



The Canadian Network of Child & Youth Rehabilitation  
Le Réseau canadien de réadaptation enfance-jeunesse



CN-CYR is a National Network of the / Le RCRE-J est un réseau de l'  
CANADIAN ASSOCIATION OF PAEDIATRIC HEALTH CENTRES (CAPHC)  
ASSOCIATION CANADIENNE DES CENTRES DE SANTÉ PÉDIATRIQUES (ACCSP)



**Canadian Network of Child and Youth Rehabilitation**

**Business Case**

**for the**

**Establishment of a National Data Set for Paediatric  
Outpatient Rehabilitation**

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**Submitted by:**  
Canadian Network of Child and Youth Rehabilitation /  
Canadian Association of Paediatric Health Centres

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# EXECUTIVE SUMMARY

## Introduction

*Rehabilitation is a goal-oriented process that enables individuals with impairments, activity limitations and participation restrictions to identify, reach and maintain their optimal physical, mental, and/or social functioning. Rehabilitation focuses on abilities and aims to facilitate independence and social integration.<sup>1</sup>*

The goal of rehabilitation services is *to enhance function for meaningful living*. Service needs and costs for children with disabilities can be high and yet there is a lack of comparable and reliable rehabilitation outcomes measures for the paediatric population to ensure service efficacy, accountability and social justice. The creation of a National Data Set (NDS) for Paediatric Rehabilitation is critical to understand how best to use finite resources to optimize client functionality and support a fulfilling and meaningful life for children with disabilities and their families.

## Background

The Canadian Network for Child and Youth Rehabilitation (CN-CYR) was formed under the sponsorship of the Canadian Association of Paediatric Health Centres (CAPHC) to support national collaboration in the paediatric rehabilitation community. CN-CYR identified a need to better understand how to strengthen the delivery of paediatric rehabilitation services and began to determine priorities for a national data set and gain stakeholder support. A survey was conducted to gain a national picture of populations served, services, performance indicators and data elements in use. Members identified priorities for data collection which include impairment level, function, service access, participation in life, parent characteristics and quality of life.

CN-CYR is now undertaking the development of a high quality national data set that includes functional/developmental outcomes and service delivery data on infants, children and youth who access rehab services. This data set will be used to facilitate provincial comparisons and identification of best practices and benchmarks across Canada to support high quality service provision. A phased-in approach to implementation is being proposed with an initial focus on outpatient services for clients with cerebral palsy or autism spectrum disorders.

## Why Now

There are three key drivers for the establishment of an NDS including social justice, accountability, and efficacy.

**Social Justice:** The principles of [equality](#) and solidarity value [human rights](#) and recognize the dignity of every human being. Paediatric rehabilitation services provide the necessary support to ensure that clients with developmental, behavioural or motor disabilities are able to participate in society to the maximum of their potential. Society also benefits from maximizing their independence. High quality standardized data and indicators are needed to support decision-making on which rehabilitation interventions best support the attainment of a meaningful and fulfilling life to the extent possible. The need to support people with disabilities to lead fulfilling and rewarding lives within a society that accepts them is a growing trend world-wide as shown in the UK Department of Health's 2010 strategy for adults with autism which states:

*While we know that some adults with autism do live fulfilling lives, making successful and important contributions to their communities, the economy and their own families, currently too many adults with autism are not able to do this. Too many are dependent on benefits for their income and on the care and support of their families, not only for housing but simply to cope with their everyday lives. For those without this support, the outlook is worse: the risk of severe health and mental health problems, homelessness, and descent into crime or addiction. The costs in financial terms to public services are enormous: the costs in emotional terms for both adults with autism and their families more devastating still.<sup>2</sup>*

**Accountability:** Individual accountability for services exists within paediatric rehabilitation facilities and programs across Canada. However, the absence of standardized outcome measures and common language severely limits accountability at a system level because it is not possible to make accurate comparisons of outcomes and resource utilization. There needs to be a greater understanding of what services provide the greatest benefits with respect to lifelong activity, participation in life and quality of life to make responsible decisions regarding service delivery. The ability to make comparisons is needed to raise the "accountability bar" at a system level to improve organizational performance by using evidence-informed data to effect positive changes in process or practice. The need for accountability is supported by a 2007 Health Canada report, in which it is stated:

*"Among 29 OECD nations, Canada ranks 21<sup>st</sup> in child well-being, including mental health, and 12<sup>th</sup> out of 21 wealthy countries in the United Nations ranking of child well-being."<sup>3</sup>*

**Efficacy:** Rehabilitation resources are finite and must be used wisely to ensure timely and appropriate access to needed services and interventions. Workload data alone cannot support administrative and clinical decision-making regarding resource allocations. Additional information is required to understand which programs and approaches generate the greatest gains in functional abilities and to identify the optimal mix of resources and/or services. While limitations do exist with respect to attributing outcomes to resource inputs given a child's interface with multiple providers across the care continuum, it does not preclude striving toward the collection of data to link outcomes to resources consumed and interventions provided.

## Next Steps

The current focus is to confirm content of an NDS and secure Canada-wide support from key stakeholders. It is imperative that the organizations that support these services be engaged and be provided with an opportunity to give feedback to ensure that any issues or concerns can be addressed. A feasibility study and a pilot implementation strategy will be used to determine the content and process requirements for the establishment of an NDS. Partnerships with other organizations will be developed to address funding and data holding issues. The strategy and proposed costs for full implementation will be developed once the findings of the pilot test of the NDS are complete.

## REFERENCES

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