

**Waiting for Child Development and Rehabilitation Services:  
A Research and Methodology Workshop**

**Vancouver, British Columbia  
24-25 August, 2006**

**SUMMARY REPORT**

**PROJECT TEAM**

**Principle Investigator**

Anton Miller

**Co-Investigators**

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**Coordinator**

Jane Shen

**FUNDING SOURCES**

Canadian Institutes of Health Research

Provincial Health Services Authority of British Columbia

## **PURPOSE OF THE WORKSHOP**

The purpose of this invitational, interdisciplinary, and intersectoral Workshop (including the administrative sectors of health, child and family services and education), was to examine issues in measurement and monitoring of waiting for child development and rehabilitation (CDR) services, and the research questions and challenges related to this waiting. By 'child development and rehabilitation services', we meant the full range of assessment, diagnostic, intervention, rehabilitational, remedial and supportive services that are provided to children with actual or suspected developmental disorders/disabilities, and their families.

The Organizing Committee believed that this was an opportune time for this Workshop for various reasons: 1) a currently high level of public and political interest in waiting-times and waitlists for medical and surgical services in Canada, coupled with relative lack of attention to waiting for CDR services; 2) anecdotal evidence of children and families waiting long periods of time for CDR services; 3) special challenges to definition and measurement in a field that involves multiple services, providers, agencies and sectors, and that has no clear data infrastructure; and 4) interest by the National Coalition for Child and Youth Health in performance indicators for child health services, with waitlists designated as a significant indicator, coupled with planning in place for a Request for Applications from the CIHR related to this topic.

The Organizing Committee set out the following specific aims:

- Exchange knowledge and information relevant to the study of waiting for developmental and rehabilitation services for infants, children and youth.
- Through such exchange, to identify opportunities for collaboration and to increase research capacity in this area.
- Define the methodological issues that present challenges to research in this area.
- Define priority questions for a research agenda.
- Formulate an action plan for building consensus on dealing with methodological issues, and for moving ahead with a research agenda

## **PROCEDURES OF THE WORKSHOP**

The participants, presenters and panelists represented service providers, managers, administrators and policy makers; wait-times and waitlist researchers and methodologists; and patient services advocates, from across BC and other parts of Canada.

The Workshop consisted of formal presentations, brief panel responses, extensive plenary discussions, and small group break-out sessions. Extensive notes were taken, transcribed, and reviewed in detail by members of the Organizing Committee.

## OUTCOMES OF THE WORKSHOP

The following emerged as common theme areas:

### 1. Complexity

Due to multiple services (assessment, diagnostic, (re)habilitative, remedial and supportive services aimed at children and families) provided by multiple service providers across multiple sites, settings and sectors.

The CDR service system seems to differ from the medical/surgical services system in which hip replacements and MRI scans are scheduled and take place. There are multiple points of entry to the system (vs. single entry point), and care may be characterized as a *process* that involves multiple pathways that may be concurrent and recursive, and that continue over time (vs. more straightforward, single point-of-time care *events*).

The implication of this is that measuring and tracking waiting for CDR services needs a different framework than waiting for a particular surgical procedure or diagnostic imaging study.

### 2. Definitions and measurement

The need to have common definitions across providers, sites, settings and administrative sectors (a) for different components of waiting along the service pathway, similar to the 'Wait 1' and 'Wait 2' terms that have been used for work with adult surgical services, but that reflect the complexity of CDR service delivery pathways; and (b) for different services and service types in CDR.

The group also felt that it was important to acknowledge that there are different kinds of waiting, including waiting that is due, for example, to a child not being developmentally ready for assessment or intervention, or due to patient choice or convenience, vs. waiting due to system-wide problems such as a poor triage, or administrative inefficiencies.

There was considerable discussion about logistics about collection of good quality data in an extensive system such as the CDR system. The existence of such data will enable research to be undertaken. However, mention was also made of two pitfalls: the burden of data collection on individuals who have to collect and enter data, and the costs and administrative barriers of trying to set up a very large comprehensive system.

### 3. Management of waitlists

There was interest in how agencies are tracking and prioritizing patients/clients on waitlists, and how this could be done better. This led to considerable discussion about two important dimensions of triage in CDR services: 1) how do we know that people on waitlists are waiting for the 'right' services, meaning services that are appropriate for their needs, and that are needed and likely to be effective and helpful effective; and 2) how to prioritize clients/patients on a waitlist fairly and ethically. When we consider the criteria that should be used for this, it links back to the question of what services are needed, appropriate and most likely to help; 3) the possibility of different triage approaches than the conventional one of placing people higher or lower on a waitlist for a particular service or package of services. For example, some patients/clients could be triaged to receive one kind of assessment or intervention, and others to receive a different kind. Currently, alternatives of this kind are feasible because there is a limited evidence base to guide recommendations in CDR. The limited evidence base for the effectiveness of various services and interventions in CDR was seen as a challenge to the field, but also an opportunity for research.

There was considerable interest in knowing more about how different service delivery models might affect wait-times as well as other outcomes such as health, well-being, function, and satisfaction

#### 4. The experience and impact of waiting

The group identified a lack of information on the experience of children and parents while they are waiting for services: what is happening while they are waiting—are they receiving any kind of support or therapy during that time? How do they feel about waiting, and what are their expectations of what they are waiting *for*? What is the impact of waiting on children, families and service providers who might have to deal with families who are frustrated with waiting? Is there anything that can be done, or is being done, to ameliorate waiting?

#### 5. Unmet need

In common with other groups who have studied wait-times and waitlists, the group identified instances where there may be no waiting because there is no service available that people are waiting for. These may be seen as instances of unmet need. Examples provided from various sites across Canada included the extent of remedial and rehabilitative services available within schools; services in rural settings; and services for specific populations, such as aboriginals, immigrants, and youth with disabilities at the time of transition to adulthood.

#### 6. Caveats regarding data collection and reporting

Participants felt that collecting good quality data on children and families waiting for CDR services (who, where, for how long, and for what services), would be important for understanding how CDR services are organized and delivered, for monitoring and potentially improving system performance, and for managing waitlists. However, a number of participants brought to the group's attention at least two caveats that need to be considered, besides issues of burden and cost that were mentioned above: 1) as with any data, there is the need to ensure the data are valid and accurate, and there was some unease that, due to complexity and other factors, wait-times data might be subject to systematic inaccuracies. There are also questions of how such data are interpreted – what do the data *mean* and what might the data *obscure*? 2) what is the ultimate purpose of data collection, and who is the intended audience for these data? Data on waiting times can be collected, and used, for different purposes. Dissemination of wait-times and waitlist data can have unintended consequences, including their use for political purposes that pit one group's needs against another's. In addition, if waitlists or wait-times are tied to financial or other incentives, there is a risk of agencies or clinics manipulating the data or "gaming" the system in perverse ways in order to maximize collection of incentives; 3) finally, there are issues around confidentiality in collecting patient data, and particularly in sharing such data and having controls on access to the data.

The above theme areas were reformulated and prioritized into four "Actionable and Researchable Themes" as follows:

Theme 1: Data

Theme 2: Measuring, understanding and improving wait-times

Theme 3: Management of waitlists through prioritization and triage

Theme 4: The experience and impact of waiting

### **Theme 1: Data**

This has two components: (a) Data quality, including defining terms and standardization of data elements; and (b) data collection, including process, logistical, confidentiality and other issues.

### **Theme 2: Measuring, understanding and improving wait-times**

There are three main avenues to approach for this theme: 1) Research efforts to describe the length of time that children and families wait for services, about which we have few data presently. These efforts could begin with obtaining a current baseline—perhaps not all services at once, but for ‘sentinel services’ or ‘sentinel conditions’; 2) Research efforts to understand determinants of wait-times through future and broader studies variation in wait-times in relation to condition type, service type; model of service delivery; agency, sector, region, and province; 3) Creation of standards or benchmarks for how long children and families should wait for different kinds of CDR services, and then checking for adherence to these standards (once the data tracking elements/systems are in place to do this).

### **Theme 3: Management of waitlists through prioritization and triage**

Assuming that there will continue to be waitlists for CDR services, consideration should be given to a variety of ways to manage such waitlists. One approach involves prioritization of patients/clients such that some receive a service sooner than others. Researchers and managers might look at creating prioritization scores for CDR services, similar to what has been done in WCWL Project for children waiting for mental health services. The prioritization tool is based on evaluation of severity, urgency, and expected benefit, with or without consideration of non-clinical factors (Hadorn D, CMAJ 2000; 163: 857-860). Alternative mechanisms might include making available a spectrum of intervention/(re)habilitation services ranging from highly intensive, specialized, child-focused therapies at one end, to less specialized, more group-oriented and family-focused services at the other end. Following a comprehensive and updated review of need and likelihood of benefit of services in CDR, waiting patients/clients could be carefully and selectively triaged to the most appropriate services for them.

A further aspect of prioritization and triage is the ethical dimension: how to ensure ethical decision-making, whether using the prioritization approach under which some patients receive a particular service sooner, or a selective triage approach under which some patients receive one service and others, another. Ethical decision-making in this area would be enabled by having better research evidence of need and benefit of services, and/or better expert consensus in areas of CDR where ‘best practice’ is poorly defined (such as the needs of young children with speech-language delay or generalized developmental delay; or older children with learning and intellectual disabilities).

### **Theme 4: The experience and impact of waiting**

There are many relevant and important questions that need to be addressed in relation to the experience and impact of waiting. These include knowing more about how parents perceive their waiting for CDR services; what their specific needs are during this time; and whether they engage in activities related to the child’s developmental concerns, and whether any supports are in place during the time that they are waiting. It would also be valuable to learn more about what parents’ expectations are of the services for which they wait, and to learn more about how they value prompt but less intensive therapy vs. delayed but more intensive therapy, within consumer utility studies.

It is also important to examine the impact of waitlists on service providers, who might be discouraged by not being able to provide services to families in a timely way, and by having

to deal with frustrated families. Are these effects present, and what effect do they have on productivity in providers' work and retention in their fields of work?

## **PROSPECTIVE NEXT STEPS FOLLOWING WORKSHOP**

### Consensus building conference

In order to address the themes of data, measurement and complexity, members of the Organizing Committee plan to partner with key provincial and national stakeholders to hold a consensus building conference. The two main aims of this conference will be (a) to deal with key issues in relation to waiting as a measurable phenomenon, i.e., the collection of data about wait-times and waitlists; and (b) to deal with complexity. Specifically, the conference will

- begin to define and specify a set of service entities that comprise the basic (or "molar") units of service delivery in CDR. These are envisaged as discrete units, episodes, or phases of service, perhaps tied to some definable end-point of each service, that will be meaningful and transposable between agencies and service sectors, thereby facilitating data collection;
- work towards consensus on a common set of definitions for different components of the service pathway, that involve waiting;
- reduce the obstacle posed by complexity in CDR services by defining key areas of focus for the immediate future – sentinel conditions, services, and service units.

An additional aim of the conference will be to examine existing and potential sources of data, such as administrative databases or potential registries, and how data may be collected and shared.

### Elaboration of research questions and projects

#### *1. Studies of the experience and impact of waiting.*

Studies of the experience and impact of waiting on the part of families seem eminently feasible. Research of this kind could be most effectively done if we involve families who are presently waiting, those who have recently waited and have now received services, or possibly the same families within a before-after study design. Studies of the this kind would examine

- the impact of waiting on the child's health, development and wellbeing, and on family health and wellbeing;
- how families feel about waiting, both before and after waiting;
- parents' perceptions of what they are waiting for, and their expectations of the assessment and intervention services for which they are waiting, or that they have recently received;
- what is happening while they are or were waiting, in terms of activities relevant to the child's development, or to support for the family.

We will explore the feasibility of such studies further, and consider their strategic significance.

#### *2. Studies of waiting for services across services, agencies, sectors, and jurisdictions.*

It would be fascinating to relate variations in wait-times for services, along with other selected indicators of outcome from services received, to the different service models that are in place across multiple domains and jurisdictions. However, it was felt that such studies are not yet feasible because of the enormous diversity in practice, and a current lack of comparability in basic terms and definitions.

*3. Further work on defining effectiveness and appropriateness of CDR assessment, diagnostic, intervention and supportive services.*

This was felt to represent a very important though vast program of research, for which there needs to be long-term planning, coordination and commitment.

Respond to an anticipated Request for Applications (RFA) from the CIHR

The Organizing Committee is aware of an upcoming RFA that is expected in winter of 2006/07, in which research related to wait-times, as one indicator of health service system performance, will be sought. The Committee is keen to participate in this RFA, and will await details before deciding how an application will be constructed. The Committee believes that this Workshop has been very helpful in focusing issues and areas of need in waiting for CDR services.

## Appendix I Participants

<i>British Columbia</i>	
<b>Robert Armstrong*</b>	Chair, Department of Pediatrics, University of British Columbia and Chief of Pediatrics, BC Children's Hospital and BC Women's Hospital and Health Centre
<b>Lillian Bayne</b> (Facilitator)	Lillian Bayne & Associates
<b>Dana Brynelsen</b>	Provincial Advisor, Infant Development Program of British Columbia
<b>Dianne Cameron</b>	Director of Physiotherapy, British Columbia Centre for Ability
<b>Herbert Chan</b>	PhD Program in Health Services Research, University of British Columbia
<b>Susan Kennedy</b>	Director of Diversity, Equity and Early Learning, Ministry of Education, BC
<b>Ronald Lindstrom</b>	Consultant, Provincial Health Services Authority Research & Networks
<b>Anne Klassen*</b>	Assistant Professor, Department of Pediatrics, University of British Columbia
<b>Stuart MacLeod</b> (24 <sup>th</sup> only)	Executive Director, Child & Family Research Institute
<b>Louise Mâsse*</b>	Associate Professor, Department of Pediatrics, University of British Columbia
<b>Mary Lou Matthews</b>	Manager, Child Health British Columbia
<b>Shirley Meaning</b>	Program Manager, Provincial Services for Children and Youth with Special Needs, Ministry of Children and Family Development, BC
<b>Anton Miller*</b>	Clinical Associate Professor, Department of Pediatrics, University of British Columbia, and Developmental-behavioral Pediatrician, Sunny Hill Health Centre for Children
<b>Duyen Nguyen</b>	Health System Planning Advisor, Vancouver Community Health Services
<b>Maureen O'Donnell*</b>	Associate Professor, Department of Pediatrics, University of British Columbia, and Developmental Pediatrician and Senior Medical Director, Sunny Hill Health Centre for Children
<b>Susan Perkin</b>	Director, Provincial Services for Children and Youth with Special Needs, Ministry of Children and Family Development, BC
<b>Lori Roxborough</b>	Clinical Associate Professor, School of Rehabilitation Sciences, University of British Columbia, and Associate Director, Therapy Department, BC Children's and Women's Health Centre
<b>Boris Sobolev</b>	Associate Professor, Department of Health Care and Epidemiology, University of British Columbia, and Scientist, Vancouver Coastal Health Research Institute

## Appendix I Participants

<b>Margaret Warcup</b>	Executive Director & Physiotherapist, Kitimat Child Development Centre
<b>Stephen Wellington</b>	Clinical Assistant Professor, Department of Pediatrics, University of British Columbia, and Developmental Pediatrician, Sunny Hill Health Centre for Children
<b>Yuanyuan Zhang</b>	Economist, Ministry of Children and Family Development
<i>Ontario</i>	
<b>Marilyn Booth</b>	Executive Director, Ontario Children's Health Network
<b>Joan Ferguson</b>	Vice President of Programs and Services Bloorview Kids Rehab, Toronto
<b>Michael Hillmer</b>	Project Manager, Health Council of Canada
<b>Mary Lysyk</b>	Vice-chair, Canadian Network for Child and Youth Rehabilitation
<b>Peter Rosenbaum</b>	Professor, Department of Pediatrics, McMaster University, and Director, <i>CanChild</i> Centre for Childhood Disability Research
<b>Greg Webster</b>	Director, Research and Indicator Development, Canadian Institute for Health Information (CIHI)
<i>Alberta</i>	
<b>David Cawthorpe</b>	Research and Evaluation Coordinator, Child and Adolescent Mental Health Program, Calgary
<b>Keith Goulden</b>	Developmental Pediatrician, Glenrose Rehabilitation Hospital, Edmonton
<b>Dianne McConnell</b>	Senior Education Manager/Team Leader, Special Programs Branch, Alberta Education
<b>John McGurran</b>	Project Director, Western Canada Waiting List (WCWL) Project
<i>Nova Scotia</i>	
<b>Sarah Shea</b>	Developmental Pediatrician, IWK Health Centre, Halifax

*\*Members of Organizing Committee*

## Appendix II Workshop Program

### WAITING FOR CHILD DEVELOPMENT AND REHABILITATION SERVICES: A RESEARCH AND METHODOLOGY WORKSHOP

24-25 August 2006 • Westin Bayshore Hotel • Vancouver, British Columbia

<b>Thursday August 24</b>	
2:30pm–3:30pm	<b>Registration</b>
<b>WELCOME AND OVERVIEW</b>	
3:30pm–4:00pm	Welcome and Introductions <b>Lillian Bayne</b>  Orientation to Workshop: Aims and Objectives <b>Robert Armstrong</b>
<b>OPENING SESSION—SETTING THE SCENE</b>	
4:00pm–4:45pm	<b>Introductory Address</b> Waiting for Child Development and Rehabilitation Services: Overview of the Field and Issues <b>Anton Miller</b>
	<b>Response to Introductory Address</b>
4:45pm–5:30pm	<u>Panel - BC</u> <ul style="list-style-type: none"> <li>• <b>Dana Brynelsen</b> (Infant Development Programs of BC)</li> <li>• <b>Dianne Cameron</b> (The Centre for Ability)</li> <li>• <b>Susan Kennedy</b> (Ministry of Education)</li> <li>• <b>Stephen Wellington</b> (Sunny Hill Health Centre for Children)</li> </ul>
5:30pm–5:45pm	<b>Coffee Break</b>
5:45pm–6:15pm	<u>Panel - Other parts of Canada</u> <ul style="list-style-type: none"> <li>• <b>Dianne McConnell</b> (Alberta)</li> <li>• <b>Peter Rosenbaum</b> (Ontario)</li> <li>• <b>Mary Lysyk</b> (Canadian Network for Child and Youth Rehabilitation)</li> </ul>
6:15pm–6:45pm	<b>Discussion</b>
6:45pm	<b>Welcome Reception &amp; Dinner</b>

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<b>Friday August 25</b>	
7:30am–8:30am	<b>Breakfast</b>
<b>MORNING SESSION—METHODOLOGY</b>	
8:30am–8:45am	Introductory Remarks, Review of Workshop Day 1 and Overview of Day 2 <b>Lillian Bayne</b>
8:45am–10:15am	<b>Methodology of measuring and tracking waiting for services: Accumulated experience and expertise in the health field</b> The Western Canada Waitlist (WCWL) Project <b>John McGurran</b>  Applying the Western Canada Wait List Project's Children's Mental Health Priority Criteria Score (WCWL-CMH-PCS) at the Regional and Provincial Levels: Implementation Model and Results <b>David Cawthorpe</b>  The Canadian Pediatric Surgical Initiative <b>Marilyn Booth</b>  Measuring Wait Times Across Canada <b>Greg Webster</b>
10:15am–10:45am	<b>Discussion</b>
10:45am–11:00am	<b>Coffee Break</b>
11:00am–11:30am	<b>Methodology of measuring and tracking waiting for services: Local experience and expertise in child development and rehabilitation services</b> Progress with a Conceptual Model for Measuring and Tracking Child Development and Rehabilitation Services <b>Herbert Chan</b>  2005 Provincial Early Intervention Therapy Baseline Data Summary Report <b>Shirley Meaning</b>
11:30am–12:00pm	<b>Discussion</b>
12:00pm–1:00pm	<b>Lunch</b>

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<b>Friday August 25</b>	
<b>FINAL SESSION—MOVING AHEAD: DEALING WITH METHODOLOGICAL ISSUES AND DEFINING A RESEARCH AGENDA</b>	
1:00pm–1:30pm	<p>Organization of Final Session <b>Lillian Bayne</b></p> <p>Overview and Synthesis of Methodological Challenges and Research Opportunities in Waiting for Child Development and Rehabilitation Services <b>Maureen O'Donnell</b></p> <p>Preparation for Small Group Sessions <b>Lillian Bayne</b></p>
1:30pm–2:30pm	<p><b>Small Group Sessions</b> Each small group is asked to identify the <u>main researchable questions</u> related to waiting for Child Development and Rehabilitation Services, and the <u>main methodological issues</u> that pose challenges to such research</p>
2:30pm–2:45pm	<b>Coffee Break</b>
2:45pm–3:15pm	<p><b>Report Back from Small Groups</b></p> <ul style="list-style-type: none"> <li>• 10 minutes for each group</li> </ul>
3:15pm–4:30pm	<p><b>Plenary Group Discussion</b></p> <p>This Plenary Group discussion is to collectively</p> <ul style="list-style-type: none"> <li>• Craft a preliminary research agenda by prioritizing main researchable questions</li> <li>• Formulate an action plan for building consensus on dealing with methodological issues, and for moving ahead with a research agenda</li> </ul>
4:30pm–5:00pm	<p>Summing Up and Next Steps <b>Lillian Bayne</b></p>
5:00pm–5:05pm	<p>Closing Remarks <b>Anton Miller</b></p>
5:05 pm	<b>Workshop Closes</b>

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