The Canadian Network
for
Child and Youth Rehabilitation Centres
Workshop

Closing the Gap -
Establishing a National Mechanism
for Bringing Research to Practice

November 7, 2004

Queen Elizabeth Hotel, Montreal, Quebec

Summary of Proceedings

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Executive Summary

The first inaugural meeting of the **Canadian Network for Child and Youth Rehabiliation Centres** (CN-CYRC) was marked by overwhelming support and enthusiasm. All participants applauded the initiative and commented on its relevance and timeliness.

Approximately 30 participants across the country attended the meeting held in Montreal, Quebec on November 7, 2004. This was a diverse multidisciplinary group of health professionals, researchers, academics and administrators from a across the country. The concept of CN-CYRC emerged from a growing recognition that a national network could promote opportunities for multi-site research and knowledge transfer, as well as provide a mechanism for enhancing the profile of children and youth rehabilitation services.

The objectives of the workshop were to:

- confirm the mandate of CN-CYRC
- discuss strategies and priority actions for moving forward in key theme areas, in particular bringing research to practice and developing common indicators
- recommend key success factors for sustaining and growing the Network.

Mandate
Participants confirmed the mandate of the Network as follows:

> *The primary purpose of the Canadian Network for Child and Youth Rehabilitation Centres (CN-CYRC)[1] is to promote excellence in the provision of rehabilitation services for children, youth and families. This will be achieved through the goals, objectives and priorities for CN-CYRC as described below. As well, CN-CYRC intends to create an infrastructure across the continuum of care that will facilitate national collaborative efforts at the level of health services and policy research, knowledge translation and practice, application and implementation[2].*

Five key goals for the network were endorsed:

1. Present a coordinated national voice for Children's Rehabilitation and children with disabilities to ensure the latter's position on the national health agenda.
2. Provide a mechanism for promoting best practices, knowledge transfer and bringing research to practice.

[1] The recommended name change for the network occurred in the final plenary discussion at the end of the workshop. See Section 7.0, page
[2] Proposal to CIHR Institute of Human Development, Child and Youth Health, September 15, 2004, p. 2

3. Create a forum for communication and networking with Children's Rehabilitation and associated partners.
4. Assist with effective service and systems planning by providing a mechanism for information sharing, including identifying emerging trends and changes in the environment.
5. Provide a mechanism for benchmarking, such as comparing structure, process and outcome indicators with like organizations as well as advancing the development of outcome indicators specific to children's rehabilitation.

Workshop Themes
The workshop focused on two key themes:

1. Identifying national barriers and enablers to bringing research, knowledge transfer and best practices to child and youth rehabilitation practice;

2. Identifying common indicators to gauge successful outcomes nationally (in partnership with the National Child and Youth Health Coalition's Health Indicator Initiative)

Bringing Research to Practice
Barriers and enablers for bringing research to practice were considered from a variety of perspectives and yielded a rich discussion of opportunities and strategies for moving forward nationally in this area.

Priority actions for CN-CYRC with respect to bringing research, knowledge transfer and best practices to child and youth rehabilitation practice were recommended:

Establish CN-CYRC Research Task Force with the following starting mandate, to:

- Identify one or two national research priorities to test/showcase the ability to collaborate nationally (confirm with Network membership)
- Determine infrastructure required to undertake national research project (including minimum data set and information systems, funding, research capacity)
- Establish research websites to facilitate communication and collaboration (eg. explore potential of CanChild intranet to expand nationally)
- Include knowledge transfer as a requirement and intended outcome of the project
- Collaborate with CAPHC to leverage its communications, partnership and advocacy structures

Developing Common Indicators
Recommendations with respect to identifying common indicators to gauge successful outcomes nationally were informed by the ongoing work of the National Child and Youth Health Coalition's Health Indicator Initiative. Breakout groups were organized along the Coalition's four dimensions and examined indicator development for children and youth rehabilitation according to: *Patient Safety, Access, Efficiency and Effectiveness*. The group made preliminary recommendations in all four areas, they provided some initial advice to the National Coalition with respect to these four dimensions and they generated recommendations for priority actions for indicator development for CN-CYRC.

Overall priority actions for CN-CYRC in relation to indicator development include:

- Establish Working Group to make recommendations as to best approach for this process
- Decide on a framework for indicator development (eg. ICF may be useful as a component or program logic model)
- From above detailed recommendations, determine how the work of CN-CYRC can best interface with the ongoing work of the National Coalition on Indicators
- Review what adult rehabilitation has done and see if there is relevance to the child and youth sector
- Start with a few indicators, determine where the key pressure points are and what is the most doable (eg. Access may be a good starting point because it is very high on most political agendas)

Sustaining and Growing the Network
The first meeting of CN-CYRC received unanimous support from participants that efforts should be made to sustain and grow the Network. In principle they agreed that membership should be *inclusive*, not *exclusive*, but that some caution should be made to not lose the focus on rehabilitation needs and services. They were highly supportive of linkages and partnerships as an effective mechanism to interface with a broader group of stakeholders.

There was a recommendation that going forward, the name should be changed to the ***Canadian Network for Children and Youth Rehabilitation Services.***

Year 1 Objectives
The workshop concluded with specific Year 1 objectives to:

1. Define the structure of the Network, using the program logic model defined by the "Effectiveness group" (eg. Clinical, Education and Research facets).
2. Establish clear terms of reference for the Network, building on the goals confirmed at this meeting, and identifying specific task forces, with clear mandates and timelines for each.
3. Establish infrastructure requirements for the network to achieve its mandate.
4. Communicate the establishment of the Network to policy-makers, key stakeholders and preferred partners of the Network. Leverage CAPHC's communication and networking ability to disseminate this information.
5. Formalize relationship with CanChild, including potentially expanding its intranet nationally.
6. Circulate proceedings to all participants of the workshop and to all CAPHC members to heighten awareness of the existence and mandate of this Network.

The meeting adjourned with enthusiasm for continuing to collaborate "virtually" throughout the year and to reconvene at the CAPHC annual meeting in Newfoundland in October 2005.

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SUMMARY OF PROCEEDINGS

1.0 Welcome and Objectives of the Retreat

Cheryl Susinski and Mary Lysyk, co-chairs of the Canadian Network for Child and Rehabilitation Centres (CN-CYRC) Steering Committee welcomed everyone to the workshop. Steering Committee members and participants were introduced. Approximately 30 participants were in attendance, with a good geographic representation from across the country and a diverse mix of researchers, health professionals, academics and administrators from a variety of disciplines.

Mary reviewed the agenda for the day and the objectives of the meeting which were to:

- confirm the mandate of CN-CYRC;
- discuss strategies and priority actions for moving forward in key theme areas, in particular bringing research to practice and developing common indicators;
- recommend key success factors for sustaining and growing the Network;
- provide an opportunity for networking and information exchange between practitioners, researchers, administrators and policy makers involved in children and youth rehabilitation.

Mary also acknowledged the sponsor of the event, the Canadian Institute of Health Research (CIHR) Institute of Human Development, Child and Youth Health for supporting this workshop with a seed grant.

2.0 Background – Where we are to date: how we got here and where are we going

2.1 Getting Started

Cheryl Susinski provided a brief background to the creation of the Network. She noted that the concept of CN-CYRC emerged from a growing recognition, from a number of like minded people, that a national network could promote opportunities for multi-site research and knowledge transfer, as well as provide a mechanism for enhancing the profile of children and youth rehabilitation services.

The idea gained traction through the connection with Elaine Orbinne and the Canadian Association of Pediatric Health Centres. CAPHC was very supportive of the network

concept and felt that it was within their mandate to provide some of the infrastructure support to both get things started and keep them going in the future.

Through its national reach and its own "network", CAPHC facilitated the creation a Steering Committee which met for the first time in January 2004. The group identified the first task as determining whether or not there was a broader interest in establishing a network and if so – what should the network be focusing on.

To that end, a survey was distributed nationally, with responses from over 20 organizations and associations from across the country. The notion of a national network for children and youth rehabilitation received strong support from all supporters.

2.2 Survey Results

Survey respondents were asked to rank possible objectives for the Network on a scale from 1 to 5, with 5 being the most important to the organization. The top themes emerged as follows, with the corresponding rank:

Rank	*Objective*
(4.8)	To provide a mechanism for promoting best practices and transfer of knowledge
(4.8)	To provide a coordinated national voice for Children's Rehabilitation to ensure its position on the national health agenda.
(4.7)	To provide a forum for communication/networking with Children's Rehabilitation and associated partners
(4.6)	To assist with service/system planning by providing a mechanism for data sharing (eg. trends and changes in the environment etc.)
(4.6)	To further the development of outcome indicators specific to Children's Rehabilitation
(4.6)	To provide a mechanism for benchmarking (eg. comparing structure, process and outcome indicators) with like organizations

The survey results provided a source of focus for this first workshop of the network and stimulated the submission of a grant application to the CIHR Institute of Human Development, Child and Youth Health in September 2004. As noted above, the application was successful based on the workshop objectives of developing a "*national mechanism for bringing research to practice*".

Hence the two major themes for this workshop:

- Identifying national barriers and enablers to bringing research, knowledge transfer and best practices to child and youth rehabilitation practice
- Identifying common indicators to gauge successful outcomes nationally

Cheryl concluded her presentation by noting that the survey also provided a starting point for determining the mandate for this new network which would be the focus of the plenary session that followed.

3.0 Confirming our Mandate

Helena Axler, workshop facilitator, led the plenary discussion to confirm the mandate of the Network. The group confirmed the following mandate:

> *The primary purpose of the Canadian Network for Child and Youth Rehabilitation Services (CN-CYRC)[3] is to promote excellence in the provision of rehabilitation services for children, youth and families. This will be achieved through the goals, objectives and priorities for CN-CYRC as described below. As well, CN-CYRC intends to create an infrastructure across the continuum of care that will facilitate national collaborative efforts at the level of health services and policy research, knowledge translation and practice, application and implementation[4].*

The key goals of the network are to:

1. Present a coordinated national voice for Children's Rehabilitation and children with disabilities to ensure the latter's position on the national health agenda
2. Provide a mechanism for promoting best practices, knowledge transfer and bringing research to practice
3. Create a forum for communication and networking with Children's Rehabilitation and associated partners
4. Assist with effective service and systems planning by providing a mechanism for information sharing, including identifying emerging trends and changes in the environment.
5. Provide a mechanism for benchmarking, such as comparing structure, process and outcome indicators with like organizations as well as advancing the development of outcome indicators specific to children's rehabilitation.

Workshop participants also confirmed their support for the following definition of childhood disabilities[5]:

> *Differences in children's development or current function (in any or all the spheres of physical, cognitive, affective, social, communicative or sensory function) resulting from interactions of conditions that are intrinsic to the child, with environmental factors which may present barriers to full development and function. Such conditions (intrinsic) and the interactions of the environmental settings including societal attitudes and values (extrinsic), present special challenges for the child and his or her family, as well as for institutional systems, communities and future employees.*

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[3] The recommended name change for the network occurred in the final plenary discussion at the end of the workshop. See Section 7.0, page

[4] Proposal to CIHR Institute of Human Development, Child and Youth Health, September 15, 2004, p. 2

[5] CIHR Consensus Conference on Childhood Disabilities 2000

It was also noted that the above definition must be considered within the context of habilitation and rehabilitation[6].

3.1 Defining our scope – who is our population?

In discussing CN-CYRC's mandate, the group had a lengthy debate around defining the scope of the network's population. The following was suggested:

- children, youth and families
- birth to "19ish" (recognition that different provinces have different age cut offs, and that there were complex issues of transitions that needed to be considered)
- physical, development and behavioral disorders
- linkages needed to be coordinated with mental health, which is particularly important for dual diagnosis
- linkages need to be established with the developmental sector

Participants initiated a preliminary discussion on membership which was fleshed out in the final plenary session. (See 8.1)

3.3 Future areas of focus for the Network

While generally it was felt that the five goals constituted an ambitious agenda for a "start up network", a few additional issues were raised as potential areas of future focus. This included human resources as well as identifying some "hot buttons" that were particularly important to policy makers to help advance the Children's Rehabilitation agenda. Some areas included access, reduction of waiting lists, etc.

4.0 Addressing our priority themes

Participants switched gears from discussing their broad, overall mandate to focusing on the two priority themes of the workshops. Participants were organized into 4 breakout groups to address each theme and reconvened in plenary for report back. The following is a synthesis of the discussions and recommendations for each theme area.

5.0 Theme 1:

Identifying national barriers and enablers to bringing research, knowledge transfer and best practices to child and youth rehabilitation practice

5.1 What do you see as the key barriers in bringing research, knowledge transfer and best practices to practice?

Barriers to practitioners

- Lack of time, lack of recognition that research is part of clinical work

[6]

- Insufficient commitment from leadership to research and knowledge transfer; needs to be embedded in corporate strategic plan and valued as part of organizational culture, as "core", not as an "add on"
- Need funding support beyond grant funded researchers
- Current focus is largely on efficiency rather than effectiveness; emphasis is on "throughput" rather than quality
- Lack of well developed outcome measures
- Research results are often not presented in a clinical context, not "user-friendly", making it both difficult to find and to apply;
- Gaps in applying research to practice, often a result of deficiencies in training; practitioners not well trained in critical appraisal/interpreting research;
- Diverse professionals in rehabilitation bring different perspectives (provides both barriers and opportunities)
- Limited research with children in settings where they are receiving service (multiple conditions, with multiple diagnoses); perceived as "low incidence population".

System barriers

- Lack of good ways to share evidence within and across provinces
- Lack of published evidence around best service delivery mechanisms
- Funders lack education around non-randomized clinical trial studies
- Links and partnerships are not well known across Canada

Policy Barriers

- Multiple ministries, silos; different ministries fund differently, have different and often conflicting expectations
- Children not as vocal, "don't vote"
- Responsibilities for children distributed amongst multiple ministries

5.2 What do you see as important enablers?

Leadership and mentorship

- Champions who "walk the talk" (with protected time)
- Supportive leadership, promoting a research culture and evidence based practice
- Research mentoring and formal education programs; develop the competencies and capacity to appraise and apply research
- Funding, dedicated budget – demonstrated commitment to research and knowledge transfer

Information and Communication

- Integrated information systems; national databases, minimum data set
- Better outcome measures and better use of measures that already exist; (eg. better use of CIHI data)
- New technologies, telehealth
- CanChild Intranet (should be operational in 3 months); will provide opportunity for information sharing and exchange across the country; need website with data links to useful resources
- CAPHC can provide starting infrastructure and function as an important communications link for CN-CYRC

Collaborative Research Initiatives

- Multi-site research on a national basis, designed with a view to transfer knowledge
- Demonstration projects in clinical settings targeted at specific gaps in research evidence
- Partnering in clinical research and translational research; this could be facilitated through increased teamwork, (particularly interdisciplinary teams)
- Granting agencies are increasingly looking for partnership, particularly in translational and clinical research

Policy Enablers

- Identify an interministerial champion within government that can create linkages across ministries
- Secure funding champions
- Promote interprovincial initiatives
- Provide evidence from other jurisdictions; provide useful information that can inform policy

5.3 Where are the opportunities and priorities for research in child and youth rehabilitation on a national scale?

Potential Research Topics

- Access, wait lists
- Determining cost-effectiveness, value for money
- Burden of care and impact on families (extremely important evidence base for advocacy role)
- Outcome measures and outcomes research
- Shift from diagnosis driven services to functionally driven services (which is the optimal approach for meeting the needs of children and families)
- Understanding impacts of habilitation and rehabilitation on outcomes
- Knowledge transfer and exchange to multidisciplinary teams in diverse settings
- Priorities proposed in the "Childhood Disabilities Agenda"[7]

Opportunities to advance research and knowledge transfer

- Continuing education requirements for increased skills is resulting in increased funding of clinical research
- National research funding agencies have increased emphasis on knowledge transfer (eg. CIHR, CHSRF)
- Increasing trend to more integrated systems, requires greater sharing of knowledge, best practices, interdisciplinarity
- International class F (ICF) presents opportunities – need to be defined
- Tap into young clinician scientists; encouraging research in child and youth rehabilitation (eg. through National Coalition)
- Public education and awareness

[7] CIHR, op cit.

5.4 What are the implications for CN – CYRC? What are our priorities for action?

CN-CYRC can:

- Provide the mechanism for knowledge transfer/exchange and a forum for collaboration across the country
- Promote and establish a minimum data set across the country (eg. intake data, functional problems, intellectual problems,)
- Share and develop a methodology for engendering a research culture
- Share strategies for expanding research capacity
- Look for opportunities to develop collaborative national research studies
- Identify sources and secure funding for these studies
- Establish/source research web sites (eg. CanChild)

Immediate Next Steps for CN-CYRC:

- Establish CN-CYRC Research Task Force with the following starting mandate:
- o Identify one or two national research priorities to test/showcase the ability to collaborate nationally (confirm with network membership)
- o Determine infrastructure required to undertake national research project (including minimum data set and information systems, funding, research capacity)
- o Establish research websites to facilitate communication and collaboration (eg. explore potential of CanChild intranet to expand nationally)
- o Include knowledge transfer/exchange as a requirement and intended outcome of the project
- o Collaborate with CAPHC to leverage its communications, partnership and advocacy structures.

6.0 Presentation: The National Child and Youth Health Coalition – Health Indicator's Initiative

Peter Rosenbaum, Co-Director, CanChild Centre for Research, McMaster University, presented on the progress to date of the National Child and Youth Health Coalition – Health Indicator Initiative. He provided brief insights to the Coalition and the focus of the group's work.

The initiative began in May 2004 and identified a starting framework of 4 dimensions (safety, effectiveness, efficiency and accountability) and 6 key themes (mental health, primary care/first point of access, **chronic conditions/diseases**, injury prevention/trauma, system-wide safety and system-wide efficiency).

Dr. Rosenbaum spoke to the complexity of the initiative, the challenges to making recommendations for specific indicators, particularly in the area of chronic conditions/diseases in which he is engaged. The latter working group is primarily focused on developing indicators for "technology dependent children".

He noted that the Coalition is still early in its work on establishing paediatric indicators and he strongly encouraged CN-CYRC to focus its efforts on developing common indicators for rehabilitation for children and youth.

7.0 Theme 2:

Identifying common indicators to gauge successful outcomes nationally (in partnership with the National Child and Youth Health Coalition's Health Indicator Initiative)

Building on Peter Rosenbaum's presentation and the framework advanced by the National Child and Youth Health Coalition's Health Indicator Initiative, participants addressed the theme of identifying common indicators for rehabilitation. To facilitate the discussion, the group used the four initial dimensions of the Coalition.[8]

Safety: the potential risks of an intervention or the environment are avoided or minimized.

Accessibility: the ability of clients and patients to obtain care and service at the right place and the right time, based on their respective needs.

Efficiency: Achieving the desired results with the most cost-effective use of resources

Effectiveness: the care, service, intervention or action that achieves desired results

The four breakout groups were asked to consider the dimensions and be guided by the following questions:

- *What are the key questions for rehabilitation for children and youth that we must address?*
- *What are the existing indicators or new indicators that need to be developed to help us answer these questions?*
- *What recommendations can we make to the National Child and Youth Health Coalition Indicator's Initiative?*
- *Are there priority actions that CN-CYRC should/can undertake in furthering this effort?*

Detailed notes for each of the breakout group discussions are included in **Appendix 3.** Highlights of the discussions and priority actions for each area are captured below.

7.1 Patient Safety Indicators

- The group considered patient safety within two domains: safety within the rehab centre and safety outside in the broader environment
- Indicators were then considered for the two domains in each of front line/clinical, system and policy areas

Priority actions include:

- Establish database to separate injury rates etc. in our population, use general population rates (also participation rates)

[8] Dimensions reflect broad areas that will be used to assess, evaluate and improve performance.

- Explore this issue further eg. establish a framework around patient safety specific to this population
- Co-sponsor a workshop
- Broaden the scope of the National Coalition to focus on children with disabilities across all sectors
- CIHI / CCHSA / Canadian Pediatric Society / CAPHC.
- Examine policies in different provinces; identify gaps between provinces, need to inventory problem

7.2 Accessibility Indicators

- Secure agreement on definition of wait time (eg. how many people waiting and for how long)
- Recognize complexity of the area that requires information from a variety of perspectives (eg. multicultural (is translation available), differing access from remote destinations, urban rural distinctions, distance traveled, telehealth access; type of services accessed while waiting for treatment; gp referrals)
- Need more comprehensive and coherent indicators; existing indicators are sporadic and ill-defined

Recommendations to National Coalition

- Identify 2-3 access indicators and standardize nationally
- Define waiting times (how to measure and what services patients are waiting for)
- Develop effective acuity tools and measures
- Measure multicultural service delivery including socio-economic status

Priority Actions for CN-CYRC

- Link and collaborate with National Coalition on indicator development
- Conduct survey on how waiting lists are managed (will need to focus on 1 or 2 populations)
- Share best practices, innovative ideas on how organizations manage their wait lists
- Developing guiding principles for members in this area
- Review research evidence on accessibility indicators

7.3 Efficiency Indicators

- The group considered a long list of input vs. output indicators (eg. global outcome scores)
- They also generated a detailed list of cost vs. outcomes indicators , emphasizing the need to distinguish between the two (eg direct cost to families vs. burden to families)

Priority actions include:

- Examine the whole spectrum of costs beyond program costs. This should be conducted as a comprehensive outcome evaluation
- Use the Network to advise the National Coalition and provide feedback to the Coalition on work that it is doing on efficiency

7.4 Effectiveness Indicators

This breakout group grappled with identifying a useful framework for operationalizing effectiveness indicators as useful outcome indicators.

They tested a few options:

- Clinical with number of goals met
- ICF model as a framework, 4 levels that include satisfaction, change in function, quality of life and cost-effectiveness
- Logic Models, considering Clinical, Research and Education

Recommendations:

- Use a logic model as a framework that considers clinical, research and education outcomes
- Distinguish between outputs and outcomes

Priority Actions:

- CN-CYRC Working Group to develop key effectiveness indicators should be formed with a mix in membership of the following:
    - Experts in data, health information
    - Clinicians
    - Consumers and parents
- Consider indicators from a range of minimum to maximum effectiveness

7.5 Overall Priority Actions for CN-CYRC for indicator development

After the report back to plenary of the specific recommendations for the four dimensions described above, participants made recommendations for more global actions for CN-CYRC in the area of indicator development. These include:

- Establish Working Group to make recommendations as to best approach for this process
- Decide on a framework for indicator development (eg. ICF may be useful as a component or program logic model)
- From above detailed recommendations, determine how the work of CN-CYRC can best interface with the ongoing work of the National Coalition on Indicators
- Review what adult rehabilitation has done and see if there is relevance to the child and youth sector
- Start with a few indicators, determine where the key pressure points are and what is the most doable (eg. Access may be a good starting point because it is very high on most political agendas)

8.0 CN-CYRC Future Directions

All workshop participants engaged in a plenary discussion around future directions of the Network and key recommendations were made in the areas of membership, structure and partnerships. There was a recommendation for a name change for the Network and a series of objectives articulated for Year 1.

8.1 Membership and Potential Structure

There were preliminary discussions around membership of the Network. A general principle was espoused that the Network should aim to be i*nclusive* rather than *exclusive.* However, there was a caution to not get so diffuse that it would lose its focus and ultimately, its impact. There was a strong recommendation that at least at the outset the Network maintain a focus on needs and on services.

It was recommended that the Steering Committee undertake a systematic review of representatives from each province, with participants in attendance at this workshop helping to identify key players from each province and the Territories.

With respect to structure of the Network, most members saw this as a "virtual network" with a national Steering Committee, represented by each province and the Territories, and lots of activity and bidirectional linkages and communications at the provincial and local levels. The notion would be to link with the "OACRS" type of organizations in each of the provinces. The key (and challenge) would be to identify where groups already exist and tap into these resources and infrastructure.

While the tripartite framework of clinical, education and research was advanced, there was a very strong urging that priority on start up should be as a research network (CanChild like researchers connecting across the country). There was an explicit recommendation to formalize this Network's relationship to CanChild.

8.2 Partnerships

Partnerships were recognized as critical to the Network in achieving its mandate and reaching the populations whose needs for services overlap with rehabilitation. Many potential groups and constituencies were identified as potential partners of the Network, such as:

- family groups, consumers
- intersectoral partners; education, justice,
- community and social services
- developmental services
- community health – primary care
- paediatric disciplines
- centres of health excellence
- regulatory partners
- national professional organizations
- international organizations
- academic arms of disciplines
- foundations
- funding bodies, granting agencies
- national professional associations
- federal agencies, Health Canada

8.3 Name of the Network

There was significant discussion around the name of the network. At this time it was recommended that the name be changed to the "Canadian Network for Children and Youth Rehabilitation **Services** (the last word changed from Centres)

8.4 Year 1 Objectives for the Network

In an effort to sustain the momentum of this workshop, participants made recommendations for the following objectives for Year 1 of the Network, to:

1. Establish clear terms of reference for the Network, building on the goals confirmed at this meeting and identifying specific task forces, with clear mandates and timelines for each
2. Define the structure of the Network, using the program logic model defined by the "Effectiveness group" (eg. Clinical, Education and Research facets)
3. Develop specific strategies and action plans for achievement of CNCYR goals.
4. Establish infrastructure requirements for the Network to achieve its mandate.
5. Communicate the establishment of Network to policy makers, key stakeholders and preferred partners of the Network. Leverage CAPHC's communication and networking ability to disseminate this information.
6. Formalize relationship with CanChild, including potentially expanding its intranet nationally.
7. Circulate proceedings to all participants of the workshop and to all CAPHC members to heighten awareness of existence and mandate of this Network.

9.0 Wrap-up and Concluding Remarks

Mary Lysyk thanked all the participants for an extremely productive day and for their contributions in the plenary and breakout sessions. She appreciated the efforts that were made to tackle some very tough issues and for the innovative and creative approaches to these issues.

As a next step, Helena Axler will prepare *a Summary of Proceedings* that will be circulated to the Steering Committee for review and to all retreat participants for further feedback and comment. The Steering Committee will review the recommendations coming out of this workshop and will develop an action plan for moving forward.

Participants were encouraged to complete their evaluation forms and to indicate the roles they would like to play in the ongoing development of the Network.

Mary invited all participants to reconvene again at the CAPHC Conference in Newfoundland on October 16, 2005.

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Appendix 1

Final Participant List
CN-CYRC Workshop – November 7, 2004

	Name	Organization
1	Sandy Litman	Administrative Director, Paediatric Division, Glenrose Rehabilitation Hospital Edmonton, Alberta
2	Lloyd Cowin	Operations Director, Rehabilitation Children's Hospital of Eastern Ontario Ottawa, Ontario
3	Vicky Earle	CEO, Ontario Association of Children's Rehabilitation Services (OACRS) The Voice for Children with Multiple Disabilities Toronto, Ontario
4	Eileen Kennedy	Professional Coordinator, Physical Therapy Montreal Children's Hospital, McGill University Health Center Montreal, Quebec
5	Joan Ferguson	Vice President, Programs and Service Bloorview MacMillan Children's Centre Toronto, Ontario
6	Heather McGavin	Program Manager Developmental Pediatrics and Rehabilitation McMaster Children's Hospital Hamilton, Ontario
7	Bill Frampton	Managing Director Orillia Soldiers' Memorial Hospital Orillia, Ontario
8	Debbi Andrews	Associate Professor of Pediatrics Division of Neurodevelopmental/Neuromotor Pediatrics Department of Pediatrics, U of Alberta Medical Director, School Rehabilitation Services (SRS) Medical Director, School-Aged Neurodevelopmental Assessment Clinic (SNAC) ,Glenrose Rehabilitation Edmonton, Alberta

9	Lucia New	Saskatoon Health Region
10	Wendy Seidlitz	Data Management Specialist McMaster Children's Hospital Hamilton, Ontario
11	Kelly Thorstad	Hôpital Shriners pour enfants *Infirmière clinicienne spécialisée* Shriners Hospital for Children Clinical Nurse Specialist Montreal, Quebec
12	Lynn Crosbie	Director, Child Health, Janeway Children's Health & Rehabilitation Centre St. John’s, Newfoundland
13	Diane Colce	McKay Rehabilitation
14	Dorothy Barnard	IWK
15	Dr. Gail Andrew	Developmental & Behavioural Paediatrician Clinical Director, 1 2 3 Go!, Preschool Assessment Service (PAS) & Fetal Alcohol Spectrum (FASD) Clinic, Glenrose Rehabilitation Hospital Edmonton, Alberta
16	Lori Roxborough	Associate Director, Therapy for Childrens & Women's Health Centre of British Columbia Vancouver, British Columbia
17	Fran Boyd	Senior Director of Operations, Sunny Hill Health Centre for Children Vancouver, British Columbia
18	Dr. Jennifer McLean	Medical Director, Medical Services Ottawa Children's Treatment Center Ottawa, Ontario
19	Maureen O'Donnell	Associate Professor and Head Division of Developmental Pediatrics Department of Pediatrics UBC c/o Sunny Hill Health Centre for Children,Vancouver, BC
20	Sandra Bressler	Director, Therapy Services, Audiology, Speech Language Pathology and Communication Development Children's and Women's Health Centre of British Columbia

		Vancouver, British Columbia
21	Debra Stewart	Occupational Therapist, Faculty of Health Sciences, McMaster University Hamilton, Ontario
22	Helen Dadiotis	Associate Director of Professional Services Alvin Buckwold Child Development Program Kinsmen Children's Centre Saskatoon, SK
23	Donna Fitz-Gerald	Nurse Manager Ambulatory Care Services Montreal, Quebec
24	Karen Barlow	Calgary Health Region Calgary, Alberta
25	Mary Lysyk	Clinical Coordinator Clinic for Augmentative Communication Ottawa, Ontario
26	Cheryl Susinski	Executive Director Rehabilitation Centre for Children Winnipeg, Manitoba
27	Karen Breau,	Director C&W Social Work Department Vancouver, British Columbia
28	Laurie Lessard	Childrens Rehabilitation Centre of Essex County Director of Physiotherapy The Childrens Rehabilitation Centre Windsor, Ontario
29	Antoinette Megens	Physical Therapist Ottawa Children's Treatment Centre Ottawa, Ontario
30	Peter Rosenbaum	Co-Director, CanChild Centre for Research, McMaster University, Hamilton Ontario
31	Danielle Grenier	Children’s Hospital of Eastern Ontario Ottawa, Ontario
32	Helena Axler	Facilitator Helena Axler & Associates Inc. Toronto, Ontario

Appendix 2.

The Canadian Network for Child and Youth Rehabilitation Centres
''CN-CYRC'
Le réseau canadien des centres de réadaptation enfance-jeunesse
'RCCREJ'
Child and Youth Rehabilitation

Closing the Gap - Establishing a National Mechanism for Bringing Research to Practice

AGENDA

Sunday November 7, 2004
Fairmont Queen Elizabeth Hotel, Montreal, Quebec
Peribonka Room

0830-0900	**Registration & Breakfast**	
0900 - 0920	**Welcome and Introductions** *Introduction of CN-CYRC Steering Committee and workshop facilitator* *Brief introduction by all participants* *Overview of Agenda and Objectives of the Meeting*	Cheryl Susinski Mary Lysyk
0920 -1030	**Background-Where we are to date how we got here… where we are going** *Establishing CN-CYRC – the drivers* *Review of National Survey Results- the findings* *Confirming our Mandate* All/ *Plenary discussion*	Cheryl Susinski Helena Axler/
1030 - 1045	**Break**	
1045 - 1050	**Overview of Breakout Group Sessions**	Helena Axler
1050 – 1150	***Theme 1: Identifying national barriers and enablers to bringing research, knowledge transfer and best practices to child and youth rehabilitation practice*** • What do you see as the key barriers in bringing research, knowledge transfer and best practices to practice? • What do you see as important enablers? • Where are the opportunities and priorities for research in child and youth rehabilitation on a national scale? • What are the implications for CN-CYRC? What are our priorities for action?	
1150 - 1230	**Report back to Plenary: Summary of priorities for action**	
1230 - 1315	**Lunch**	

1315 – 1345 ***Presentation: National Child and Youth Health Coalition – Health Indicator's Initiative*** Dr. Peter Rosenbaum

1345 – 1445 ***Theme 2: Identifying common indicators to gauge successful outcomes nationally (in partnership with the National Child and Youth Health Coalition's health indicators initiative)***

- What are the key questions for rehabilitation for children and youth that we must address?
- What are the existing indicators or new indicators that need to be developed to help us answer these questions?
- What recommendations can we make to the National Child and Youth Health Coalition Indicator's Initiative?

- Are there priority actions that CN-CYRC should/can undertake in furthering this effort?

1445 - 1500 BREAK

1500 - 1545 **Report back to Plenary: Summary of priorities for action**

1545 - 1630 ***CN-CYRC: Future Directions*** *Helena Axler/All*
Casting the net broadly….

Interactive plenary session with Steering Committee members to brainstorm around the future directions of CN-CYRC.
Areas for discussion may include:

Membership
Communications & networking
Partnerships
Priority areas for future focus

1630 - 1645 **Next steps and closing remarks** Mary Lysyk/Cheryl Susinski

CN-CYRC 2005 – Annual Meeting –
October 16, 2005, St. John's Newfoundland

Appendix 3.

Breakout Group Session Notes for Indicator Development

The following section includes the detailed (largely unedited) notes of the four breakout groups on Indicators that include: Access, Patient Safety, Efficiency and Effectiveness.

Each were charged with responding to the following questions:

- *What are the key questions for rehabilitation for children and youth that we must address?*
- *What are the existing indicators or new indicators that need to be developed to help us answer these questions?*
- *What recommendations can we make to the National Child and Youth Health Coalition Indicator's Initiative?*
- *Are there priority actions that CN-CYRC should/can undertake in furthering this effort?*

A. Patient Safety Indicators

	At Rehab Centre	In Environment
Front Line/Clinical Level	. adapted equipment/toys - quality control/safety of product - is child progressing vs regressing as a result of usage (outcomes) - pain/pressure areas - access/waiting lists	. caregiver stress – indicators of parent health) . respite access . equipment in homes – safe use . social safety skills - participation rates in community activities - street smarts - abuse rates(in our population vs other)
System Level	- critical incidents - abuse episodes - choking/aspiration episodes - falls/injuries - allergies – latex/food	Safe Transportation - adapted car seats - injury rates from MVA in our population vs other
Policy Level	Policies/indicators re: - criminal records checks - child abuse registry checks - pharmaceuticals - sedation - respiratory	- Accessibility policies - Policy gaps between provinces – need to inventory problem

Priority Actions

- Database to separate injury rates etc. in our population use and in the general population, (also participation rates)

Need more exploration of this issue → Need a framework around patient safety specific to this population → co-sponsor workshop

- Broaden scope of National Coalition to focus on kids with disabilities across all sectors
- CIHI / CCHSA / Canadian Pediatric Society / CAPHC.
- Examine policies in different provinces
  Re: Safety issues – gaps between provinces – need to inventory problem

B. Accessibility Indicators

- **Key questions**
  Define wait time-agreement on this. How many waiting and how long.
  How many people accessing – age, location, language – what they are waiting for (diagnosis, assessment, treatment, etc.)

- Multi-cultural access
  Need a measure to determine if this is available and # of times a translator is used.
  Don't know who we're not reaching but could extrapolate from pop. Data for an estimate – not just language – could be other cultural values/issues.
  Are we reaching people remote from Centres, satellites, outreach, etc. – measure distances traveled – look at distribution of population telehealth access.

- Lack of knowledge & GP's of services availability
  - comparison & referral rates

  We need to understand who is not accessing services.
  What services are being accessed - Time between access and treatment.

  Track where referrals coming from – helps identify awareness.

- Activity – should / does access vary according to activity.
  Value in measuring what people are being provided while they are waiting e.g. Referral and education services

Existing or new indicators

- (Very sporadic if defined)
  Referral rates / patterns – awareness
- Number on wait list / wait time

- Priorities: greater need – quicker access
  # of complaints & analysis
- Time to move through various referrals to get to centre
- Appropriateness with individuals on wait list
- Teach referrers when referrals are appropriate
  Sometimes people are served more appropriately with an alternate model
- Does anyone need to be on this wait list?
- Effective screening

Recommendations to NCYHC indicators initiative

- Identify 2 or 3 indicators for accessibility & standardize them
- Define wait time – a way of measuring
    - # waiting
    - who is waiting
    - relate to what waiting for
    - location of service
- Need to get at urgency of need – activity tools
  Would help us to determine priority actions
- Measure & multi-cultural service delivery incl. soci-economic status

Priority actions for CN-CYRC

Link with and support the initiatives of NCYHC survey members re: their own definitions are wait times may want to focus on one or two populations. Gather info from members re: service models which enhance accessibility, innovative idea, & status report on access indicators – share the knowledge. How do the members report, manage etc. High need clients accessibility – how is this managed – guiding priorities – develop and share. – How to manage wait lists

Review research evidence on accessibility indicators.

C. Efficiency Indicators

Indicators – input vs. output

- Length of stay
- Readmission and complication rate
- Cost per patient
- Number of rehab centre visits
- Family income (at points during outcome)
- Waiting list time / number
- Prevention: long term outcomes and comorbidities
- Functional outcome measure
  - global
  - specific & others
  - Weefim / Fim
  - Mayo-MPAI

- CBCL / Vineland

- Quality of Life Measures
  - Peds QL etc.
  - Film efficiency measures

- Impact on Family Scale
- Parenting Stress Index
- Common Functional Assessment Tool

Recommendations

- Look at the full range of the cost – When we examine an implementation , e.g. beyond program specific costs.

- Comprehensive outcome evaluation of child and family and spectrum of domains of outcomes

Priority actions for CN-CYRC

- Create a network to advise **CN-CYRC**
- Provide feedback to the coalition.

COST	Outcome
• Cost to families • In patient costs • Out patient in rehab. Facilty • Out patient in community • Technology • Medication • Equipment & Supplies • Education / different modes • Prevention / 1º 2º 3º • Cost of education & vocational training • Transition series • Out of Region costs • Burden to society Need large population	Burden to families - Financial - Psychological - Family Function • Functional outcome of child - short-term - intermediate - lont-term • Self rated parent/caregiver (does this change with time/age) - independence - Psychological - Cognitive - Communication - Physical

D. Effectiveness Indicators

This group had some difficulty coming up with a useful framework for effectiveness indicators and explored a number of options. Ultimately, they recommended a logic framework that should be considered for ongoing indicator development in this area.

Indicator # of facilities utilizing (Network) ICF framework / # of facilities
(# of standardize measures used / # clinicians)
Clarify / Common language around effectiveness

- 4 elements in ICF model
- satisfaction (common tone)
  MPOC

Change in function

- community
- child
- family
- environment

Quality of life - Is it too big but important +++
Cost effectiveness

OUTPUTS VS OUTCOMES
Need to consider:
Q1 - Clinical
- Education
- Research
- Staff satisfaction

Clinical Outcomes

- # goals met / # goals set (gas)
- use / CF model Three levels :
  - Body function / structure
  - Activity
  - Participation
  - Context Environment

Clinical
Child/Youth
Family / respite
Community recreation
Transition
Consulting
Education
Respite

System
Cost effectiveness
Integration
Collaboration / cooperation
Transition between systems

Policy
? ODSP
? Managed competition
Interministerial

Waiting group includes people at all levels

- Data
- Outcomes
- Clinicians
- Research
- Consumers/parents

Recommendations:

- Use a logic model, considering Clinical, Research and Education as a framework that considers clinical, research and education outcomes
- Distinguish between outputs and outcomes

Priority Actions:

- Working Group to develop key effectiveness indicators should be formed with a mix of the following:
  - Experts in data, health information
  - Clinicians
  - Consumers and parents
- Consider indicators from a range of minimum to maximum effectiveness

CN-CYRC Inaugural Workshop Questionnaire

1.) Did the 2004 CN-CYRC Inaugural Workshop meet your expectations?

Yes	No	Did not answer/unsure
20	1	4

Comments:
Yes

- I certainly feel that I am leaving this workshop with much more info that I had in the morning with regards to pediatric rehab on a more global level
- A little daunting is the task before us
- It would have been great if we could have generated some specific tasks for members to do – rather than simply CN-CYRC as a group – so that the momentum would be maintained. Hopefully people will sign up for sub committees and thereby the progress will be built on – I think this was a time issue
- More than met expectations –Exceeded them
- First Experience with participating with putting in place an inaugural workshop. This productive group articulated which facilitated process
- Great to meet with individuals dealing with the same issues – begin to share practices, stimulus to research into best practices
- I did not have much information other than the agenda when I registered so I really did not have any expectations, however, I was very pleased with what transpired
- Brainstorming around 2 survey themes
- Great idea sharing and development of awareness of resources nationally
- Great discussion; good networking
- I think we accomplished all we could in a 1 day workshop
- Lots of big ideas and visioning that imply a lot of work but there seems to be a lot of energy

No

- My concept of rehabilitation in Canada was very different to the reality – so a learning curve for me

Did not answer/unsure

- Not sure – didn't really have any expectations but it has been a worthwhile day
- I really had no expectations other than it would be built around the title "Establishing a National Mechanism for Bringing Research to Practice" which really could not happen without an opportunity to build common foundations with the group. So we didn't really get to the "title" stuff but the day was useful in seeking common ground
- Had few expectations other than "I wonder what this is about and if I and my agency need to get in on the ground floor?!"
- I wasn't sure what to expect to be honest

2.) Were the themes discussed relevant to you?

Yes	No	Did not answer/unsure
25	0	0

Comments:
Yes

- This was a huge topic and probably not really “doable”. All themes were relevant
- To an extent – my work environment is more acute care focused where rehab/habilitation is merely the beginning. Unfortunately, there is no inpt, pediatric rehab centre in SK.
- Now the work begins
- Perhaps we could have heard more from researchers and their ideas for “bridging the gap”
- Absolutely, the need for this type of network clearly identified
- There were several levels of expertise (clinician, research, etc) contributing to discussions touched on many dimensions. Lots of info! The goal will begin to streamline and focus on specific priorities and goals
- Especially access to services and transfer of knowledge/information
- They were common to us all; good to get info on National Coalition but it confused me more
- Absolutely yes; Reassuring to hear that nationally we are all sharing common pains
- It appeared to be a very policy level/ administration focused discussion. Maybe less at the front-line clinician level.
- Very relevant, all the same issues across the country

3.) Do you have any suggestions for improvement (organization, content, etc.)?

- We need to set tasks which we can actually do
- I am not convinced we are really any nearer to communicating and collaborating with each other in Canada
- Discussions could have been longer; greater than 1 day
- One day was very short to meet the stated objectives. I am impressed at what was accomplished within this time
- Next meeting will need a narrower focus
- Continue to balance inclusiveness with focus
- Probably needed more time to discuss role of CN-CYRC, but discussion very helpful and productive
- Establish task groups; Better communication during the year via teleconference – email to update group on “what’s happening”; Include stakeholders outside of health; Presentation of existing evidence and linked organizations
- Well organized, great discussion
- Not enough time for discussion, but useful place to start
- Will be more focused once framework defined

- Staying connected, ie: providing input to members on progress since meetings. What comes out of meetings, what was done? – progress reports
- Review evidence and initiatives for presentation to the group to provide evidence for consideration
- I find the plenary sessions in which all groups report back very tough to maintain attention through – a more efficient reporting back approach may be useful (if it exists)
- Start small – achievable goals
- Too large of a job – need to start narrowing the scope
- Add as annual stream/theme within CAPHC to build on this inaugural foundation
- Larger room or alternate for breaks to encourage networking and more room for breaks
- I think more time could have been spent for each section of the agenda – perhaps 1 ½ - 2 days would have allowed us more time to further develop some of the agenda topics
- Develop a logic model for this network
- Just a continuation of process. There were many good ideas generated – it would be a shame to lose momentum and repeat this process a year from now
- Next meeting hopefully we can see results of our work today and be somewhat more focused but also don't want to focus too quickly in a new initiative

5.) Additional Comments

- Committees: Membership; Establishing task forces; Task force – enabling provincial centres to develop champions of research in their communities
- Thank you
- Good day, Thank you to the Steering Committee
- A wonderful beginning
- Very much enjoyed the day; concerned about how we keep this momentum moving forward and whether or not we will make a difference through CN-CYRC; Thanks to many for successful grant application
- Thanks to all those who put so much time and energy into pulling this workshop together; Especially kudos to Elaine Orrbine, Mary Lysyk, Cheryl S. and the Steering Committee members who facilitated throughout the day
- Being in an area that is attempting to create an organized children's rehab service system, this event was extremely valuable
- Common concerns and interests which facilitated discussions
- Excellent initiative – I am very excited about the prospects
- A great start!; I think clarification of the terms eg. "Children's rehabilitation" is critical to the success of the network
- Remember that we need to stay focused and make our goals achievable

- I still fear that momentum will be lost, that notes of the day will not be detailed enough for interpretation and to help us remember the nuances of what we were discussing. Other Ontario associations – PABIAC (Pediatric Acquired Brain Injury Assoc.), OACCAC (Ontario Assoc. of CCACs)
- Excellent process/discussion/targeted priorities as outcome of this first national pediatric rehab forum on priorities re indicators and ped rehab research
- Important to contribute to continue with good work off today and update us about the network's working groups through CAPHC
- Excellent workshop!!; Lots of good ideas; Name – please use (Re)habilitation; rehabilitation for this population has so many problems for clients and families