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Welcome to the Spring 2004 issue of backtolife.ca in which we celebrate and review the CWGHR sponsored Forum held recently in Toronto. Designed to develop capacity in disability and rehabilitation in the context of HIV, this national Forum was an opportunity to exchange knowledge, experience, skills and tools in a collaborative multi-sector approach. The aim was to build expertise in rehabilitation and HIV for a broad range of stakeholders and to increase capacity to respond to the diverse rehabilitation needs of people living with HIV across Canada.

As you will read in the following pages, the Forum accomplished this and more! This newsletter is designed to bring you some highlights of the Forum content as well as provide insights from various perspectives so that you might get a sense of the event even if you were not there. If you find this leaves you wanting more, please visit the CWGHR website (www.hivandrehab.ca) or contact the office (416-324-4182) to get more information.

Thanks to all of you who contributed generously of your time to write articles for this issue and make it what it is.

The Forum in Review: Summary of the Rapporteur Report

Prepared by Stephanie Nixon

Over the weekend of January 31 and February 1, 2004, approximately 80 people from across Canada gathered in Toronto to discuss rehabilitation issues in the context of HIV. Some arrived with expertise in HIV, others with expertise in rehabilitation, but everyone left with insight and appreciation for the intersection of HIV and rehabilitation.

Participants were from various sectors including: community (mostly from AIDS service organizations), health care professionals,

government, private industry, universities and unions. Overall, approximately one quarter of all participants were people living with HIV. Participants came from across the country; about 10 people from BC, 10 from the Prairies, 35 from Ontario, 15 from Quebec and 10 from the Atlantic Provinces. The conference also included one expert in rehabilitation in the context of HIV from Philadelphia.

It was interesting to note that while the participants were all experts in local and/or domestic issues, more than half of the participants had also worked or volunteered in developing countries and thus brought insight into the relevance of thinking in a global context.





Stephanie Nixon sets the tone for the Forum in her opening remarks.

The two-day event began with an introduction to the “why” of rehabilitation in the context of HIV and the “what” of this field in terms of the nine Global Benchmarks for Learning (see page 11) identified to best advance the field of rehabilitation in the context of HIV. This introduction to the issues was followed by five presentations of practical examples alternating with small group discussions to further flesh out the issues. The formal presentations included the following topics:

- Interdisciplinary health care models
- Policy issues in the Canada Pension Plan Disability Program (CPP-D)
- Challenges in developing employment policies to deal with HIV
- Evaluation of a grief and loss intervention project
- International issues in HIV and rehabilitation

Along with the formal discussions, participants enjoyed nine informal opportunities to engage each other in dialogue about their new insights. These formal and informal discussions presented many opportunities for people to meet and network with participants from other sectors, thus promoting CWGHR’s commitment to multisectorality. This idea is premised on the belief that the sophisticated challenges embraced within rehabilitation in the context of HIV demand sophisticated responses from all parts of society.

Issues discussed throughout the Forum, included the following four highlights.

- a) **Issues related to employment and income security** – including support when off work, support to stay at work, facilitated return to work, entering the workforce for the first time, and the value of work, both financial and as it relates to self-esteem and living a meaningful life

- b) **Multisectorality** – participants realized that working with people from other sectors (such as community, private, government) can be difficult in terms of terminology and ways of understanding the issues, but embraced these challenges and made the most of the opportunity to share the weekend with such a diverse gathering of people
- c) **Impairments, activities and participation as a framework for thinking about HIV** – these three concepts as outlined in the World Health Organization’s International Classification of Function, Disability and Health (the ICF) were found to be a useful springboard for organizing ideas about rehabilitation in the context of HIV

ICF: A way of thinking and talking about the impact of living with HIV

International Classification of Function (ICF) belongs to the "family" of international classifications developed by the World Health Organization (WHO) for application to various aspects of health. The overall aim of the ICF classification is to provide a unified and standard language and framework for the description of health and health-related states :

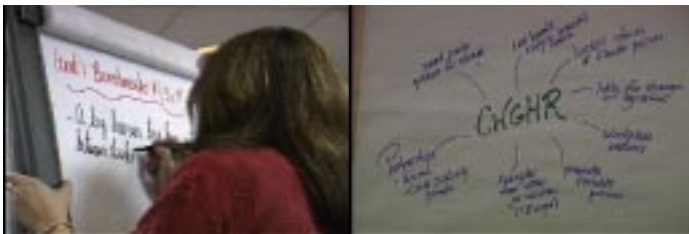
- **Impairment:** Any problem in body function or structure. For example; pain, weakness, decreased range of motion.
- **Activity Limitation:** Any difficulty an individual may have in carrying out a task or action. For example; difficulty walking, bathing, dressing.
- **Participation Restriction:** Any problems an individual may experience in involvement in life situations. For example, difficulty maintaining employment, education, social life.

- d) **Frontline rehabilitation services** – participants regularly described concerns about the quality of and access to rehabilitation services including but not limited to: (a) mainstream health services such as occupational therapy, (b) complementary and alternative medicines, (c) vocational rehabilitation services

These preceding issues directly reflect various Global Benchmarks, which received general support from meeting participants. However, two key issues were also raised beyond the Benchmarks as follows:

- a) The potential value of a rights-based approach
- b) The impact of stigma and discrimination in this field

Overall, by the end of the two days, participants and organizers alike acknowledged that the meeting accomplished its goal of developing capacity in disability and rehabilitation in the context of HIV by exchanging knowledge, experience, skills and tools in a collaborative multi-sector approach. Participants left the Forum full of new insights and a collection of outcome actions at the individual, organizational and policy levels. They also left with a range of new contacts and friends.



Participants produced pages and pages of notes during small group work that will be disseminated to all Forum participants as part of the Forum follow up.

The CWGHR Forum – A Nurse’s Perspective

Jane McCall BSN, RN

As an acute care nurse, I have always held a rather narrow view of what constitutes rehabilitation. Rehabilitation is what Physiotherapists and Occupational Therapists do. It involves helping clients improve strength, muscle mass and balance as well as learn to adapt to changing physical abilities. That’s about it, right? Well, within the first few hours of the forum I was experiencing the illuminating realization that I was way off base. Stephanie Nixon’s excellent presentations introducing global learning benchmarks (see page 11) expanded my perspective. Having the opportunity to meet people from diverse sectors and gain an understanding that we are all working, from different directions, towards the common goal of ensuring that people living with HIV/AIDS have the ability to achieve a maximum state of well-being served to solidify the concepts that Stephanie presented. All in all, it was an extremely valuable conference, even though it was on a weekend!

Sadly, utilizing a broad rehabilitation perspective to provide HIV/AIDS care is not the norm in our health care system here in Vancouver. I plan to take what I learned from this forum and take it out to a broader audience. As the outreach educator for the BC Centre for Excellence in HIV/AIDS I talk to health care professionals and undergrads around the province. I am working to incorporate some of what I learned at the forum into my presentations so that I can get people thinking about their role in rehabilitation and engender discussions about how to push this process. The goal of the forum was to “develop capacity”. I hope in my own small way to do just that. If any of you are out my way and think you can help, give me a call or email me. I’ll be happy to hear from you.

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An Atlantic Perspective

Renee Masching

The Canadian Working Group on HIV and Rehabilitation’s National Forum at the end of January offered a new learning opportunity for me. Working with Healing Our Nations, Atlantic First Nations AIDS Network, I have the opportunity to travel across the Atlantic region and occasionally across the country. Issues that touch on rehabilitation have often been discussed as a part of the overall picture of the HIV/AIDS movement. What was missing in the past was an understanding of exactly what rehabilitation meant and how it might relate to Healing Our Nations’ work in the Atlantic region with Aboriginal peoples.

The forum drew together a diverse group of people, professions, organizations and perspectives. It was clear from the beginning of the forum that the reason I wasn’t sure about what rehabilitation meant is because the range of rehabilitation services is so vast. Before I went to the forum, I was worried that I would have little to contribute because I do not have a medical background or detailed knowledge about HIV medications. It was reassuring to learn that while rehabilitation does include physical therapy, it also includes mental, emotional and spiritual health. ➡



Renee Masching from Healing Our Nations in Nova Scotia participates in the making of a video about the Forum that will feature the various presentations and be distributed in CD Rom format as part of the Forum follow up. (See Renee's article on pg 3)

Presentations regarding existing services, employment, financial stability, managing grief and developing policy offered information and suggestions for action. Stories from the international community provided additional context for the role of rehabilitation and the terrible lack of personnel and services available to those living with HIV in other parts of the world. Throughout the discussions, regional disparities across the country became apparent, urban versus rural dynamics were shared. Despite the challenges, however, a spirit of enthusiasm and dedication flowed throughout the two days.

“When I returned to the Atlantic region, I came home with greater confidence regarding the value of rehabilitation”

When I returned to the Atlantic region, I came home with greater confidence regarding the value of rehabilitation and the range of services that Healing Our Nations can explore for referrals. With papers, brochures and new connections with colleagues in the AIDS movement I am optimistic that as an organization, and personally, there is a little bit more we can offer to our membership. The forum answered many questions and raised new questions for investigation. It was time well spent!

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Disclaimer: While the content of these articles is, to the best of our knowledge, current and reliable, information is not a substitute for actual health care and treatment. Articles do not necessarily reflect the official policy of CWGHR or any sponsoring organizations.

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An Occupational Therapist's Experience

By Todd Tran with Carolyn Gruchy

CWGHR's national forum brought together a group of representative individuals who shared a wealth of information across sectors and stakeholder groups. This national forum demonstrates the power of individuals working together to become a team of experts. The learning format was innovative, thought provoking and allowed individuals, within the breadth of knowledge available, to discuss issues that were relevant to everyone. The results were accelerated learning and the formation of new partnerships among the stakeholder groups represented.

As an occupational therapist, the forum gave me many insights, which will impact my work. First, I learned that occupational therapy interventions not only have to be client-centred, but also future-focused. Although people living with HIV now have a longer life expectancy, they also experience progressive levels of impairment. Given the episodic nature of HIV-related disabilities, as characterized by intermittent periods of illness and wellness, occupational therapy interventions must be dynamic in addressing the changing needs of the individual in their day-to-day activities. Occupational therapy focuses on three major domains of life activities: 1) *productivity* – issues related to work, study and/or home management; 2) *leisure* – issues related to recreational and/or social pursuits; and 3) *self-care* – issues related to hygiene, dressing, feeding / swallowing etc. By adopting a forward-looking approach in our occupational therapy interventions, we can assist individuals to identify their needs, establish goals and expected outcomes, and maximize their functional independence in daily life roles and activities.

Second, I developed a more comprehensive understanding of rehabilitation in the context of HIV through the broad, multi-sector collaboration at the forum. Topics ranging from the individual experiences of persons living with HIV to cross cultural differences in rehabilitation in developing countries demonstrate the complexity of the issues presented. Thus, as clinicians we have to think broadly in order to fully appreciate and effectively provide support for the challenges faced by those living with HIV. One of the tools introduced during the forum was that of the Global Benchmarks (see page 10) for Rehabilitation in the context of HIV. These benchmarks were developed with multi-sector input to guide the clinician, or other stakeholder, to think in a broader context in addressing the rehabilitation needs of persons living with HIV.

“an individual living with HIV, described his experience as that of sitting on a three-legged chair. He observed that this involved the constant struggle of trying to maintain one’s balance. On a good day, one is able to stay balanced on the chair. However, on a bad day, one may tip and fall.”

One of the forum participants, an individual living with HIV, described his experience as that of sitting on a three-legged chair. He observed that this involved the constant struggle of trying to maintain one’s balance. On a good day, one is able to stay balanced on the chair. However, on a bad day, one may tip and fall. Our role as rehabilitation professionals is to intervene and provide support, in a holistic and forward-looking manner, to persons living with HIV. By doing so, we may in essence provide the fourth leg of the chair.

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Todd Tran is with the Canadian Association of Occupational Therapists and writes about his experience at the Forum on pg 4.

Recreation Therapy and the Forum

By Sherri Tremblay

It was a privilege to spend a weekend with various stakeholders who are so keen to create networks and “cross pollinate” as it was so eloquently called. What a wonderful, proactive approach to explore the varied issues of people living with HIV!

I was proud to be one of 3 multi-disciplinary team members from Casey House at the Forum. We represented Physiotherapy, Massage and Complimentary Therapies and Recreation. Casey House is a 13-bed, free standing hospice with an extensive home hospice program commit-

ted to providing exceptional palliative and supportive care for people living with HIV/AIDS.

As one of very few Recreation Therapists (R.T.s) in Canada doing groundbreaking work in rehabilitation in the context of HIV, it was an honour to represent my profession at this Forum. I had the opportunity to explain the importance of recreation & leisure in the overall wellness of people living with HIV and the integral role Recreation Therapists play in the multi-sector team approach to care. Therapeutic Recreation is a process that utilizes, treatment, education and recreation participation to enable persons to acquire and/or maintain the knowledge, skills and behaviours to allow them to enjoy leisure optimally, function independently and participate as fully as possible in society.

Therapeutic recreation interventions, provided by trained professionals in clinical and/or community settings aim to:

- facilitate the development, maintenance and expression of an appropriate leisure lifestyle.
- focus on the skills, knowledge and confidence essential to meaningful choices, a rewarding leisure lifestyle and enhanced quality of life.

The role of the R.T. is to assist clients to feel in control of events, rather than being controlled by them. People with an illness or disability often sense a lack of control and in turn feel helpless. Leisure experiences provide a sense of freedom and personal choice and can help restore feelings of well being.

Recreation Therapy focuses on three key areas: 1. Therapy; 2. Leisure Education; and 3. Recreation Participation.

1. Therapy focuses on team identified treatment goals & addresses unique aspects of leisure-related functional behaviours where the RT is an integral member of the comprehensive treatment team.
2. Leisure education is a broad category of services focusing on development & acquisition of various leisure-related skills, knowledge & attitudes to increase understanding of self and self in the context of leisure activity.
3. Recreation participation is an expression of a leisure lifestyle. The client holds responsibility for his/her own experience and outcome(s) from engaging in the activity. The role of the Recreation Therapist is one of a facilitator. ➡

The activities of an RT include:

- assessment of client need
- development of a related program strategy
- monitoring and evaluating client outcomes.

Special thanks to CWGHR for the brilliant job done facilitating the Forum. The exchange of knowledge, skills and resources was inspirational and I continue to sing the praises of this experience.

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The View from British Columbia

By Glyn Townson

The National Forum was probably the best possible introduction to CWGHR anyone could ask for. My personal schedule for January was very full: the week of the National Forum had me returning from a four day skills building retreat with BCPWA and I was unsure at that point if my energy would hold out.

The Forum began early Saturday morning. The energy in the conference room was amazing; everyone in attendance certainly appeared to want to be there. That energy carried me throughout the entire weekend.

Stephanie Nixon provided an introduction to the issues of rehabilitation in the context of AIDS in Canada, and the global situation. In order to find a common language, she introduced us to the International Classification of Functioning Disability and Health concept (see page 2) and how that could be applied to HIV.

Then Stephanie provided data from a study, "The Prevalence of Impairments, Activity Limitations and Participation Restrictions among people living with HIV in British Columbia."

We were then introduced to the idea of using a system of "benchmarks" (see page 11) that helped to create a common language to facilitate work between the various sectors. From my work with other disability groups, having a common language when you are dealing with various sectors is incredibly important.

The weekend was built around several presentations and group discussions. It was wonderful to be part of a diverse group that had people living with AIDS, a person representing organized labour, an insurance industry consultant, an occupational therapist, a recreation therapist, and staff from numerous non-government organizations. Our group had the entire country covered from coast to coast, from Vancouver to Prince Edward Island. Certainly not a situation I have found myself in before.

One of the presentations that had the greatest impact on me was the one by the AIDS Bereavement Project of Ontario on their "Survive and Thrive" multiple loss retreats for long term survivors. Our organization each year holds one spiritual workshop and two healing retreats. It was encouraging to hear that there are other established programs that we may be able to use or adapt to support our work.

I certainly left the forum with a lot of new information and several new contacts that should prove useful to the BC Persons With AIDS Society.

Kate Reeve did a remarkable job at organizing the Forum. From the outside it looked effortless, but I know from past experiences how much work goes into making an event of this size and magnitude.

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Workplace Policy Development & Implementation

By Mary Alderwood

When I was invited to attend the National Forum I looked forward to having an opportunity to learn from the experiences of others as well as having an opportunity to talk about my work with employees and employers in relation to HIV and rehabilitation.

My presentation focused on the importance of policy development and implementation. Having an opportunity to speak with individuals who are currently facing employment challenges around income replacement, lack of

workplace policies, lack of clarity around insurance benefits, current health challenges, concerns about confidentiality, and uncertainty about who to approach for information regarding employee rights and employer obligations reinforced for me the significance of the work we were engaged in throughout the course of the weekend.

The opportunity for multi-sector identification and discussion of the challenges and the successes broadened my personal understanding of how closely linked our work in this area is. It also challenged my thinking in terms of the question of HIV and rehabilitation and how this can be responded to in practical terms and better supported in the workplace via policy development, training and education.

Highlighted for me were the implications for individuals living with HIV as a lifelong episodic condition. With intermittent periods of illness and wellness, what challenges are being faced related to this? One theme that quickly emerged was the issue of income replacement and the relationship to HIV as an episodic condition. There is no doubt that this issue is inextricably linked to the well being of individuals striving to balance active participation in the workplace with eligibility requirements for disability insurance or other income replacement programs.

Because many disability income programs do not respond to the intermittent nature of an episodic illness we need to ask ourselves how we can begin to address the need for responsive and effective income replacement programs. Bringing stakeholders together established a common awareness and understanding of the issues and challenges. As we return to our workplaces and the community, what steps can we take to continue to raise awareness about these challenges? Keeping these issues visible by talking about what we have learned and asking key questions about existing or yet to be developed workplace policies and/or disability income programs, expressing our concern, seeking clarification and putting forward concrete ideas and recommendations will strengthen the response in this critical area.

A variety of human resources initiatives were also identified as concerns for today's workplace. These include, but are not limited to:

- policy development and implementation
- training and education
- specific awareness about episodic conditions

- flexibility in the application of policy with respect to episodic conditions
- staff planning
- disability awareness and management programs.

The National Forum was an important opportunity to bring people together from a number of sectors to identify and discuss the challenges being experienced and the successes that we can build on.

The strong commitment to advance the work in this area was evident during the weekend through the concrete understanding of the issues and the creative presentations, discussions, ideas, recommendations and solutions that were put forward. My understanding and my work in this area have been greatly enriched by these experiences.

Congratulations and thank you to CWGHR and everyone involved in the National Forum on HIV and Rehabilitation!

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Canadian AIDS Society Benefits Project

As is mentioned in other sections of this newsletter some of the discussion at the Forum focussed on benefits, back to work and income support. These under-researched areas are currently receiving attention from a number of fronts.

1. CWGHR is embarking on an income support research project that will look at the Canada Pension Plan Disability Program and the private insurance industry.
2. The Canadian HIV/AIDS Legal network is completing their report on income security.
3. The Canadian AIDS Society has just started a 27 month project funded by the former Human Resources Development Canada, Office for Disability Issues. This exciting project (the "Benefits Project") will bring together policy makers, researchers, people living with HIV/AIDS and others affected by episodic illnesses to discuss the challenges of accessing public income support programs and health benefits. ➡

This project emerged from the concerns of the HIV community that the social safety net was not being reached by the people who needed it most. Bureaucratic loopholes and under-funded programs have meant that many people living with HIV have been falling through the cracks and are currently living in poverty.

For over twenty years AIDS Service Organizations (ASOs) have attempted to support people living with HIV/AIDS seeking income assistance. However, two major roadblocks hinder this work: A lack of accessible information about federal and provincial programs and services in the area of income support and health benefits for people living with an episodic illness such as HIV; and, a lack of documented information about income and poverty levels among people living with HIV/AIDS. In response to these roadblocks, the project proposes the following objectives:

- Increase the capacity of the ASOs, and people living with HIV/AIDS to participate in policy and program development.
- Create stronger interprovincial ties and networks between ASOs.
- Empower people living with HIV/AIDS to access to the full range of benefits to which they are entitled, either within a province or when moving between provinces.
- Identify a strategy to respond to the need for information on HIV and income

Through partnerships and research, the project will make information about current programs and benefits widely available to people living with HIV/AIDS, ASOs, other anti-poverty and disability organizations, and to program administrators and policy makers. The project will also establish the groundwork for a National HIV and Income Project, and long term research and action plan that will ensure that this important work will continue after this phase is complete.

*For more information about the project or potential partnership opportunities, please contact:
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Note: Acronyms to describe people living with HIV vary from community to community (PWAs, PHAs, PLHAs, etc). Wherever possible, we have kept these regional variations and used the acronym suggested by the author.

A View from our Neighbours

By Karen Escovitz

I was privileged to attend CWGHR's Forum on Rehabilitation in the Context of HIV as the sole delegate from the United States. My background for attending the forum is as a person involved with efforts here to develop an active network for coordination of efforts to develop better knowledge about and services for helping people with HIV/AIDS with employment.

I was struck by how prominent issues of employment were in discussions at the Forum, but not surprised. Everywhere I go, it seems like consumers and providers of HIV services are talking about work issues. I read this as the good news-that medical and social interventions have been effective to the point that people are talking about employment. Now the question is how to make the necessary systems catch up.

I see strong similarities in the obstacles in US and Canada and they are generally related to trying to make large inflexible systems (e.g. benefits, insurance, employers, etc.) be more flexible and responsive to the unique needs and experiences of persons living with disabilities that are episodic and unpredictable in nature. In addition, there is work to be done to promote understanding of the abilities and work capacities of people living with episodic disabilities. People with episodic disabilities, if given the supports and flexibility they need, have much to offer as a component of the workforce.

I noticed very similar themes at the Forum as those I have encountered in other discussions of HIV and Work. There is an individual level of uncertainty and fear about attempting to work and simultaneously manage HIV. But it is clear that much of that fear is related to systemic barriers (particularly related to benefits), disincentives, inflexibility, failure to accommodate and failure to protect from discrimination. There is multifaceted uncertainty at the program level that relates to how to fund employment support services, and how to provide services to people with multiple barriers (e.g. addiction, psychiatric disability, language barriers, etc.), and whether work stress or risk of disclosure is too much to expect PLH/As to handle.

However, despite these uncertainties, it was pretty clear that once we are talking about rehabilitation in a general way, the question of "rehabilitation for what?" has to be asked and answered. For many people, work must be part of that answer, whether for economic reasons or reasons more related to social, psychological and/or spiritual well-being.

I want to reiterate my compliments to the Forum organizers for an extraordinarily well-run event, and my thanks for being invited to participate. I think the benchmarks are well-conceived and a worthwhile conceptual tool, and that the ICF approach is worth applying more broadly in our work. I hope to be able to bring some of these concepts to my colleagues in the US and to be part of future CWGHR dialogues.

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Speech Language Pathologist - A Role for People Living with HIV

by Penny Parnes

I recently attended the National Forum hosted by CWGHR. My role at the Forum was to address the learning benchmark which dealt with understanding ways that issues and strategies related to rehabilitation (needs, services, programs, policies, research, etc.) in the Canadian context relate to rehabilitation issues and strategies in developing countries. Given my role at the International Centre for Disability and Rehabilitation, I was very excited to do this.

As I listened to speakers, participated in group discussions and read some of the print materials which were available at the forum, I realized that I had another potential role to play. As a trained Speech Language Pathologist (SLP), I realized that despite a fantastically diverse and well thought out group of participants, there were no other representatives of my discipline among the invitees. Particularly

when I looked at Module 7 of the "Comprehensive Guide for the Care of Persons when HIV Disease", I felt that there were some ideas from the perspective of an SLP that should be shared.

The field of speech language pathology

The field of speech language pathology deals with issues related to communication and/or oral functioning. Two areas which are of considerable focus in the profession right now seem like they should have significant importance to people living with HIV and people interested in their care and quality of life. Specifically the areas of dysphagia (swallowing and feeding difficulties) and the area of augmentative communication seem highly relevant.

Many SLPs as both part of their academic preparation and as part of their ongoing professional development develop expertise in dysphagia. This expertise is very important when dealing with rehabilitation issues focussed on the ability to swallow. Eating and drinking are dependent on swallowing and are essential to the maintenance of life. As well as nourishing the body, eating and drinking provide pleasure and play a key part in our social lives. Difficulties in swallowing can be extremely dangerous in terms of the potential consequences of choking and/or aspirating materials. In the worst case scenario such difficulties can result in death. Swallowing is also significant in terms of quality of life. If swallowing and eating become times of stress and fear for individuals and their caregivers, the consequences are obvious in terms of lack of sustenance to sustain life but also their role in many



Penny Parnes from the International Centre for Disability and Rehabilitation writes about the role of Speech Language Pathologists on pg 9.

¹ *Rehabilitation Services, Module 7 of A Comprehensive Guide for the care of persons with HIV disease, by Wellesley Central Hospital and Health Canada, and is available on line at www.hivandrehab.ca*

social interactions. With swallowing difficulties, eating and drinking may become social situations which are no longer enjoyable for people living with HIV. Interventions from a trained and specialized SLP can do much to assess and treat the issues related to swallowing and eating.

Augmentative Communication

A further area of expertise which many SLPs acquire is in the area of augmentative communication. This is an area which focusses on communication through means which augment or replace traditional speech. When for any number of reasons a person's ability to articulate speech in the "normal" fashion becomes impaired, there are a host of things which can be done. These can range from simple clarification strategies to help transmit a message to systems which fully replace speech. Interventions can be technologically simple like a letter board or can be sophisticated like a specialized computer system which employs a speech synthesizer. While the technology can be simple or complex the decisions about how to design the system and make it accessible to people is complicated. Even with a "simple" word or alphabet board decisions have to be made as to what to include, how to place items on the board, strategies for speeding up communication (which can be painfully slow if all words are spelled out letter by letter). Add on to this decisions which become important if the person who is to use the board has vision or hearing problems or problems with pointing. Then think about the people with whom the user wants to communicate. Do they have vision or hearing problems? Do they speak and read English? Now think about using a more complex computer based system and you can quickly see that the issues are compounded.

These were some of my thoughts during the National Forum which led to this small summary. I am sure that with more SLPs involved and dialoguing with others involved with CWGHR, many more issues would surface and provide important directions for improving the function and participation of people living with HIV.

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As lead facilitator, Ross Hammond helps guide participants through the many sections of the two-day Forum contributing significantly to the overall success of the event.

CWGHR would like to thank the many people who contributed to the success of the Forum: the national advisory committee, the facilitators and presenters. The Forum was made possible through a financial contribution from Health Canada. The project was also funded in part by the Government of Canada's Social Development Partnerships Program. Additional support provided by:



Global Benchmarks for Learning Related to Rehabilitation in the Context of HIV

These benchmarks, developed in consultation with stakeholders through national associations, serve as ideals for all of us to work toward in our response to rehabilitation issues in the context of HIV. We hope that these global and stakeholder-specific benchmarks help build capacity of stakeholders to respond to the rehabilitation needs of people living with HIV by:

- Helping to create common language to facilitate working across sectors with other stakeholders
- Identifying and articulating critical areas in rehabilitation in the context of HIV
- Demonstrating interconnections between sectors and disciplines
- Promoting multi-sector, interdisciplinary, culturally competent, and client-centered approaches to care
- Supporting program and policy development, and advocacy initiatives to meet these minimum standards.

Global Benchmarks for Learning

1. Understand the **social determinants of health** and their impact on the experience of living with HIV
2. Understand the **basic principles of HIV disease**, including:
 - a. an understanding of the biology of HIV disease, its progression and its transmission from person to person.
 - b. an understanding of the implications of living with HIV as a lifelong, episodic condition (a condition characterized by intermittent periods of illness and wellness)
3. Demonstrate an ability to conceptualize rehabilitation broadly, as a range of services, programs and policies to improve the quality of life of people living with HIV
4. Understand the roles and contributions of stakeholders in the rehabilitation of clients at different stages of HIV disease, including a range of medical and non-medical interventions and ways that stakeholders can work together.
5. Understand the similarities and differences between HIV and other lifelong, episodic conditions, and permanent disabilities, (cross-disability perspective)
6. Develop an understanding of the central role that income plays in the rehabilitation process, including:
 - a. an awareness of issues related to public income support programs and benefits
 - b. an awareness of issues related to employment, private insurance and benefits
7. Understand the ways that the work of individuals and organizations contributes to efforts by organizations at the national level, such as the Canadian Working Group on HIV and Rehabilitation and other partners, in promoting awareness of rehabilitation issues and in supporting the development of relevant programs and policies.
8. Understand ways that issues and strategies related to rehabilitation (needs, services, programs, policies, research, etc.) in the Canadian context relate to rehabilitation issues and strategies in developing countries
9. Other benchmarks specific to each stakeholder group