

# **ICF Knowledge Sharing Collaborative 2010**

**March 10-11, 2010**

Prepared by  
*D. Parker-Taillon and Associates*

# ICF Knowledge Sharing Collaborative 2010

March 10/11, 2010

## Summary Report

### Table of Contents

1.0	Welcome and Opening Remarks.....	1
2.0	Setting the Stage.....	1
3.0	Sharing Our Experiences.....	5
4.0	Reflections on Day 1 .....	18
5.0	Taking Stock.....	20
6.0	Where Do We Go From Here? .....	21
7.0	Moving Forward .....	25
8.0	Closing Remarks/Next Steps .....	26
	APPENDIX A .....	27
	APPENDIX B .....	28

## 1.0 Welcome and Opening Remarks

On Wednesday morning, March 10, 2010, Diane Caulfeild welcomed participants to this first International Classification of Functioning, Disability and Health (ICF) knowledge sharing meeting in Canada. Ms. Caulfeild introduced Dianne Parker-Taillon as the facilitator to guide discussions during the meeting and Anik Bédard who would record discussions and views expressed. Ms. Caulfeild also introduced and thanked Ms. Sandy Duncan who played a key role in coordinating the planning of the meeting.

Ms. Caulfeild introduced Mr. Jack Bingham, CIHI Executive Director for Ontario, who welcomed participants on behalf of John Wright, CEO of CIHI. Mr. Bingham then provided participants with a brief overview of the role and structure of CIHI, including stakeholders and main clients.

Ms. Parker-Taillon followed with an overview of the agenda. She also highlighted the four objectives for the workshop, which are to identify:

- How ICF or ICF-CY is being used in Canada
- What ICF and ICF-CY activities / projects have been undertaken in various regions and fields of practice
- The potential for new ICF and ICF-CY activities/projects
- How CIHI may be of assistance.

Ms. Parker-Taillon then invited participants to briefly introduce themselves. A list of participants is included in Appendix A.

## 2.0 Setting the Stage

### ***Background and History of ICF/Role of CIHI/WHO Committees***

Ms. Caulfeild described ICF as the newest of the World Health Organization (WHO) classifications, with its most recent publication being the ICF-CY Children and Youth. She explained how, in Canada, ICF has not been mandated at a pan-Canadian level for data collection in any field. However, it is used in many individual projects and settings in surveys, academia, research, administrative, clinical, government and policy. Interest in mandating its use may change with the coming of electronic health records. Ms. Caulfeild reviewed the relationship between the WHO and CIHI, with CIHI contributing to the WHO Family of International Classifications (WHO-FIC) and Collaborating Centre meetings and the development of WHO classifications.

Ms. Caulfeild briefly reviewed ICF activities in Canada. These included:

- CIHI has partnered with the National Centre for Health Statistics (NCHS) in a number of initiatives on ICF.
- Statistics Canada, where the Participation and Activity Limitation Survey (PALS) is based on the ICF framework and other StatsCan involvement in Disability Tabulations (DISTAB) and the Washington City Group on Disability Statistics.
- Universities: ICF is included in the curriculum of all the Schools of Rehabilitation in Canadian universities from the baccalaureate to the PhD level.

- At the Federal Government level: Human Resources and Skills Development Canada (HRSDC), the Royal Canadian Mounted Police (RCMP) and the Canadian Medical Protective Association (CMPA) are incorporating ICF into initiatives.
- Many provinces are also incorporating ICF into activities, in using the ICF language and/or the framework itself.
- Global activities with ICF are occurring in many countries, with a range of implementations.

Ms. Caulfeild concluded her presentation by mentioning the WHO-FIC Annual Meeting in Toronto from October 16 – 22, 2010, where she hopes to have an ICF specific component. She also presented the ICF eLearning Tool, which is to be field tested from March 2 – July 31, 2010.

### ***CIHI Data and Reports – A Context for Exploring Activities for ICF***

Ms. Caulfeild introduced Kathleen Morris, Head of Emerging Issues with the CIHI Research and Analysis Division who presented on CIHI Data and Reports as a context for exploring activities for ICF.

Ms. Morris began with an overview CIHI's data and analytical work and highlighted the three Strategic directions for 2009–2012: data collection, analysis, and understanding/use:

- **Data:** Ms. Morris explained how standards are laying the foundation for information. She described the areas in which CIHI is collecting data, the most comprehensive of which is in Acute and Ambulatory Care. Data collected on Health Professionals, Health Expenditures, as well as future directions for collecting data in Primary Health Care, Community Mental Health and Aboriginal Data were also discussed.
- **Analysis:** Ms. Morris described the two types of reports produced by CIHI: Annual Reports (one report per data base), and Special Studies (40–50 per year, triggered by special questions, policy-relevant topics of varying lengths). She then described the analytical plan CIHI is developing, which adds value for decision-makers/stakeholders, and makes the best use of CIHI's growing data holdings.
- **Understanding and use of the information:** Ms. Morris explained that this is facilitated through education (website / CIHI portal, media releases, specific tools and presentations), as well as through E-Reports.

Ms. Morris then discussed on how CIHI activities could relate to ICF. One of the challenges is that ICF is not well known or understood and there is also the cost of collection of data in a cash-strapped system. However, she noted that opportunities do exist and while CIHI reports focus on what we know, they also mention what we don't know. ICF could potentially provide a framework for what we don't know.

To illustrate this point, she provided an example on health indicators, and the question of why knee replacement rates in Quebec are so much lower than in other provinces with the trend being the similar for hip replacements. Could ICF data provide information? CIHI has used data that they have (e.g., numbers of orthopedic surgeons, capacity for hospitals, wait times, arthritis rates, obesity rates), but there is something missing to understand this. One of the factors being considered is the role of pain and activity as factors in the decision to have such surgery, and the thought is that ICF may provide information to better understand this. Participants raised the issue of access, and Ms. Morris indicated

that regional data did not offer an explanation. Another point raised by participants was that many such surgeries in Quebec are done in private clinics, so this data would not be collected. The question remains, as specified by Ms. Morris, as to whether CIHI is missing a piece in terms of the decision to have such surgery, and if ICF data could help in understanding the variation rates.

Another example is to explore higher levels of self-reported good health in certain regions compared to rates of certain procedures (e.g., hysterectomies). An additional example is the need for a certain type of surgery (e.g., cataract surgery) is evaluated in the same way in all provinces: that is, are patients getting the surgery at the right time, what is the benefit of the surgery and the impact. These questions become important in decisions for funding, because knowing the benefits could play a role in making the funding decisions.

Ms. Morris explained that CIHI is still in the beginning stages of work on Patient Pathways and Outcomes. They are beginning to follow the patient with the data that they have (number and profile of patients following different pathways) and also looking at the cost of an episode of care. What is not known is why patients may have a similar starting point but have different outcomes. There is a need to look beyond readmissions and FIM status, to look at whether patients return to productive healthy states, and whether or not the pathway makes a difference.

Ms. Morris concluded her presentation with the thought that, while it is a difficult road to build a classification, it is a worthwhile one, in that it is all about improving our health status.

Ms. Caulfeild thanked Ms. Morris and invited participants to ask questions. The following points were raised:

- The focus has been on the health service and the provider, but more could be learned from following the patient. ICF can help with the collection of this data. Ms. Morris commented that the questions remain as to whether there is incentive to collect the data, who will collect it, what will be done with it, and how will it be used.
- It would be interesting to also collect data on those that do not have surgery – whose decision is it, and why. Ms. Morris responded that there are many potential applications, especially in looking at wait times. There may be an advantage to look at issues that are in the news when looking at potential applications of ICF.
- CIHI may need to reframe its own vision and mandate to redefine health, as it currently is collecting data that is very much disease related. ICF could be used to collect data on more than diagnosis.
- There is a need to educate so that ICF will not only be talked about in the context of rehabilitation.
- CIHI and Statistics Canada have a great deal of information, some of which is missing in the literature base. The data is valuable, even with small sample sizes, if solid scientific methods are used.
- Looking at the whole picture will be important if/when we do start to look at people and function rather than the health system.
- How can functional data be compared in the future? Up until now, there has not been much emphasis on data collection that could give us answers. ICF does not have a perspective; for example, quality of life cannot be mapped onto the ICF.

There is a need to use what data is available while continuing to try to make the data better by building on what exists.

- To date, data collected is close to the episode of care, in control of the health care provider. There is a sense that the data collected with the ICF is further from this, so it would be more difficult to collect and have more variables that could affect the outcome.
- As a front line clinician, only the time being spent with a patient is being collected.
- The perceptual framework component of the ICF may be easier to integrate than the numbers component. We are lacking the measures of participation in various areas, so one can backtrack into the numbers. There is a need to make the differentiation between the framework and the numbers, as the global areas of life need to be looked at before the numbers. A response to this comment was that the environment piece can only really be captured with the numbers component of ICF.

At the conclusion of the presentation, Ms. Parker-Taillon thanked Ms. Caulfeild and Ms. Morris for setting the stage and stimulating lively discussions.

### **3.0 Sharing Our Experiences**

In preparation for this workshop, participants were organized into panels according to themes. Each presenter provided a brief description of their ICF activity/project identified key lessons learned and described future directions.

In this section of the report, a brief summary of each presentation is provided. Further details from the Power Point presentations specific to each presenter will be available on the CIHI website which will have a link to this specific meeting.

#### **PANEL 1: OUTCOME MEASURES AND MINIMUM DATA SETS**

##### **1.1 Sandy Litman and Shawna Wade (Canadian Association of Paediatric Health Centres (CAPHC) and Canadian Network of Child Youth Rehabilitation, Toronto ON)**

Ms. Litman presented the CAPHC as having a mandate to effect system-wide change in the delivery of health services to children and youth across Canada. To achieve its goals of promoting data sharing and benchmarking with like organizations as well as promoting the development of outcome indicators for children's rehabilitation, a survey was completed in September 2009 to define who the organization is, identify indicators currently used, determine how data is currently reported and identify a priority set of national indicators.

Lessons learned from this brought forward indicator priorities for a National Minimal Data Set, including the need for two primary patient groups, common elements and population specific elements, as well as common data set elements ranging from parent stress and quality of life to activity and participation.

Future directions indicated a need for consensus on common and population specific outcome measures that reflect ICF dimensions, and issues related to valid/reliable outcome measures and implementation at a national level.

##### **1.2 Sandy Loewen (The Rehabilitation Centre for Children, Winnipeg, MB)**

Ms. Loewen described the process by which the Physiotherapy/Occupational Therapy Paediatric Clinician's Network was formed in October 2004, as part of the Children's Therapy Initiative (CTI) in Manitoba. The goal of the CTI was to improve therapy services for children and youth in Manitoba. The project undertaken by the Network was to develop a single outcome measure that described the functioning of children and youth (0-21 years) receiving PT and/or OT services in Manitoba and to define service delivery and client outcomes. This was done using the ICF as a framework, using performance indicators from the Activity and Participation section of the ICF and using ICF definitions for each of these functions. As a result, the Manitoba Outcomes Services by Therapists (M.O.S.T.) Performance Indicators were developed for both physiotherapy (PT) and occupational therapy (OT). A pilot study was completed in May 2007, and was included as part of the Integrated Clinical Services Outcomes Project.

A summary of lessons learned included: the ICF provides clinicians with a common language; collaboration takes work, time and resources; clinicians think differently than IT people, so must learn to talk the same language; ongoing need to update Privacy Impact

Assessment; charter is excellent document to help remain focused; numerous government departments involvement creates a challenge in sharing information; core sets make the ICF manageable for clinicians; needs to be user-friendly, with training on how to use and have updates available.

Future directions for this project include: final completion of the electronic database; updates to privacy forms; completion of training manuals for therapists and managers; training sessions to be held; data entry anticipated to start in the fall 2010; creating reports based on the data; updating the data collection as needed; and sharing the information.

### **1.3 Nancy Mayo (McGill University Health Centre: Research Institute, Montreal QC)**

The goal of ICF activities presented by Dr. Mayo was to use the ICF to create coded functional status indicators suitable for inclusion of information on function on electronic health records and on health administrative databases. She described how an outcome measure score alone does not have meaning, but that if the measure is matched to the ICF, it can provide functional status indicators. Examples of activities/publications include: the development of a mapping protocol, mapping the Stroke Impact Scale (SIS-16) to the ICF, and an ICF Mapping of the ICF was completed, incorporating the ICF into an electronic health record to create indicators of function.

Current activities include the Implementation of the ICF in an Acute-Care Hospital Setting, where the objective is to identify barriers, facilitators, risks and benefits of implementing a standardized method identifying the functional limitations rendering a hospitalized individual at higher risk of complications or interventions leading to a delay or change in discharge destination. Next steps include the form to be approved by the Documents Committee, creating an electronic version of the form, making the form part of the electronic chart for Geriatrics and Internal Medicine, codes FSI available on the facility Clinical Data Warehouse, and Function being added to Diagnoses, Procedures, Drugs and Test results.

### **1.4 Nora Fayed (PhD student, McMaster University, Hamilton, ON)**

Ms. Fayed described her involvement in a number of projects using ICF and ICF-CY. The first of these was a project looking at methods for linking existing tools to the ICF to determine content equivalence between clinical practice areas, language and cultures. Another project looked at selecting and planning future studies in childhood research using the ICF-CY.

One of the main lessons learned was that there are many dimensions on measures – mapping onto the ICF is only one aspect. It was felt that at the core is knowledge sharing in terms of conceptual issues, clinical use and methods and use in research, with many opportunities for collaboration being present.

Future directions include further work on methods and health services research, as well as knowledge sharing surrounding the ICF.

### **1.5 Veronica Schiariti (Department of Pediatrics UBC, Vancouver BC)**

Dr. Schiariti was involved in a project where the objective was to develop the ICF-CY core sets for children and youth with Cerebral Palsy (CP), and to identify which ICF-CY categories best represent the functional profile of children and youth with CP. She described the methods used in the study, including the systematic reviews and the Global Expert survey.

The next step in this study is to summarize results and present at the WHO Consensus Conference to get a first version of the core sets. Based on the evidence, brief and comprehensive ICF-CY core sets for children and youth with CP can then be developed.

### **1.6 Questions and Comments related to Panel 1**

- To Dr. Schiariti: Is there a plan to use these core sets for adults with CP, as there is not much information on this population? Dr. Schiariti identified that at this time, the plan is to use the core sets to transition ages (i.e., 18-25 years of age.)
- Has M.O.S.T. been published and do clinicians find this easy to use? This would be a good example of how ICF can be used. Ms. Loewen explained that it has not been published because the data is not complete, and therefore it is not being used yet. It has been used as a pilot, with the goal being to make it functional and easy to use by therapists. It is also a way of showing information on the type of client population they are seeing, so may help with information to recommend more therapy time.
- A paradigm shift is needed as it appears that a more functional approach has been taken with children than with adults. In addition, ICF is used much more for children than adults.
- Need for a national voice, to get the messages out on all of the great practice going on, making the work in one place available to others.
- Need pressure on CIHR to work on knowledge transfer.
- Points for later discussion: discussions on how ICF can be applied in an individualized way to patients, how clinicians can use it; also on e-learning tools and how these can be used.

## **PANEL 2: MAPPING TO OTHER TOOLS/MODELS**

### **2.1 Tanya Eimantas (Occupational Therapist, ErinoakKids, Mississauga, ON)**

The goal of this work was to develop A Functional Client Groupings (CGM) Model for Children and Youth with Physical and Developmental Disabilities (CGM) in order to have a systematic method of caseload management using available resources which would, among other sub-goals, use the ICF as a framework. The team developed steps to achieving the goals, including identifying the clients at the facility, determining the typical client journey and critical junctures, classifying each client using the grid, projecting required resources and identifying and developing practice pathways. Through this process, they discovered that 67% of their clientele fit into the 'least involved' category. This information could then be used to decide on service delivery and resource allocation, for example having groups or classes to serve a greater number of clients.

Lessons learned were based on what the CGM could offer to Children's Treatment Centres and the broader health care system: using it as a descriptive tool for the client population, using it as a communication tool between multidisciplinary team members, using it as a management and workload tool to provide a framework for resource allocation and consistency of client care through the development of care pathways and using it as an educational tool for new clinicians.

Future directions at this facility include evaluating the inter-rater reliability and the test-retest reliability, as well as evaluating the clinical utility of the CGM.

## **2.2 Genevieve Martin (Canadian Institute for Health Information, Ottawa ON)**

Ms. Martin described CIHI's National Rehabilitation Reporting System (NRS) history and its current context. Of note is that it is conceptually based on the ICF. The Data Sets were meant to reflect the ICF components, with a heavy focus on body functions and structures, as well as activities, and limited data and information on participation. The follow-up assessment component is voluntary, so there is a limited amount of data available; much more would be available if the follow-up assessment could be promoted.

What is known through NRS is that ICF is partly incorporated in Canada's National Rehabilitation Reporting System; that ICF has potential value for organizing inpatient rehabilitation services data; and that inpatient rehabilitation data of relevance to social participation are currently limited.

What is not known is: whether there is an 'appetite' for ICF in inpatient rehabilitation reporting; if mapping to ICF codes without qualifiers provides enough added information; if any research is being done on mapping the Functional Independence Measure (FIM) instrument scores to ICF qualifiers; and to what extent do the users of NRS perceive the collection of ICF data as a coding burden.

Future directions for the Rehabilitation team at CIHI include exploring the feasibility of mapping (behind the scenes) some of the NRS data elements to ICF codes and the team discussing the potential uses of ICF codes with stakeholders.

## **2.3 Susan Stobert (Statistics Canada, Ottawa ON)**

Ms. Stobert began by describing the importance of information as the foundation for action on disability issues. The Participation and Activity Limitation Survey (PALS) is Canada's principal national survey focusing on persons with disabilities. She proceeded to describe the relationship between PALS and ICF, with PALS following ICF as a model, but not 100%.

Ms. Stobert reported that the future of PALS is uncertain, with options for the collection of information about persons with disabilities in 2011 being considered, but no decision having been made. She also reported that if a children's PALS were to be approved, changes would be made to incorporate the ICF-CY.

## 2.4 Questions and Comments related to Panel 2

- The above information reinforces the fact that there is no need to re-invent the wheel. Rather, there is a need to improve on PALS. The information /data is there; need to coordinate it, not re-invent it, and ICF needs to take a central role in these initiatives.
- To Ms. Stobert: In PALS, why are chronic conditions not identified in adults? Ms. Stobert indicated that they are easier to identify in children. In adults we have to ask for an underlying reason for the disability/condition.
- To Ms. Stobert: There is a big implication if PALS is not on the 2011 census, as the age group is increasing and demands are increasing. It is comparable to the early warning sign for a tsunami. Are issues of addiction included? Ms. Stobert suggested that it is not overtly included as it is a telephone survey; we would not necessarily obtain good information.
- Decisions made based on caregivers being able to do certain things – barriers or facilitators on ICF are important.
- Having the availability of the professional at the bedside is better than the assistant; e.g. the SLP being available for direct care rather than a SLP assistant.
- Train-the-trainer model: in the children's system it has been shown that this is a better utilization of services and can reduce wait times.
- On mapping: uniform data sets and FIM / WeeFIM: more elements being added, with a webinar being planned for the spring 2010; mapping is to occur for the new FIM to ICF
- Overall question: where does mental health fit in here, and are they at the table? In Manitoba, for the M.O.S.T., an OT in mental health participated in the development of the questions; it is important that they be included.
- There is a population of adults dropping off the map – misdiagnoses of adults has an impact on their lives: for example, fetal alcohol syndrome; these would not be captured by the survey. Need to look at alternate ways to capture the information and to be innovative in looking at some of these developmental disabilities.
- Appeal for nursing to be at the table, so that ICF could inform the data they collect.
- Need to look at how to save money by looking at ICF data, and how decision makers could use this data.

## PANEL 3: CHRONIC CONDITIONS AND PARTICIPATION

### 3.1 Elizabeth Badley (Dalla Lana School of Public Health, University of Toronto and Arthritis Community Research and Evaluation Unit, Toronto Western Research Institute, Toronto ON)

Dr. Badley presented various theoretical and empirical studies being done with the ICF, some published and some not.

Lessons learned included: the need for more conceptual work to clarify and better define ICF concepts and their relationships; ICF being a valuable tool for studying disability over time; the need to understand more about relationships and mechanisms; implications for measurement of outcomes; both salience and satisfaction are important; and that overall 'role' performance in major life areas is distinct from activity.

Future directions included: further work on the distinction between personal and environmental contextual factors; suggested modifications to the model; conceptual model

for social role participation; ongoing analytic studies of impairment, activity and participation relationships using existing data sets; further analysis of the 'importance of time' data; and using and further developing the Social Role Participation Questionnaire (SRPQ).

### **3.2 Gillian King (Bloorview Research Institute, Toronto ON)**

Dr. King presented and provided examples on the use of the ICF Framework in the design of research studies and on how the ICF can be incorporated in organizational service delivery frameworks to meet goals of participation and quality of life for children with disabilities.

She presented the lessons learned to promoting psychological wellness and implications for service delivery. Key lessons learned were identified as: the need to see individuals as 'at promise' rather than 'at risk' (i.e., facilitating rather than fixing); the importance of a biopsychosocial approach; and the importance of a broad lifespan approach to practice.

In terms of future directions, she mentioned the CIHR Emerging Team in Optimal Environments for Severely Disabled Youth, with the notion of participation in 'activity settings', measurement of youth's experiences in activity settings, and measurement of qualities of activity settings.

### **3.3 Betsy Mustard (Private Practice, Calgary, AB)**

Ms. Mustard presented on using ICF style assessment tools to document efficacy of treatments in clients with multifactorial issues and/or predisposing factors in a private practice setting. These would provide a broad ability to measure changes over time in a client population which is often not in a position to be funded for holistic treatments through the standard payers (MVA, WCB, Government health funding) due to predisposing and complicating factors.

Ms. Mustard reviewed their trial of the ICF short form by holistic physiotherapists with a select client population. Findings suggested that the short form was not precise enough to show change over time, that there needs to be core sets for specific cases, that documentation was too time consuming to be practical and that therapists need more formalized training in coding and best choice of relevant domains.

In this population, future users of ICF would be insurance companies and governments (e.g., policies for health funding, disability coverage, housing options, and school support), and practitioners would be allowed to measure change over time. Future directions would be to bring this tool into common practice to assess efficacy of holistic practices and to enhance communication between professions, to discuss core sets for chronic conditions and to have more training opportunities.

### **3.4 Vanessa K. Noonan (University of Washington, Post Doctoral Fellow Blusson Spinal Cord Centre, Vancouver BC)**

Dr. Noonan presented various projects in which she was been involved using the ICF. These included: her PhD thesis (comparing participation measures), the Rick Hansen SCI Registry: development of new measures, the International SCI Data Set project and the SCI Rehabilitation Evidence (SCIRE).

Lessons learned included: that the ICF model is a powerful tool to understand health and disability; that the ICF provides a common language; that published methods using the ICF classification are helpful. She also presented on lessons learned regarding areas to improve: the need to differentiate the concepts of activity and participation, the need to clarify how quality of life fits in the model, and the need to include a classification for personal factors.

Future directions presented by Dr. Noonan included: the need for further development of the ICF model and classification; further research testing the relationship among the concepts; using the ICF to design research studies, develop and present data sets; and integrating the ICF into clinical practice.

### **3.5 Rebecca Renwick (University of Toronto, Toronto ON)**

Dr. Renwick presented on a research project, The Children's Quality of Life Project, which looked at quality of life for children with intellectual and developmental disabilities. She specified that they did not use the ICF.

The Research Program looked at both the parental perspective as well as the child's perspective, through two different research methods, and identifying a conceptual framework for both.

From the parental perspective: findings indicated that parents' concerns emphasize the role of the environment and inclusion in children's QOL; highlights the need for greater community-based opportunities, resources and supports; and the implications are that it provides for "accurate" information on which to base policy, programs, services, and enhancement of community environments.

From the child's perspective: findings indicated that information about what children see as important in making their lives good needs to be considered; and there are implications for policy developers and professionals.

### **3.6 Questions and Comments related to Panel 3**

- Need to find a way to inform (the government) that maintenance can be good (i.e., in older kids, looking for maintenance rather than improvement)
- In pediatrics, this was felt to be an important component, as there is still that growth factor
- Complex relationship between quality of life and ICF

- How do you define quality of life? It seems personal perception and expectations distinguish the two. How clear would the link between quality of life and ICF be?
- Health is optimal functioning and is quality of life
- To Elizabeth Badley: Did you create measures that were used over time? Did you have information on what physicians have prescribed in limiting activities? We used what was there to put the measures together on how we could represent participation over time. We did have some of the restrictions from physicians, i.e., what would have been as a result of the surgery, but are not suggesting there is a direct 1:1 relationship.

#### **PANEL 4: KNOWLEDGE AND USES OF ICF**

##### **4.1 Michel Lacerte (University of Western Ontario and Université de Montréal)**

Dr. Lacerte presented on various projects involving the ICF. These included: the Medical Taxonomy collaboration; and rehabilitation models such as Life Ability Box, Medically Unexplained Disablement and Preventing Needless Disability which examined the importance of not medicalizing what is often a social issue, and also the need to get labour and employers involved in returning people to work; education in various institutions, including noting the need for basic training at various levels; and with Disability systems and Insurance Rehab Political Analyst.

Key lessons learned included: the Americanization of rehab delivery; the politicizing of science; disablement by “lawyerization”; causal chain and ICF interaction; and contextual factors as the most important elements in rehab outcomes.

Future directions presented included: looking for sociopolitical solutions – social environment that is enabling or disabling; rehabilitation code; and ICF as an analytic tool for policy development.

##### **4.2 François Sestier (Université de Montréal)**

Dr. Sestier presented on the Université de Montréal’s program of Insurance medicine and medicolegal expertise. This is a web-based curriculum. In 2006, lectures were recorded to teach ICF to medical experts, and in 2008, the ICF core sets were added, but this terminology has not been adopted by the American Medical Association (AMA) Guides.

The program looked at ICF core sets in various groups (e.g., in Cardiology-Coronary Artery Disease (CAD), Low Back Pain and Depression). From these examples, an Independent Medical Evaluation (IME) template was developed, using the 6<sup>th</sup> edition of the AMA Guide – which would be easy for a medical expert to use.

Future directions include developing core set summary sheets for more medical conditions, and following new models of impairment evaluation, adding more weight on quality of life.

#### **4.3 Debra Stewart (McMaster University, Hamilton ON)**

Ms. Stewart presented on two surveys (Canadian and Global) designed to measure the current knowledge and use of the ICF by occupational therapists, to increase awareness of the ICF through research and knowledge translation, and to share examples of ICF applications with occupational therapists in order to increase its use/application.

Lessons learned from the surveys were broken down into:

- Barriers to use in Clinical Practice: lack of familiarity, knowledge and awareness; too detailed; resistance to change/no buy-in; website hard to use; hard to explain/use with families; can't code personal factors; activity and participation not clearly distinguished; not used in Québec; and mental health issues not fully addressed.
- Strategies suggested by OTs to increase the use of ICF in Clinical Practice: all university programs to include ICF; website information readable and guidance on how to link to clinical practice; case examples; training; Short Red Book seen as more useful to clinicians; core sets very helpful; and delineate activity and participation to decrease the confusion.

Future directions include: posting of the global survey results on the World Federation of Occupational Therapists (WFOT) Website and send to WHO for information and feedback; provide some examples of presentations by OTs on the ICF as well as relevant articles and post on the WFOT website; and recommendations to increase the use of the ICF will be reviewed and implemented.

#### **4.4 Questions and Comments related to Panel 4**

- To Dr. Sestier: Was this tool being translated into clinical practice? The tool is really for medical experts in IME, but workshops for various practitioners have also been developed, which are web-based. They are recognized by the Royal College for Continuing Education.
- A possible future direction would be a repository of well constructed vignettes which could be used by everyone.
- A major training program is available in France, and was presented at a meeting in 2006; we need to look at the value of in-person training vs. only having it web-based.
- There is a need to get the data out there; with the system as it is, there is a problem with physicians who are willing to write what is needed so their patient can have access to benefits.

### **PANEL 5: PEDIATRICS AND CHILDREN'S REHABILITATION**

#### **5.1 Diane Calce (Marie Enfant Rehabilitation Centre of Sainte-Justine University Hospital Centre, Montreal QC)**

Ms. Calce presented on the Disability Creation Process (DCP), comparing it first to the ICF. Differences that stand out between the two conceptual models include: the DCP terminology is "social participation" and "capabilities", while the ICF terminology is "participation" and "activities"; also, the DCP measurement tools of participation are "life-habit", while the measurement tools of the ICF are a checklist of performance.

Ms. Calce showed an illustration of the DCP model; she also presented the application of the DCP model at her facility for program development, knowledge transfer and professional development. A practical case example was provided to illustrate the use of the model.

Ms. Calce provided the steps taken to implement the DCP model in Quebec. The DCP as a conceptual model, like the ICF-CY version, provides continuity of documentation in transitions from child to adult services. Included in these steps is the teaching of the DCP model in university curriculum since 2006; it is also now included as part of orientation in facilities and is the model endorsed by government agencies such as l'Association des établissements de réadaptation en déficience physique du Québec (AERDPQ).

Lessons learned include: use of taxonomy can be extensive and exhausting; need to involve clinicians in the identification of data collection; dedicate time for resource person to accompany teams; and have a computerized intake sheet and database that translates the words into codes found in the DCP or ICF taxonomy.

### **5.2 Olaf Kraus de Camargo (McMaster University, Hamilton ON)**

Dr. Kraus de Camargo presented various projects and initiatives at McMaster Child Health Research Institute, which include: collaborating informally in Canada; developing teaching materials for students and residents; and applying the ICF-CY to different research questions.

In terms of future directions of the Research Institute, Dr. Kraus de Camargo described examples of potential activities including: collaborating with teaching and knowledge sharing (interdisciplinary from the beginning, creating a course that aggregates disciplines); collaborating with research (linking and mapping, potentially displaying impact of environmental diversities, complicated lives and families); and collaborating with Health Information Services (electronic health charts, health definition, data sets).

Next steps were described as holding the August 12 – 13<sup>th</sup>, 2010 International Meeting at McMaster to Facilitate the Use of the ICF (funded by a grant from CIHR). The goal is to create an international consortium for the implementation and research of the ICF-CY.

### **5.3 Jonathan Down (Vancouver Island Health Authority, Victoria BC)**

Dr. Down presented an overview of the changes in Developmental-Behavioral Paediatrics at the Queen Alexandra Hospital, which is now the Queen Alexandra Centre for Children's Health. He presented the changes from the 'visible' to the 'invisible', for example, in terms of visible physical impairments and invisible disabilities, with function playing an important role in the continuity of care, adding another dimension to the understanding.

Dr. Down proceeded to present the progression from Maturational vs. Transactional changes (static and predictable, to dynamic and continuous), as well as from Medical (disorder, disease, dysfunction) to Biopsychosocial (resiliency, function, abilities). The implications of these changes are that there is a move from the hospital to the community, and from a top down medical approach, to a bottom up social approach.

Dr. Down indicated that the time is right to introduce the ICF to the BC Representative for Children and Youth (RCY)/Educators/Physicians; for clinical referrals to include assessment of function; for measurement of change to take place; for a common language to be used for health/education e.g., Individual Education Plan (IEP); and there is a need for collaborative leadership. He concluded with the question of what is the role of the physician, the single practitioner in bringing about change.

#### **5.4 Anne Marcotte (Ottawa Children's Treatment Centre (OCTC), Ottawa ON)**

Ms. Marcotte presented projects and initiatives in which the OCTC has been involved and which use the ICF. These included: using the ICF to develop a framework for children and youth that the Childrens Treatment Centres serve; championing its use within rehab teams at OCTC; participating in research projects, internal and external, using ICF; integrating it with their family centered model of care; using it for wait list strategies; and the Client Satisfaction Questionnaire. ICF has also been imbedded into the service model for the Botox clinic, and has been integrated into the development of services and new initiatives.

Lessons learned included: need more of a health component; communication and knowledge transfer to staff; and integrating its use with other service providers and agencies involved with the client.

Future directions include: expanding its use within other teams and services in the organization; and collaboration with other children's treatment centres (CTCs) and children's providers to further develop best practice guidelines using and integrating the ICF.

#### **5.5 Janette McDougall (Thames Valley Children's Centre, London ON)**

Dr. McDougall presented on five different pieces of work that have been conducted at the Thames Valley Children's Centre (TVCC), in collaboration with other organizations. These included:

- Mapping ICF codes to Canada's health and disability surveys for school-aged children;
- Providing a national profile of chronic conditions and disabilities among school-aged children;
- Enhancing services at TVCC;
- Describing how individualized measurable goals can be set for children and youth using ICF/ICF-CY and goal attainment scaling; and
- Considering how quality of life and human development may be incorporated into the ICF model.

#### **5.6 Marilyn Wright (McMaster Children's Hospital, Children's Treatment Centre, Hamilton ON)**

Ms. Wright presented on various projects involving ICF-CY. These incorporated education/sharing of knowledge, research, and service delivery (individual care, processes, and documentation). For example, they looked at Children and Youth receiving treatment for Cancer, where ICF provided a nice framework to look at activity limitations and participation restrictions. They also looked at goals and approaches, and how ICF-CY can

help look at these; for example, from spasticity management to participatory functions such as sledge hockey and home programs and advocacy.

Another project looked at how the ICF could be used to look at processes for program delivery, for example, to develop clinical pathways. The ICF was also used to consider barriers to service delivery, for example, the challenges to serve families. In Health Record Documentation, the ICF was used throughout, including in the analysis, goals and recommendations.

## 5.7 Questions and Comments related to Panel 5

- To Ms. Caulfeild: If OCTC is not funded by the Ministry of Health, does that mean that CIHI is not receiving their data? Ms. Caulfeild replied that CIHI collects for acute care facilities, so there is other data not being collected. The next phase will be collecting from primary care, but it will still be health. As the data repository, all of the Children's Treatment Centres in Canada are not reporting data to CIHI.
- In Canada, the use of ICD-10-CA has been mandated for over 10 years. The WHO is currently building ICD-11, and they are exploring an option to have an ICF code behind each code as a bridge between ICD and ICF. Disciplines other than physicians are using ICD, e.g., the Insurance Board of Canada, PTs, OTs and nurses who submit insurance claims are using ICD codes.
- The concept of ICF needs to be taught to family members, the community and teachers.

## PANEL 6: ADULT REHABILITATION

### 6.1 Linda Garcia (University of Ottawa, Ottawa ON)

Dr. Garcia presented on work where the goal was to understand the lived experiences of adults and their families with communication disorders of neurogenic origin (aphasia, dementia), and the role of social (and physical) environmental factors. She described the methodology they used, as well as the grant and scholarship application process they went through.

Lessons learned included: the need to improve understanding of the model (nuances, codes); Environmental Factors (EF) need to be teased out (potential for international comparisons); not much funding exists to study ICF per se; need to look at clinician's needs; and "social participation" is not a term that people like.

Future direction include: coordination of studies across the country; core sets; comparisons with DCP; international – focus on environmental factors; clinical relevance – applicability (data on time for administration, ease of coding); more mapping from existing tools to ICF; and the need to move forward with good, solid funded studies to test the model.

### 6.2 Isabel Henderson (Glenrose Rehabilitation Hospital (GRH), Edmonton AB)

Ms. Henderson presented on various initiatives and projects using the ICF. In the GRH Service Redesign, the number of in-patient admissions would double. As a result, focus on

ICF was seen as essential, as there was a need to focus on participation and function to support successful discharge and community integration.

Other initiatives included: the Leaders in Rehab Conference, which had specific areas of focus, including development of program frameworks based on the ICF model and strategies to incorporate function and participation into 'everyday' therapy; Glenrose Strategic Planning, in which the foundation was a rehab framework based on ICF; linkages with community partners, including the University of Alberta, Industry Partnerships and Community; as well as a Rehabilitation Service Model: Enhancing Function for Meaningful Living.

### **6.3 Questions and Comments related to Panel 6**

- To Dr. Garcia: What would be a better term than social participation? Dr. Garcia indicated that life participation – seems to resonate and be broad enough to encompass more.
- Need to clarify function vs. functioning; rehab professionals use function differently than physicians; different people understand different things by it.

## 4.0 Reflections on Day 1

On Thursday March 11, 2010, Ms. Caulfeild welcomed participants back for the second day of the meeting. She provided participants with further information on the eLearning training tool for ICF. The links will be forwarded to participants via e-mail.

Ms. Parker-Taillon provided participants with reflections of the ICF “Shared Experiences” from Day 1 of the meeting to set the stage for Day 2 discussions. Notes from the presentations were reviewed and key themes identified for both lessons learned and potential future directions. Five key themes were identified for lessons learned including: ICF/ICF-CY, Collaboration, Communication, Knowledge Transfer/Training and Political Environment. Examples for each theme are presented in Table 1 in alpha order. Five key themes were identified for Future Directions including: advocacy, broaden use, collaboration, grow the tool and knowledge transfer. Examples for each are presented in Table 2, in alpha order.

<b>Table 1: Reflections on ICF Shared Experiences Lessons Learned: Key Themes</b>	
<b>About ICF/ICF-CY</b>	
<ul style="list-style-type: none"> <li>• Environmental factors need to be teased out</li> <li>• ICF valuable tool to study disability over time</li> <li>• Implications for outcome measures</li> <li>• Importance of biopsychosocial approach</li> <li>• Importance of lifespan approach</li> <li>• Many dimensions of each measure and many aspects need to be considered</li> <li>• Need for mapping to other tools</li> <li>• Need to look at clinicians needs</li> <li>• Need to see individuals as “at promise”</li> <li>• Need to understand relationships and mechanisms</li> </ul>	
<b>Collaboration</b>	
<ul style="list-style-type: none"> <li>• Need to integrate with other service providers</li> </ul>	
<b>Communication</b>	
<ul style="list-style-type: none"> <li>• ICF effective in fund raising as it resonates with the public</li> <li>• Importance of knowledge transfer and communication</li> <li>• Need to use same language between professions and with IT professionals</li> </ul>	
<b>Knowledge Transfer / Training</b>	
<ul style="list-style-type: none"> <li>• Need to train users well</li> <li>• Value of teaching ICF to medical experts</li> </ul>	
<b>Political Environment</b>	
<ul style="list-style-type: none"> <li>• More research funding required</li> <li>• Need to be aware of “Americanization” of rehabilitation and “disablement” by lawyers</li> </ul>	

<b>Table 2: Reflections on ICF Shared Experiences Future Directions: Key Themes</b>	
<b>Advocacy</b>	<ul style="list-style-type: none"> <li>• Encourage continuation of PALS 2011</li> <li>• Encourage research funding (?CIHR)</li> <li>• Explore how to “sell” use of the ICF (e.g., cost effective use of resources, make better decisions)</li> <li>• Harness a national voice (?CIHI)</li> <li>• Link to electronic health records</li> </ul>
<b>Broaden Use</b>	<ul style="list-style-type: none"> <li>• Encourage adoption of a lifespan approach (e.g., increase use in adult populations)</li> <li>• Encourage use of ICF into clinical practice</li> <li>• Encourage use with other populations (e.g., mental health)</li> <li>• Implement in other settings (e.g., acute care centres, inpatient rehabilitation)</li> <li>• Use by insurance companies</li> </ul>
<b>Collaboration</b>	<ul style="list-style-type: none"> <li>• In teaching, in research, with health information organizations</li> <li>• Involve/integrate with other service providers (e.g., nursing)</li> </ul>
<b>Grow the Tool</b>	<ul style="list-style-type: none"> <li>• Develop more core sets/summary sheets</li> <li>• Find out what is the burden of collecting data and who is responsible</li> <li>• Further develop model and classifications</li> <li>• Mapping to other tools</li> <li>• Privacy Impact Assessment</li> <li>• Reliability testing</li> <li>• Test relationships between concepts</li> </ul>
<b>Knowledge Transfer</b>	<ul style="list-style-type: none"> <li>• Develop some type of “clearing house” for information</li> <li>• Develop training programs</li> <li>• Develop vignettes/case examples</li> <li>• Improve website</li> <li>• Include in university curricula</li> <li>• Share information (e.g., present/publish findings)</li> </ul>

Feedback from the participants on the above lessons learned and future directions included:

- A reminder that ICF is not a measure but rather a classification system.
- A reflection was made on the vast amount of data currently available through CIHI, which is underutilized.
- A proposal was made to establish a task force to start coordinating activities related to ICF in order to maintain momentum for the present meeting, as CIHI cannot do it alone.
- In terms of ‘Growing the Tool’, this feedback needs to be brought to the WHO to inform them of what is working and what is not.

## 5.0 Taking Stock

Participants were randomly assigned to work in three groups to brainstorm their response to two questions:

- What are the key gaps/challenges associated with using ICF/ICF-CY in Canada?
- What are the key enablers that would facilitate the use of ICF/ICF-CY in Canada?

Each group identified their top three gaps/challenges and their top three enablers, which were presented to the entire group. These are identified in Table 3. Following the presentations, it was clear that there were many similarities amongst the three groups.

Table 3: Gaps/Challenges and Enablers with Using ICF-CY in Canada	
Gaps/Challenges	Enablers
<p>Group 1:</p> <ul style="list-style-type: none"> <li>• Being savvy about getting funding</li> <li>• It has multiple uses – how to hone in on each</li> <li>• Lack of a structure for sharing various aspects/uses</li> </ul>	<p>Group 1:</p> <ul style="list-style-type: none"> <li>• Fiscal realities – a way to identify functional difficulties</li> <li>• Policy system level push for interdisciplinary work (collaborative practice)</li> <li>• Provides a common language that can be taught to all disciplines in universities</li> </ul>
<p>Group 2:</p> <ul style="list-style-type: none"> <li>• Lack of funding/ money</li> <li>• Lack of understanding of decision-makers</li> <li>• Paradigm Shift</li> </ul>	<p>Group 2:</p> <ul style="list-style-type: none"> <li>• Champion collaborative research program including people with disabilities – evidence for Pan Canadian plan mandated approach for ICF</li> <li>• Clearing house needed for us to share what we already know</li> <li>• Education/Knowledge dissemination that is user friendly</li> </ul>
<p>Group 3:</p> <ul style="list-style-type: none"> <li>• Daunting</li> <li>• ICF not known – don't know about it or think it is a measure/tool</li> <li>• Paradigm shift from diagnosis to functioning</li> </ul>	<p>Group 3:</p> <ul style="list-style-type: none"> <li>• Develop teaching tools tailored to audience</li> <li>• Get people together at all levels – champions, experts, admin, clinical, kids, adults</li> <li>• Marketing to all levels – show value to all stakeholders</li> </ul>

## 6.0 Where Do We Go From Here?

Working in the same groups, participants were invited to reflect on the question: “Considering the gaps/challenges and enablers identified, what potential new ICF and ICF-CY activities and projects in Canada would you suggest:

- At a Pan Canadian level? (discussed by all 3 groups)
- At a jurisdictional level? (discussed by Groups 1,3)
- At a regional/organizational level? (discussed by Groups 1,2)
- Within specialty areas? (discussed by Groups 3,2)

Each group identified their top three potential new activities and projects in Canada in these areas, which were presented to the entire group. These are identified in Tables 4, 5, 6 and 7.

<b>Table 4: Potential Activities and Projects at a Pan-Canadian Level</b>
<p>Group 1</p> <ul style="list-style-type: none"> <li>● Advocating for National Data – PALS maintained</li> <li>● CN-CYR – explore and exploit – can provide a model for adult networks</li> <li>● Develop a national adult network, building on lessons learned from children’s network</li> </ul> <p>*link child-adult to lifespan model throughout</p>
<p>Group 2</p> <ul style="list-style-type: none"> <li>● Team grant through CIHR – KT program to promote collaborative (interprofessional) functional, lifespan patient-centred care. Team includes consumers, patients, front line workers, CIHI, information managers, IT</li> <li>● Funding for smaller pilot studies to try new initiatives – e.g., the MB work and dissemination of results</li> <li>● Clearing house at PC level to share ideas, info that is emerging from research and front-line programs</li> </ul>
<p>Group 3</p> <ul style="list-style-type: none"> <li>● Website – or wiki site                             <ul style="list-style-type: none"> <li>○ Interactive</li> <li>○ Password protected component</li> <li>○ Links to other websites</li> </ul> </li> <li>● Have Canadian ICF content at national conference (e.g., IBC, CLHIA, NACC)</li> <li>● Lobby to get easier access to a more complete data set (e.g., ped. Rehab) at CIHI and at Stats Can (PALS); new MDS should have ICF embedded</li> <li>● T-SHIRTS</li> </ul>
<p>Feedback on proposed Pan-Canadian Level Projects and Activities:</p> <ul style="list-style-type: none"> <li>● Common based activities going through the lifespan</li> <li>● In terms of creating a national group, could use professional organizations and facilities with jurisdiction over rehab, using CN-CYR as an example</li> <li>● In terms of funding: it will be important to be organized so that when calls for funding requests go out, we are ready</li> </ul>

**Table 5: Potential Activities and Projects at a Jurisdictional Level**

Group 1

- Hub/spoke concept for FPT for: communications, KTE facilitate lessons learned and common projects, change agent support
- Education and sharing of data bases for decision-makers: policy pipeline from local to regional to provincial
- ICF implemented from acute care through to community; include public, private continuum of care. ICF may facilitate quality standard indicators, with emphasis on private sector

Group 3

- Develop and disseminate issue briefs/position papers to governments
- Survey advocacy groups in relation to ICF – people with limitations. After survey teach how ICF can help
- Influence issues where there is interministerial collaboration and lobby for ICF – use brief/policy paper
- T-SHIRTS

Feedback on proposed Jurisdictional Level Projects and Activities:

- Could also have a speaker bureau, with speakers trained related to disciplines and specific areas
- There are groups that could already be accessed – easy to implement as the money is there. Examples are the International Association of Industrial Accident Board Commission, and the Canadian Worker Compensation Board Association, as well as groups within it

<b>Table 6: Potential Activities and Projects at a Regional/Organizational Level</b>	
Group 1	<ul style="list-style-type: none"><li>• ICF service access – cross boundary flow across health jurisdictions</li><li>• ICF used for organizational framework and process indicators for patient and program outcomes</li><li>• Framework/guidance for how to facilitate organizational/interorganizational spread</li></ul>
Group 2	<ul style="list-style-type: none"><li>• Work towards imbedding ICF language/terms into accreditation framework (CCHSA) (influence language that is functional, patient-centred)</li><li>• “Follow the patient” – imbed ICF language into transfer of care forms and EHR</li><li>• Use ICF to guide regional planning (e.g., LHIN’s in ON) with geospatial mapping (Google Trojan technology)</li></ul>
Feedback on proposed Regional/Organizational Projects and Activities:	<ul style="list-style-type: none"><li>• The timing from an accreditation point of view is ideal as they are having a conference in August and there is a call out for ideas and speakers. Who sets the accreditation standards, and can that Board be used to leverage change?</li><li>• Suggestion made to use Google, or another such group, where there would be a place where people could voluntarily sign up to store their personal health records or information – based on ICF.</li><li>• Need to use an innovative way to get ICF out there – push ICF as the underpinning framework</li><li>• ICF based data could be used to understand centers of excellence, how they use their resources, how they get their services</li><li>• Could apply the concept of “click on one item and have other items suggested” in terms of planning software, applying it to ICF</li><li>• Need to make sure we deal with continuity of care, which accreditation does not capture</li></ul>

<b>Table 7: Potential Activities and Projects within Specialty Areas</b>	
Group 2	<ul style="list-style-type: none"> <li>• Champions are needed to take a positive and mentoring approach to go out to different groups to help them see the benefit of using ICF and link what they are doing</li> <li>• Educational info/guidelines for administrators and funders to see the benefit of using ICF, taking staff time to learn</li> <li>• Clearinghouse to share info/resources (see Pan-Canadian section)</li> </ul>
Group 3	<ul style="list-style-type: none"> <li>• Education – develop marketing materials for target audiences: disciplinary, interdisciplinary/interprofessional                             <ul style="list-style-type: none"> <li>○ Adapted to discipline</li> <li>○ Modules with common core</li> <li>○ Vignettes</li> <li>○ Include in Objective Structured Clinical Examinations (OSCE's)</li> </ul> </li> <li>• Knowledge transfer of education to target audiences – identify champions in faculties and professional groups</li> <li>• Influence professional associations to grant credits for ICF training</li> </ul>
Feedback on proposed Activities and Projects within Specialty Areas:	
	<ul style="list-style-type: none"> <li>• It is important not to lose sight of what is already being done internationally</li> </ul>

A discussion on the possible role of CIHI followed these presentations. Below is a brief summary of suggestions and feedback from participants and CIHI:

- CIHI has data collection and reporting as its function. It could be involved in gathering the group to keep momentum going, possibly forming committees and subcommittees to give it shape. Unclear if CIHI could be ready for more at this time. There is a need to support the WHO in the furthering of classifications.
- Bringing people together again at the CIHI meeting in October 2010 would be desirable and ideal.
- There has not been thought yet on how these groups could be structured; would need to look at areas where ICF can be applied, as well as looking at high level administrative data needs for planning resources and lobbying.
- The comment was made that the information on ICF and WHO has been out there for a long time (10 years), and that there is need to have some type of Canada wide study or reaction in order to provide a collaborative response when the WHO is looking for feedback for ICF-2. The question was raised as to how CIHI deals with this.
- CIHI does submit new codes feedback to WHO on an annual basis for ICD. Codes must go through an approval process.
- Discussion regarding the splitting of the concept of activity and participation. The WHO must be careful that what is chosen is representative and usable world-wide. In Canada, we may feel there is a need to split activity and participation, but this may not be usable in other countries. The question was raised as to whether there could be a Canadian position supporting the split of activity and participation in North America (or internationally), as data from 10 years ago showed that we could separate the two.
- There was confirmation that CIHI could be involved in some knowledge transfer in next steps and future activities.

## 7.0 Moving Forward

In this final session, Ms. Parker-Taillon invited participants to discuss the following question: “What potential steps could be taken to move forward?” Participants were divided into three groups based on the panels from the “Sharing Our Experience” session. Group A (panels 1 & 2) considered short term steps (0 – 6 months); Group B (panels 3 & 4) considered medium term steps (6 – 18 months); and Group C (panels 5 & 6) considered long term steps (greater than 18 months).

The groups then presented their findings back in plenary. A summary of the potential steps to move forward is presented in Table 8.

<b>Table 8: Potential Steps to Move Forward</b>
<b>Short Term Steps (0-6 months)</b>
<ul style="list-style-type: none"> <li>• Prioritize goals and strategies                             <ul style="list-style-type: none"> <li>○ Delphi methodologies and identify what you can contribute</li> </ul> </li> <li>• Develop clearing house for education, research, core sets, speakers bureau                             <ul style="list-style-type: none"> <li>○ Define how it is structured</li> </ul> </li> <li>• Create a data request for CIHI                             <ul style="list-style-type: none"> <li>○ Define what already exists</li> <li>○ Define what can be gathered and what instruments are being used</li> </ul> </li> </ul> <p>*Note: short term goals are dependent on long term goals</p>
<b>Medium Term Steps (6-18 months)</b>
<p>*Assumptions: That short term structure is set up for KT, info sharing, e-learning tool tested</p> <ul style="list-style-type: none"> <li>• Education/Information (package of educational material put together; methods developed, ‘core/essential’ information then let specialty groups expand; identify benefits to planning; e-learning tool and speakers bureau implemented)</li> <li>• Data collection (needs/gap analysis; use information to develop educational materials; pilot studies; learn from DCP experience)</li> <li>• Clearinghouse (proposal – sustainable funding for ‘champion’ – set up a framework; Wiki site)</li> </ul>
<b>Long Term Steps (&gt; 18months)</b>
<ul style="list-style-type: none"> <li>• CIHI will use ICF for reporting – Canadian ICF-CA</li> <li>• Embed ICF language in accreditation process</li> <li>• Personal health record/geospatial (idea of personal health record being tied into a chip associated with the health card)</li> </ul>

At the conclusion of this session, Ms. Parker-Taillon invited participants to reflect on how they and/or their organization can make a contribution to moving forward and thanked the group for all of their contributions to the discussions over the course of the meeting.

## 8.0 Closing Remarks/Next Steps

Prior to the end of the meeting, Ms. Caulfeild reminded participants to complete the evaluation form. In response to a request from participants at the meeting, she will be circulating an email to the group asking if they would like to share their coordinates with the rest of the group. She summarized the next steps as follows:

- A report of the proceedings will be disseminated to the participants and the presentations will be posted on the CIHI website
- CIHI would explore organizing another such meeting for October 16<sup>th</sup>, 2010 in Toronto.

She also noted the following:

- At this time, building a database for ICF/ICF-CY data is a tremendous commitment that cannot be made within the confines of this meeting but it was acknowledged that this is an essential component if there is to be such data in Canada
- A Wiki could be a leading edge project for CIHI
- Participants were invited to visit the CIHI website, in particular the ICF page, as a large amount of information exists on available data
- Participants were invited to become involved in the e-learning tool and coordinates for this were provided.

Ms. Caulfeild thanked everyone for attending and for their enthusiastic participation. She felt that a wealth of information was brought forward, upon which there is a need to reflect on how it can be used by CIHI.

The meeting was adjourned at 3:00 p.m. on Thursday, March 11<sup>th</sup>, 2010.

## APPENDIX A

### Participants

Name	Affiliation	Email
Anne Marcotte	Ottawa Children's Treatment Centre, Ottawa	<a href="mailto:amarcotte@OCTC.CA">amarcotte@OCTC.CA</a>
Betsy Mustard	Private Practice, Calgary	<a href="mailto:betsymustard@shaw.ca">betsymustard@shaw.ca</a>
Debra Stewart	McMaster University, Hamilton	<a href="mailto:stewartd@mcmaster.ca">stewartd@mcmaster.ca</a>
Diane Calce	Sainte-Justine University Hospital Centre, Montreal	<a href="mailto:diane.calce.hsj@ssss.gouv.qc.ca">diane.calce.hsj@ssss.gouv.qc.ca</a>
Diane Caulfeild	CIHI, Ottawa	<a href="mailto:dcaulfeild@cihi.ca">dcaulfeild@cihi.ca</a>
Elizabeth Badley	University of Toronto, Toronto	<a href="mailto:e.badley@utoronto.ca">e.badley@utoronto.ca</a>
Francois Sestier	University of Montreal, Montreal	<a href="mailto:francois.sestier@umontreal.ca">francois.sestier@umontreal.ca</a>
Geneviève Martin	CIHI, Ottawa	<a href="mailto:gmartin@cihi.ca">gmartin@cihi.ca</a>
Gillian King	Bloorview Research Institute, Toronto	<a href="mailto:gking27@uwo.ca">gking27@uwo.ca</a>
Heather Marrin	ErinoakKids, Toronto	<a href="mailto:hmarrin@erinoakkids.ca">hmarrin@erinoakkids.ca</a>
Isabel Henderson	Glenrose Rehabilitation Hospital, Edmonton	<a href="mailto:Isabel.Henderson@albertahealthservices.ca">Isabel.Henderson@albertahealthservices.ca</a>
Janette McDougall	Thames Valley Children's Centre, London	<a href="mailto:janettem@tvcc.on.ca">janettem@tvcc.on.ca</a>
Jonathan Down	Vancouver Island Health Authority (VIHA), Victoria	<a href="mailto:jonathan.down@viha.ca">jonathan.down@viha.ca</a>
Linda Garcia	University of Ottawa, Ottawa	<a href="mailto:linda.garcia@uottawa.ca">linda.garcia@uottawa.ca</a>
Marilyn Wright	McMaster Children's Hospital, Hamilton	<a href="mailto:wrightm@hhsc.ca">wrightm@hhsc.ca</a>
Michel Lacerte	University of Western Ontario, London	<a href="mailto:mlacerte@uwo.ca">mlacerte@uwo.ca</a>
Nancy Mayo	McGill University Health Centre, Montreal	<a href="mailto:nancy.mayo@mcgill.ca">nancy.mayo@mcgill.ca</a>
Nora Fayed	McMaster University, Hamilton	<a href="mailto:fayedn@mcmaster.ca">fayedn@mcmaster.ca</a>
Olaf Krause de Kamargo	McMaster University, Hamilton	<a href="mailto:krausdc@mcmaster.ca">krausdc@mcmaster.ca</a>
Rebecca Renwick	University of Toronto, Toronto	<a href="mailto:r.renwick@utoronto.ca">r.renwick@utoronto.ca</a>
Sandy Litman	Glenrose Rehabilitation Hospital, Edmonton	<a href="mailto:Sandy.Litman@albertahealthservices.ca">Sandy.Litman@albertahealthservices.ca</a>
Sandy Loewen	The Rehabilitation Centre for Children, Winnipeg	<a href="mailto:sandyl@rccinc.ca">sandyl@rccinc.ca</a>
Shawna Wade	Bloorview Kids Rehab Centre, Toronto	<a href="mailto:swade@bloorview.ca">swade@bloorview.ca</a>
Susan Stobert	Statistics Canada, Ottawa	<a href="mailto:Susan.Stobert@statcan.gc.ca">Susan.Stobert@statcan.gc.ca</a>
Tanya Eimantas	ErinoakKids, Toronto	<a href="mailto:teimantas@erinoakkids.ca">teimantas@erinoakkids.ca</a>
Vanessa Noonan	Canadian SCI-Solutions Network, Vancouver	<a href="mailto:Vanessa.Noonan@vch.ca">Vanessa.Noonan@vch.ca</a>
Veronica Schiariti	University of British Columbia, Vancouver	<a href="mailto:vschiariti@cw.bc.ca">vschiariti@cw.bc.ca</a>

## APPENDIX B

### Lexicon of Acronyms/Abbreviations

Acronym	Related Term
AERDPQ	l'Association des établissements de réadaptation en déficience physique du Québec (AERDPQ)
AMA	American Medical Association
CAD	Coronary Artery Disease
CAPHC	Canadian Association of Pediatric Health Centres
CGM	Client Groupings Model
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institutes of Health Research
CMPA	Canadian Medical Protective Association
CP	Cerebral Palsy
CTC's	Children's Treatment Centres
CTI	Children's Therapy Initiative (Manitoba)
DCP	Disability Creation Process
DISTAB	Disability Tabulations
EF	Environmental Factors
EHR	Electronic Health Record
FIM	Functional Independence Measure
FPT	Federal/Provincial/Territorial
GRH	Glenrose Rehabilitation Hospital
HRSDC	Human Resources and Skills Development Canada
ICD-10	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICF – CY	International Classification of Functioning, Disability and Health – Children and Youth Version
IEP	Individual Education Plan
IME	Independent Medical Examination
IT	Information Technology
KT	Knowledge Transfer
M.O.S.T.	Manitoba Outcomes of Services by Therapists
NCHS	National Centre for Health Statistics
NRS	National Rehabilitation Reporting System (CIHI)
OCTC	Ottawa Children's Treatment Centre
OT	Occupational Therapy
PALS	Participation and Activity Limitation Study (Statistics Canada)
PT	Physical Therapy/Physiotherapy
RCY	Representative for Children and Youth (Province of BC)
SCI	Spinal Cord Injury
SCIRE	Spinal Cord Injury Rehabilitation Evidence
SIS-16	Stroke Impact Scale
SRPQ	Social Role Participation Questionnaire
TVCC	Thames Valley Children's Centre
WFOT	World Federation of Occupational Therapists
WHO	World Health Organization
WHO - FIC	World Health Organization Family of International Classifications
WeeFIM	Functional Independence Measure for infants (0-3 years old), children, and adolescents with either acquired or congenital disease
Wiki	A website that allows the easy creation and editing of any number of interlinked web pages