

CN-CYR

*Summary of Proceedings
Second Annual Workshop
Sunday, October 16, 2005
St. John's Newfoundland*

In 2003, informal discussion revealed an awareness of the need to look at pediatric rehabilitation resources from a national perspective; to establish common indicators and benchmarks, a process for sharing information and to add strength and momentum to lobby efforts. In the fall of 2004, the first conference of stakeholders was held in conjunction with the CAPHC annual general meeting in Montreal. Participants used results from a national survey regarding interest in developing a pediatric rehabilitation network to shape the mandate and objectives for the network. CN-CYR was born!

Our 2nd annual CN-Cyr meeting October 16th, 2005, reflects activities of the steering committee and communications / intranet subcommittee over the past year (Oct. 2004 – Oct. 2005) and commits to developing a framework for national outcome measures in child/ youth rehabilitation in Canada. Thirty participants including clinicians, administrators and researchers representing child and youth representing rehabilitations services and centres from across the country attended. All participants expressed enthusiasm for the initiative in terms of its need and timeliness.

SESSION 1: CN-CYR Update

Presented by Cheryl Susinski and Mary Lysyk

Highlights:

- A background on the history of CN-CYR was provided
- The following workshop sponsors were recognized for their contribution to this years event:
 - Canadian Association of Pediatric Health Centres, Ottawa, Ontario
 - Shriners Hospital for Children, Montreal, Quebec
 - Bloorview-Mcmillan Children's Centre, Toronto, Ontario
 - Glenrose Rehabilitation Hospital, Edmonton, Alberta
 - McMaster Children's Hospital, Hamilton, Ontario
 - Ontario Association of Children's Rehabilitation Services, Toronto, Ontario
 - Ottawa Pediatric Rehabilitation Research Alliance, Ottawa, Ontario
 - Rehabilitation Centre for Children, Winnipeg, Manitoba
- The steering committee and intranet sub-group's progress towards achievement of Year 1 Objectives was reviewed including:
 - establishment of terms of reference,
 - creation of workplan,
 - definition of infrastructure requirements,
 - expansion of CanChild Intranet nationally,
 - initiation of work on CN-CYR program logic model and
 - planning for 2005 annual conference.

The steering committee and intranet sub-group were thanked for their work over the previous year.

Feedback from participants:

- Agreed that a substantial amount of work has been accomplished by the steering and communication committee(s) in this first year
- Agreement that the momentum must be supported
- Communication with all potential partners must be a priority: ...

Suggestions to facilitate communication:

1. Look for opportunities to have work of CN-CYR presented at meetings and workshops, in college and professional interest publications, informal newsletters i.e. Easter Seals News, OACRS news etc.
2. Need to recognize / encourage relationships with and participation of acute care rehab. providers / CAPHC and Community Care Provider groups: i.e. initial relationship building at CAPHC meeting on Oct. 19 "Bridging the Divide" session / Cheryl on joint committee of CAPHC.
3. Members should assist in developing local networks i.e. establish a data base of potential partners in their communities and advise of efforts of CNCYR.
4. Participants to encourage 'intranet champions' to maintain up to date information on CN-CYR activities and info exchanges.
5. Solicit participation / representation from un-represented areas including Alberta, North West Territories and Nunavut.

SESSION 2: Considering Outcome Measures:
Presented by Dr. Virginia Wright

Click on the slide to view the entire presentation

Outcome Indicators in Pediatric Rehabilitation

By Virginia Wright, BSc(PT), MSc, PhD
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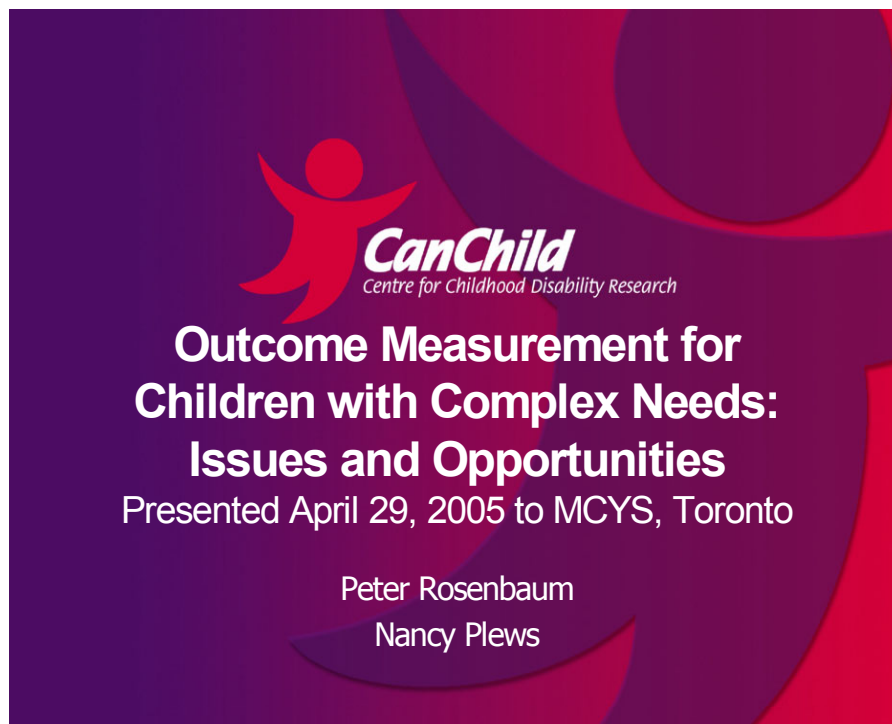
Highlights and audience feedback:

- We should try to avoid “analysis paralysis” by recognizing that we just need to start somewhere.
- We are not likely to find one measure that will capture all clients. Rather we should look away from diagnosis and more toward evaluating + / - function.
- Measures need to be provided in multiple languages.
- We need to develop an infrastructure to gather and analyze data then determine how to interpret and share results with partners especially recognizing resource limitations of smaller centers.

SESSION 3: A provincial project in Ontario looking at ‘Outcome Measurement for Children with Complex Needs’

Presented By Dr. Peter Rosenbaum

Click on the slide to view the entire presentation



Highlights and feedback:

- There are multiple levels of issues to measure.
- We do not currently share a common approach to problem identification or data collection.

- Government require particular types of information for their purposes that may not be as relevant to clinicians.

SESSION 4: Developing Outcome Measures for CN-CYR
(group interaction and consensus building)
Dr. Rosenbaum and Dr. Wright facilitating

What key issues do we want to address today?

Participants:

- We agreed that our major initiative for the day was to develop national outcome indicators for child and youth rehabilitation.

Other issues that were raised included:

- How do lobby groups influence government policy?
- How do we develop surveys or questionnaires that are user friendly ie. multiple languages and literacy levels?

Where do we want to start?

Participants:

- The task seems overwhelming...we need to develop a big picture of what we want to look at nationally, a vision of where we want to end up and then develop a phased in approach, don't look too specific.
- We could consider primary issues in a variety of functional domains ie. similar to the PEDI which captures function in mobility, self care, communication etc.
- We might consider capturing functional perspective from families as well as clinicians ie. what might be perceived as a potential issue for a clinician may not contribute to a life issue for the family.
- We want evidence that demonstrates the value of rehabilitation services.
- Need to capture services in both acute care i.e. in patients and long term care i.e. outpatient and community rehab.
- We have no data base to identify who do we serve and who do we turn away.
- We could consider broad categories of diagnosis ie. 'kids with motor disabilities', which might include ie. CP, spina bifida etc.
- Intake / entry is not necessarily a good time to capture diagnosis since many children are yet undiagnosed ie. labeled with developmental delay.
- Rather than collect "diagnosis" at entry, we might be better to collect "presenting issues" as identified by families and referral source.
- We need to have a better understanding of who we are so we can communicate more immediately ie. with partners in a similar type of care ie. if you want to talk to partners in 'autism' nationally, who are they, where are they?
- Example: NICUs participate in a Canadian Neonatal Network in which units research, communicate and benchmark...easy to do since they are similar in structure and autonomy at a specific level of care ie. tertiary vs. research/ teaching hospital etc.

The general consensus is that we need to better clarify:

- **Who are we?:** a wide variety of service providers in acute care, long term care, community care, with different funding sources, service models, data collection systems
- **What do we want to know about what we do?:** are we efficient, responsive, family centred? Includes issues related to access to care, reasonable wait times etc. We have numerous service models.
- **Who do we serve?** Who are our clients, what are their presenting problems/functional abilities/ diagnosis. We have potentially vast differences in our clients i.e. developmental, oncology, multiple diagnosis to traditional rehab. I.e. CP
- **How do we demonstrate** that we make a positive difference? Objective vs. subjective, using the WHO / ICH or other outcome measurement / what do clients need? what do families need? what do governments need? Participation and Quality of Life are important dimensions to consider beyond functional classifications.

Ultimately:

A/ we want to benchmark with other parts of the country

B/ we want to roll out some data that reports ie. *“as a country we recognize, or believe or serve*

C/ develop the project in 5 year ‘blocks’

Consensus: The primary starting point should be “Who do we Serve”. We need to be able to describe our population using common language before we can meaningfully compare outcomes.

What do we already have that can serve as a benchmark tool that clinicians are familiar with, that cross all populations and that are commonly used across the country?

Participants:

- MPOC: to what extent are clients / families satisfied with our provision of Family Centred Care?
- Demographics: how many children present with a particular diagnosis given Health Canada statistics?
- A variety of checklists that report current problems identified by parents
- CIHI framework
- as per World Health Organization/ ICH, participation may be more representative of success

What are some of the logistics?

Participants:

- Do we need to count or just begin to describe what we look like?
- What do we need to help us begin a systematic process?
- Keep it simple ie. report on your immediate service area vs. on your community
- Develop a common language despite our differences in clients and services
- We need infrastructure to develop tools, distribute, collect and interpret
- data collection needs to be electronic for ease of sharing with partners

SUMMARY:

- Pediatric Rehabilitation is a complex business that requires clients to receive services in a variety of domains and ways and over a long period of time
- Outcomes can be subjective and objective
- We need to determine what tools will we use to figure out who we serve....to develop a picture of who we are and what are the key outcomes of our services

PHASE ONE:

- should capture a stable moment in time i.e. as at April 1, 2006 (to be determined)
- data collection might:
 - a) include an epidemiological analysis captured under broad categories
 - b) reflect the complexity of our client's needs
 - c) reflect characteristics from both families / clients and service providers
 - d) include both subjective and objective data
 - e) be appropriate and useful for reporting back to funders

OTHER IDEAS

- the 'intranet' subgroup will get the ball rolling (might consider a name change) – additional volunteers are welcome
- generate a list of data base models already in use... we might find one that is generally satisfactory with some of our own customization / common data might include name, d.o.b., postal code, diagnosis, sex, reason for referral, key parent/caregiver issues and clinicians issues (i.e. top 3 from @), services or interventions being requested
- consider a smaller scale pilot project which with appropriate resources / infrastructure
- have all working groups to present at our next annual workshop Nov. 06 in Vancouver in conjunction with next CAPHC AGM including:
 - a. steering committee
 - b. intranet / communications committee
 - c. any other subgroups that have developed over the year
 - d. a presentation of the data tools that have been developed and action plansrequest papers / presentations from outcome projects across the nation
- work on infrastructure development in the areas of communication, to monitor the workplan, to apply for grants and to increase technology
- members are encouraged to network and establish sub interest groups ... as an outcome of this meeting, Virginia Wright agreed to spearhead a small interest group regarding outcome measures for clients with ABI perhaps using the WEEFIM to determine key benchmark
- look to CAPHC and Canchild websites for today's proceedings and updates on progress in all working groups
- consider next workshop to be available via video conference / indicate possible interest on feedback forms
- show of hands suggests that participants would be willing to pay a nominal fee to support the cost of the meeting
- participants to offer potential sponsors for the network and for the AGM

OUR PLAN for 2006: we agreed that the priorities for the next year will include...

Task	Responsible
Outcome Indicators Project – Phase 1 – Who Do We Serve <ul style="list-style-type: none"> • Continue to work on expansion of the Intranet • Post MPOC results/discussion on Intranet • Establish common demographic reporting format (including diagnosis) • Develop common Family Problem Checklist • Begin discussion on common Service Provider/Functional checklist • Establish Weefim ABI Sub-group • Explore National DataBase Options • Explore database issues related to Ethics/Confidentiality 	Intranet Sub-group Intranet Sub-group Intranet Sub-group Intranet Sub-group Intranet Sub-group Intranet Sub-group Virginia Wright Steering Committee Steering Committee
Other <ul style="list-style-type: none"> • Conference Planning for 2007 – Continue focus on national outcome indicators • Completion of CN-CYR Logic Model • Continue to pursue Infrastructure Dollars • Increase Communication links with potential partners 	Steering Committee Steering Committee Steering Committee Steering Committee

*****SEE YOU IN VANCOUVER in 2006*****