

National Children's Alliance Document for Presentation to the Romanow Commission

Introduction

The United Nations Convention on the Rights of the Child (1989) calls upon all of its signatories – including Canada – to first and foremost, act in the “best interests of the child¹” in all that we do.

The debate over the future of Canada's health care system touches every Canadian's life, but perhaps no single group more than children² and youth. Representing about one-quarter of the population, Canadians under 19 are not only major users of the universal health plan, but also will live the longest with the consequences of decisions made by today's policy makers.

The irony, of course, is that children and youth themselves have little or no voice in this process. Their best interests must be represented by their families and by the wide array of professionals who care for them. Health professionals, public health workers, teachers, social services workers, parents and many others play an essential and collaborative role in caring for Canada's children and youth.³

Childhood represents a highly sensitive developmental period that is unique to each child. These developmental needs are currently not considered within the existing system and as a result they need particular considerations. A missed opportunity to support children's health at any stage in this cycle may reverberate negatively across the life span. Scientific research has demonstrated that early detection of developmental problems or challenges coupled with a swift, appropriate response are critical to a healthy childhood trajectory.⁴

Adolescence is a unique time of tremendous change and for many youth it is a time of significant risk. Certain populations of youth, such as youth on the street and sexually exploited youth, are at extreme risk for injury and illness. We know that comprehensive, confidential, accessible and youth friendly services can make a difference. Youth focussed services address multiple indicators of effective development, including health, housing, income, employment, nutrition, education, non-criminal behaviour, etc.

In the past, Canada's health care system has done an effective job in supporting the healthy development of children and youth in some areas, particularly through public

¹ The term “child” is defined within the context of the Convention on the Rights of the Child as a boy or girl from birth to age 18 years of age.

² Throughout this document the word children or child, when used alone, always refers to children and youth, aged 18 or under.

³ Canadian Paediatric Society. Planning a Healthy Future for Canada's Children and Youth: Report on the 1999-2000 Paediatrician Resource Planning Survey, 2001.

⁴ Tipper, J. & Avard, D., 1999. *Building Better Outcomes for Canada's Children*. Discussion Paper No F|06. Canadian Policy Research Networks Inc., Ottawa

health, prevention and health promotion initiatives such as SIDS and immunization strategies. Unfortunately, capacity is being seriously threatened. Over the past 20 years, Canada has posted a disturbing decline in our public sector expenditure on healthcare in comparison to other OECD nations. In 1984, we ranked 15th out of 22 industrialized countries; by 1998, this had declined to 18th out of 22.⁵

The severity and significance of this decline is best understood when considered in the context of a growing number of new morbidities as they relate to environmental and mental health (i.e., asthma, cancer, suicide, depression) threatening young Canadians. Of particular concern is the health profile of those young Canadians living in Aboriginal communities, those of recently immigrated visible minorities, those who are in care of the state and those who live in inner cities whose health is being severely compromised by factors such as poverty and violence. Equally compelling are the stories of courageous families attempting to help and encourage their children and youth with disabilities without adequate support services. These realities represent some of the new challenges facing our health services system as it struggles to meet the changing needs of Canadian children amid severe financial cutbacks and critical human resource shrinkages.

Perhaps the time has never been more appropriate for the federal government to refocus its commitment to children's health and develop a more robust, family and child-centred service-delivery model that responds directly to need in the most appropriate manner – a model that reaches out to children and families where they live, learn and play, and that focuses attention on prevention and promotion, not simply on reparation. An integrated model that utilizes resources wisely will be essential if the health care system is to remain sustainable well into the 21st century.

The following document addresses the four main points as outlined in the Commission on the Future of Health Care in Canada's Interim Report as they relate to children and youth issues, needs and priorities. This document has been developed collaboratively by the National Children's Alliance, in consultation with some members of the Health Action Lobby (HEAL), to focus on the health service system through the lens of children, youth and their families.

Recommendations

1. Establish a protected, sustained, comprehensive, timely, long-term budget targeted for universally accessible child and youth health care services and programs, funded regardless of family income.
2. Expand and re-distribute essential health care services within the Canada Health Act to ensure equitable access for children and youth.
3. Develop integrated human resources strategies, for health matters specific to children and youth.

⁵ Health Action Lobby (HEAL), October, 2001. *Reconfiguration and Renewal: Ideas and Options for the Future of Canada's Publicly Funded Health Care System*. Submission to the Royal Commission on the Future of Canada's Health Care System.

4. Develop increased accountability within the health system based on national goals for child health outcomes.
5. Create integrated systems between health, education and social programs/services at the community level so that children and their families are the central focus.
6. Explore alternative models of service delivery to promote cost-effective integration and coordination of the broad range of health services.
7. Develop disease prevention and health promotion strategies that address children and youth through public health programs and services.
8. Implementation of policies, programs and services to address the determinants of health.
9. Exempt health care from the rules of international trade.
10. Increase funding to support the design and management of research, surveillance, data collection systems and regulatory frameworks that recognize the special susceptibilities and vulnerabilities of children and youth.
11. Support the delivery of technological advances in geographically, socially and economically isolated communities.
12. Recognize the role environment plays in child/youth health and include environmental health strategies within the health care reform system.
13. Expand health services to include adequate and accessible access to mental health diagnosis, treatment and care.
14. Create opportunities for children and youth to participate in decisions that affect them- children have a right to be heard.

Canadian Values

It is clear that Canadians want and need more for their children. Research conducted by the Canadian Policy Research Network has demonstrated that, across the country, Canadians feel that:

- Children are a high priority for public spending
- Healthy child development in the early years requires a sustained high investment by all stakeholders, and
- Health care and education are essentials that should continue to be the backbone of Canada's universal social programs.⁶

⁶ Stroick, Sharon M. & Jenson, Jane, 1999. *What is the Best Policy Mix for Canada's Young Children?* Canadian Policy Research Networks, Study No. F-09

Canada has made a commitment to children and youth nationally and internationally, through its participation in the UN Convention on the Rights of the Child. Based on this, there are two articles (Article 12 and 24) that need to be considered when developing health services for children and youth. Article 12 states that “a child shall 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 24 recognizes that “the right of the child to the highest standard of health and to facilities for the treatment of illness and rehabilitation of health”. Both of these articles reflect the need for children and youth to have a voice in health care services that affect them, feel empowered to request the highest standard of care and be supported by professionals who provide services for them.

Research has made clear the relationship between poverty and population health: the lower the income, the poorer the health. A low level of family income is associated with a higher rate of low birth weight and potentially, with associated adverse effects such as chronic illness, developmental delays and disabilities. With an estimated 20% of all Canadian children living in poverty⁷, we are facing an unacceptably large and growing population of young people at risk of failing to reach their developmental potential. Systems built on user fees have consequences for children and youth. Children are our poorest and most vulnerable citizens and should have adequate access to care through the public health system. No child should be denied services based on their parents’ income.

Another important Canadian value is access to timely and appropriate care. Based on this, the health system needs to recognize and respond to the special developmental needs of children and youth. From birth to adulthood, children grow and change at a rapid pace. Treatments, medications or specialized services diagnosed one month may be ineffective six months down the road if a child is forced to wait. As part of the criteria being proposed for waiting lists it will be important to make special considerations to ensure appropriate and effective care is provided.

“Alberta pays for leg braces only once a year, but my six-year-old needs new ones every six months (at a cost of about \$2,000 a pair). He also requires inserts for his shoes, at about \$400 per pair and that is not covered either.”⁸

Disease prevention and health promotion initiatives need to play a more prominent role in the re-shaping of the health care system and targeting programs to children and youth will go a long way in building a sustainable future for Canada. Current rates of physical inactivity, obesity and type 2 diabetes in Canadian children and youth are creating a great deal of concern among health professionals. The health care system needs to include programs that encourage healthy lifestyles to reverse this current trend and build a healthy society.

⁷ Canadian Institute of Child Health, 2000. *The Health Of Canada’s Children, 3rd Edition*. Ottawa.

⁸ Canadian Coalition for the Rights of Children. 1999. *The UN Convention on the Rights of the Child: How does Canada measure up?* Ottawa. P. 69.

One of the values Canadians take great pride in is their ability to work co-operatively. The team approach is something we embrace whether we are cheering on Olympic hopefuls or pulling together aid for victims of a forest fire. There is a great deal of interest among health professionals to work together in teams to provide the best possible care for their patients. This team approach is particularly important for children and youth who often have many professionals involved in their care. Reorganizing service delivery in a way that integrates services across the continuum of care (acute to long term) in a seamless manner will be extremely beneficial to children, youth and their families. It is time to consider new models of health service delivery for our Health Care team.

Currently the Canada Health Act allows provinces to cover a wide range of health services beyond the originally defined hospital and physician based services. Preventative and community based programs/services such as home care and prescription drugs, are not necessarily covered by provinces. This greatly limits access for children, youth and their families as their need for hospital or physician based services are often minimal compared to the longer term care that is required when they arrive back home. Because of this, families often over-use expensive hospital based services that are funded under the Canada Health Act. Access to a broader basket of services provided by a wide range of professionals has been possible under the CHA since 1984, yet provinces have not designed a system to take advantage of this flexibility in a multi-sectoral way. Expanding the Canada Health Act to include community-based services which are not widely considered in the implementation of the CHA (such as home care) would make the system more accessible to children, youth and their families, reduce the burden on hospital and physician based services and save the health care system money.

“Our 11-year-old son, Shawn, has severe cerebral palsy. He communicates by means of gestures, a picture board and a computer. He cannot move or use his hands independently. And still he is part of his school, his church, his hockey team, his after-school day care... His self-esteem is high; our belief in his capacity to contribute to his community and to have a fulfilling life is solid. None of this would have been possible had he not been in inclusive community child care right from the beginning.”⁹

Sustainability and Funding

The current health care system operates in a number of silos. Silos exist in funding allocations for education, health and social services- each group working separately, competing for funding and often vying with each other for similar, complementary initiatives.

This silo approach creates an unnecessary competition for dollars as well as a lack of understanding of how groups can work together to improve situations. Health, education, social services and criminal justice cross over in many ways such as immunization

⁹ Canadian Coalition for the Rights of Children. 1999. *The UN Convention on the Rights of the Child: How does Canada measure up?* Ottawa. p. 61.

programs, breakfast programs and mental health services. To be effective these sectors must work together to plan strategies and set priorities as opposed to individually planning and then linking their plans afterward. Working together from the beginning will decrease unnecessary overlap and better integrate services. This will result in services being provided in a more efficient and cost-effective manner.

For children and youth, health is linked closely with education and social services. Childcare and school settings are excellent places where prevention, early detection and primary care services could be delivered. This is the environment where children spend a great deal of their waking time. Much of the inefficiency that leads to higher costs and poor service is explained by system redundancies and ineffective inter-system and inter-professional communications. Children, youth and their families are asked for the same information by multiple systems and providers. The complexity of the system and available services is all too often overwhelming, confusing and prevents appropriate access. Systems and providers do not readily inform each other of findings, contacts and services.

Coordinated approaches that encourage collaboration will expand opportunities to work together, maximize limited resources and integrate services in a seamless manner. This will create better health opportunities for children and youth as well as reduce the costs to the health care system.

As part of health care system reform, it will be essential that long-term funding commitments be made to allow groups to plan for the future. It will also be important that this process be transparent in terms of how much money is being spent, by whom, on what basis and with what results. Monitoring of results will be essential in determining future spending priorities.

To assist in collecting results, a number of health goals and indicators will need to be developed for the general population as well as other especially vulnerable groups such as children and youth, seniors, visible minorities, aboriginals and persons with a disability. What is needed is a clear identification of the health service gaps and what is required to fill these gaps more effectively.

National child and youth health goals need to be determined through multi-disciplinary collaboration. These goals will contribute to the framework of accountability. Health funding specifically allocated to children and youth should come with conditions to ensure governments are accountable for spending health funding on improvements that impact on health outcomes for children and youth. This accountability should also contain incentives for groups to work collaboratively to achieve improvements in children and youth health outcomes and demonstrate cost savings.

Professionals working with children need longer patient time and find it difficult to maintain a reasonable salary in the fee-for-service system. This fact is particularly apparent when managing a child and family with a complex behaviour, genetic or developmental problem. Consultations often take considerable time and a comprehensive

reimbursement strategy for professionals who provide services to children and youth must take this into account.

Quality and Access

What is currently being provided by the provinces under the umbrella of the Canada Health Act is not meeting the needs of children and youth. Home care, long-term care, rehabilitation services, occupational therapy, physiotherapy, psychology, social work services, pharmacare, public health and primary health service delivery are all essential services for children and youth. Additionally, innovations such as tele-medicine are usually developed for the adult population and are not easily accessible for children and their families.

“There is a desperate need for good home child care for children with special needs. It takes a special person to look after our kids. I would stay home if I could afford it, but I have to work for our family to be financially secure”¹⁰

A multi-faceted national public health strategy is needed to increase public understanding about the factors that influence individual and community health and well-being. The purpose of this strategy would be to broaden people’s understanding of health, provide accurate information about current and anticipated future expenditures, identify pressures and alternate solutions and build public support and political will. Under this strategy, successful preventative approaches could be featured, champions could speak out about the value of preventative approaches and political leaders could help build bridges across sectors, especially between medical institutions and other community organizations committed to health and wellness.

Addressing the determinants of health contributes to positive health impacts, while the health care system, it has been argued, makes a relatively small contribution to health. With this in mind, the implementation of policies, programs and services that address the determinants of health could:

- Result in reduced disruption in children’s lives.
- Allow vital resources to be maximized and reallocated towards need – providing broader support for the programs offered
- Improve literacy levels because of a sense of self-esteem
- Allow for an incremental shift of emphasis to prevention
- Reduce dependence upon downstream resources as the child matures.
- Improve long-term economic benefit.
- Focus on wellness not illness– emphasizing the positive side of health and the long-term health benefit.

Canada will not meet its developmental potential if it fails to offer its youngest members every opportunity to meet their needs.

¹⁰ Canadian Coalition for the Rights of Children. 1999. *The UN Convention on the Rights of the Child: How does Canada measure up?* Ottawa. p. 61.

Quality and Access Issues for Children and Youth

Professional reimbursement: Access to appropriate services is jeopardized by reimbursement systems. Fee-for-service schedules do not allow physicians adequate time to spend with children, youth and their families. Salaried positions for other health professionals are controlled by hospital global budgets with the consequence that services are all too often non-existent, under-funded or cut. Research has shown that user fees reduce access for those in the lower socio-economic categories.

Medication: Pharmacare coverage is available for children in the social service system, but many low-income families do not receive prescription benefits. Consequently, low-income families do not have access to necessary pharmaceuticals.

Waiting lists: Children and youth have unique developmental needs that amplify their need for immediate care. Growing children do not have time to wait for treatments as their bodies are changing too rapidly and corrective opportunities are missed requiring longer and more costly interventions. For example, a child who waits 4 months for a prosthetic leg, may find out that it does not fit because he has grown 2 inches.

Geography: Geography plays a key role in determining access to child health services. Canadians living in remote or rural locations are less likely to receive the services they need than their urban dwelling peers. Families should be supported to remain in their own social, cultural and historical communities if possible. Addressing this problem will require a multi-faceted approach that should include adequate access to the following:

- specially trained nurse practitioners
- health professionals with special training in paediatrics (the equivalent of a Diploma in Child Health, but financially recognized)
- improved and subsidized transport services for children and parents
- no or limited cost parental accommodation at regional centres
- collaborative integration of services by smaller regional centres
- employer recognition of parent/child needs when children require care or services at remote centres
- development of the technical delivery system to allow telemedicine and other technological advances in isolated communities.

Paediatric Home Care: Children in need of home care remain underserved¹¹. This deficiency may be partially explained as paediatric home care is philosophically different in its objectives from home care for adults. For example, rather than focus on individual capacity building (as with seniors and adults), paediatric care aims to teach the family or caregiver(s) ways to provide appropriate care for their child's growth and development. Families, therefore, are a critical factor in determining the extent of home care services for children. Unfortunately, our current homecare system is not flexible enough to offer

¹¹ Canadian Home Care Human Resources Study, 2001. *Phase I Draft Report: Setting the Stage: What Shapes the Home Care Labour Market?*. Unpublished, Canadian Association of Community Care, Ottawa.

families the type of support and respite that they may need to continue to care for their children in the home. Failure to meet the needs of children and families in the home results in an increased burden on the hospital-based service delivery system and on the family.

At-Risk Populations: Aboriginal children, children living in poverty, children living with FAS/FAE, children with physical and learning disabilities, street youth and children in care of the state are among those at greatest risk of experiencing the negative health outcomes. For example, children with learning disabilities often experience lack of access to appropriate support because diagnostic services are not covered under public Health Care. Of particular concern is the health and status of Canada's Aboriginal children. Aboriginal children are more likely than non-Aboriginal children to live in substandard housing; Aboriginal children are slightly more likely than non-Aboriginal children to have a disability; Aboriginal infants are more than twice as likely as their non-Aboriginal peers to suffer from Sudden Infant Death Syndrome; and, among Aboriginal youth aged 15-24, the suicide rate among males is more than 5 times that of national male youth. For female Aboriginal youth, the rate is almost 8 times that of female national youth¹².

Mental Illness: Mental illness is often termed the “new morbidity” for children. Mental health problems cut across all income lines and have the potential to negatively effect children of all ages. Access to appropriate, universal mental health services is critical to the long-term well-being of all children. Accessing mental health services is confounded by a critical shortage of trained professionals available to meet the needs of children and youth with mental health and behavioural disorders¹³. Waiting lists of 2 years are not uncommon. For adolescents, attempted suicide may be the only means of having their need for urgent care recognized. Services required are both universal, such as school-based mental and social health services, and targeted specialist clinical services.

Environmental Health: Many factors determine whether a child is born healthy and stays healthy into adulthood. The environment is a critical, yet rather unconventional factor that must be considered. The developing body systems of the child, particularly tissues, the central nervous system and organs, are very vulnerable to environmental toxicants. Children who live in poverty typically live in the most polluted parts of the community, thereby increasing their risk of exposure to environmental contaminants. Failure to address issues of environmental degradation, contamination, and toxic exposure as they relate to children will result in continually growing rates of childhood mortality and morbidity (asthma, poisonings, cancers, etc.) as well as the resulting long-term stress on the health care system. An environmental health strategy needs to be developed to expand environmental health clinics, environmental health research, environmental health

¹² Canadian Institute of Child Health, 2000. *The Health Of Canada's Children, 3rd Edition*. Ottawa

¹³ Watters, Nancy E. & Robeson, Paula, 1999. *Health Human Resources for the Future Health Care of Children and Youth in Canada*. Canadian Institute of Child Health, Ottawa

training for health professionals, primary prevention and surveillance. Fewer allergies, asthma, better health and sleep would decrease health costs down the line.

Leadership, Collaboration and Responsibility

To create a model based on best-practices, common wisdom and mutual support, the transfer of knowledge must be supported by a proper infrastructure at the community, regional and national levels, and remunerated as a legitimate function of the service delivery system. Building a successful health care system of the future will require cross-disciplinary, cross-sectoral and cross-jurisdictional alliances. Bridging these gaps is no simple task. To do so will require an unprecedented degree of knowledge transfer among health care professionals, families, teachers, social workers and other critical players.

A broad range of health service professionals play a critical role in supporting the healthy development of children in Canada. For many families, access to one or more of these professionals is critical to a child's health and well-being and their ability to reach their potential. Many of these services are not publicly funded and cost is a barrier to access for many families.

The development of a health service delivery model that focuses on a collaborative, integrated, innovative, accountable and holistic approach to supporting children and youth in the settings of their lives: childcare, home, school and communities are essential if we are going to properly service this population. We know that traditional health providers and hospitals are struggling and cannot possibly address all the demands and expectations. We believe that locally initiated and led partnerships across sectors can produce cost-effective solutions for a number of the health issues confounding the health care system. Our experience is that locally designed solutions that build on best practices, utilize local assets and involve those affected, are usually the most successful. The public health system needs to be seen as a vehicle for the delivery of health promotion and disease prevention.

Health, education and social services must work more closely together at all levels so that children with problems are more adequately cared for. The childcare and school settings are excellent places where prevention, early detection and primary care services could be delivered. This is the environment where children spend a great deal of their waking time. By integrating services available to children, youth and their families in the school, there would be greater collaboration among professionals and greater ease for families to use the system, thereby offering more accessible and cost-effective services.

“I worked with an extremely disturbed grade one student who would bite, kick stab and punch. Students, teachers, and teacher aids were all victims of his anger and frustration. For five months I worked with a children's hospital attempting to get him into a special program in a hospital setting. A hospital caregiver observed him and told us that they were not equipped in a group of five students to support him. Consequently he remained in a grade one class of 28 students and was heavily medicated. The symptoms were masked but not treated.” Maureen Morris, Canadian Teacher's Federation

Health based NGO's have a critical role to play in bringing together this diversity of interests and perspectives. Dedicated to the promotion of health and prevention of illness in regard to children, NGO's are in the unique position of having the capacity to bring together service providers, parents, researchers, national and community based organizations, professional associations and coalitions to explore the best ways to meet the developmental needs of Canada's children and youth.

To this end, the voluntary sector, in general, needs the continued financial support of all levels of government if it is to continue its success in reaching out to Canadians, identifying issues, and building a common set of values.

Professionals that service children and youth maintain high standards and are regulated. It is essential that this be maintained if we are to continue providing quality care. All publicly funded services should be protected in terms of standards and accessibility, with the Charter of Rights and Freedoms attached to trade agreements. This will allow Canada to maintain standards and not lower them. We must protect our ability to set and maintain the Canadian standard, as trusted and respected by Canadians and around the world. Additionally, training programs need to be adequately funded if we are to foster a new generation of well-qualified health professionals.

Canada's ability to meet the health needs of its youngest citizens requires a more substantive, representative system of data collection across a broad range of health indicators. This data needs to be nationally representative and internationally comparable. To develop a more integrated, responsive system of service delivery for Canada's children, we need timely health related data that addresses questions, such as:

- What are the current or emerging health needs among children and youth?
- Which indicators best reflect the state of child health now and over time?
- How well are Canadian children achieving certain developmental outcomes or goals?
- Which child health services are in greatest demand?
- Where are the greatest number of child health services being delivered?
- What, if any, are the delays in treatment?
- What impact are waiting lists having on healthy child development?
- Which health service provider and services have the most positive effect on which health outcomes and in what context?

The federal government has a key role to play in providing the leadership and resources necessary to ensure that we can meet the needs of children, youth and their families through the delivery of services and supports. Recognizing the broad determinants of child health means that the federal government has a responsibility to consider the implications of its full range of policy decisions on children's health and well-being. From the perspective of children, youth and their families, the comprehensive basket of supports and services they require transcend the traditional boundaries of health, education and social services. The federal government is responsible to ensure that its negotiated international trade agreements do not compromise the rights of children in Canada to access the supports and services they need.

Recommendations

1. Establish a protected, sustained, comprehensive, timely, long-term budget targeted for universally accessible child and youth health care services and programs, funded regardless of family income.
2. Expand and re-distribute essential health care services within the Canada Health Act to ensure equitable access for children and youth.
3. Develop integrated human resources strategies, for health matters specific to children and youth.
4. Develop increased accountability within the health system based on national goals for child health outcomes.
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12. Recognize the role environment plays in child/youth health and include environmental health strategies within the health care reform system.
13. Expand health services to include adequate and accessible access to mental health diagnosis, treatment and care.
14. Create opportunities for children and youth to participate in decisions that affect them- children have a right to be heard.

Conclusion

Children and youth are not little adults. They have particular needs that are different and as a result require special considerations within the health care system.

Children do not have time to wait for services, their bodies are developing and growing at a rapid rate and as a result require timely interventions. Children do not have money. They cannot afford user fees and a system should not be designed based on parental income to determine access for the child. Children spend a great majority of their time in the school, at home, and in their communities. Recognizing this, children and youth health care services should be developed within school and community settings. If children and youth are to be adequately served, the provinces must expand their currently funded services beyond hospital and physician based approaches. Access to a broader basket of services provided by a wide range of professionals has been possible under the Canada Health Act since 1984, yet provinces have not designed a system to take advantage of this flexibility in a multi-sectoral way.

A broad range of health service professionals play a critical role in supporting the healthy development of children in Canada. It is essential that service delivery be better organized, funded and integrated to include the broad range of services. Through integration, health service delivery for children and youth will become seamless and easier to use for families. Additionally, resources will be shared which will result in more appropriate treatment that will cost the health system less in the long run.

A sustainable health care system starts with an investment in children and youth.