their families manage their health and behaviours as autonomously as possible. The public officials working on the ISD Framework and other service providers have almost unanimously insisted on the fact that the service interventions for children with complex needs are best understood as a pyramid, at the base of which most children and youth will find themselves. They will all benefit from universal public services such as pre-natal preparation courses, neo-natal screening, early childhood public health screening, universal kindergarten and public schooling. The ISD Framework and preventative intervention services are situated on the lower levels and are vital components of the process in order to ensure that children and youth step up and step down appropriately.

Some children, however, require specialized services and interventions to help them adapt to school and family situations. At other times, children with special needs and those who have experienced considerable trauma, or a combination of both, may require psychiatric assessment or treatment outside their parental home. A clear and integrated referral process will need to be developed in line with the ISD Framework in order to avoid over-dependence on the Centre and uncoordinated referrals.

Traditionally, the service pyramid has been represented with institutionalized interventions in psychiatric hospitals and youth correctional centres at the apex of the pyramid. Under the new model of care, the Centre of Excellence would be the top of the pyramid and children with the most complex needs in the province would no longer be sent to prisons or adult psychiatric facilities.

Most of the residential capacity at the Centre would be used for short-term care and training services for youth with complex needs and their families, using step-up expert interventions while in residential care as required and properly planning the young client's discharge with step-down services to ease their return to their family and community. The Centre would serve the dual purpose of ensuring that expert, safe and appropriate clinical resources are always available in New Brunswick to the youth who most need them, while at the same time ensuring that no dependency on institutional care is developed. Ultimately, the services available through the Centre should be as much about training, multi-disciplinary case-planning, in-home and extra-mural

supports, research, monitoring, and the sharing and implementation of best practices in the area of child and adolescent psychiatry, mental health and wellness.

**Family Enhancement Services**

One of the programs which best exemplifies the new focus on families and nurturing strength and resilience within the family context is the new direction for Family Enhancement Services (FES) within the Department of Social Development. These services offer collaborative approaches provided in conjunction with Social Development's Child Protection Program. FES is intended to engage the family, enhance family functioning, maintain the child's security and development, and support the family when a plan for the care of a child is developed and implemented. FES is especially useful when the youth is beyond the control of their parents or caregivers. For FES interventions to be successful, research suggests that these interventions will have to be carried out in an interdisciplinary context. The ISD Framework and the Centre of Excellence can help ensure that this is always the case for children with complex needs.

**Family Group Conferencing**

Similar to FES, Family Group Conferencing (FGC) is a family-centered decision-making process which brings together a family, extended family members, a social worker and other service providers to develop a plan to keep their child safe. It turns the old risk-based management approach on its head and requires child protection service providers to focus first on strengths and relationships rather than on risks. In its first year of application, the FGC model has met with great success in New Brunswick, leading to an 18% reduction in the number of children placed in care within the first year alone. This translates into millions of dollars in savings which, in our view, should be reinvested in improved mental health services for children in need. International experts in this field have pointed to New Brunswick's success with this family-centric program as a leading best practice in social work worldwide.

**Youth Engagement Networks**

The Department of Health's Addiction and Mental Health Services Unit is currently running a three-year youth engagement pilot project. Through this initiative, Youth Engagement Networks have been developed in communities across New Brunswick. Youth in various communities around the province are invited to take ownership of the challenges youth face in combating addictions and help devise solutions to be implemented by their communities. The New Brunswick Youth Strategy has also included youth engagement as one of the three pillars of the new provincial youth strategy debated at the Youth Summit in February 2011.

The Centre of Excellence will have to listen closely to the voices of youth as a condition of its success, not only in individual case interventions, but in its operational and governance policies as well.

**A Note Regarding First Nations Youth**
Special care must be taken to ensure cultural appropriateness when working with First Nations youth. Whereas provincial services have traditionally been more disengaged in First Nations child welfare than in other Canadian jurisdictions, this has now begun to change. The Departments of Social Development, Education, Health, Public Safety and others have taken notice, hired new staff and developed new programs to support First Nations child and family services in partnership with Band Councils and the federal government. Much more work still lies ahead on this front in New Brunswick, but the trends are encouraging.

**Patient Portals, Telehealth and Electronic Health Records**
During the consultation process, we were provided with a demonstration of the Stan Cassidy Centre's Telerehabilitation project. Using the repositories and system architecture of the province's Electronic Health Record, the Stan Cassidy Centre has developed a patient portal (a first of its kind in North America) which allows patients and their clinical team to interface electronically and gives patients greater access to their medical records. The web portal gives access to a specialized clinical library, allows clients to view and manage appointments and generally promotes greater control by patients over their health and rehabilitation process. It also allows various experts in the care team to consult on the patient's case more easily and at a distance, offering the prospect of significant savings and efficiencies in reducing wait times and improving client care. The Stan Cassidy Centre's director indicated that the technology holds great promise for children and youth with mental health challenges and their families and could easily be adapted for their use.

We were also impressed to note that the province currently has 22 locations equipped in its health regions for the practice of tele-psychiatry, allowing physicians and patients to consult remotely. While early adopters of the service note that patient consults at a distance are often just as effective as office visits, these new technologies are not used to their full potential. The combined usage of these innovative technologies could be especially crucial in New Brunswick due to our large rural population.

**Community Youth Justice Committees**
In the fall, we took part in a training session held at the RCMP's provincial headquarters in Fredericton, where RCMP, municipal police staff and many other stakeholders and community volunteers met to learn about the *Youth Criminal Justice Act* (YCJA) and the role of Community

Youth Justice Committees and conferencing processes in the administration of youth justice. Many tools are available, but currently unexploited, that are designed to increase the involvement of family and other stable relationships in a young person's life when they are charged or likely to be charged with a criminal offence. Using these provisions proactively, more youth, particularly those with significant mental health challenges, can be diverted from the traditional criminal justice process. A number of local committees have been established over the past year, often on the initiative of the RCMP Community Program Officers or of municipal police officers, to deal with youth crime at the policing and community level without a formal charge process.

The trend towards an appropriate public safety response, oriented to the young person's rehabilitation through timely and limited strengths-based interventions with youth and their families, is more in keeping with Parliament's intent in enacting the *YCJA* and is equally consistent with the other changes described above.

All in all, the programs reviewed show a compelling pattern of new supports to families and a willingness to help families and communities take more ownership and be more self-reliant in meeting the needs of children and youth, including those with the most complex needs.

## 4. Children with Complex Needs and the Rights of the Child

Since the change towards community-based delivery of services to children with complex needs in the late 1970s, the world has also witnessed a significant legal development with respect to the rights of the child with the adoption and ratification of the *United Nations Convention on the Rights of the Child*. Since the Convention came into force, Canada has submitted several reports to the UN Committee on the Rights of the Child regarding our implementation of these rights, but we tend to pay too little heed to the Committee's advice. As a result, children's rights at home, like elsewhere in the world, are quite often proclaimed but then quickly forgotten. The Committee has repeatedly insisted that signatory states to the Convention must establish national children's commissioners to enforce the convention and has urged states to use Child Impact Assessments (CIAs) to ensure that the Convention and children's rights are taken into consideration every time a major policy or legislative change affecting services to children is introduced.

For over a year now, the Child and Youth Advocate's Office has been consulting with the Attorney General's Office to help determine a process to use CIAs in the public policy-making process in New Brunswick. Ideally, these CIAs would accompany every relevant Memorandum to Executive Council where impacts on children's rights are anticipated. The Child and Youth Advocate's role in this process has not been determined, but CIAs could hopefully be filed and

periodically reviewed by the Office to ensure due diligence in the process. The CIA attached in Appendix II to this report was carried out by Child and Youth Advocate staff. This process is not ideal but it may serve as a proof of concept and has been instructive for us in formulating the recommendations below.

Many of the rights of the child guaranteed under the Convention come into play in relation to our recommendations. Article 3 sets out the "best interests of the child" standard as the basic criterion guiding all actions and decisions by courts, legislators, administrators and public or private social welfare institutions that impact children. Article 4 binds signatory states to undertake all appropriate measures to implement the rights guaranteed to children. Article 6 guarantees not only the right to life but also the State's obligation to support the child's survival and development to the maximum extent possible. The right to identity, including the right to one's family relations, is protected by Article 8. Article 12 sets out the child's right to be heard in all matters affecting his or her case. The provisions setting out the child's right in relation to information (17), adoption (21), health (24), social assistance (26), an adequate standard of living (27), education (28 & 29) and to minimum legal protection when charged with a criminal offence (40) also come into play in relation to the proposed mandate of the Centre of Excellence and these provisions also speak to the role of the family in ensuring the child's enjoyment of these rights. For ease of reference and context, the most salient provisions of the Convention related to our review are set out in Appendix II.

The kernel of the child's rights which concern us most is set out under Article 23 of the Convention, which states that "a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community." But many other provisions insist forcefully on the role of the child, family and extended family members. These principles influence the proper interpretation of all other rights guaranteed to children under the Convention. Keeping track of all these various rights and seeking to respect and advance their enforcement while achieving the gains sought is no small task. As policy makers and elected officials involved in decisions stemming from this report's recommendations undertake their work, they should keep the provisions of the *Convention on the Rights of the Child* squarely in mind.

# Part II – Recommendations

The mandate we received provided helpful direction to design a Centre of Excellence for Children and Youth with Complex Needs that would itself be a service centre but would also support service delivery throughout the province. We start, therefore, by looking at what services should be provided by the Centre of Excellence before turning to the question of what services, approaches and interventions the Centre could support in other communities. We then discuss a series of recommendations related to the location of the Centre of Excellence and its physical set-up before addressing matters related to governance, mission, finances and operations in the final section.

## 1. Services Available through the Centre of Excellence

Many New Brunswickers, especially children and youth with complex needs (along with their parents, friends and families) have many great expectations for the Centre of Excellence. While it can't be all things to all people, if viewed and understood as a facilitator for a complex array of programs and services, the Centre can achieve great things. Essentially, we think the Centre must focus on excellence in treatment services and research. The Centre, therefore, has a clinical vocation and a research vocation. Public education and training should be an important component in both aspects of the Centre's mandate. While we were not mandated to devise a strategic plan or suggest how the Centre will establish its priorities, we view a number of core services involved in carrying out the two main aspects of the Centre's work.

The tertiary-level treatment services provided by the Centre of Excellence would not be the "end all, be all" of mental health interventions; not all children and youth with complex needs will require these tertiary services, and even when they do, for most it will only be temporary in nature. Referrals may result from a need for acute crisis intervention, observation, diagnosis, evaluation, medication adjustments or court-ordered psychological evaluation. There needs to be clear integration, collaboration and linkages with other services currently available throughout the province to ensure that primary and secondary interventions are also employed when appropriate.

**Residential Capacity**

In our view, the Centre must provide some response to the situations that arise from week to week in the province when a youth in crisis, at risk of harming themselves or others, has no safe place to reside. Our goal, however, is to avoid any possibility that the Centre become a new institution. The Centre will have to manage increased residential capacity for these young people, but that capacity should be offered in the community in a setting which is safe and secure, yet as much like a home as possible. Step-up interventions would be available at the Centre with sufficient beds for diagnostic and acute care interventions, but the Centre would

also manage step-down interventions to community-based beds in localities around the province and the further step-down back into family and legal guardian settings. Thus, while the Centre would have the capacity to take in and treat children and youth with complex needs when they are in crisis, it would specialize in de-escalating these situations and normalizing interventions as quickly and as effectively as possible by working with families and community supports.

It came out very strongly at the provincial dialogue session that this residential capacity should not be located exclusively in one community but rather dispersed more widely in communities around the province and managed centrally through the Centre of Excellence. A nucleus of residential units could, however, be located in one community with sufficient capacity to provide diagnostic and treatment services. Experts have identified to us that co-locating up to six or eight youth with complex needs in any one treatment centre, even just for diagnostic purposes, is often impossible and inconsistent with best practices in clinical care. However, we were not able to determine the exact number of beds that would be required to meet the needs of youth with complex needs in our province today. Estimates range from 12 to over 70. Some have urged us to limit residential capacity, pointing to the "build it and they will come" risk which could place too many young people on the slippery slope of dependency on institutional care. Others have said that we should not plan to leave children in crisis without access to services or to continue relying on jails and criminal courts when youth with complex needs are acting out. On the whole, we believe that government still has to do some serious work ahead to determine the actual needs of youth with complex needs in our province, and must not cut corners in meeting those needs.

Rather than limiting the Centre's residential capacity out of the fear of institutionalizing children and youth with complex needs, we think the Centre must provide an approach that is inherently family- and community-based and that supports families rather than doing things for them. We propose a Centre of Excellence that is well-resourced in order to be able to do so. Thus, while the Centre of Excellence may, for instance, have a clinical capacity of 50 beds, 20 of these could be dispersed in communities around the province, 10 or 12 could be located in institutional care facilities associated with the Centre, and another 20 or so could be located around the community where the Centre is headquartered. All of these services should be understood as transitional step-up services and not as long-term care. All of the efforts dispensed through the Centre must be focused on the child's optimal development and with the goal of making him or her as ready as possible for independent living or to increase the quality of life with their family. The Centre would also operate in an extra-mural capacity and be actively involved in the young person's discharge plan, with step-down services to ensure positive connections to family, school and community.

**Diagnosis and Evaluation Services**

The Centre would play a central role in diagnosis and offer a comprehensive evaluation service that would help reduce the wait times parents have been faced with in accessing child and adolescent mental health diagnostic services (currently up to three years in some cases). In our view, there is no need for the province to "reinvent the wheel" in terms of diagnostic and evaluation services. The province already has expert tertiary level services for diagnosis and evaluation of Autism Spectrum Disorders, child and adolescent psychiatric disorders and other behaviour disorders common in youth. The Centre of Excellence should be established with the necessary budgets and authority to manage and coordinate an array of diagnostic services already available (for instance, services available through the Stan Cassidy Centre, the Pierre Caissie Centre and the Child and Adolescent Psychiatric Unit at the Moncton Hospital). These services must be dispensed with equal access and benefit to all health regions and for both official language communities in the province. Access to diagnostic services would be based on referrals from the Regional Advisory Committee responsible for Child and Youth Development Teams under the ISD Framework[4]. In our view, evaluation services would include returning youth post-diagnosis whenever their care plan was significantly disrupted or unsuccessful, providing a new period of observation, step-up intervention or assessment when required to stabilize the young person, adjusting medications and providing whatever step-up interventions are deemed necessary.

The Centre of Excellence should be designated as a hospital under the *Criminal Code* and the *Youth Criminal Justice Act* to provide clinical evaluation and assessment services for youth facing criminal charges and subject to court-ordered evaluations. The Centre should also work with the Attorney General's Office, local Community Youth Justice Committees and Child and Youth Development Teams to ensure that court-ordered evaluations happen only when necessary for criminal justice processes and that youth with mental health conditions which explain or impact their criminal behavior are diverted from the criminal justice process in all appropriate cases at as early a stage as possible. Too often, youth in court are sent for assessment when recent assessments are available. The Centre of Excellence should be able to offer direction to the court as to whether further assessment is necessary or beneficial, or whether a conference with local Child and Youth Development Team members and court staff could instead determine a more appropriate intervention or case plan.

**Wrap-around Discharge and Reintegration Services**

The post-discharge case planning, treatment and support services that the Centre could support will be the most critical element in improving the situation that families face today. All too often, children are seen at the Child and Adolescent Psychiatric Unit in Moncton for

[4] See fuller description of the ISD Framework in Appendix I.

observation and diagnosis, but there are insufficient resources to ensure treatment after discharge or a smooth transition back to family life. Residents at NBYC, the Portage drug addiction facility or other treatment centres often experience the same lack of resources and supports at this stage. Working with the youth and their family before and after a step-up intervention in a residential services facility will be critically important. There should be a collaborative case management process between the professional team at the Center and the Child and Youth Development Team in order to ensure a smooth transition back into the family, school and community upon discharge. We expect that the vast majority of clients being followed by the Centre of Excellence at any one time will be living with their families and coping well. The step-up residential interventions will be a critical element of the service offering but will be an exceptional one and as brief as possible.

However, there should be no fixed time limit on the period of stay available at the Centre and no firm limit on the age of residents or clients. As a youth service facility, the Centre will obviously seek to reunite youth and their families as soon as possible and young people 19 years and under will have a clear priority in access to the Centre's services. The client's needs will be the main factor in the triage of cases. At the same time, the Centre should also take a life-cycle approach to the interventions, services and programs it offers to youth and their families. The Centre can work from the earliest ages with the families of children with complex needs and assist them in developing comprehensive plans to provide for their child's well-being today, tomorrow and even after their parents are gone or can no longer care for them. Some children will always be entirely dependent on their parents' care and these parents may need or benefit from the Centre's support and advice well past the child's chronological age of majority.

**Guidance and Counseling Services to Families**

Our consultation process revealed a lack of services and support structures to family members, especially parents and siblings of youth with complex needs. If we are really focused on helping a child understand and develop insight into a mental health condition, parents and siblings also need guidance and support in order to help their loved one. The Centre of Excellence will need the clinical capacity to intervene directly with families and to provide guidance and counseling services to parents, guardians and siblings. It must be able to do this on a regional and local basis.

**Information and Educational Services**

In our view, the Centre of Excellence will play a critical role in public education and information services. If child and adolescent mental health has been so chronically underfunded for so many years, it is because the public is not sufficiently informed about the risks and costs to our society of not investing more effectively in treatment and supports to these youth and their

families. An untreated or misunderstood mental health condition in one child can drag an entire family into a cycle of deteriorating health, while imposing serious financial implications and nixing that child's opportunity to lead a more productive life. The financial consequences to the child's family and to the province are very significant. Moreover, some families have no idea how to access mental health supports or services, or when to do so. For the families and friends of children and youth who have been recently diagnosed, there is a great need to educate and better inform them about specific health conditions and illnesses and how they can play a role in helping the youth.

Much of this work can be coordinated through the Centre's online resource library and in collaboration with schools, libraries, hospitals and other public education and information services. One of the major components of the ISD Framework is to have a complete inventory of programs and services available in the province so that parents, youth, professionals and caregivers are aware of the array of available services and how to access them as rapidly as possible. We also anticipate that the Centre will be actively involved in educational outreach, presenting frequently to diverse audiences around the province on child and adolescent mental health topics and bringing in experts from across the country and abroad to keep New Brunswick care-providers on the leading edge of therapeutic approaches. The Centre of Excellence would therefore become a champion for the implementation of provincial and national mental health strategies in relation to children and youth.

**Training and Professional Development**

The Centre of Excellence will be closely tied with universities and educational centres in the province and will work closely with them in training specialized intervention workers. Moreover, the Centre will play a lead role with its university partners in training specialized foster parents, personal care workers, social workers, nurses, educators and other professionals on how to intervene with youth with complex needs. The Centre will also advise the province and universities and colleges on the development and review of training programs and professional degree programs to keep them current and responsive to the needs of children and youth with complex needs. In many ways, the Social Policy Research Network has begun this work of connecting policy development with academic research. The Centre of Excellence will help ensure that these connections are made for the benefit of youth with complex needs and that our frontline services and practice standards are informed and kept current by the most up-to-date research.

**Research and Innovation**

The Centre of Excellence should be closely tied to the province's universities with endowed Research Chairs in several institutions. While new funding for the Centre's endowed Research Chairs would be critical to the success of the Centre's research and global mandate, care should

be taken to consult with existing university research chairs interested in the Centre's proposed work, to renew and consolidate these research efforts where appropriate and to establish collaborative networks.

In collaboration with the provincial Social Policy Research Network, these Research Chairs could assist the Centre of Excellence in keeping training programs current with the most successful and progressive trends worldwide, in helping keep children safe and thriving within their family settings, in keeping laws and regulatory approaches up-to-date, and in informing the Centre's policies and approaches based on experiences and successes in the field. The Centre would be expected to develop ongoing collaborations with other research centres in Canada and around the world and to be actively engaged in observation, monitoring and reporting on best practices. The Centre would be involved also in supporting professional and academic research, applied research efforts and the publication of research findings. It is expected that through these operations and activities, the Centre will be able to recruit and retain leading researchers from a broad cross-section of academic fields and clinical and professional practice groups related to child and adolescent health and wellness. The Centre of Excellence could, in this way, strive to meet a global standard and seek to be among the best in this area of research.

**One Child, One Record**

In consultation with the Electronic Health Initiative and other partners, the Centre of Excellence could help move forward the ISD Framework's goal of integrating information management and information sharing practices. The parents and family members of youth with complex needs who turn to the government for help should know and expect that the government will share their information across its agencies whenever the best interest of the child demands it, rather than forcing parents to re-explain themselves every time. Current confidentiality provisions and privacy laws prevent information flows between government agencies regarding services to children they are involved with as common clients. Rather than running the risk of having someone point to a privacy breach, we must currently work through cumbersome consent management protocols and forms which pose roadblocks to timely and meaningful collaborations in handling a health crisis. The laws need to change and the Centre of Excellence could help make that case.

Even within existing legislative frameworks, much work can be done to adapt existing technologies (such as the Stan Cassidy Centre's Telerehabilitation Portal) for use with child and adolescent mental health patients and their care-providers in schools, group homes, foster care homes, hospitals and custodial settings. It is currently all too frequent that a disconnect occurs when a child's file is passed from one department to another. Very often, youth with complex needs are no longer in school and are completely off the radar of educational services. The

Centre of Excellence can ensure that this disconnect no longer happens through the support of these leading-edge New Brunswick technologies.

**Monitoring and Evaluation**

A final critical element of the services provided by the Centre of Excellence would be to monitor, evaluate and provide recommendations to service providers on leading practices for educational, mental health, correctional, child welfare and child protection services to children and youth with complex needs in the province. The Centre of Excellence could partner in this task with both the provincial Child and Youth Advocate's Office and the New Brunswick Health Council, but as a specialized centre that operates at arm's length of government. The Centre of Excellence would be well positioned to help carry out peer reviews and clinical audits of service providers up and down the chain of intervention and ensure further quality control in the delivery of public services to children and youth with complex needs. The Centre of Excellence would also have the expertise required to monitor, measure and recommend programs and policies designed to help children with complex needs. Its mandate should reflect the goal of improving clinical practice throughout all of its efforts.

## 2. Community Services Supported by the Centre of Excellence

As mentioned previously, the mandate we were given and the questions we were asked to answer directed us to inquire into the type of services that a Centre of Excellence could support in communities around the province. This question gave rise to a provoking discussion at our provincial dialogue session last fall. Did the Centre of Excellence have to be a bricks and mortar institution in a given community? Why not a virtual centre? How could the Centre be as decentralized as possible in order to support children and youth where they live and where their families are? We were challenged by these questions. We have opted to recommend a middle way where some of the residential capacity managed by the Centre would be located in communities around the province, ideally, but not exclusively, in those with regional hospitals with staff psychiatrists. At the same time, we believe that the Centre's mission is first and foremost directed towards supports to families in communities throughout the province working in tandem with regional Child and Youth Development Teams under the ISD Framework. There are many ways in which the Centre will be able to support services locally. We touch on a few examples only after sketching very roughly the services which the Centre should be mandated to carry out or support at the local level.

**Clinical Supervision of Local Therapeutic Foster Homes and Residential Services**

One principal activity of the Centre at the local level will be to manage the residential services dispersed in communities around the province. These will preferably be therapeutic foster homes run by specialized foster parents and supported by the Centre, regional Child and Youth Development Teams and other clinical supports as required. Exceptionally, they may be beds

placed in a child and adolescent psychiatric unit, a dedicated pediatric unit of a regional hospital or a special care home dedicated to child and adolescent mental health services operating under a staff model of care. However, our review of the literature suggests that residential treatment placements are not as effective as therapeutic foster home placements. We learned several years ago that both mental health and probation services supported a network of therapeutic foster homes with specialized training, supports and fee structures. While the programs held forward great promise and were very successful places of intervention, subsequent budget cuts did away with such programs. Today we are paying the price by using far more institutional capacity to meet the needs of youth, even though therapeutic foster homes can be operated at a fraction of the cost.

There is no question in our minds that the best place for an intervention is with the family, provided that the intervention can occur in a timely, preventive fashion with adequate supports. But when family supports are insufficient to stabilize a child and meet his or her complex needs, therapeutic foster homes offer the next best thing, and the province must support and develop its capacity in this area. The Centre of Excellence should have a clear priority of 1) helping kids cope at home in their family setting; 2) supporting them if need be in a therapeutic foster home placement as a step-up intervention with family support and involvement; and 3) only as a further alternative in the most complex cases, supporting them in an institutional residential care setting. Throughout its caseload, the Centre of Excellence should share its clinical supervision function with child and adolescent psychiatry units established in each regional hospital zone.

**Clinical Supervision of Discharge and Step-Down Interventions**

One clear benefit of having more step-up residential treatment capacity in local communities will be to ease the step-down process for children returning to their family's care. Regardless of where the step-up intervention occurs or where the child's home is located, it is important that the clinical team at the Centre of Excellence have the capacity to remain involved in the post-discharge care. In most cases, regional Child and Youth Development Teams will adequately manage the wrap-around services for youth coming out of care. Eventually, the Centre staff may be consulted regarding youth with complex needs returning home from various care settings other than the Centre of Excellence. Whether it is a school official, a community service volunteer, a staff member at the Centre of Excellence or a Child and Youth Development Team member intervening with the youth, the focus will be on helping the family or foster family help their child, "doing with" rather than "doing for."

**Family Supports**

In keeping with this focus on relationships, we recommend that the Centre's main activity at community and local levels will be in ensuring that adequate family supports are available as

required. Families with children with complex needs require adequate respite care and peer support groups. We have outlined above the need for education and training for families and care providers, and we anticipate that to be effective, much of this educational effort will have to be delivered by the Centre locally, through home visits and training sessions that are accessible to families in every corner of the province.

**Supports to Regional Advisory Committees and Local Child and Youth Development Teams**
The main service partner of the Centre of Excellence at the local level will be the Regional Advisory Committees and school-based Child and Youth Development Teams. In most cases, these will be the teams that refer children and youth for step-up interventions and will ensure the implementation of step-down discharge plans. At every level, the Centre of Excellence will want to assist and provide advice and direction to the Regional Advisory Committees and the Child and Youth Development Teams as requested, and also help ensure that all Regional Advisory Committees and local Teams are working well and to standard around the province. Team members may be the prime target audience for professional upgrading and training programs put on by the Centre of Excellence, and may in fact assist in implementing or rolling out the training sessions to interveners and staff in their communities. As the ISD framework is rolled out in all regions in the province, it will replace existing inter-departmental protocol for case planning for children and youth with complex needs.

**Supports to Primary Care Physicians**
The online survey and provincial dialogue session revealed strong interest in ensuring that the Centre of Excellence work first and foremost with primary care physicians as frontline partners in treating and improving child and adolescent mental health. We agree wholeheartedly with this suggestion. The training programs developed by the Centre of Excellence should be planned regularly in partnership with family medicine practice groups, the Canadian Pediatric Society and the New Brunswick Medical Society, ensuring proper accreditation of the courses and participation by this critical target audience.

**Support to Mobile Mental Health Crisis Units**
In 2008, the Government of New Brunswick announced the creation of mobile mental health crisis units that can be called upon as first responders when children with complex needs are in crisis or acting out. Rather than calling in the police whenever there is a problem, these crisis units can be called in to de-escalate the situation and redirect the youth and families towards appropriate responses to manage the crisis and avoid future incidents. The Centre should play a role in making sure that these units are available equally in all regions of the province and that the service is well known and accessed effectively. The Centre should also offer a 24-hour crisis support service to these first responders and prioritize their involvement in training programs initiated by the Centre.

**Supports to Community Youth Justice Committees**

Since 2003, the *Youth Criminal Justice Act* (YCJA) has called for the creation of Community Youth Justice Committees that would place the onus and responsibility for the administration of youth criminal justice at the local community level. New Brunswick remains one of the few Canadian provinces not to have funded or implemented any Community Youth Justice Committees. However, on the initiative of local police forces and the RCMP, some communities have begun to pull together and form committees that play some of the roles that the legislation assigns to these local committees. The Child and Youth Advocate's Office, with funding from the Youth Justice branch of the Department of Justice Canada, has developed a model to implement Community Youth Justice Committees in our province, based on Canadian best practices and taking into account the paradigm shift underway with the ISD Framework in New Brunswick. One of the key objectives of the committees proposed under this model is to ensure that criminal justice processes are not accessed or misused as a surrogate for mental health or social welfare programs. They are also the key process under the YCJA for ensuring that alternative measures to criminal justice proceedings are considered and preferred in every appropriate case. In our view, the Centre of Excellence should play a role in promoting the establishment of Community Youth Justice Committees and ensuring their integration with Regional Advisory Committees under the ISD Framework and their smooth collaboration with Child and Youth Development Teams at the local level.

**Clinical Supervision and Direction to Local Autism Centres**

In many communities, families have spoken to us about the tremendous support available to them through their local autism centres. These centres play a critical role in supporting parents and involving them and other interveners as required in the treatment plans of young children on the autism spectrum, whose numbers have been increasing dramatically over the past 15 years. The Centre of Excellence should be given a clear mandate to provide clinical support, audit services and peer mentoring services to these centres so that all New Brunswick families benefit from the best practices and models of care available, no matter where they live. Similarly, there have been repeated calls for the extension of autism supports from pre-school to age 19. The Centre of Excellence could work with the provincial government and local autism centres to gradually extend services this way.

**Advocacy and Local Improvements**

There are many ways in which the Centre of Excellence will add value locally. A number of suggestions were made during our consultation process which we could note here, although these are merely illustrative. For instance, it has been mentioned that child psychiatry units could be designed to facilitate access to outdoor play, leisure and physical activity, and that the Centre of Excellence should advocate on this front to Regional Health Authority boards for progress at the local level.

There are so many developments happening in other Canadian jurisdictions and elsewhere in the world that the Centre would have much work at hand tracking best practices and helping them be adopted and implemented in New Brunswick. Many of these best practices are focused on providing more services and counseling to families and individuals impacted by mental illness. Early on in its mandate, the Centre should consult with the Department of Finance and canvass other jurisdictions to consider which are the best and most proactive tax credit systems and incentives to help families offset the costs of mental illness, particularly as it affects one's children and dependents. A further area that deserves some early attention and investigation would be to revisit the insurance programs that could help offset some of the costs of managing mental illness and what employers should be doing through employee and family assistance programs and similar mechanisms to keep their workforce healthy and productive. A 2010 study[5] assessed the lost productivity costs from mental illness to Canadian businesses as a whole last year at CAD $51 billion. Surely some preventative measures here would be not only in the best interests of our children but of our industry and economy as well.

## 3. Location

Initially, deciding upon the location of the Centre of Excellence appeared to be the most difficult task assigned to us, given the politics and prospect of displeasing many more people than could be pleased by preferring one community over all others. With the help of Ascentum Consulting, however, we designed an online questionnaire and held an in-person dialogue session to solicit feedback from respondents with respect to the criteria they found most important in selecting the location of the Centre of Excellence. We had interesting feedback about the need for the Centre to operate in a decentralized fashion, to operate virtually in partnership with universities, and to focus on supports to families rather than residential services per se, although the advice was strongly divided on this latter point. In the end, the decision was not very difficult at all.

The feedback we received pointed strongly to the fact that the Centre of Excellence needs to be in a location that is accessible geographically to residents of both linguistic communities, is close to a university research community and is in an area that would facilitate recruitment and retention of leading experts in the field of children and youth with complex needs. In the end, the debate centred around Fredericton or Moncton with Moncton coming out clearly on top due to its greater level of specialized services in both official languages, its relative accessibility owing to the highway infrastructure, traditional demographics of youth with complex needs by region and, most significantly, the strengths of the specialized treatment services currently offered there. Moncton already stands out in many ways as the province's nerve centre of

[5] Centre for Addiction and Mental Health. "Mental health leaves most costly to Canadian employers." <http://www.camh.net/News_events/News_releases_and_media_advisories_and_backgrounders/Dewa_cost_per_person.html>.

services in this field, since it is home to the provincial Child and Adolescent Psychiatric Unit, the Pierre Caissie Centre and the Peel Children's Centre, as well as the Moncton Youth Residences and its extensive network of residential care homes. The Portage drug addiction facility is also within the same geographic region. Furthermore, the Université de Moncton has faculties of social work, psychology, medicine and law. Moncton is also one of the fastest growing metropolitan regions in the country and is geographically the hub of the Maritime provinces, which may facilitate the provision of contracted services to youth from neighbouring provinces.

Our view remains, however, that while it is important that the Centre of Excellence have an administrative head office and perhaps a greater residential capacity in that region, the Centre and its basket of services should be decentralized and operate as much as possible at the family and community level. Our few brief recommendations under this chapter are directed mainly towards those ends.

**Treatment Centre with Residential Capacity in Community**

While we recommend that the Centre of Excellence be headquartered in the Greater Moncton region, we want to stress the need for residential capacity to be distributed to foster families and therapeutic care homes in that metropolitan region and not housed in a single facility or institution. We recommend that the residential capacity at the Centre be mainly distributed in community placements, in keeping with the best practices reviewed in the literature. We recommend that the Centre operate most of its beds (one-half to two-thirds) in the greater Moncton region and another third or so in other communities around the province. A number of the beds in the Moncton region, in either treatment centres or in the community, could be operated on a fee-for-service basis, based on the demand from other provinces or regions.

**Distributed Residential Capacity in Other Communities**

We recommend that the Centre of Excellence operate at least two beds in other major centres and also in smaller communities so as to meet the needs of families with children with complex needs from every part of the province and in both official language communities.

**Distributed Research Nodes on University Campuses**

It is our recommendation that the Centre of Excellence maintain its main research operations on university campuses in Moncton and Fredericton. We recommend that a distinct Research Chair be endowed by the province at each of the campuses at Université de Moncton and UNB Fredericton. Neighbouring universities such as Mount Allison, St. Thomas or UNBSJ may partner with the nearest Research Chair to assist and collaborate in research projects. Each of the endowed Research Chairs should be established in consultation with other research institutes nationally and abroad, based on current research activities and local partners. For instance, the UNB Social Policy Research Network, the Canadian Research Institute for Social Policy (CRISP), the Muriel McQueen Fergusson Foundation, the St. Thomas Centre for Research on Youth at

Risk, UNB's Health and Education Research Group and the Stan Cassidy Centre for Rehabilitation would be natural allies and research partners.

**Design Standards for Residential Placement Facilities**
Several parents raised concerns with us about security and safety standards at the Centre of Excellence. This will be an ongoing concern that will require vigilance by the Centre's staff, considering how varied and widely distributed the residential placements will be. We recommend that prior to the Centre's opening, clear and detailed standards be developed on the basis of existing practice standards and national best practices as to how best secure and make safe the residential placements for youth with complex needs.

At the same time, we believe that the Centre will have an important role in ensuring that design elements for therapeutic foster homes consider residential location, proximity to nature, recreational amenities and services. Beyond that, we would want staff and the Centre to pay particular attention to the details of design in services and facilities operated in order to make the residential care facilities as homelike as possible and welcoming to children and youth as places of healing and learning.

## 4. Governance

The last few recommendations we need to make touch on matters of governance and operations. Various models exist and have been canvassed. The consultation results strongly favoured measures to ensure the Centre's autonomy from government, but with clear public accountability; principles of transparency, accessibility and quality of services were highlighted as well. We propose a model which sees the Centre governed by a board of experts as an independent Crown Agency run along not-for-profit business models, purchasing services from the private sector and offering some services for a fee. In our view, the Centre should also establish an endowment fund and rely significantly on public and private donations to support its operations. Its core funding, however, would be through the annual budget process as a distinct budget line similar to other departments and agencies. The Centre's budget would not be new money but would be reallocated from each of the public sector departments whose caseloads will be reduced through the Centre's interventions.

Our goal throughout this process has been to formulate recommendations and a governance model that are progressive but cost-effective. We are satisfied that the majority of recommendations made can be implemented through a reallocation of existing resources and that any new investments in community- and family-based interventions will generate significant savings in productivity costs and lost labour and will help make our economy stronger. On the contrary, continuing to ignore the problems of child and adolescent mental health would have a crippling effect on provincial budget processes and the economy in general. Finally, the board governance model will be critical in determining how successful the

Centre will be in positioning itself as a world-class research and treatment centre. We believe and have been told that this goal is within our grasp and we further believe that if we are seriously committed to meeting the best interests of our children, we shouldn't aim for anything less.

**Arm's Length and Independent**

It is recommended that the Centre of Excellence be created by an Act of the Legislature that would establish the Centre as a world-class research and treatment centre for children and youth with complex needs. The Centre should be set up as a Special Operating Agency such that any annual surpluses would not return to the Consolidated Revenue Fund but would be deposited into an endowment fund established for the Centre of Excellence and its Research Chairs. The Centre's endowment would be a publicly registered charity and the Centre itself would operate on a not-for-profit basis. The Centre would prepare and file its Annual Report with the Legislative Assembly.

**Expertise**

The Centre of Excellence should be operated by a Board of Governors of up to 15 members appointed on the basis of their merit as experts in the treatment of and service delivery to children and youth with complex needs. Each of the provincial Departments of Justice, Social Development, Education, Health and Public Safety should name a representative to the Board. The Board should also include representation from the federal public sector, the business sector and leading jurists in the field of children's rights, as well as representation from youth, parents and community leaders within the province. The Centre should also recruit into its fold leading researchers through academic appointments and fellowships associated with its endowed Research Chairs and experts to lead its clinical teams and services. A global standard of excellence should permeate all aspects of the Centre's services, including its Board appointment criteria, and form part of the Centre's vision and mission.

**University Research Chairs**

In our view, it is critically important that the Centre's research mandate be based in university institutions. This is why we recommend that at least two academic Research Chairs be endowed as part of the Centre's governance model: one at the University of New Brunswick, perhaps in collaboration also with the St. Thomas University research community, and one at l'Université de Moncton. The Research Chairs could be, for instance, in the Faculty of Medicine or the Department of Psychology, but this would have to be determined in consultation with the research community, with regard given to the work of other research centres already established in Canada and the potential for collaboration and linkages there. The Centre should explore with its partner university campuses the possibility of establishing further research fellowships through the endowed Research Chairs associated with the Centre. It would be

expected that leading researchers recruited to take up appointment as the Centre's Research Chairs would sit as ex-officio members of the Centre's Board of Governors.

**Business Model Operations, Service Privatization and Capitalization**

In our view, the Centre's corporate structure should allow for a full exploration of the most cost-effective and efficient operational models. The Centre should be established in partnership with existing public and private sector agencies already involved in service delivery to children and youth with complex needs. The Centre could decide and negotiate which services might most effectively be run through a centre such as the Peel Children's Centre or the Portage drug addiction facility. The renewal and administration of these contracts and the budget to administer them should be transferred from line departments to the Centre of Excellence. It may be that the capital infrastructure required to house the Centre of Excellence could be more efficiently built by private sector partners and leased back to the province, or that the residential capacity required for the Centre to operate exists within or can best be developed by private sector partners. The Centre could lease the facilities or purchase turnkey therapeutic residential care home services from these partners. Other municipalities or community non-profit agencies may wish to partner with the Centre to finance, gift over or operate residential care facilities in their communities. All of these options should be explored and the Centre's corporate structure should give it the maximum latitude possible in this respect.

The development model which has been identified to us as most promising is the opportunity to lease back services from a treatment centre that could be developed by a private developer active in the area of services for youth with complex needs on public land adjacent to the Pierre Caissie Centre. Services delivered by the Child and Adolescent Psychiatric Unit at the Moncton Hospital could be relocated to this venue and collocated in proximity to Pierre Caissie's services. The capital costs for developing the Centre of Excellence could then be borne largely by private interests and the Province would only have to shoulder the operational costs. Similarly, other residential services for youth with complex needs in the Moncton region could be offered in existing infrastructure leased to the Centre of Excellence and through specialized therapeutic foster homes with caregivers trained and directed by the Centre's clinical team.

**Services to Residents Outside of New Brunswick**

In our view, the diagnostic and treatment services made available through the Centre will be in high demand, not just in New Brunswick but by families across the Atlantic region and beyond. We learned through our consultation that New Brunswick children have been sent for observation or treatment to Texas, Maine, Ontario, Quebec and Alberta. The Centre of Excellence and the Province should jointly explore the feasibility of cost-sharing their operations with other Atlantic provinces (as was done, for instance, with the Atlantic Provinces Special Education Authority, the IWK Hospital and the Agricultural College) or at the very least

of making some diagnostic and treatment capacity available to other provinces or private sector care providers on a fee-for-service basis that will benefit the Centre's bottom line.

**Provincial Review Panel for Referrals to the Centre of Excellence**
One of the important details of the governance model will be the gatekeeping and referral process to the diagnostic and treatment services and supports available through the Centre of Excellence. We have outlined above the role that Regional Advisory Committees will play in making referrals to the Centre of Excellence. However, Regional Advisory Committee decisions which determine whether or not a child's case is complex and if they are referred to the Centre of Excellence should be reviewable in order to protect the child's right to be heard in decisions affecting him or her. We recommend a provincial review panel constituted of three members named from a roster of clinical and departmental experts appointed on the recommendation of the Centre of Excellence. The review panel should be chaired by a member in good standing of the New Brunswick Law Society with a minimum of ten years experience and demonstrated expertise in the area of children's law.

**A Collaboration of Specialized Agencies**
Finally, we believe that the Centre of Excellence will operate most efficiently if it is conceived of from the start as a collaboration among existing public and private partners involved in service delivery to youth with complex needs. Possible partners include the Peel Children's Centre, the Pierre Caissie Centre, the Child and Adolescent Psychiatric Unit at the Moncton Hospital, the Restigouche Hospital Center, the Stan Cassidy Centre for Rehabilitation and provincial autism agencies. The Centre may step up to a purchasing or coordinating role with respect to a number of these agencies, but it should be available and accessible to all of them in an advisory capacity and play a coordinating function to ensure that their services are always interdisciplinary and collaborative when dealing with youth with complex needs and their families.

**Cost Projections**
The timelines and scope of our mandate preclude us from making detailed projections and forecasts of the costs and savings associated with the recommendations we have outlined. At the same time, we have strived to put forward a series of recommendations that are feasible over the short-term without major new investments, given the difficult fiscal situation the Province of New Brunswick is currently facing. We believe that the recommendations set out above will require some new spending, but we are confident also that they will achieve significant savings and that the long-term impacts on our youth, our population and our economy amply justify the new directions.

Some of the data and assumptions that informed our analysis include the following:

- The average cost of services per year to a youth in closed custody at the New Brunswick Youth Correctional Centre is $118,300; however, youth with complex needs spend more time in isolation, require more services and often cost considerably more;
- The annual costs for a youth in an open custody/group home setting is $83,700;
- Institutionalized hospital care costs are usually more expensive than probation services;
- The average yearly cost for a youth in a drug addiction program at Portage is $51,000
- Open custody foster homes operate on average costs of $15,000 per youth; and
- The average annual cost of a youth sentenced to a community supervision order is about $13,300

We know that oftentimes, youth are ordered to NBYC or the Restigouche Hospital Center for assessment when recent assessments are already available. Sometimes the assessments provide 30, 60 or 90 days of respite in institutional care while the youth is stabilized or an intervention plan is developed. We believe that the costs of a number of these assessments, court proceedings, and hospital stays could be easily avoided by working more proactively with youth through the Centre of Excellence, Child and Youth Development Teams and community youth diversion programs.

One danger that we feel the province must guard against as it undertakes significant cost-cutting and fiscal restraint measures is the bureaucratic tendency to cut programs rather than staff. Our review shows clearly that community-based programs and interventions are often far more effective and less costly in addressing the needs of youth with complex needs than public sector service offerings in institutional care or otherwise. Therefore, we feel community-based programs and services should be enhanced as required and financed through the savings realized by fully integrating the service delivery system while maximizing the use of tele-medicine whenever possible.

# Conclusion

We have put forward a vision of a Centre of Excellence that is a world-class research and treatment centre for children and youth with complex needs. We hope that this institute will be able to attract and retain leading researchers and clinicians to improve services and the lives of young New Brunswickers and other children from around the Atlantic region. We know that safe and stable places of treatment and step-up interventions are greatly needed, but this need is urgently felt, we think, because of our current failure to adequately support and wrap services around families in communities where children with complex needs are being raised.

The Centre of Excellence proposed in this report will reach out to young people and their families in need, offering guidance, support and services to them where they live. It will spare no effort in working with stakeholders, families and communities to meet the needs of children and youth with complex needs without disrupting family life and routines. However, when a placement outside of the home is required for assessment or step-up intervention purposes, the Centre of Excellence will help ensure that clinicians, educators, social workers and all interveners work together and from the same page in meeting the child’s needs. Increased and improved therapeutic foster home settings will be established in communities around the province under the Centre’s clinical direction to ensure that stable family relationships are supported, nurtured and maintained while the child’s needs are addressed. When the child’s best interests require the severing of parental or fraternal ties, increased efforts will be made to maintain and stabilize other essential relationships in the child’s life in order to normalize the child’s situation as much as possible in addition to the counseling and clinical care plan established for the child.

As a treatment centre, the Centre of Excellence will manage and direct existing clinical treatment programs and services, work in tandem with local and regional interdisciplinary Child and Youth Development Teams and draw from established best practices nationally and internationally. However, it is the Centre of Excellence’s research mandate that will ensure that children with complex needs in the Atlantic region benefit from the very best interventions and clinical services possible. Through endowed Research Chairs at the Université de Moncton and the University of New Brunswick and in partnership with similar research centres across Canada and abroad, the Centre will help train professional staff in our region on the newest and most promising methods.

We know that by making better use of our resources, we can greatly improve the quality of care provided to children and youth with complex needs. The millions expended to date for step-up interventions abroad could benefit many more children if they were spent here in New Brunswick; those expenditures could develop expertise, services and employment in communities around our province. We expect that by reducing our reliance on institutional care and public sector services and by relying more on families, communities and not-for-profit sector service agencies, we could significantly reduce high-end expenditures and reallocate resources to areas of greatest need. We also know that if we make these choices and investments, the number of children with complex needs who go on to become productive members of society will be improved, thereby improving the health of our population and our economy. These are all compelling reasons to move ahead with the proposed recommendations which are neither startling nor new.

It has become clear to us, however, that despite an encouraging degree of cooperation and collaboration among the four main government departments involved in services to children and youth with complex needs, bureaucracies have a strong and dominant tendency towards silo management. We are convinced that for the recommendations outlined above to be implemented, a strong dose of political will and leadership will be required. Public engagement and awareness lead by stakeholders, communities and families will be critical to the successful implementation of this vision. We have consulted broadly and heard from New Brunswickers of every region, opinion and persuasion. Our report is greatly informed by their visions, thoughts and aspirations. Stakeholders, parents and family members have spoken with conviction and in earnest, motivated by a concern for the welfare of the children with the greatest needs. To paraphrase John F. Kennedy, they have spoken “for those who have no voice.” Decision-makers should take heed.

## Appendix I: Integrated Service Delivery: A child- and youth-centred framework for New Brunswick

### Introduction

In 2009, the provincial government announced sweeping reforms to services and programs for vulnerable children and youth. It made a specific commitment to integrate these services and programs.

This child- and youth-centred approach, known as the Integrated Service Delivery (ISD) framework, is intended to provide a seamless range of services across several departments involved with children and youth, including Social Development, Education, Public Safety, Health and Justice and Consumer Affairs.

The provincial government has been developing the ISD framework in response to recommendations made by Bernard Richard, the ombudsman and child and youth advocate, in two 2008 reports: *Connecting the Dots: A report on the condition of youth-at-risk and youth with very complex needs in New Brunswick;* and *Ashley Smith: A report of the New Brunswick Ombudsman and Child and Youth Advocate on the services provided to a youth involved in the youth criminal justice system.*

The development of an ISD framework was informed by two additional, related reports – Judge Michael McKee's *Together into the Future: A transformed mental health system for New Brunswick* and the Department of Education's *MacKay Report on Inclusive Education*. All four reports clearly identify a strong need for better co-ordination among departments to increase support to children and youth with multiple needs.

The main goal of the ISD framework is to provide seamless services and programs to children, youths and their families, by:

- improving services and programs to at-risk children and youth as well as young people with complex behavioural, emotional, mental-health, education and physical health/well-being needs. These services and programs address the needs that are often the result of unsafe/unstable social circumstances such as homelessness, poverty, delinquency and fragile family relationships;
- providing prevention and early intervention services designed to promote positive conditions for a child's healthy development and to prevent the development of child abuse, emotional/behavioural problems, substance abuse and criminal behaviour;

- providing relevant and timely services and programs to meet the needs of children and youth between five and 18 (up 21 for those within the education system), including connections for early childhood intervention for the zero- to five-year-old age group and those making the transition to adult services;
- establishing an early care system, with a clinical team, that is focused on direct interventions within the school, community and family contexts; and
- creating an inventory of regional and community-based services and programs and making them available to families, youth and service-providers.

In June 2010, the provincial government selected two regional ISD demonstration sites - one on the Acadian Peninsula (School District 9), the other in Charlotte County (School District 10) - as it moved forward with its plan to improve services for children- and youth-at-risk; children and youth with complex needs; and youth involved in the criminal justice system.

The demonstration sites are expected to be in place by the spring of 2011 and are the first phase in a province-wide implementation plan.

### Our purpose for action: our mission

To foster the positive growth and development of children and youth; and to prevent harm and alleviate suffering.

### The mission to which we are committed: our central goal

To enhance system capacity to respond in a timely, effective and integrated manner to the strengths, risks and needs profiles of children, youth and their families.

### Our vision: desired outcomes

***Positive child and youth development***: It is expected that the implementation of the ISD framework will contribute to increased student engagement and academic success as well as to strengthened family, school and community relationships.

***Timely services***: It is expected that the implementation of the ISD framework will contribute to increased awareness and timely access to needed assessment, intervention services and community-based supports.

***Effective case planning practices***: It is expected that the ISD framework will increase continuity of case planning services for children, youth and their families, and greater service capacity to adjust service intensity and duration as needed.

***Enhanced relationships***: It is expected that the ISD framework will improve working relationships and job satisfaction as well as development of collaborative alliances among ISD service-providers and stakeholders.

***System efficiencies:*** It is expected that the ISD framework will increase co-ordination of departmental and community services and enhanced information management processes.

***Effective use of resources***: It is expected that the ISD framework will reduce duplication of services and decrease expenditures associated with intrusive intervention strategies and use of residential placements.

## Our focus for service delivery: our mandate

The ISD framework is designed to focus directly on providing services and programs to New Brunswick children and youth five to 18, (and up to 21 for those within the public school system) with identified multiple needs as defined by core areas of adaptation, including:

- physical health and wellness;
- emotional and behavioural functioning;
- family relationships;
- educational development; and
- mental health and addictions.

To ensure appropriate referrals to the services offered by child and youth development (CYD) teams, children or youth must present moderate to severe internalizing and externalizing (emotional/behavioural) features (using the Child and Adolescent Functional Assessment Scale) and demonstrate significant impairment or disruption in functioning in at least one of the other four core areas of adaptation.

In instances where children and youth may demonstrate more complex needs requiring more intensive interventions, ISD personnel will collaborate to ensure access to appropriate tertiary level supports with emphasis placed on “step-down” transition planning for less intensive and/or intrusive services.

For children younger than five, ISD personnel will collaborate with Early Childhood Intervention (ECI) services to offer consultation services, transition planning and clinical support for prevention and early intervention programs at school or in the community.

ISD personnel will provide clients who turn 18 (or those up to 21 and within the public school system) with transition planning to appropriate adult services.

## Governance

The governance structure is comprised of provincial interdepartmental committees with involvement from the departments of Education, Social Development, Health and Public Safety. The provincial co-ordinating committee and its sub-committees will collectively provide an accountability framework to ensure timely and effective decision-making, apply sufficient and appropriate use of resources, oversee quality improvement practices, and report annually on all levels of activities, indicators and outcome measures.

## Philosophy

***Child-, youth- and family-centred services***: The ISD service philosophy and its application reinforce a commitment to positive child and youth development by strengthening universal family-focused programs; and by providing early intervention services for children, youth and their families identified as at risk.

***Inter-professional team approaches***: Increasing collaboration among professions is intended to reduce duplication of effort, make more effective use of limited resources and more effectively meet the complex needs of clients.

***Strength-based methods***: Strength-based methods affirm that clients and their respective contexts have a range of unique internal and external resources that should be used as part of case planning.

***Service intensity and duration***: The ISD framework is able to adjust the level of service intensity and duration to match effectively the needs of clients to support and sustain adaptive functioning in the home, school and community.

***Continuum of services***: The ISD framework organizes services within a framework that provide a comprehensive vision from which to co-ordinate, assess and build service delivery capacity responsive to the needs of children, youth and their families (a continuum of universal preventative services, a continuum of early intervention and support services and a continuum of treatment and residential services).

## ISD regional intake process and information management

Referrals to the ISD program shall be completed at specific locations in the community, including physicians' offices, emergency departments, local schools and youth-serving agencies.

A regional call-in system shall be implemented to provide a common point of entry for referral, screening and intake assessment processes for children, youth and families being referred to or seeking assistance from community-based ISD supports. This service will not replace emergency call-in services, but it will provide a proactive daytime service to facilitate earlier responses to child, youth and family concerns and needs.

Upon completion of appropriate screening and assessment processes, intake professionals shall respond to clients' presented needs by linking them with the appropriate service intensity support intervention or program option based on the ISD three-level service continuum (universal, early intervention and tertiary).

### Information management

The Department of Health's online Mental Health Client Information Management System will be adopted and used by ISD personnel to support intake, assessment, intervention, and case management activities in the school and community contexts. In the case of co-case management between ISD personnel and other departmental representatives or in accessing key information from other public service sectors, consent and release of information protocols will be used as the basis for facilitating information exchange.

### Service delivery components

The ISD framework builds on better practice knowledge and ultimately extends the regional inter-service capacity of front-line workers and their respective services and programs. The program delivery level of operations and direct services shall be responsible for ensuring the consistent and effective implementation of the ISD framework, including the provision of step-up and step-down services, as well as the integration of departmental and community resources to address service gaps and meet the comprehensive needs of children and youth with emotional and behavioural concerns. Key components are:

- CYD teams;
- regional advisory committees (RACs);
- the Provincial Clinical Team (PCT);
- regional community mobilization committees; and
- centres of knowledge development and exchange.

### CYD teams

CYD teams are assigned to provide integrated assessment and intervention services to a cluster of schools within a given region. Clusters would include elementary, middle and high school levels in urban and rural settings.

Each CYD team is composed of a minimum of four service professionals who have expertise in the delivery of assessment and intervention services in school, community, and family settings. CYD teams may be composed of:

- school psychologists;
- mental-health and addictions social workers (school-based);

- school counsellors;
- support services to education social workers or psychologists;
- interventionists (child and youth care workers); and
- residents and interns.

Each CYD team is led by a senior level clinician responsible for assigning cases and monitoring clinical service delivery and team functioning.

Evidence-informed practices and concepts from *Assertive Community Treatment (ACT)* and *Intensive Case Management (ICM)* service delivery frameworks will be adopted by the CYD teams for structuring case management practices.

The CYD teams hold biweekly organizational meetings to review clients' progress and the outcomes of the most recent intervention strategies as well as to assign newly received referrals. In addition, team members develop a work schedule to co-ordinate key assessment and treatment support activities for clients. Following the organizational staff meetings, team members depart to schools and community locations to fulfill their assigned assessment, intervention and consultation related activities.

**Core clinical activities** of the CYD teams include:

- ***Direct assessment, intervention and support services:*** Provision of direct intervention services, including:
    - crisis intervention;
    - short-term counselling support;
    - design and implementation of individual and small group intervention strategies; and follow-up with children and youth or their families;
    - provision of assessment services, including completion of file synthesis, targeted evaluations and comprehensive data collection processes;
    - collaboration with other CYD team members in the design and delivery of comprehensive and integrated assessment and intervention activities;
    - provision of short-term interventions or supports to caregivers and families to facilitate delivery of services to children and youth; and
    - provision of assistance to caregivers and families in identifying and connecting with essential community and departmental services.

- ***Case co-ordination:***
    - provision of primary case co-ordination activities to ensure continuity of service provision for assigned clients;
    - participation in CYD weekly case planning meetings;
    - co-ordination of intervention strategies with school personnel and departmental and community service providers;
    - collaboration with other departmental service-providers in the organization and delivery of step-up and step-down supports or interventions;
    - consultation with the CYD team leads and other team members on areas of clinical concern; and
    - execution of administrative functions such as recording case management notes and completion of written assessment reports.
- ***Consultation and training:***
    - participation as clinical consultants on individual student cases or educational service delivery programs/approaches at school-based student service team meetings;
    - provision of consultation to school and community leaders on approaches for promoting positive mental-health perspectives and practices***;***
    - provision of training to other educational and service professionals in effective approaches for working with children and youth with emotional and behavioural features; and
    - supervision of student interns from counselling, psychology or social work from accredited or provincially recognized clinical programs.

## Regional advisory committees (RACs)

The RACs are comprised of senior regional managers or their designated representatives from the departments of Social Development and Public Safety, the appropriate regional health authority and the school district. These committees provide expert peer consultation for more complex and challenging cases within each demonstration region. The RACs are able to organize and make decisions regarding more intensive supports to help the CYD teams. These may include ensuring timely access to psychiatric services, residential assessment or other forms of specialized clinical or rehabilitative services based on the ISD three-level service continuum.

### Provincial Clinical Team (PCT)

The PCT is composed of three senior level clinicians who have expertise in the delivery of community, family and school-based assessment and intervention services. PCT members shall include a social worker, a clinical psychologist and an educational specialist. The team's clinical work will include carrying out targeted staff training, providing case consultations and participating in onsite CYD team and RAC meetings.

### Regional community mobilization committees

Regional community mobilization committees are comprised of non-governmental agency and community representatives. These committees consult and collaborate with regional and provincial ISD personnel on actions designed to enhance services for children, youth and their families. Such activities will include the design and execution of community engagement and mobilization initiatives related to addressing the needs of children, youth and their families.

### Centres of knowledge development and exchange

The centre(s) of knowledge development and exchange will be located in graduate university settings that train inter-professional child and youth specialists. The roles of the centre(s) include:

- carrying out applied research initiatives;
- executing knowledge exchange activities related to better practice intervention approaches with other service sectors and universities across the Atlantic provinces; and
- co-ordinating inter-professional graduate training internships in collaboration with the CYD teams and RACs.

## Appendix II – A Child Impact Assessment on the proposed Centre of Excellence

Report and Recommendations on the proposed Centre of Excellence for Complex Needs Children and Youth in New Brunswick

*The Child Impact Assessment (CIA) is an analytical tool by which the development and implementation of any new governmental/public initiative, policy or legislation is assessed in terms of how it may impact, positively or negatively, the rights and interests of children and youth in New Brunswick, guaranteed under the International Convention on the Rights of the Child. The UN Committee on the Rights of the Child recommends that government and policy-makers around the world use CIAs in their legislative and policy-making processes as a methodological tool to improve existing programs, policies and legislation and to ensure that the rights guaranteed to children under the Convention are protected and fully implemented.*

**1. New program or change**

- In July 2010, Bernard Richard and Shirley Smallwood were appointed as Co-chairs of a provincial task-force mandated to lead a provincial consultation process that would allow citizens to help the New Brunswick Government define how a Centre of Excellence for Children and Youth with Complex Needs could help change the dynamic of service delivery and clinical intervention for New Brunswick youth and their families. The task-force was specifically asked to focus on what services the Centre should provide and support, what services should be accessible in communities to support the work of the Centre, where the Centre should be located and how it should be governed.
- The Centre of Excellence was a concept recommended in the 2008 New Brunswick Ombudsman and Child and Youth Advocate report *Connecting the Dots*: *It is recommended that Government establish a provincial centre of excellence for youths with highly complex needs. This centre of excellence should be located in a provincial community and mandated to recruit and retain expert services in child and adolescent psychiatry, developmental psychology, audiology, speech pathology and other support services in matters of child welfare.*
- A number of consultation opportunities were provided to citizens: public sessions, individual and group meetings with the Co-chairs and electronically (on-line questionnaire and email).
- The task force's final report and the recommendations contained therein result from the totality of the feedback provided.
- The recommendations put forth are proposing

   - Services that should be provided by the Centre of Excellence and how the service-delivery structure should be managed
   - Community services that should be in place or are already present to best support the activities of the Centre of Excellence
   - Location of the Centre of Excellence based on the services provided by the Centre and the existing community-based resources
   - Governance structure that allows the Centre of Excellence to operate independently from yet collaboratively with governmental departments

**2. Responsible body**

- It is recommended that to ensure autonomy from government yet be publicly accountable, the Centre of Excellence should be governed by a board of experts as an independent Crown agency operating as a non-profit special operating agency.
- The Centre's core funding would be provided through annual budget appropriations.
- The Centre would be created by an Act of the New Brunswick Legislature.

**3. How it is likely to affect children and youth**

- Establishing a Centre of Excellence to provide care and support to children and youth with complex needs as well as their families will likely have a highly positive impact on the effectiveness and sustainability of new and existing models of clinical services and interventions. It will also coordinate and ensure that multidisciplinary initiatives are structured and imbedded in a community-based setting, thereby facilitating step-down initiatives while ensuring continuity and consistency of services to the young person and his or her family. The clinical interventions will likely result in a systemic decriminalization of mental health behaviour.

**4. Application of the Convention of the Rights of the Child**

- There are a number of CRC provisions that are relevant in the context of this project, namely Article 3 which speaks of the "best interests of the child" as the cornerstone of all intervention by public and private officials. Articles 4, 8, 12, 17, 21, 24, 26, 28, 29 and 40 are also relevant in terms of linking the duty of the signatory States with fundamental rights that every child must enjoy in order to live a productive childhood and transition successfully (physically and intellectually) into adulthood.
- Most relevant to the Centre of Excellence as an inclusive clinical intervention mechanism and resource centre are the provisions found in Article 23 of the CRC:

**Article 23**

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development. (…)

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

## 5. Any disagreements over the likely impact on children

- Although most interested parties and stakeholders are in agreement that the concept of a Centre of Excellence is a major step in the area of service delivery to children and youth with highly complex needs, there are legitimate apprehensions from some citizens – namely parents of young persons with highly complex needs – that a Centre of Excellence would, in fact, act as a physical institution providing uncoordinated respite services or worse, allow for a prolonged institutionalization of children (non-residential philosophy vs need for crisis residential care).

- Arguments have been brought forward that a Centre of Excellence may detract from and diminish efforts to wrap services around children in their families and communities.
- There are also concerns with regards to the Centre of Excellence's ability to recruit and retain professionals, thereby shedding doubt on the long-term operational feasibility as well as the quality and the sustainability of the services provided to children and youth.
- It has also been stated that in light of the province's financial state, it is unlikely that any additional or sufficient funds can be invested into the Centre for it to operate effectively on a long-term basis.
- Another shortcoming identified through the Child Impact Analysis was the lack of any appeal mechanism for review of referral decisions to the Centre of Excellence. Too much gate keeping by one departmental stakeholder at the regional advisory committee level, or in one region over others, could impede service delivery and place children at further risk.
- Finally other parents have objected that the Centre's mission of supporting as many interventions with families as possible and minimizing any residential services to short term step up clinical interventions fails to meet their expectations for a stable, secure and long term care setting where their children, who will never live independently, can enjoy happy and rewarding lives long after their parents are gone.

## 6. How to avoid impact

- By focusing on the importance of involving the young person's family in the clinical process, as well as acknowledging fundamental principles such as those stated in the CRC, the likelihood of prolonged institutionalization is very low.
- It will be important for the Centre to adopt a clear vision and mission that will permeate all its service offerings to ensure that clinical diagnostic and treatment services in step-up intervention setting are always directed towards the child's continued development with the goal of living as independently as possible within his or her family and community. In other words the "Build it and they will come" risk of re-institutionalisation must be clearly stated and avoided as a potential outcome. The Centre's close links with the existing Integrated Service Delivery framework will help achieve these goals and ensure that wrap-around service delivery plans are improved and not diminished.
- In addition, early investment and development of a one child/one file case management system reduces the risk of detracting services from a young person. Service providers will be virtually connected to one another via the young person's file.
- Clinical intervention plans will be developed and guided by a step-down philosophy in cooperation with community partners.

- Although the option of having a youth reintegrate the family home may not prove to be an option for therapeutic reasons in some situations, the community network of services will be positioned and supported by a clinical team that will oversee a family-type oriented integration back into the community.
- The costs of establishing a Centre of Excellence will likely not be measured as an additional cost but rather as a new cost paid by redirected savings from governmental stakeholders that no longer incur the annual expenses related to services now offered and coordinated by the Centre. As a Crown Agency the Centre should receive its own annual appropriation and be able also to diversify its funding and programs from research endowments, grants, bequests and other contributions.
- RAC decisions deeming when a child is a complex case or not or deserving of referral to the Centre of excellence should be reviewable by a provincial review panel constituted of three members named from a roster of clinical and departmental experts appointed on the joint recommendation of the Centre of Excellence and the Provincial Child and Youth Advocate. The Review panel should be chaired by a member in good standing of the New Brunswick Law Society with a minimum of ten years experience and demonstrated expertise in the area of children's law.
- Finally, this proposal recognises that not all parents and stakeholders will be satisfied with the community inclusion orientation taken. However this approach is most consistent with the Child's rights guaranteed under the convention and is premised upon a belief that every child should be raised in the hope and expectation of living as independently as possible. Childhood is fleeting and when a child is still young and developing it is much too early to be making plans for institutional care. This raises as a subject for further inquiry and study the best policy framework for the Province's Adult Long Term Care programs and how the ISD and Centre of Excellence initiatives may impact and inform that review.

## 7. Limitation of the Child Impact Assessment (CIA)

- The analysis and findings in this CIA are based on the successful implementation of all recommendations by the New Brunswick Government and the ability of other interested stakeholders to act in partnership within the proposed model.

## 8. Children and youth's views

- Children and youth participated in the consultation process by way of group consultation and activities in various locations. Some of the youth consulted struggle with highly complex needs. Facilitators introduced the concept of the Centre of Excellence and provide a forum for constructive dialogue. Young people were mainly

invited to provide the Co-chairs with their thoughts on how the services provided by such a centre could improve lives of those who are serviced by it. By tapping into their own life experiences, the young persons who participated focused on identifying some environmental factors that could have a negative impact on a youth's mental health as well as reflecting on the mechanisms required to bring families and service providers together to implement preventive and rehabilitative options.

**9. What's next?**

- Monitor and follow up on the implementation of the recommendations.
- Assist in the implementation of the recommendations.
- Offer continued support in the development and broadening of services provided by the Centre of Excellence.
- The Child and Youth Advocate continues to offer advocacy services to children and youth who are serviced by the Centre of Excellence.

**10. Applicable provisions of the United Nations Convention on the Rights of the Child**

**Article 3**

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.

3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

**Article 4**

States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention. With regard to economic, social and cultural rights, States Parties shall undertake such measures to the

maximum extent of their available resources and, where needed, within the framework of international co-operation.

**Article 5**

States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention.

**Article 6**

1. States Parties recognize that every child has the inherent right to life.

2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

…

**Article 8**

1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.

2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.

**Article 9**

1. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.

2. In any proceedings pursuant to paragraph 1 of the present article, all interested parties shall be given an opportunity to participate in the proceedings and make their views known.

3. States Parties shall respect the right of the child who is separated from one or both parents to maintain personal relations and direct contact with both parents on a regular basis, except if it is contrary to the child's best interests.

4. Where such separation results from any action initiated by a State Party, such as the detention, imprisonment, exile, deportation or death (including death arising from any cause while the person is in the custody of the State) of one or both parents or of the child, that State Party shall, upon request, provide the parents, the child or, if appropriate, another member of the family with the essential information concerning the whereabouts of the absent member(s) of the family unless the provision of the information would be detrimental to the well-being of the child. States Parties shall further ensure that the submission of such a request shall of itself entail no adverse consequences for the person(s) concerned.

…

**Article 12**

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

…

**Article 18**

1. States Parties shall use their best efforts to ensure recognition of the principle that both parents have common responsibilities for the upbringing and development of the child. Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern.

2. For the purpose of guaranteeing and promoting the rights set forth in the present Convention, States Parties shall render appropriate assistance to parents and legal guardians in

the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children.

3. States Parties shall take all appropriate measures to ensure that children of working parents have the right to benefit from child-care services and facilities for which they are eligible.

**Article 19**

1. States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.

2. Such protective measures should, as appropriate, include effective procedures for the establishment of social programs to provide necessary support for the child and for those who have the care of the child, as well as for other forms of prevention and for identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment described heretofore, and, as appropriate, for judicial involvement.

**Article 20**

1. A child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.

2. States Parties shall in accordance with their national laws ensure alternative care for such a child.

3. Such care could include, inter alia, foster placement, kafalah of Islamic law, adoption or if necessary placement in suitable institutions for the care of children. When considering solutions, due regard shall be paid to the desirability of continuity in a child's upbringing and to the child's ethnic, religious, cultural and linguistic background.

**Article 21**

States Parties that recognize and/or permit the system of adoption shall ensure that the best interests of the child shall be the paramount consideration and they shall:

(a) Ensure that the adoption of a child is authorized only by competent authorities who determine, in accordance with applicable law and procedures and on the basis of all pertinent

and reliable information, that the adoption is permissible in view of the child's status concerning parents, relatives and legal guardians and that, if required, the persons concerned have given their informed consent to the adoption on the basis of such counselling as may be necessary;

(b) Recognize that inter-country adoption may be considered as an alternative means of child's care, if the child cannot be placed in a foster or an adoptive family or cannot in any suitable manner be cared for in the child's country of origin;

(c) Ensure that the child concerned by inter-country adoption enjoys safeguards and standards equivalent to those existing in the case of national adoption;

(d) Take all appropriate measures to ensure that, in inter-country adoption, the placement does not result in improper financial gain for those involved in it;

(e) Promote, where appropriate, the objectives of the present article by concluding bilateral or multilateral arrangements or agreements, and endeavour, within this framework, to ensure that the placement of the child in another country is carried out by competent authorities or organs.

…

**Article 23**

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible

social integration and individual development, including his or her cultural and spiritual development.

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

**Article 24**

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

(a) To diminish infant and child mortality;

(b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;

(c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;

(d) To ensure appropriate pre-natal and post-natal health care for mothers;

(e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;

(f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

**Article 25**

States Parties recognize the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.

…

**Article 37**

States Parties shall ensure that:

(a) No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment. Neither capital punishment nor life imprisonment without possibility of release shall be imposed for offences committed by persons below eighteen years of age;

(b) No child shall be deprived of his or her liberty unlawfully or arbitrarily. The arrest, detention or imprisonment of a child shall be in conformity with the law and shall be used only as a measure of last resort and for the shortest appropriate period of time;

(c) Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner which takes into account the needs of persons of his or her age. In particular, every child deprived of liberty shall be separated from adults unless it is considered in the child's best interest not to do so and shall have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances;

(d) Every child deprived of his or her liberty shall have the right to prompt access to legal and other appropriate assistance, as well as the right to challenge the legality of the deprivation of his or her liberty before a court or other competent, independent and impartial authority, and to a prompt decision on any such action.

…

**Article 39**

States Parties shall take all appropriate measures to promote physical and psychological recovery and social reintegration of a child victim of: any form of neglect, exploitation, or abuse; torture or any other form of cruel, inhuman or degrading treatment or punishment; or armed conflicts. Such recovery and reintegration shall take place in an environment which fosters the health, self-respect and dignity of the child.

**Article 40**

1. States Parties recognize the right of every child alleged as, accused of, or recognized as having infringed the penal law to be treated in a manner consistent with the promotion of the child's sense of dignity and worth, which reinforces the child's respect for the human rights and fundamental freedoms of others and which takes into account the child's age and the desirability of promoting the child's reintegration and the child's assuming a constructive role in society.

2. To this end, and having regard to the relevant provisions of international instruments, States Parties shall, in particular, ensure that:

(a) No child shall be alleged as, be accused of, or recognized as having infringed the penal law by reason of acts or omissions that were not prohibited by national or international law at the time they were committed;

(b) Every child alleged as or accused of having infringed the penal law has at least the following guarantees:

(i) To be presumed innocent until proven guilty according to law;

(ii) To be informed promptly and directly of the charges against him or her, and, if appropriate, through his or her parents or legal guardians, and to have legal or other appropriate assistance in the preparation and presentation of his or her defense;

(iii) To have the matter determined without delay by a competent, independent and impartial authority or judicial body in a fair hearing according to law, in the presence of legal or other appropriate assistance and, unless it is considered not to be in the best interest of the child, in particular, taking into account his or her age or situation, his or her parents or legal guardians;

(iv) Not to be compelled to give testimony or to confess guilt; to examine or have examined adverse witnesses and to obtain the participation and examination of witnesses on his or her behalf under conditions of equality;

(v) If considered to have infringed the penal law, to have this decision and any measures imposed in consequence thereof reviewed by a higher competent, independent and impartial authority or judicial body according to law;

(vi) To have the free assistance of an interpreter if the child cannot understand or speak the language used;

(vii) To have his or her privacy fully respected at all stages of the proceedings.

3. States Parties shall seek to promote the establishment of laws, procedures, authorities and institutions specifically applicable to children alleged as, accused of, or recognized as having infringed the penal law, and, in particular:

(a) The establishment of a minimum age below which children shall be presumed not to have the capacity to infringe the penal law;

(b) Whenever appropriate and desirable, measures for dealing with such children without resorting to judicial proceedings, providing that human rights and legal safeguards are fully respected. 4. A variety of dispositions, such as care, guidance and supervision orders; counselling; probation; foster care; education and vocational training programs and other alternatives to institutional care shall be available to ensure that children are dealt with in a manner appropriate to their well-being and proportionate both to their circumstances and the offence.

**Appendix III: Consultation Summary Report**

# Consultation on a Centre of Excellence for Children and Youth with Complex Needs

## CONSULTATION SUMMARY REPORT

DECEMBER 2010

*This report was prepared by:*

ascentum

*for the Office of the Ombudsman/Child and Youth Advocate.*

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# Executive Summary

The consultation on establishing a Centre of Excellence for Children and Youth with Complex Needs (the Centre) was lead by a special Task Force, co-chaired by Bernard Richard, Ombudsman and Child & Youth Advocate, and Shirley Smallwood, a parent of a child with special needs. The Task Force was supported by an Advisory Committee, consisting of Dr. Simon Davidson, Dr. Tara Kennedy, and Dr. Jacques Richard.

The consultation had two streams: *an online consultation* and *a provincial in-person dialogue*. The online consultation offered anyone interested an opportunity to learn about the issues and options under consideration, and the ability to share their views on the development of the Centre through an online Choicebook. The in-person dialogue, held November 5-6, 2010 in Fredericton, brought together parents and guardians of children and youth with complex needs, care-givers, frontline workers and stakeholders.

The Task Force was mandated by the Government of New Brunswick to consult on four strategic questions.

- What types of services should be offered through the Centre?
- What types of services should be available in New Brunswick communities to support and complement the services offered through the Centre?
- What criteria should be used to choose the location of the Centre?
- What principles should guide how the Centre is governed?

In total, 216 New Brunswickers participated online, while 64 attended the in-person dialogue. The Task Force recognizes an imbalance of stakeholders to family members at the in-person dialogue, and has undertaken other means of engaging families and youth (the outcomes of these consultations will be addressed in a separate report).

## Key findings

This report is a summary of what was heard from participants of both the online Choicebook and in-person dialogue streams of the consultation. The in-person dialogue rendered qualitative data, while the online Choicebook yielded both quantitative and qualitative data, which largely echoed what was heard at the dialogue.

*Participants' own words are used as much as possible throughout in order to honour how each sentiment was expressed. Even when direct quotations are not used, the terms come from what participants recorded during the dialogue and in the Choicebook, or reported verbally during the dialogue.*

The following key themes summarize the opinions and suggestions put forth by participants, and will inform the Task Force's recommendations to the Government of New Brunswick on establishing a Centre of Excellence for Children and Youth with Complex Needs.

## Services in the Centre and in Communities

In order to stimulate thinking on what services might be required to better meet the needs of children and youth with complex needs and their families, both Choicebook (online) and dialogue (in-person) participants were presented with: 1) a list of potential services that could be offered through the Centre, and 2) a list of potential services that could be offered in New Brunswick communities.

The online Choicebook participants were asked to rate each item in the list, suggest additions or modifications to the list, and then choose their “Top 3” services. Overall, Choicebook respondents were in favour of the proposed list of potential services that could be offered in the Centre. When asked to rate each potential service, over 90% either ‘agreed’ or ‘strongly agreed’ with the following four services:

- comprehensive evaluations for those not yet diagnosed;
- mental health treatment and support (e.g. pediatric psychiatry, counseling);
- family support services and resources; and
- learning/development opportunities for professionals who work with the Centre.

When asked specifically to choose their “Top 3” services to be offered through the Centre:

- 57.2% of Choicebook respondents chose **mental health treatment and support services**;
- 44.7% chose **comprehensive evaluations for those not yet diagnosed**; and
- 42.3% chose **family support services and resources**.

It is also noteworthy that addiction services came in last place with 7% (see Chart 3.1).

Likewise, online Choicebook respondents were overall in favour of the potential list of services that could be offered in communities throughout the province. When asked to rate each potential service in the list, over 97% of respondents either ‘agreed’ or ‘strongly agreed’ with:

- family support (e.g., respite care, education and training, peer support groups); and
- transition teams for seamless, coordinated service and reintegration into school or work.

In addition, over 90% of Choicebook respondents either ‘agreed’ or ‘strongly agreed’ with these services:

- primary care physicians specialized in diagnosis, treatment of complex needs;
- 24-hour crisis support (e.g., telephone response line, mental health mobile units as first responders);
- program to redirect complex needs youth away from the criminal justice system.

When asked specifically to choose their “Top 3” services to be offered in New Brunswick communities, responses were fairly evenly spread out across the proposed options, with **family support (e.g., respite care, education and training, peer support groups)** standing out with a majority at 58.1% support, as shown in Chart 3.2. Again, it is noteworthy that methadone clinics came in last place with 2.3%.

At the in-person dialogue, participants moved into smaller breakout rooms to allow more time for small group discussions on services they felt were most needed to better serve the needs of New Brunswick's children and youth with complex needs and their families. The following common themes emerged from what each breakout group reported back to the plenary assembly.

- Family support and resources
- Residential care
- Crisis intervention
- Evaluation and assessment
- Specialized care, individualized treatment
- Multi-disciplinary approach
- Mental health services
- Case coordination, navigation and integrated services
- Community-based teams
- Transitional support
- Learning, training, and professional development
- Research and best practices

## Criteria for Selecting a Location

In both the online Choicebook and the in-person dialogue, participants were asked to consider what criteria need to be taken into account in selecting a location for the Centre. In the online Choicebook, participants were asked to rate a list of possible criteria for selecting a location for the Centre, suggest additions or modifications to this list, and then choose their top three criteria. Respondents were somewhat divided over certain criteria, for example whether the Centre should be located in an area that is currently under-serviced, and to a lesser degree, whether the Centre should be located in an area that is densely populated.

There was strong support to have **the Centre in a community that is supportive of the Centre, its work and those who use its services** with 92.2% of respondents either 'agreeing' or 'strongly agreeing' with that criterion.

Additionally, over 80% of Choicebook respondents either 'agreed' or 'strongly agreed' with the following criteria:

- in a community that facilitates access from across the province;
- in a community that facilitates services in both official languages; and
- close to a hospital and/or community mental health centre/services.

When asked specifically to choose their "Top 3" criteria for selecting a location for the Centre:

- 45.1% of participants chose **a central location to facilitate access from across the province**;
- 39.1% chose **services in both official languages**; and
- 33% chose **community willingness to host/support the Centre** as their priority criteria, as shown in Chart 4.1.

At the in-person dialogue, participants were given the same list of potential criteria for selecting a location as was used in the online Choicebook, and were asked to explain which criteria they thought were most important and why. They were also invited to suggest any new criteria, which they thought would be important to consider, and again provide the reasons why.

Five criteria emerged as predominant areas of focus in the in-person dialogue, and are expanded upon in the body of the report.

- Close to a hospital, community mental health services
- Central location to facilitate access from across the province
- Community willingness to host and support the Centre
- Close to a college or university campus
- Community ability to offer services in both official languages

## Guiding Principles for Governance

Participants in both streams were asked to consider high-level principles that should guide the governance of the Centre. In the online Choicebook, participants were asked to consider the potential guiding principles for governing the Centre and choose their top three from the list.

**Child/youth centred** received the most votes at 47.5%; **family-centred** received 42.8%; and **accountabilit**y 33.5%, as shown in Chart 5.1.

Both Choicebook and dialogue participants generally supported the list of potential guiding principles (Accountability, Transparency, Representative, Shared responsibility, Child/youth-centred, Family-centred, Empowerment, Fiscal prudence, Independent oversight and Respect). Participants provided feedback (see Table 5.1), and suggested a few additions, including community involvement; code of ethics; continuous improvement.

## Closing Thoughts

The Task Force collected a wealth of data – hopes, concerns, ideas – from participants in the two streams of the consultation on a Centre of Excellence for Children and Youth with Complex Needs. Both Choicebook and dialogue participants expressed that although health care workers are trying hard to meet the needs of children and youth with complex cases, participants believe it often isn't enough – that the services that are currently available are disjointed, difficult to access and insufficient.

There was a sense among participants that they wanted to see things done differently. They viewed the development of the Centre as an opportunity to improve on the way things are done currently, and implement a new approach to meeting the needs of children and youth with complex needs – one that would build on all the best New Brunswick has to offer and be truly innovative.

*"A Centre of Excellence means …an approach to working with young people with complex needs is developed based on what works for them. This implies the training, development and support of a new brand of professional outside the normal "health and psychological" competencies. Our community's difficulty in dealing positively and successfully so far with many of the young people in need cannot be changed by doing more of the same. Let us explore a different approach based on the models … that have been found to be valuable in recent years." [Online participant].*

*Task Force Co-Chairs, Bernard Richard and Shirley Smallwood, would like to thank all consultation participants for sharing their time, perspectives and experiences to help inform the establishment of a Centre of Excellence for Children and Youth with Complex Needs.*

# 1. INTRODUCTION

In 2008, the Child and Youth Advocate report, *Connecting the Dots*, recommended that the Government of New Brunswick establish a Centre of Excellence for Children and Youth with Complex Needs (the Centre). The Government responded by committing to the development of such a Centre and appointed Bernard Richard, Ombudsman and Child & Youth Advocate, and Shirley Smallwood, a parent of a child with special needs, to lead a Task Force to provide recommendations on the establishment of the Centre. The Task Force was supported by an Advisory Committee, consisting of Dr. Simon Davidson, Dr. Tara Kennedy, and Dr. Jacques Richard.

The Task Force was mandated by the Government of New Brunswick to consult on four strategic questions.

- What types of services should be offered through the Centre?
- What types of services should be available in New Brunswick communities to support and complement the services offered through the Centre?
- What criteria should be used to choose the location of the Centre?
- What principles should guide how the Centre is governed?

To answer these questions, the Task Force conducted a consultation with parents of children and youth with complex needs, stakeholders, and experts in the field through two streams: *an online consultation* and *a provincial in-person dialogue*. The online consultation offered anyone interested an opportunity to learn about the issues and options under consideration, and the ability to share their views on the development of the Centre through an online Choicebook. The in-person dialogue, held November 5-6, 2010 in Fredericton, brought together parents and guardians of children and youth with complex needs, care-givers, frontline workers, and stakeholders. The in-person dialogue rendered qualitative data, while the online Choicebook yielded both quantitative and qualitative data, which largely echoed what was heard at the dialogue.

This report is a summary of what was heard from participants of both streams of the consultation. The key themes presented summarize the opinions and suggestions put forth by participants, and will inform the Task Force's recommendations to the Government of New Brunswick on establishing a Centre of Excellence for Children and Youth with Complex Needs.

*Participants' own words are used as much as possible throughout this report in order to honour how each sentiment was expressed. Even when direct quotations are not used, the terms come from what participants recorded during the dialogue and in the Choicebook, or reported verbally during the dialogue.*

## 1.1 Centre of Excellence for Children and Youth with Complex Needs

The vision and mandate of the Centre have yet to be fully articulated, and will be informed by the input of consultation participants. However, to aid participants in their understanding of what a Centre of Excellence for Children and Youth with Complex Needs might be, the Task Force outlined possible roles for the Centre:

- serve as a single access point for services delivered by various government departments (integrated service delivery model, or ISD);
- foster collaborative planning and service coordination for the benefit of children and youth with complex needs and their families;
- provide both residential and non-residential care and services;
- help manage children's and youth's transition to/from the Centre to/from their community (where applicable);
- recruit and retain specialized health professionals whose services are not always available or easily accessible in New Brunswick;
- develop research interest and capacity (relating to children and youth with complex needs) within New Brunswick; and
- share knowledge and best practices with those who care for or work with children/youth with complex needs across the province.

## 1.2 Hopes and expectations

In-person dialogue participants shared some of their own hopes and expectations for the dialogue and establishment of the Centre.

- "I came to share my perspective as a parent in the hope of contributing some first hand knowledge."
- "Find a solution to reduce burden of hopelessness and abandonment for families trying to cope with daily living."
- "I hope for a Centre that has a group of experts that are available/accessible to address the needs of our complex youth and children in New Brunswick. It is important that there are experts that have specialty in each area, and not just a general knowledge of different diagnoses."
- "I hope that we will be able to work towards and achieve treatment/help for clients and family affected by mental illness and to make these services available to all who need them."
- "I hope that this consultation will assist in the development of new service(s) and higher levels of cooperation between government departments, community agencies, parents and young people in need of high levels of support."
- "To increase awareness of the needs for children, youth, and their families who struggle with developmental disabilities, mental health issues, and child welfare issues, and to have this awareness translate into action for these vulnerable members of our province. Action should include public education, prevention efforts, primary, and tertiary care services."
- "I hope that New Brunswick will become a leader in Canada in delivery of effective treatment services for children and adolescents who have special or complex needs."

# 2. METHODOLOGY

The consultation on a Centre of Excellence for Children and Youth with Complex Needs had two streams: 1) *the consultation website*, which provided background information, and collected participant feedback through an online Choicebook; and 2) *the in-person dialogue*, which allowed participants to learn about the topic through expert panel presentations, and gave participants time to reflect on the issues, and have discussions at their tables and in small groups.

## 2.1 Online consultation

The consultation website launched on October 27th and ran for a month before closing on November 24th, 2010. The consultation was open to anyone who wished to register; participants were recruited through an email campaign, web notices on various Government of New Brunswick websites and a press release. The website provided information about the consultation, and biographies of the Task Force Co-Chairs and Advisory Committee members. The Reading Room contained reports and news articles relevant to children and youth with complex needs to provide further background information to anyone interested.

*Figure 2.1 Online consultation website "splash" page*

Consultation on a Centre of Excellence for Children and Youth with Complex Needs

C&Y Advocate | About | Task Force | Reading Room | Help | Français

C&Y Advocate » Welcome

Participate!

Welcome

How to Participate

Launch Choicebook

Log in

Help

Welcome!

The Government of New Brunswick has created a Task Force, whose mandate is to formulate recommendations to guide the creation of New Brunswick's first **Centre of Excellence for Children and Youth with Complex Needs.** As co-chairs of this Task Force, we are keenly aware that the most important part of our role is to ensure that the voices of those who have first-hand experience with this issue be heard. Children and youth, their families and caregivers, and those who care for, and work with them, all hold an important piece of the puzzle...and it is by putting these pieces together that we will paint the most accurate picture of what this Centre of Excellence must become. This online consultation offers you one way of learning about the issues and options under consideration, and to share your views on the questions we have been asked to address in our report. Additional information on this process, and on the issues, can also be found in the **About** and **Reading Room** sections of this website. We welcome *all* perspectives on this very complex question, and look forward to reading your comments and suggestions.

The Task Force Co-Chairs
Bernard Richard, Ombudsman and Child & Youth Advocate
Shirley Smallwood, Parent of a child with special needs

How to Participate

The online consultation offered anyone interested the opportunity to register to participate and contribute their perspectives, opinions and ideas about the Centre of Excellence for Children and Youth with Complex Needs by completing the online Choicebook. The Choicebook was structured around the four strategic questions that the Task Force was mandated to address.

- What types of services should be offered through the Centre?
- What types of services should be available in New Brunswick communities to support and complement the services offered through the Centre?
- What criteria should be used to choose the location of the Centre?
- What principles should guide how the Centre is governed?

For each of these strategic areas, participants were asked to rate proposed lists (of services, criteria on location, and guiding principles, respectively), and then choose their top three items from each list. They were also given the opportunity to provide new ideas via open text boxes (see Appendix A for screenshots of the entire Choicebook).

*Figure 2.2 Example of a rating question in the Choicebook*

Consultation on a Centre of Excellence for Children and Youth with Complex Needs

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C&Y Advocate » Welcome » Choicebook

**What Do You Think?**

Please indicate to what extent you agree or disagree that the following types of services should be offered **through the Centre**:

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree | I don't know |
|---|---|---|---|---|---|---|
| Comprehensive evaluations for those not yet diagnosed | ○ | ○ | ○ | ○ | ○ | ○ |
| Mental health treatment and support (e.g., pediatric psychiatry, counseling) | ○ | ○ | ○ | ○ | ○ | ○ |
| Addiction services (e.g., methadone clinic, services for drug and alcohol abuse) | ○ | ○ | ○ | ○ | ○ | ○ |
| Multi-disciplinary (e.g., speech language pathology, occupational therapy) | ○ | ○ | ○ | ○ | ○ | ○ |
| Social workers | ○ | ○ | ○ | ○ | ○ | ○ |
| Life skills coaching and mentoring | ○ | ○ | ○ | ○ | ○ | ○ |

*Figure 2.3 Example of a "Top 3" question and open text box in the Choicebook*

Consultation on a Centre of Excellence for Children and Youth with Complex Needs

C&Y Advocate | About | Task Force | Reading Room | Help | Français

C&Y Advocate » Welcome » Choicebook

**What Do You Think? (*continued*)**

Consider the types of services that could be offered **through the Centre of Excellence**. Although all of the following services are important, which do you see as being the **most needed** in New Brunswick today? *Please select your "Top 3."*

- ☐ Comprehensive evaluations for those not yet diagnosed
- ☐ Mental health treatment and support services
- ☐ Addiction services
- ☐ Multi-disciplinary services
- ☐ Social workers
- ☐ Life skills coaching and mentoring
- ☐ Health system "navigation" services
- ☐ Family support services and resources
- ☐ K-12 educational services
- ☐ Learning and development opportunities for professionals
- ☐ Other – please specify in the textbox that follows

*Please specify what you feel needs to be **added, modified** or **removed** from this list and why:*

Characters remaining: 750 of 750

## Demographics

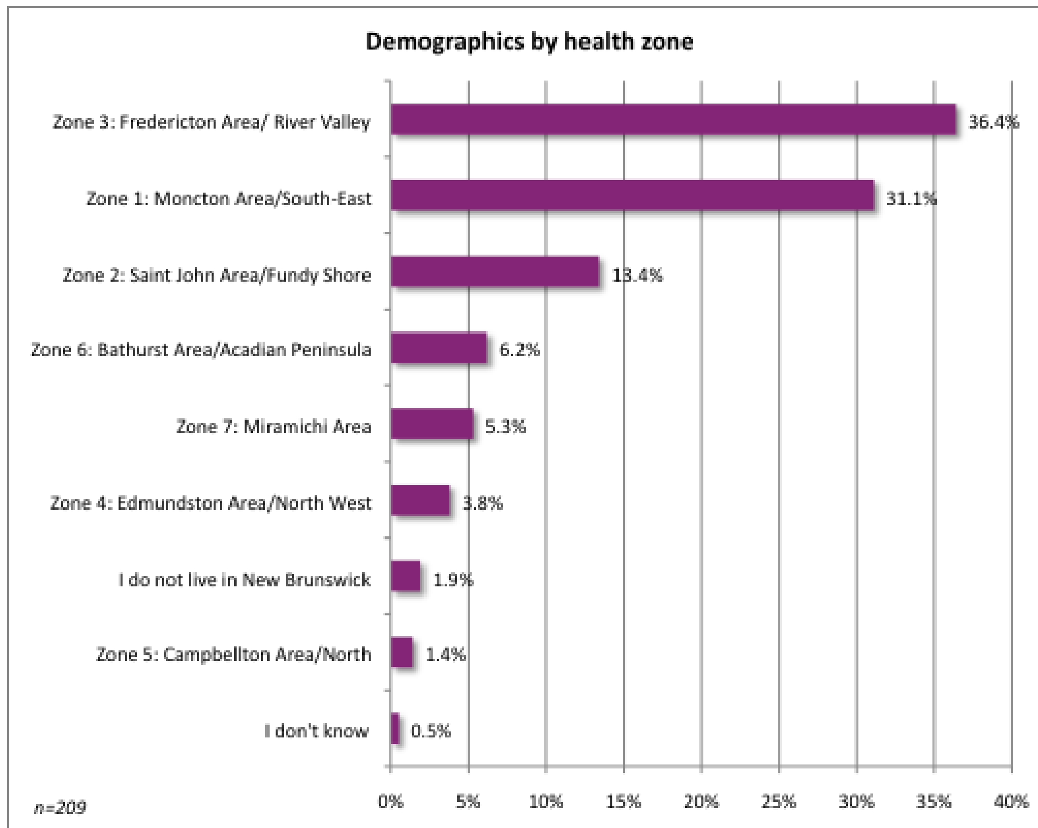
The online Choicebook was completed by **170 participants**. An additional **46 participants** began the Choicebook but did not complete it, for a total of **216 respondents**. Due to privacy concerns, a full profile of participants was not collected; however, participants could choose to share some demographic information at the beginning of the Choicebook.

Choicebook data indicates that 81% of participants prefer to communicate in English, and 19% in French. Participants were also asked to identify their primary perspective on the issue – approximately half of participants identified themselves as either a family member/legal guardian of a child/youth with complex needs (27.5%), or as a youth care worker/health professional (24.6%). The remainder of participants self identified as follows: 15% as a government official/public service worker; 13% as a concerned citizen over 19 years old; 13.5% as "other"; and the rest were dispersed over the remaining categories, e.g. child/youth, academic, advocate, etc. (see Appendix B for online Choicebook results).

When asked if they were participating as the official representative of a group or an organization, only 12% said that they were. Portage Atlantic, the New Brunswick Association for Community Living, United Way of Greater Moncton and Southeastern NB Region, Elizabeth Fry Society of Saint John, Restigouche Residential Agency, New Brunswick Foster Family Association, and the RCMP were some of the organizations represented by Choicebook respondents (see Appendix B).

In terms of geographical information, close to two-thirds of participants (62%) indicated that they live in an urban community, while the remainder (38%) indicated that they live in a rural community. Participants were also asked to select which health zone they live in. As shown in Chart 2.1 below, two-thirds of online participants were from Southern New Brunswick, predominantly from Zone 3 (Fredericton Area/River Valley – 36.4%) and Zone 1 (Moncton Area/South-East – 31.1%). The balance of participants were distributed across the other zones as follows: 13.4% live in Zone 2: Saint John Area/Fundy Shore; 6.2% in Zone 6: Bathurst Area/Acadian Peninsula; 5.3% in Zone 7: Miramichi Area; 3.8% in Zone 4: Edmundston Area/North West; and 1.4% in Zone 5: Campbellton Area/North.

*Chart 2.1 Demographics by health zone*



## 2.2 In-person dialogue

Parents and guardians of children and youth with complex needs, care-givers, frontline workers and stakeholders came together for the in-person dialogue, held November 5-6, 2010 at the Fredericton Inn (see Appendix C for the dialogue Agenda). A **total of 64 participants** registered on Friday afternoon, with a few unable to attend on Saturday. The participants consisted of **14 parents** of children and youth with complex needs, with one youth in attendance, and **49 stakeholders** who work in the field. Stakeholders represented various organizations, such as the John Howard Society, the New Brunswick Association of Social Workers, Spurwink, Stan Cassidy, Woodstock Early Intervention, and Child and Youth Services in Fredericton. The Task Force recognizes the imbalance of stakeholders to family members at the in-person dialogue, and has undertaken other means of engaging families and youth (the outcomes of these consultations will be addressed in a separate report).

The Task Force Co-Chairs, Bernard Richard and Shirley Smallwood, welcomed participants to the dialogue Friday afternoon. Francois Levert, from the office of the Ombudsman and Child and Youth Advocate, served as lead facilitator, and the dialogue began with a personal testimonial from Maureen Bilerman, the mother of a child with complex needs. An expert panel consisting of Dr. Tara Kennedy, Dr. Simon Davidson and Dr. Jacques Richard, presented on “what makes complex cases so complex” commenting on what experts mean by “complex needs” and offering their perspectives on the challenges to meeting these needs. Participants shared their hopes and expectations for the dialogue and for the Centre, and discussed the challenges and opportunities in creating a Centre of Excellence for Children and Youth with Complex Needs. The first day of dialogue closed with a keynote address from Dr. Simon Davidson who shared his knowledge of best and promising practices in treating children and youth with complex needs.

On the second day of dialogue, discussions were focused around the Task Force’s strategic questions on services in the Centre and in communities throughout the province, selecting a location for the Centre and determining guiding principles for governing the Centre. Before each segment, participants were asked for volunteers to perform that following tasks at each table: a Table Leader to read the activity’s instruction sheet; a Recorder to fill in the table’s Worksheet, record what was said at that table, and return the completed Worksheets; and a Reporter to report back to plenary on the table’s discussion.

The Table Worksheets, along with Post-It notes from other activities, and plenary notes, served as textual data for this report, in addition to the data collected from the open- and close-ended questions in the online Choicebook.

# 3. SERVICES

The Task Force was mandated to investigate two strategic questions on the services required to address the needs of children and youth with complex needs:

- What types of services should be offered through the Centre?
- What types of services should be available in New Brunswick communities to support and complement the services offered through the Centre?

In the online Choicebook, participants were asked to rate each item in a list of services that could be offered through the Centre, and then choose their top three items. They proceeded to do the same for a list of services that could be offered in communities (see Appendix A). Overall, Choicebook respondents were in favour of the potential list of services that could be offered in the Centre. In particular, over 90% either 'agreed' or 'strongly agreed' with these four services:

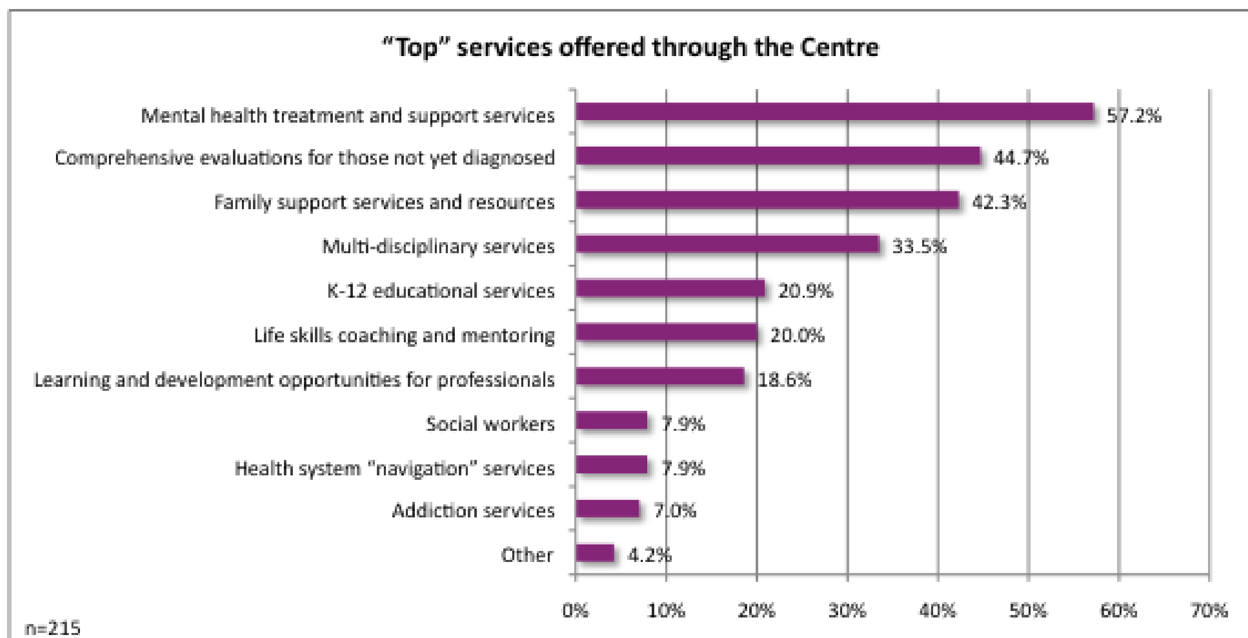
- comprehensive evaluations for those not yet diagnosed;
- mental health treatment and support (e.g. pediatric psychiatry, counseling);
- family support services and resources; and
- learning/development opportunities for professionals who work with the Centre (see Appendix B).

When asked specifically to choose their "Top 3" services to be offered through the Centre:

- 57.2% of Choicebook respondents chose **mental health treatment and support services**;
- 44.7% chose **comprehensive evaluations for those not yet diagnosed**; and
- 42.3% chose **family support services and resources**.

Social workers, health system "navigation" services and addiction services garnered the least support (8%, 8% and 7% respectively, see Chart 3.1, below).

*Chart 3.1 "Top" services offered through the Centre*



Likewise, online Choicebook respondents were overall in favour of the potential list of services that could be offered in communities throughout the province. Over 97% of respondents either 'agreed' or 'strongly agreed' with:

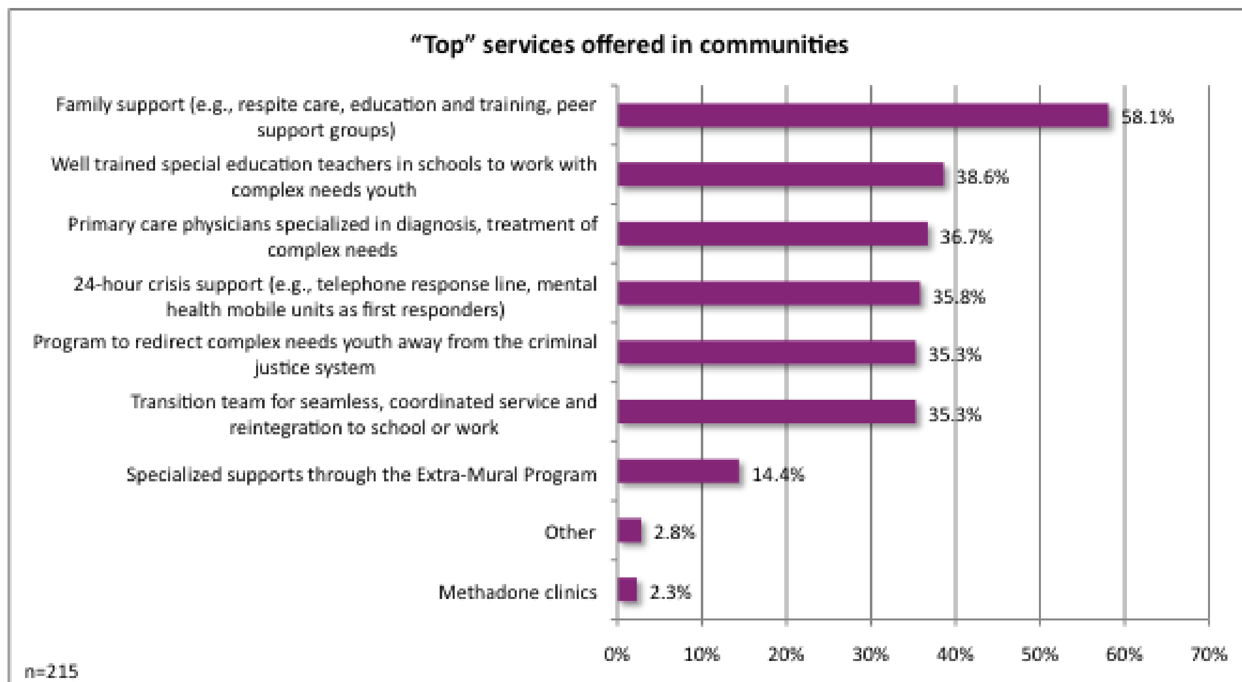
- family support (e.g., respite care, education and training, peer support groups); and
- transition teams for seamless, coordinated service and reintegration to school or work.

In addition, over 90% of respondents either 'agreed' or 'strongly agreed' with these services:

- primary care physicians specialized in diagnosis, treatment of complex needs;
- 24-hour crisis support (e.g., telephone response line, mental health mobile units as first responders);
- program to redirect complex needs youth away from the criminal justice system (see Appendix B).

When asked specifically to choose their "Top 3" services to be offered in New Brunswick communities, responses were fairly evenly spread out with **family support (e.g., respite care, education and training, peer support groups)** standing out with a majority at 58.1%, as shown in Chart 3.2, below. Specialized support through the Extra-Mural Program garnered comparatively less support (14%), and again, methadone clinics ranked last with 2.3% support.

*Chart 3.2 "Top" services offered in communities*



At the in-person dialogue, participants moved into smaller breakout rooms to allow more time for small group discussions on the question of services. In their breakout groups, they were asked to discuss what services or supports they think are most needed to better serve the needs of New Brunswick's children and youth with complex needs and their families.

As a starting point for discussion, dialogue participants were provided with the same list of services as was provided in the online Choicebook (see Appendix D for the participant handout). Dialogue participants went through personal reflection and table discussions before prioritizing services within their larger breakout groups. While acknowledging that many services are required, the following common themes emerged from the top services that each breakout group reported back to the plenary assembly.

## 3.1 Family support and resources

The in-person dialogue participants were in agreement with online participants that family support services and resources are a top priority for a service to be offered through the Centre. Dialogue participants noted that the family is the foundation of care for children and youth with complex needs, and as such, need to be supported.

Dialogue participants recorded the following ideas on how the Centre could offer supports and resources for families:

- respite care;
- immediate support when needed in crisis and debriefing after a crisis;
- networking opportunities;
- support for siblings of children and youth with complex needs;
- aid in navigating the system;
- assistance in understanding, and learning how to deal with, a diagnosis; and
- funds/opportunities to access learning and training for parents.

*"We do not pay enough attention to the siblings of kids who have mental health problems. There are tons we can do in terms of prevention and health promotion." [Dialogue participant].*

Dialogue participants also wanted to see resources in the community to help families who care for children and youth with complex needs. For example, they wanted "strong family support systems in school, in the home and in daycare settings." Likewise, Choicebook respondents voted that family supports (e.g., respite care, education and training, peer support groups) should be a priority service to have in New Brunswick communities.

Dialogue participants wrote that supporting families was important because it would:

- give parents the skill set to cope, and help families make decisions;
- nurture families, keep them intact, have better relationships;
- reduce stress in family life and help parents avoid "burnout";
- give parents confidence; and
- help families to come together and have a voice.

## 3.2 Residential care

Some dialogue participants felt that the Centre should be equipped as a residential facility to provide intensive, tertiary treatment services. They felt that the Centre would need well-trained staff, and the ability to provide the level of care required in each complex case.

Dialogue participants envisioned a warm and welcoming Centre, not one with an institutional feel. They were concerned about the long history of abuse that has occurred in mental institutions in the past, and wanted to distance the Centre from that type of institution and legacy.

The importance of developing a transition plan from the outset, as soon as a youth is admitted to residential care, was highlighted. Participants stressed that the goal must be to get the youth back to his or her community as soon as possible, and to ensure a continuum of care between the Centre and the family/community.

Another idea put forth was that the Centre coordinate "satellite" residential care facilities in communities throughout the province, so that children and youth do not have to leave their region and can remain near their family and regular caregivers. This was envisioned as a "Centre without walls" but with the Centre playing a central role in developing and coordinating the distribution of expertise and services throughout all regions of the province.

> *"We want to keep youth in the community. We don't want them to spend their lives in a Centre. On the other hand, the Centre of Excellence should be able to offer residential treatment as a last resort or in severe cases." [Dialogue participant].*

Differing perspectives arose during plenary discussion at the in-person dialogue on the topic of residential care. Although having adequate and available residential care was a top priority for some, for others it was far preferable to keep children and youth at home, and in their community. Most participants agreed that some residential services are needed in emergency situations. Where opinions seemed to differ was on pediatric psychiatry services. Some participants felt strongly that New Brunswick is lacking residential facilities for minors with mental health issues, whereas others felt strongly that children and youth should not be "institutionalized." In short, while some participants were in favour of the Centre offering residential care services, others were opposed, or thought that residential care through the Centre should be small scale (no more than 12 beds) and short term.

## 3.3 Crisis intervention

Crisis support emerged as a top priority in both the online consultation and the in-person dialogue. Dialogue participants felt that crisis intervention was lacking in the province. Providing 24-hour, short-term crisis support for children and youth with complex needs was regarded as an important service, as was the need for the Centre to provide a safe place for treating youth in crisis. Some put forth the idea of having physical de-escalation centres across the province, the benefit of which, as participants expressed, would allow children to stay in their communities while being treated.

> *"In a crisis situation, parents call for help, and the help is not always there." [Dialogue participant].*

Participants reported that crisis support through the Centre is important for the following reasons:

- for the safety of all concerned – the child, their siblings, parents, care givers, etc.;
- to minimize trauma and the escalation of already complex cases;
- to keep youth out of correctional services, decrease criminal records incurred during crisis; and
- to mitigate other long-term ramifications resulting from short-term situations.

> *"Empower family and youth before it becomes a crisis." [Dialogue participant].*

Online participants agreed that 24-hour crisis support (e.g. telephone response line, mental health mobile units as first responders) is needed; they would like to see this in communities throughout the province.

## 3.4 Evaluation and assessment

Early, comprehensive evaluation and assessment is important to dialogue and online participants alike. Dialogue participants called for earlier referrals and assessments from birth and pre-school age with standardized protocols for assessment, and multiple entry points to access evaluations. They felt that the Centre could be a main access point for evaluation, and coordinate appropriate testing and assessments.

With proper diagnosis early on, dialogue participants felt that there would be better outcomes for children with complex needs. With less delay, they would have more success in receiving the services that they needed and there would be fewer children falling through the cracks.

In other words, dialogue participants believed that early diagnosis can facilitate access to early treatment, and help avoid crisis and other complications, such as over-medicating or prescriptions errors (which can have long lasting side effects).

Likewise, online participants agreed that it is important to have comprehensive evaluations for those not yet diagnosed. Furthermore, they felt there needs to be primary care physicians specialized in diagnosis, and treatment of complex needs, in communities throughout the province.

## 3.5 Specialized care, individualized treatment

Dialogue participants expressed that they want to see specialized supports for children and youth with complex needs, both in the services offered through the Centre and services available in communities throughout the province. For example, services specialized for children and youth with complex needs could be offered through the already established Extra-Mural Program.

> *"There is no cookie cutter approach… People have unique needs. Not all our children are at the same level."*
> *[Dialogue participant].*

Dialogue participants did not want to see a "one size fits all" service delivery model. They were concerned that the current system is too *rigid* and needs to become more *flexible*. Treatment plans should be tailored to the specific needs of the individual child. They also noted that if service providers know the history of the child (with access to a shared patient or client file, an argument in favour of electronic health records), they could better react to the unique situation.

## 3.6 Multi-disciplinary approach

According to dialogue participants, the Centre should have a team of experts (psychiatrists, behavioural consultants, and educators were some examples given) to provide diverse services, and work in collaboration across their disciplines, to better meet the needs of children and youth with complex needs.

A multi-disciplinary approach, it is believed, will better meet the various needs in complex cases because children and their families have more than one issue. Dialogue participants felt that a multi-disciplinary team would be able to provide more holistic care – caring for the whole child, not just one aspect or issue at a time.

> *"Develop a system of care and not just a cadre of services."*
> *[Dialogue participant].*

Dialogue participants felt that the Centre should have fewer bureaucratic barriers so that their team of professionals can have access to the child at home, at school, in the community, and be able to treat the child whenever or wherever necessary. Participants saw other benefits of a team approach, such as creating synergy of ideas for treatment, increasing accountability, and decreasing burnout.

## 3.7 Mental health services

Choicebook respondents (57.2%) chose mental health treatment and support services as their top service to be offered through the Centre. Dialogue participants expressed particular concern that there is a service gap when it comes to the availability of comprehensive diagnosis, treatment, and services for children and youth with serious mental health issues. Dialogue participants felt that often addictions are treated without treating the root mental health issue. As a result, the judicial system is often used, when what the adolescent really needs is mental health services. Online participants also viewed having programs in communities to redirect complex needs youth away from the criminal justice system as a top priority.

Dialogue participants expressed that they would like to see:

- flexibility in access, information on options, and greater accessibility to treatment;
- individualized treatment that suits the child's needs, and is not administered only because there is space available there;
- consistency and coordination of services;
- crisis intervention for mental health issues; and
- applied behaviour analysis for children who need it, along with school-based interventions at any age.

## 3.8 Case coordination, navigation and integrated services

Dialogue participants would like to see a strong role for the Centre in the coordination of complex cases. Case coordination, participants thought, would promote equitable access to available services and family supports. Rather than struggling to 'figure out' what services exist and how to access them, families would be informed and assisted by a navigation team at the Centre. As was previously noted however, the idea of a "navigation" team garnered somewhat less support from online participants than the other proposed options.

*"We have a small province. We need to avoid duplication of services by coordinating services in centre and services that already exist." [Dialogue participant].*

Dialogue participants wanted the Centre to facilitate integrated service delivery – coordination and collaboration between government departments to provide "seamless" service delivery for children and youth with complex needs. The Centre could be the single point of entry to access services, so that "territorial" issues (e.g. not being able to access a service because a different department or service provider is in charge of it) do not interfere with service delivery.

"One child, one file" (or "one patient, one file") came up across tables at the dialogue, referring to the desire for a child to have only one medical file, accessible (electronically) to all of the child's service providers, rather than each service provider having their own separate file on the child. Participants expressed frustration as parents going to a new doctor and having to repeat the child's history over and over again each time. From a doctor or social worker's point of view, they noted, it would be helpful to have access to the child's history and past treatments in order to formulate the best treatment plan.

## 3.9 Community-based teams

Dialogue participants discussed having community-based teams to consult, train and coordinate services in local communities. These teams could provide family support services regionally to rural communities, and extend intensive therapeutic programs from the Centre to the community.

A recurring sentiment among participants was that it is best to keep children with their families, and in their communities, whenever possible. Based on this opinion, some participants thought that the Centre should only treat the most acute cases, and otherwise, children and youth with complex needs should receive services from multi-disciplinary teams in their home communities.

*"We need to fill the gaps existing in the community. The Centre can provide… support and services near to the child in their community. When children leave their families, schools and neighbourhoods, bonds are broken and are difficult to reconnect." [Online participant].*

## 3.10 Transitional support

The idea of having transitional support teams to help youth reintegrate into their community recurred across tables at the dialogue, and was also a top priority for online participants. Dialogue participants envisioned community-based transition teams throughout New Brunswick to serve as a bridge between the Centre, parents and the community.

Transition teams would support youth during the reintegration process back into the home and into school after being away for treatment to make this difficult time easier for the youth, and to ensure that they are not returning home without supports. Dialogue participants expressed that at times the effectiveness of an intervention is stymied when the youth returns to the same conditions that may have led to a crisis intervention in the first place.

Dialogue participants emphasized that transitional teams would provide a continuum of care. Consistency, continuity and coordination of services were seen as key factors for transitional success.

## 3.11 Learning, training, and professional development

In the discussion on services that could be offered through the Centre, learning opportunities came up at every table. Dialogue participants consistently called for training for frontline workers and parents alike, as well as professional development and apprenticeship opportunities. The Centre's role, they suggested, could be to coordinate training. "Virtual centres" could be set up to facilitate learning around the province. Online participants were in agreement that learning/development opportunities should be a service offered for professionals who work with the Centre.

Training models could be set up based on best practices – what we know works based on research across the country or around the world. Dialogue participants also felt that specialty training is needed for care teams, and needs to be consistent and high quality.

Ideas recorded by dialogue participants on training include:

- continued education for teaching assistants in applied behaviour analysis and other evidence-based therapies;
- mental health training for doctors;
- coaching and mentorship programs; and
- partnerships with universities for training.

Dialogue participants felt that training is important because:

- "a child needs to have access to the people who are trained to meet his needs";
- it will support more effective service delivery;
- it forms a foundation for good treatment; and
- it could help prevent crisis and remove road blocks to success.

## 3.12 Research and best practices

The Centre should partner with university research centres in order to tap into applied research on the ground, according to dialogue participants. The Centre needs to research best and promising practices in Canada and around the world. Information on best practices should be conveyed to all levels of support staff, "from frontline workers to bus drivers," to provide the best services possible to children and youth with complex needs.

In a similar vein, dialogue participants suggested that the Centre could become a leader in child protection and welfare by employing experts in the field, and implementing best practices for dealing with child protection issues for children with complex needs. Through its assessment and intervention services for children and youth with complex needs, the Centre could mitigate the negative impact of maltreatment on these children with the proper expertise.

Attention was also paid, during dialogue discussions, to researching evidence-based interventions, and using treatments that have been proven successful. This was very important to some participants; however, there was also some hesitancy on this issue, as discussed with the keynote speaker during a question and answer period. Participants did not want "evidence-based" interventions to be over-emphasized, as they require stringent scientific proof, including in-depth studies. They felt such studies are rare and did not want interventions to be stalled while waiting for the results. They stressed that frontline workers' experience on what works and does not work is valuable "evidence-informed" evaluation, and this input should be taken into consideration in planning interventions.

## 3.13 Other services

Online participants were given the opportunity in the Choicebook to specify anything they thought should be added, modified or removed from the list of potential services offered through the Centre and list of potential services offered in the community.

They added the following ideas about services they felt should be offered through the Centre (these comments are presented in participants' own words).

*Table 3.1 Online comments on services offered through the Centre*

| Online comments on services offered through the Centre | |
|---|---|
| **Services** | **Comments** |
| Professional services | • Counsellors certified with the Canadian Counselling and Psychotherapy Association. |
| Services for violent behaviour | • Lacking services for adolescents with autism spectrum disorder or with intellectual deficiencies with severe violent behaviour. |
| Separate addiction services | • Remove addiction services. This should be at a separate centre. |
| Technical services | • Internet coaching, online monitored chat groups, interactive positive re-enforcement programs and online life skills games and examples, online parent training. |
| Cost of services | • If the family has to pay, make sure it is at a reasonable cost for a family who is already heavily burden or at no cost to the family. |
| Services for neuro-disorders | • In addition to services to address mental health, addictions, those undiagnosed we need to include support for children/youth with neuro-disorders – including acquired brain injury. |
| Eating disorder services | • Eating disorder services – there are no official multidisciplinary teams working together in the same organisation who are pioneers in this field and who can provide expertise to other professionals in small communities who don't know how to address this growing problem. |
| Rights of parents | • Parent should not have to relinquish their rights to garner services for their child. |
| Educational services | • The 'K-12 educational services' for children and youth should be removed. The centre should not ever become a residential school...ever!!!<br>• The Centre of Excellence should NOT become a residential school.<br>• Educational services should be provided in a school situation as much as possible. |
| Rural access | • It is absolutely necessary that rural communities can benefit from these services. |
| Early diagnosis and intervention | • You must address the pre-natal and early years of life in order to address youth problems successfully.<br>• Mental health services for 0-5,early intervention serving children and families with complex needs. |

Online participants added the following ideas on services they felt should be offered in the community (again, these comments are presented in participants' own words).

*Table 3.2 Online comments on services offered in the community*

| Online comments on services offered in the community | |
|---|---|
| **Services** | **Comments** |
| Special needs services | • A special needs school. |
| Educational services | • Resources put into educational services through schools, not through the Centre.<br>• Early identification screening in the school system. |
| Remove methadone clinics | • Remove from list – …many with complex needs suffer from birth causes that have nothing to do with voluntary drug abuse.<br>• I believe that methadone clinics are important but I don't think that they should be in the same building as young children will be.<br>• Methadone clinics are more justifiable for long term users such as adults who have been using for many years, not for youth who have only been using for a short time. |
| Away from criminal justice system | • Referring to programs to redirect youth away from criminal justice system: "We certainly require emergency secure residential crises services to be available for youth and their families/care givers. We need complete wrap around services in the community that run the continuum of services from prevention right through to secure residential care...we cannot wait until we have "out of control" situations to provide supports for youth and their families." |
| Early diagnosis and intervention | • Again, if you do not consider addressing the catastrophic problems caused by drug and alcohol exposure in utero – many of the supports you put in place during middle childhood will have minimal effect. Early, early, early intervention is needed. |

As noted at the beginning of this chapter, only 7% of Choicebook respondents voted for addiction services to be offered through the Centre, and 2.3% in support of methadone clinics in communities in the province. Again in their comments, Choicebook respondents expressed their concerns that children and youth may have substance abuse problems that should not be confused with long-term drug abuse and addictions, and questioned the safety of exposing children and youth to methadone clinics. Likewise, dialogue participants expressed concerns that the root cause of substance abuse be addressed, such as mental health issues, rather than only treating substance abuse, which may only be a symptom of a deeper rooted problem.

It is also interesting to note that while the majority of Choicebook respondents were in favour of K-12 educational services for children/youth who can't attend school, 15.6% 'disagreed' or 'strongly disagreed' with this notion. Those who disagreed felt that educational support was important, but they wanted to see improvements in the school system itself. They wanted to see: "well-trained resources teachers that support New Brunswick classroom teachers to work effectively with youth with complex needs." [Online participant].

*"I would remove K-12 educational services if this means the Centre is to become a 'residential school.' Services to support youth within their neighbourhood schools would be appropriate and helpful." [Online participant].*

On the other hand, as noted, the majority of Choicebook respondents were clearly in favour of K-12 educational services for children/youth who can't attend school (78.7% 'agree' or 'strongly agree'). Therefore, there was some divergence of opinion on the question of educational services.

*"In regards to educational services, it is extremely important that the province work towards alternative educational programs to meet the needs of those youth who are unable to function in the current public school system. Public school often causes tremendous anxiety and stress for youth with mental health issues and often magnifies the symptoms of their illness." [Online participant].*

# 4. CRITERIA FOR SELECTING A LOCATION

While the Centre will provide services to children and youth with complex needs from all over the province, it will operate out of one community. The Task Force has the responsibility to recommend to the Government of New Brunswick where the Centre should be located. To inform their recommendation, the Task Force requires clear and transparent criteria. In both the online Choicebook and in-person dialogue, participants were asked to consider what criteria need to be taken into account in selecting a location for a New Brunswick Centre of Excellence for Children and Youth with Complex Needs.

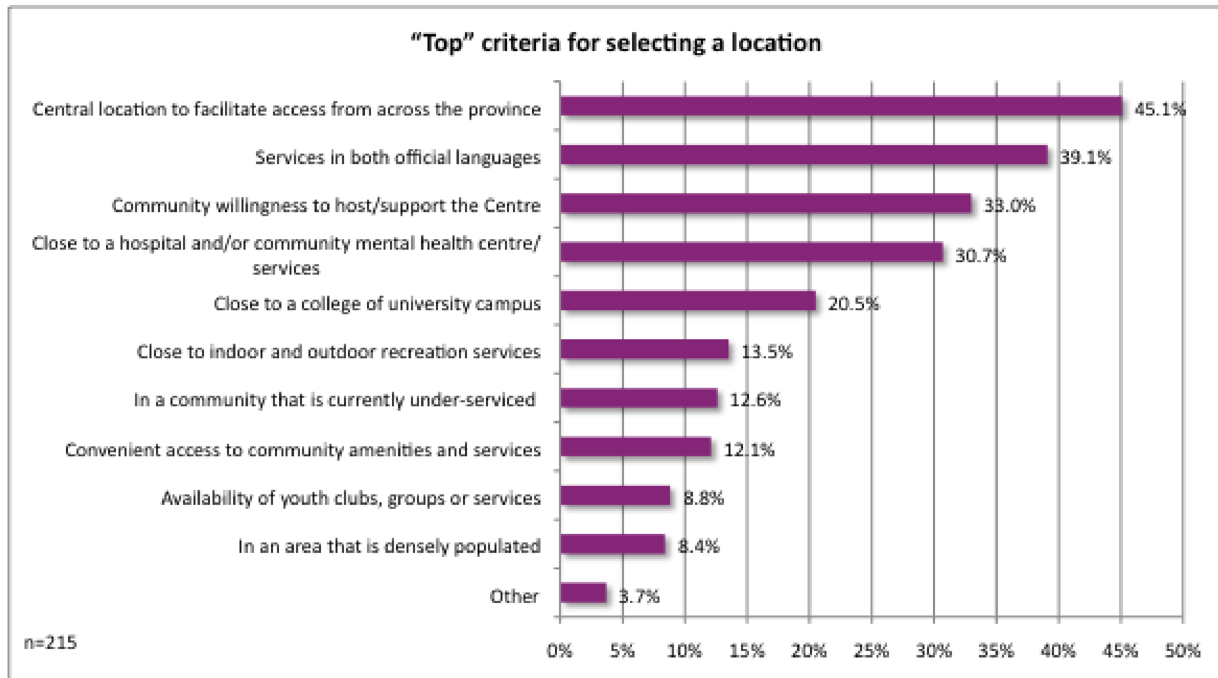
In the online Choicebook, participants were asked to rate each criterion for selecting a location for the Centre, and then choose their top three criteria (see Appendix A). Respondents were somewhat divided over certain criteria, for example whether the Centre should be located in an area that is currently under-serviced, and to a lesser degree, whether the Centre should be located in an area that is densely populated. There was strong support to have the Centre in a community that is supportive of the Centre, its work and those who use its services, with over 90% of respondents either 'agreeing' or 'strongly agreeing' with that criterion. Additionally, over 80% of Choicebook respondents either 'agreed' or 'strongly agreed' with the following criteria:

- in a community that facilitates access from across the province;
- in a community that facilitates services in both official languages; and
- close to a hospital and/or community mental health centre/services (see Appendix B).

When asked specifically to choose their "Top 3" criteria for selecting a location for the Centre:

- 45.1% of participants chose **a central location to facilitate access from across the province**;
- 39.1% chose **services in both official languages**;
- 33% chose **community willingness to host/support the Centre** as their priority criteria, as shown in Chart 4.1, below.

*Chart 4.1 “Top” criteria for selecting a location*




At the in-person dialogue, participants were given the same list of potential criteria for selecting a location as was used in the online Choicebook, and were asked to explain which criteria they thought were most important and why. They were also invited to suggest any new criteria, which they thought would be important to consider, and again provide the reasons why (see Appendix E for handout). Five criteria emerged as predominant areas of focus in the in-person dialogue.

## 4.1 Close to a hospital, community mental health services

Dialogue participants shared Choicebook respondents’ support of establishing the Centre close to a hospital, and/or near community mental health services. They felt it would provide access to the appropriate professionals, expertise, resources and services to complement and support the Centre.

> *“It is important for the Centre to be close to a hospital or mental health centre to recruit more professionals, and in a crisis to be able to access mental health treatment close by.” [Dialogue participant].*

They also thought it was important to be near a hospital in case of medical emergencies, and would be beneficial for medication assessment – to provide a safe place to monitor medication changes, which can be risky without the proper support.

## 4.2 Central location to facilitate access from across the province

Online Choicebook respondents agreed that locating the Centre in a centrally located community, which would facilitate access from all regions of the province, was important from an equity perspective. Participants wanted the travel distance to the Centre to be reasonable, and not be a deterrent to access. Some highlighted that not all families can afford to travel to be with their children while they receive treatment out of the community. Participants felt that a central location was key to maintaining family and professional relationships in the home community.

## 4.3 Community willingness to host and support the Centre

The community's willingness to host the Centre was voted a top priority by online Choicebook respondents, and was essential, according to dialogue participants. If the community (municipal government, associations and residents) is accepting of the Centre, then children and youth will feel welcome in the community, and will feel comfortable using community services, facilities, amenities, and so forth, according to dialogue participants. They thought that awareness-raising was necessary to dispel stereotypes, promote understanding about the Centre and its work, and build support from the Centre's neighbours.

## 4.4 Close to a college or university campus

Dialogue participants felt that locating the Centre close to a college or university campus would increase the potential for partnerships between the Centre and the academic institution, allowing the Centre to potentially access resources and funding for research and training opportunities that it could not otherwise fund or run on its own.

Participants also noted that proximity to a university would potentially be a draw for professionals considering employment at the Centre, and the Centre could recruit staff from appropriate college or university programs. It may even attract new students to the field – with more job openings in the field, students would be more enticed to study such programs. The Centre can tap into the expertise on campus, and could even partner to bring in a Research Chair on complex needs.

*"Being close to a university will give a level of accessibility to both new and old professionals, students and professors. It will help the Centre attract expertise and create knowledge." [Dialogue participant].*

## 4.5 Community ability to offer services in both official languages

Choicebook respondents agreed that the community's ability to offer services in both official languages should be a criterion in selecting the location of the Centre. Dialogue participants felt that children and youth need to be treated in their own language and that this can be critical to the child's health and well-being (and to the family's ability to fully participate in the child's care). If a child is having trouble communicating with their care givers and the professionals who are supposed to be helping them, there will be a negative impact on their treatments' efficacy.

*"Bilingual staffing will be paramount."*
*[Dialogue participant].*

## 4.6 Other criteria

Although the discussion was intended to identify *criteria* for selecting a location, and not to identify a specific community, participants did choose to voice their opinions on the matter. It is worth noting here that there was some tension about having the Centre in the Miramichi, with some participants expressing that it would be convenient to be near the New Brunswick Youth Centre, while others were adamant that proximity would be a negative factor.

Online participants were given the opportunity to specify anything that they thought should be added, modified or removed from the list of criteria for selecting a location for the Centre. The following table summarizes the ideas put forth by Choicebook respondents, as well as additional ideas that were collected from dialogue participants (all comments are presented in participants' own words).

*Table 4.1 Online and in-person comments on criteria for selecting a location*

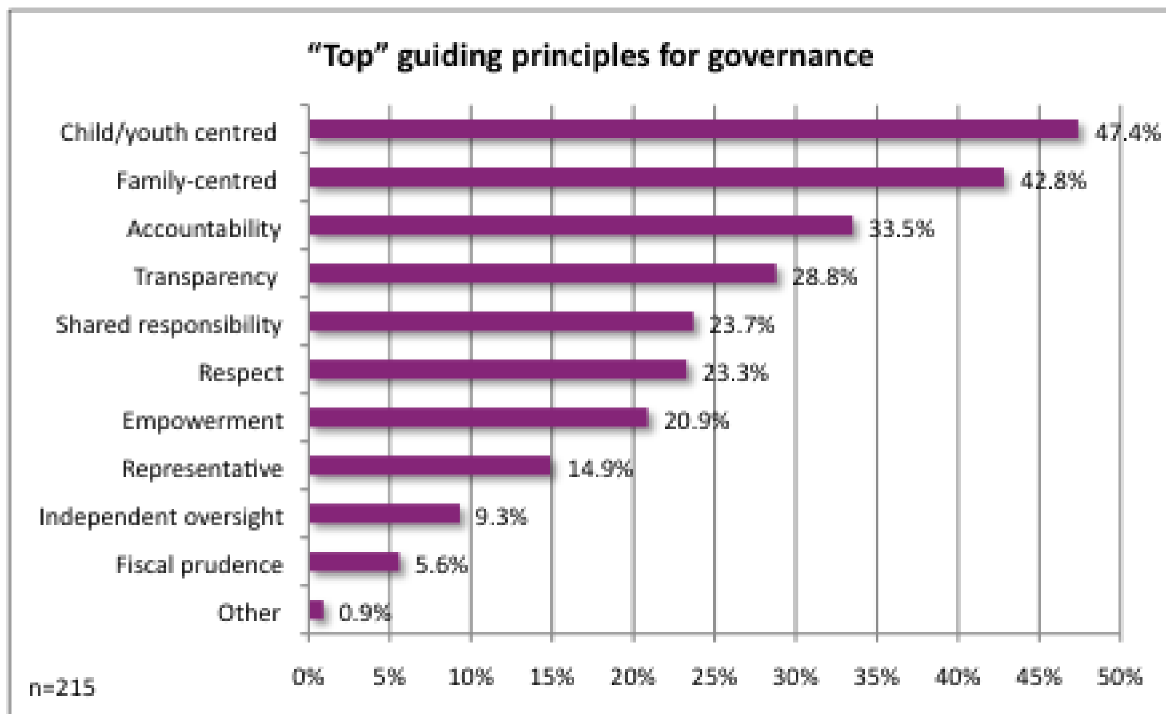
| Online and in-person comments on criteria for selecting a location | |
|---|---|
| **Criteria** | **Comments** |
| In a community that is currently under-serviced | • To increase services, particularly in rural areas.<br>• Negative characteristic and should be removed from the list of criteria. |
| In an area that is densely populated | • Assumes there would be more services available (than in a less populated area).<br>• Better able to attract professionals to work at the Centre. |
| Close to indoor and outdoor recreation services | • Children and youth need to participate in recreational activities.<br>• Good way to model appropriate behaviours in a community setting.<br>• Can interact with other youth. |
| Availability of youth clubs, groups or services | • Uncertain that this is necessary if treatment is short term. |
| Convenient access to community amenities and services | • Children/youth and families need to experience positive social contact, and make resource connections. |
| Property | • The property should be large enough to expand if necessary in the future, e.g., to increase residential capacity. |
| Develop services | • In a community with the potential to develop services to meet the needs of children and youth with complex needs. |
| Proximity to Government | • Benefit in being located near the provincial government. |
| Multiple locations | • A Centre of Excellence should be available in ALL major cities – modify the present Mental Health Centres to be Centres of Excellence. Not just one Centre for the whole province, but modify and change the way EXISTING Centres operate. |
| Transportation | • Availability of public transit. |
| Youth population | • ADD: geographical area with the highest density of children and youth 0-19 (not the population density in general but density of under 19). |
| Youth programs | • Youth programs (if not already established) can be developed once the centre's location is determined. |
| Northern region | • I would like for [the Centre to be located] not in the same regions that are always selected… often in the south of the province. The north also has many strengths that should be considered. |
| No physical centre | • I am not sure there needs to be a physical structure in place for the goals of a Centre of Excellence to be achieved. I would rather see resources invested in communities and families, than money spent on building something. |

# 5. Guiding principles for governance

The Task Force's fourth strategic question has to do with the governance of the Centre. Participants were asked to consider high-level principles that should guide the governance of the Centre. In the online Choicebook, participants were asked to consider potential guiding principles for governing the Centre and choose their top three from the list (see Appendix A).

**Child/youth centred** received the most votes at 47.4%; **family-centred** received 42.8%; and **accountabilit**y 33.5%, as shown in Chart 5.1, below.

*Chart 5.1 "Top" guiding principles for governance*




At the in-person dialogue, participants reflected on a preliminary list of guiding principles developed by the Task Force (the same list as was provided in the Choicebook), and had group discussions at their tables on possible additions to the list and how these principles might be put into practice (see Appendix F for participant handout).

*"Involve youth, families, non-governmental advocates and direct service workers in developing the vision and guiding the ongoing development of the Centre. If the development is steered by government or major non-profit agencies, it will likely only replicate the "silo" approach and turf-protectionism that contributes to the inadequate status quo." [Online participant].*

The following ideas on guiding principles were collected from text submitted in the online Choicebook and recorded on table Worksheets at the in-person dialogue (comments are presented in participants' own words).

*Table 5.1 Online and in-person comments on guiding principles*

| Online and in-person comments on criteria for selecting a location | |
|---|---|
| **Guiding principles for governance** | **How we might put this principle into practice** |
| **Accountability** – The Centre's stakeholders, including parents and children/youth, can hold decision makers to account | • Start with a mission statement<br>• Regular program audits<br>• Advisory board<br>• Board of directors<br>• Measure "excellence," evaluate and report that goals have been met<br>• Annual report<br>• Holding decision-makers to account based on standards and ethical principles<br>• Accountability would include on-going evaluation of the efficacy of programs/services. Too often professionals are restricted to implementation of programs that have little empirical evidence as to their effectiveness. Follow-up evaluation is often sacrificed because of time/client constraints. |
| **Transparency** – Communications are open and information is made readily available | • Regular reporting<br>• Full disclosure and participation from all involved government departments<br>• Dissemination of data<br>• Decisions need to be made openly<br>• To build trust of parents, youth and the public |
| **Representative** – The Centre's stakeholders, including parents and children/youth, are represented at the decision-making table | • Families and youth are supported to participate<br>• Urban and rural representation<br>• Language representation<br>• Empower parents and youth in decision-making process from the beginning<br>• Family, professional, academic |
| **Shared responsibility** – Families, professionals, communities, not-for-profit organizations and government all contribute to the development and coordination of services | • Tap into volunteer services<br>• Set mandatory, consensual participation criteria<br>• Community-based advisory and decision-making committees<br>• Shared responsibility of each person involved in the child's treatment plan, e.g., parent, psychologist, and government representatives |
| **Child/youth-centered** – Decisions are made with the needs and best interest of the child/youth in mind | • Representation of family<br>• Individualized planning<br>• Youth involved beyond "tokenism" |
| **Family-centered** – Families have the primary responsibility and capacity to care for their children and are actively involved in planning services | • Representation of the family<br>• Implement principle in day to day operations<br>• Define family from youth's perspective |
| **Empowerment** – The strengths of | • Those who are empowered can become a resource and |

| | |
|---|---|
| children and youth with complex needs and their families are celebrated and supported | champion for the Centre<br>• Look to strengths of youth, family, school, community<br>• Involve them in all decisions<br>• Seems misplaced here ("motherhood and apple pie statement") this principle might be more applicable to a management team than to the governance<br>• Because of a lack of services and advocates, parents have often had to be the advocate for their child – parents need to be empowered to support their children<br>• Empower families and youth before it becomes a crisis |
| **Fiscal prudence** – Public and community funds and resources are used in a responsible manner | • Fiscal prudence through community stakeholders being involved in decision-making and through accountability<br>• Provide funds to support family advocacy and travel to and from the Centre<br>• In order to be sustainable |
| **Independent oversight** – An independent entity is responsible for monitoring the activities of the Centre and has the power to make recommendations to improve its operations | • Advisory board<br>• Child and youth advocate<br>• Selected based on expertise<br>• Define independent entity<br>• Government needs to stay out of it so that when there is a shift in government the Centre is not compromised<br>• To protect from political will and governmental changes |
| **Respect** – Everyone is treated equitably, with respect, fairness and impartially | • All programs and policies must be mindful of varying levels of ability, cultural linguistic, socio-economic background, etc. |
| **New guiding principles added by participants** | **How we might put this principle into practice** |
| Community involvement | • Empower communities to come up with their own definition of governance and build upon this |
| Code of ethics | • Standards that are not subject to political influences<br>• Consultation of advisory committee |
| Continuous improvement | • Make a commitment to continuous improvement |

# 6. Closing Thoughts

Dialogue participants expressed in their evaluation forms that they gained a better understanding of the views and experiences of other participants, and gained a deeper understanding of the various dimensions associated with creating a Centre of Excellence for Children and Youth with Complex Needs. Furthermore, 100% of dialogue participants said that they valued the opportunity to contribute through the consultation (see Appendix G for dialogue evaluations).

Likewise, online Choicebook respondents agreed, in their evaluations, that they now have a better understanding of the proposed Centre, and that the Choicebook allowed them to effectively share their views with the Task Force (see Appendix B for Choicebook evaluations).

The Task Force collected a wealth of data – hopes, concerns, ideas from participants in the two streams of the consultation on a Centre of Excellence for Children and Youth with Complex Needs. Both Choicebook respondents and dialogue participants expressed that although health care workers are trying hard to meet the needs of children and youth with complex cases, participants believe it often isn't enough – that the services that are currently available are disjointed, difficult to access and insufficient.

> *"I have such a child, and right now what is in place is entirely inadequate in very many areas… especially … in dealing with some of the exceptionalities of these children." [Online participant].*

Given their concerns about the current challenges to meeting the needs of children and youth with complex needs, participants had many hopes and suggestions for the services a Centre of Excellence for Children and Youth with Complex Needs could provide both through the Centre and in communities throughout the province; advice on the criteria to consider when selecting the location of the Centre; and considerations on what guiding principles should influence the governance of the Centre.

> *"I hope for greater understanding of the issues facing the youth with complex needs and the development of the best services for these youth." [Dialogue participant].*

Through this consultation the Task Force received feedback from a variety of perspectives – parents and guardians of children and youth with complex needs, social workers, staff from various organizations, and many others. Although their perspectives were varied, overall, participants seemed to agree on important factors for moving forward with establishing a Centre of Excellence for Children and Youth with Complex Needs. There was divergence of opinion on some issues, such as whether the Centre should be involved in addiction services and methadone clinics, whether the Centre should offer long term residential services, and what role the Centre should have in educational services. However, participants from both streams agreed on a number of key points:

- Parents are struggling to cope with the needs of their child or youth, and require supports ranging from having access to timely diagnosis, to navigating the health care system, to learning how to care for their child, to supporting and addressing the needs of siblings.
- There is a shortage of adequate beds and services available, particularly in times of crisis, when protecting the safety of the child or youth is paramount. Parents have no other recourse but to bring their child to the hospital emergency room, where they are later released without proper treatment or support thus increasing the risk of relapse and/or harm.
- Early diagnosis and treatment is critical. The sooner a child's needs are recognized, the sooner they can receive the care they need and avert a small issue escalating into lifelong problems.
- The system must be *flexible* and able to adapt to the specific needs of each child or youth – the child or youth (and his or her circle of care) should not have to be made to adapt to the system.
- The Centre can act as an invaluable coordination body: a single point of access to services for children and youth; a link across government departments to mitigate the "silo" effect; and an enabler for multi-disciplinary teams to come together (with particular emphasis on addressing the lack of mental health services available for children and youth).
- Transitional supports to/from the Centre to/from communities is critical, because ultimately, children and youth need to be as close as possible to their families and their communities. Maximizing opportunities for care to be provided in the child's or youth's home community is of the utmost importance.
- Recruiting and training professionals for the Centre is key, but so is ensuring that learning and training opportunities are available to parents, teachers, resource teachers, professionals and anyone else in contact with complex needs children and youth.
- The Centre can and should make a contribution to research on best and promising practices, particularly through innovative partnerships with the province's academic and research institutions. This will both aid recruitment and retention efforts, and help advance research on best and promising practices, and evidence-based and evidence-informed interventions.
- The Centre cannot operate in a vacuum: linkages with local hospitals and mental health services, as well as the active support of the host community (e.g., the municipality, the local police force, residents) will be key to its success.
- Children and youth (and their families) must be able access services in their maternal language – the Centre must be equipped to offer its services in the province's two official languages.
- The Centre must be located in an area that will facilitate easy and equitable access from all corners of the province, so as to ease the barriers posed by travel and help the Centre's users to maintain their connections to their home communities.
- The Centre's governance must be guided by a focus on accountability, an unwavering commitment to putting the needs of the child or youth first, and to supporting the families.

Lastly, there was a sense among participants that they wanted to see things done differently. They viewed the development of the Centre as an opportunity to improve on the way things are done currently, and implement an approach to meeting the needs of children and youth with complex needs – one that would build on all the best New Brunswick has to offer and be truly innovative.

*"A Centre of Excellence means …an approach to working with young people with complex needs is developed based on what works for them. This implies the training, development and support of a new brand of professional outside the normal "health and psychological" competencies. Our community's difficulty in dealing positively and successfully so far with many of the young people in need cannot be changed by doing more of the same. Let us explore a different approach based on the models … that have been found to be valuable in recent years." [Online participant].*

*Task Force Co-Chairs, Bernard Richard and Shirley Smallwood, would like to thank all consultation participants for sharing their time, perspectives and experiences to help inform the establishment of a Centre of Excellence for Children and Youth with Complex Needs.*