Operationalizing Human Rights and Human Security Through a Dynamic Model of Health

Mary Anne Burke, M.A.

President, *BIAS FREE* Co-operative, Inc.

# Abstract: The UN *Convention on the Rights of Persons with Disabilities* challenges nations and the global community to address the long-standing, systemic discrimination and disenfranchisement experienced by disabled people throughout the world. This can be accomplished by understanding and paying attention to the dynamics linking human security and social inclusion. A healthy and secure society is one in which the needs of individuals are met and their contributions are encouraged and recognized. It upholds the value of diversity and recognizes that the extent to which every person realizes his or her unique potential, and the capacity of society to accommodate and honor that person's contribution, is the ultimate measure of health, both for the individual and for society. This paper draws on the *Dynamic Model of Health* (Burke, Bach, Colman, McKie, & Ward Stewart, 2000) that roots health in the values of self-determination, equality, and democratization and in community processes that support social solidarity and inclusion as a framework for analyzing the existing situation of disabled peoples and the way forward. It presents work currently being undertaken in a project aimed at developing an "inclusive" Kyrgyzstan, drawing on work that operationalized the *Dynamic Model of Health* and the *BIAS FREE Framework* **(Eichler & Burke, 2005; Burke & Eichler, 2006)**in the context of disabled children. The paper calls into question the existing health and development model that perpetuates benefits for a few and leaves disabled peoples off the agenda. It argues that the *logic* *of domination* underlying all forms of discrimination and oppression is the same in all instances, although the types of discrimination are specific to a particular hierarchy –whether it is built on disability, gender, race, or other factors – and historical or cultural context. Understanding how to "get it right" for disabled peoples will point the way to improving human security more broadly.

**Key Words:** health equity, human rights, social inclusion

# Introduction

Violation of human rights puts human security at risk. Violation of an individual’s rights puts that person into a situation of risk to his or her health and well-being. When people’s rights are violated *because* they belong to a particular social group – such as disabled people – it puts the health and well-being of the entire group at risk. When violations become systemic and social machineries ensure the oppression of groups of people, the human rights and security of everyone are risked. Understanding how to undo the machineries of oppression for disabled people – among the most oppressed in every society – will point the way to undoing the machineries that oppress all others, leading to human security more broadly.

This paper examines the international human rights framework1 as a blueprint for action. It explores the *Convention on the Rights of Persons with Disabilities’* (United Nations, 2006) call for social inclusion and participation and general promotion of human rights as essential for peaceful and equitable societies. It presents the *Dynamic Model of Health* (Burke, Bach, Colman, McKie, & Ward Stewart, 2000)that laysout the interconnections between human rights and health and well-being, and calls into question the various instruments typically used to measure health, pointing to how they have been part of the machineries of oppression. It examines how this machinery operates in the field of child development and the detrimental effect it has on the health and well-being of disabled children. It presents a set of instruments that operationalize the *Dynamic Model* in the context of policies and programs for disabled children, but that serve as models for identifying the machineries of oppression at work more broadly. Finally, it explores the *BIAS FREE* Framework– a rights-based tool used in the development of these instruments – and an application of the Framework to the situation of disabled children in Kyrgyzstan. It can be used to embed human rights and social inclusion at each step of the research, policy, programs, service delivery processes and in everyday practices, improving the health, well-being and security of all people.

# United Nations Convention on the Rights of Persons with Disabilities: A Call for Action

The United Nations (UN) *Convention on the Rights of Persons with Disabilities* challenges the global community to address the long-standing, systemic discrimination and disenfranchisement of disabled people everywhere. The *Convention* begins with the assumption that all people are equal and have inviolable rights that adhere to them because of their inherent human dignity. Human rights are essential for health and well-being (United Nations, 2006) of individuals and of communities, and as such are the foundation for secure societies.

The *Convention* stresses the need to protect the collective well-being of disabled people, as a matter of rights, not charity. The *Convention* issues a call to action for social justice and social solidarity:

“While human rights have often been interpreted in individualistic terms in some intellectual and legal traditions…human rights guarantees also concern the collective well-being of social groups and thus can serve to articulate and focus shared claims and an assertion of collective dignity on the part of marginalized communities. In this sense, human rights principles are intimately bound up with values of solidarity and with historical struggles for the empowerment of the disadvantaged” (Solar & Irwin, 2007).

The *Convention*, as with all other instruments within the international rights framework, lays out a blueprint for action:

“Human rights are those rights which are essential to live as human beings – basic standards without which people cannot survive and develop in dignity. They are inherent to the human person, inalienable and universal.

The United Nations set a common standard on human rights with the adoption of the Universal Declaration of Human Rights in 1948…its acceptance by all countries around the world gives great moral weight to the fundamental principle that all human beings, rich and poor, strong and weak, male and female, of all races and religions, are to be treated equally and with respect for their natural worth as human beings.

The United Nations has since adopted many legally binding international human rights instruments…used as a framework for discussing and applying human rights. Through these instruments, the principles and rights they outline become legal obligations on those States choosing to be bound by them. The framework also establishes legal and other mechanisms to hold governments accountable in the event they violate human rights [...]

As part of the framework of human rights law, all human rights are indivisible, interrelated and interdependent. Understanding this framework is important to promoting, protecting and realizing […] [human] rights” (UNICEF, 2005).

The *Convention* builds on the existing international human rights framework and on the principles and policy guidelines of the *World Programme of Action Concerning Disabled Persons* and *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. It calls for the promotion, formulation and evaluation of policies, plans, programs and actions at national, regional and international levels to further equalize opportunities for disabled persons, given the failure of existing mechanisms to do so:

“The existing human rights system was meant to promote and protect the rights of persons with disabilities, but the existing standards and mechanisms have in fact failed to provide adequate protection to the specific cases of persons with disabilities. It is clearly time for the UN to remedy this shortcoming” (Arbour, 2007).

# Social Inclusion and Respect for Human Rights Essential for Peaceful Societies

A United Nations report states that, "Groups with special needs remain marginalized in the political process, even though their participation is critical to address their concerns effectively and, generally, to promote an equitable society" (United Nations, 2005). It argues that social inclusion and participation and general promotion of human rights are essential for peaceful and equitable societies:

“Social integration…is essential for a society that respects every individual. In many places, however, this remains a distant goal…The social ills of increasing inequality, poverty and lack of opportunities have had a forceful, negative impact on community well-being. Social integration has economic, environmental, political, human rights and security dimensions: any attempt to create peaceful societies must foster social integration based on the promotion of human rights, non-discrimination, equality of opportunity and the participation of all people... Yet, in many countries, groups with special needs remain marginalized in the political process, even though their participation is critical to address their concerns effectively and, generally, to promote an equitable society. In particular…persons with disabilities…frequently suffer discrimination and the denial of their basic human rights” (United Nations, 2005).

# Structural Violence has Negative Impacts on Individual and Community Well-Being

Discrimination experienced by disabled people is a deeply rooted expression of structural violence, with profound negative impacts on the health and well-being of disabled people, their families and communities. Structural violence is defined as “social arrangements that put individuals and populations in harm's way,” stopping “individuals, groups, and societies from reaching their full potential,” and “is linked very closely to social injustice and the social machinery of oppression” (Farmer, Nizeye, Stulac, & Keshavjee 2006).

Power structures within a society serve to reinforce and maintain social hierarchies (Burke & Eichler, 2006) based on characteristics such as gender, age, race, class, caste and disability2. Society’s resources are distributed according to an individual’s position within a given hierarchy. The machinery of oppression is maintained by cultural, economic, political, trade, monetary, health and other systems.

Structural violence leads to interpersonal violence (sexual violence, family violence, racial violence, hate crimes, terrorism, genocide, and wars/conflicts); poverty; social exclusion; stress, shame, discrimination and denigration; deficits in community infrastructure/environments (housing, sanitation, clean water, health care services, roads, education, employment, etc.) and lack of access to the resources needed for well-being. The underlying spirit, philosophy and principles of equality, participation and inclusion embedded in the *Convention* call for concerted efforts across society to right historical, structural and systemic discrimination that perpetuates the exclusion, social disadvantage and health inequities of disabled peoples.

The *Convention* represents:

“A paradigm shift in attitudes that moves from a perception of persons with disabilities as objects of charity, medical treatment and social protection to subjects of rights, able to claim those rights as active members of society. The Convention achieves this paradigm shift by affirming that persons with disabilities hold civil, cultural, economic, political and social rights, are entitled to full protection against discrimination and by establishing monitoring mechanisms at the national and international levels to ensure that persons with disabilities are able to enforce those rights…

…disability is not considered as a medical condition as such, but rather as a result of the interaction between negative attitudes or an unwelcoming environment with the condition of particular persons. By dismantling attitudinal and environmental barriers - as opposed to treating persons with disabilities as problems to be fixed - those persons can participate as active members of society and enjoy the full range of rights” (United Nations, 2007, p. 7).

Article 3 of the *Convention*, sets out the general principles as follows:

“The General Principles can be grouped as follows: respect for inherent dignity, individual autonomy and independence of persons; equality of opportunity and equality between men and women; participation and inclusion; respect for difference and acceptance of human diversity; accessibility; and, respect for the evolving capacities of children with disabilities and respect for their right to preserve their identities” (United Nations 2007, p. 8).

Article 5.4 of the *Convention*, states that, "Specific measures which are necessary to accelerate of achieve de facto equality of persons shall not be considered discrimination under the terms of the present Convention" (United Nations, 2006) and:

“While all the general principles are of equal importance, the present section illustrates the relevance of three of these, namely: the principle of non-discrimination; the principle of accessibility; and the principle of participation and inclusion. First the principle of non-discrimination is one of the basic principles of international human rights law. "Discrimination on the basis of disability" is defined…as follows: "Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the effect of impairing or nullifying the recognition, enjoyment or exercise on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation" (United Nations, 2007, p. 8).

Principles of equality, participation and inclusion embedded in the *Convention* call for representation of disabled people proportionately in all aspect of social and economic life.

# Linking Health and Human Rights: The Dynamic Model of Health

The *Convention* makes clear that dignity, respect, social inclusion, participation, equality, and human rights are key determinants of health – physical, mental, social and spiritual well-being – for disabled people. The social determinants of health approach (Lalonde, 1974; Epp, 1986; Jenson & Stroick, 1999; Health Canada, 1999; Novick, 1997; Romanov Report, 2001; Odom, 2000; Odom et al., 2001) stresses the importance of these:

“…This dimension of *empowerment* is central to operationalizing the right to health and making this principle relevant to people’s lives. ‘A right to health based upon empowerment’ implies fundamentally that ‘the locus of decision-making about health shifts to the people whose health status is at issue’...the full expression of empowerment is people’s effective freedom to ‘decide what the meaning of their life will be’. In this light, the right to health aims at the creation of social conditions under which previously disadvantaged and disempowered groups are enabled to ‘achieve the greatest possible control over … their health’. Increased control over the major factors that influence their health is an indispensable component of individuals’ and communities’ broader capacity to make decisions about how they wish to live” (Solar & Irwin, 2007, p. 9).

The social determinants approach aims to reduce health inequities, defined as differences in health that are “socially produced; systematic in their distribution across the population and unfair” (Dahlgren &Whitehead, 2006). Yet health typically has been measured within a paradigm that equates disability with ill health and physical, sensory, and psychosocial impairments, deficits and disorders.

Existing measures provide information on types of impairments that are used, for example, to determine eligibility for services, or to assess one’s health status based on “quality of life,” and variance from normative standards. Measures such as the QALYs and DALYs (Murray, 1996; Nord, Menzel, & Richardson, 2003) and related models fall into this category, assume that increments of healthy life/quality of life are lost due to impairments, and assign a value to one’s life based on discounted values of life lived with disability (World Health Organization, 2007). They do not measure inclusion in various social domains, personal, family, and community skills and capacities for inclusion, and the relevant barriers to inclusion, human rights and overall health and well-being of disabled persons. Instead, they reinforce the discrimination and exclusion of disabled people.

The Dynamic Model of Health3

The *Dynamic Model of Health (Burke, Bach, Colman, McKie, & Ward Stewart, 2000)* begins with a broader, holistic definition of health, such as that adopted by the World Health Organization (WHO)4 implicitly challenging the conventional distinction between "healthy" and "sick." It goes beyond the WHO definition to define health as a state of complete physical, mental, *spiritual,* and social well-being.

The *Dynamic Model* shifts from an individualized, diagnostic, and pathological model of health to one rooted in the values of *self-determination, democratization* of decision-making processes and *equality*, as articulated by The Roeher Institute’s values-based health model (Roeher Institute, 1998). Put into policy and practice, these values result in equal respect for diversity, and in individuals and communities having increased control over the factors that maximize their potential and unique developmental paths, which as discussed above, are essential ingredients for peaceful and secure societies.

*Self-determination* refers to capacity. It recognizes that legal status and economic status effect individuals’ ability to make decisions about their lives. Diminished status in either realm diminishes self-determination, with potential negative health outcomes. *Democratization* refers to process. Health is not merely a characteristic possessed by individuals, but rather is relational. Well-being has a lot to do with how we are treated by others. To the degree that individuals feel vulnerable, stereotyped, objectified, and treated without dignity, democratization is not realized. This is an essential piece of the framework because it goes to the heart of protecting the valuable diversity and difference in society. *Equality*5 refers to equality of outcomes, rather than equality of opportunity. It recognizes that, without equality, individuals cannot enjoy their full human rights and their full potential to contribute to society and to benefit from the results of their contributions, leading to detrimental health outcomes.

The *Dynamic Model* sustains the notion that a healthy society is one in which the needs of individuals are met and their contributions are encouraged and recognized. It embodies a holistic view of health, upholds the value of diversity, and challenges restrictive concepts and definitions. It recognizes that the ability of every person to realize his or her unique potential, and the capacity of society to accommodate and honor that person's contribution, is the ultimate measure of health, both for the individual and for society.

The *Model*, presented in diagrammatic form below, is built on a number of basic principles, including that a) persons are ineffable (indefinable in words) and thus cannot ever be fully defined even by themselves, let alone by others, nor, it follows, can their health ever be fully defined by themselves or others, and b) health itself is at heart a self-defined condition and hence that indicators of health that are self-determined must be held to be prior over objective and reductionist indicators by social scientists and others.

The *Model* is multidimensional, operating on different planes akin to a gyroscope, rather than the flat instrument portrayed here. Each plane represents a different dimension of health: individual, family, community, region, state, or global community. At the heart is a flexible circle representing health. Along the circumference are four nodes representing the four domains of physical, mental, spiritual and social well-being. In keeping with a holistic definition of health as a "complete state of well-being," this model does not assign priority to any node over another. Full health depends on a balance among all domains.

The nodes are connected by elastic cords calibrated to permit individuals, families, communities and states to record their self-assessed health status in each domain, and for these to be measured and compared. The shape of the circle becomes distorted if ill health in any of the domains is not counterbalanced by a countervailing support in one or more of the other domains. For example, individuals with physical impairments who have their needs fully accommodated by supports in the physical, social, spiritual and mental domains may report a state of complete health. Within the *Model*, this would lead to a strengthening of the force exerted by the connecting cords, such that equilibrium would be maintained in the center.



The *Dynamic Model of Health*

Encompassing and supporting the core are the environments in which people play out their lives. Thus, the shaded outer circle represents the physical, cultural, economic, social, spiritual, and other environments that affect the well-being of individuals, families, communities and states. When these environments are detrimental to health, the shaded circle compresses and puts pressure on the rest of the model, leading to disequilibrium.

The *Model* is dynamic. Just as the elastic cords between the four domains can adjust to achieve equilibrium, so too can the different planes. If an individual with ill health is well supported by a healthy family, community and state within healthy environments, the *Model* can maintain stability. Conversely, unhealthy families, communities, environments, states and global community can destabilize the *Model* and lead to ill health for the individual.

# Operationalizing the Dynamic Model of Health

The *Dynamic Model* calls for new measures to understand the situation of disabled people and the interrelationships among social inclusion and the overall health, well-being and development of disabled persons. The *Dynamic Model* transcends the confines of a limited view of health and measures progress people and communities make in pursuing and achieving what constitutes for them a complete state of physical, mental, social and spiritual well-being.

It supplants the normative approach that underpins many indicators of healthy child development and educational progress. Assumptions about child development guiding the development of a public monitoring framework are not inclusive (Burke, Bach, & Crawford, 2002; Canadian Association for Community Living [CACL]., 1999). Commonly-used standards of “readiness to learn” and norms of child development define disabled children as deficits from the outset (National Association for the Education of Young Children, 1997; Federal-Provincial-Territorial Council of Ministers, 2000; Doherty, 1997; North Carolina Ready for School Team Goal, 2000).

Families of disabled children understand the negative implications of a normative approach to healthy child development, as many have witnessed firsthand the exclusion and negative treatment which results (Burke, 2002; Canadian Association for Community Living (CACL)., 1999; Hanvey, 2002; Roeher Institute, 2000b). In contrast, inclusive family life, childcare, and education help all children to develop and grow up healthy and with dignity. Research also shows that inclusive settings result in developmental opportunities for all children as they learn about respect for difference, new forms of communication, empathy, friendship and solidarity.

A child’s development is a unique, personal, familial, and community adventure shaped by developmental opportunities and outcomes (Graue, 1992; Love, Abers, & Brooks-Gunn, 1999; Pianta & Walsh, 1996.). The challenge is to maximize a child’s chances to be valued, nurtured, recognized, engaged, and included in many environments.

The child development literature makes clear that children are "wired" to learn and develop (Kagan, 1999; Kagan, Moore, & Bredekamp, 1995; Meisels, 1996; Meisels, 2000; Meisels, 1999; Meisels, Atkins-Burnett, Xue, Nicholson, & Bickel, 1998; Shore, 1997; McCain & Mustard, 1999) in unique ways (Burt, 1937; Novick, 1997). Research on developmental paths has often used methods to draw "normal" patterns of development that do not account for the cultural, linguistic, communicational, and developmental diversity that children actually display (Amundson, 2000; Bernhard, 2000; Mackelprang & Salsgiver, 1999; Skrtic, 1991).

Children’s development is shaped by the kinds of expectations others hold about them, and how they are seen, recognized and known by others. They are formed in the stories written, told, and remembered by parents, families, teachers, mentors, and friends (Ricoeur, 1992; McIntyre & Caplan, 1994; Bruner, 2000; Benjamin, 1988; Polkinghorne, 1982; Lindemann-Nelson, 1997). This "intersubjective" fact of child development makes clear that the more children can be included in valuing settings and relationships with others, the more likely they are to develop a sense of self that gives them the resilience and capacity to venture into the world of education, community, civic participation, employment, and productive adulthood.

Children and their families require supports to maximize their developmental potential. The most enabling supports draw on their knowledge, are coordinated and accountable to them, meet their particular needs, strengthen their capacities, and enable transitions into inclusive educational and other environments (Allen, Cornell, Engel, & Paasche, 1998; Case, 2000; Murray, 2000; Marquis & Jackson, 2000; Roeher Institute, 2000c).

All children develop according to their own unique paths and have unique physical, emotional, intellectual, spiritual and creative capacities and multiple cognitive, kinesthetic, and communicational intelligences (Gardner, 1978; Armstrong, 1994) developed “intersubjectively” – through inclusion with others, and through spiritual development (Bronfennbrenner, 1999; Doherty, 1997; McCain & Mustard, 1999; Vygotsky, 1978). This was the essential starting point for a monitoring and accountability framework that is inclusive of all children and recognizes all paths equally – a path where one child learns to walk and another where a child learns to move by using a wheelchair – and upholds the inherent value of every child.

## Towards an Inclusive Monitoring and Accountability Framework

Drawing on the *Dynamic Model of Health,* the author undertook a large body of work (Burke, 2002; Burke, Bach, & Crawford 2002; Burke, Crawford & Pegg 2002a; 2002b; 2002c) to address the failure of existing measures and indicators of health to address the needs of disabled people, their families and their communities. The work is situated within a human rights framework, and grounded in the lived experience of disabled people, their families and communities (Roeher Institute, 1998; Roeher Institute, 2000a; 2000b; 2000c; Roeher Institute, 1993). It includes a framework of inclusive indicators for monitoring child outcomes, various co-requisites of child well-being and healthy child development, and the impact of public policies on child outcomes and their co-requisites (Roeher Institute, 1999; Bach & Burke, 2002).

The framework identifies personal and interpersonal descriptors for children across seven developmental outcomes formulated to be inclusive in their conception and terminology, and consistent with the findings of research and assumptions about the uniqueness and diversity of children. The framework also identifies family, school, community and other co-requisites that play a role in shaping a child’s growth and development in each of the seven outcome areas. Woven throughout the framework is a broad set of public policy decisions that have a direct or indirect impact on children.

The framework identifies the many factors that influence and shape child well-being and development, and helps us to understand and to think about these factors in a coherent way that is inclusive of all children. The framework maps out the areas where indicators are needed to monitor the effectiveness and efficiency of specific inputs, activities, outputs and outcomes in meeting developmental goals and objectives.

Individual scores on a number of measures can be aggregated to determine how individuals and subgroups are faring towards healthy development and progress in health status compared to others. In this way, systemic problems that disadvantage some groups relative to others can be identified and corrected. Communities can develop indicators that best measure the health and well-being of children within their communities.

Instruments developed to measure the inclusivity of communities, programs and services, and public policies and their impact on the overall well-being and development of children and their families (Burke, Crawford, & Pegg, 2002a; Burke, Crawford, & Pegg, 2002b; Burke, Crawford, & Pegg, 2002c) were piloted with success across Canada within the Early Child Development Sector. The results were published (Burke & Pegg, 2003a; 2003b), shared with participants, and used to facilitate a dialogue about their strengths in each domain, and where they could make improvements. In some cases, officials made an immediate commitment to improve their scores in a given domain, sometimes setting target dates for addressing identified problems.

Both the instruments and the process of consultation and feedback were critical for helping officials to see how deeply the structural barriers to inclusion were entrenched within policies, programs and service delivery. Only by identifying them could the process of dismantling the “machineries of oppression” begin.

# A Case Study: Building an Inclusive Kyrgyzstan Using the *BIAS FREE* Framework

In 2007, UNICEF supported an “assessment of the situation of children with special needs in Kyrgyzstan,” using instruments adapted from the Roeher research. The research findings (UNICEF, 2009) identified many violations of the rights of disabled children and their families, and physical and social barriers that risked their health, well-being and security.

**The final activity of the UNICEF project was a workshop for sharing the research findings with a broad range of stakeholders and exploring the *BIAS FREE* Framework (Eichler & Burke, 2005; Burke & Eichler 2006) and its usefulness as a tool to move towards a more inclusive Kyrgyzstan:**

“*BIAS FREE* stands for ***B***uilding an***I***ntegrative ***A***nalytical ***S***ystem ***f***or ***R***ecognizing and ***E***liminating in***E***quities. The Framework is a rights-based tool for identifying and eliminating biases deriving from social hierarchies in research, policies, programs, service delivery and practices. It is premised on the equal entitlement of all people to be treated with respect and on the inviolability of human rights, understands health as a human right, and uses a rights-based model of health and well-being, as articulated in the *Dynamic Model of Health*” (Burke, Bach, Colman, McKie, & Ward Stewart, 2000).

The Framework is built on the theoretical notion that the *logic of domination* (Warren, 1987) “does not change across hierarchies, although it manifests in diverse ways across social hierarchies and contexts” (Burke & Eichler, 2006). The Framework distinguishes among a number of complex and interrelated problems, identifying the roots of the problems and points to appropriate and responsive solutions. As such, w**orkshop participants expressed great interest in undertaking further work to improve the situation for disabled children, using the *BIAS FREE* Framework as a tool for identifying how human rights violations occur and how to eliminate them.**

**Consequently, UNICEF launched a follow-up project in 2008 as its priority project aimed at creating “**a fully inclusive Kyrgyzstan that values, welcomes and treasures diversity and provides the conditions in which all people may grow, develop and contribute to society to their fullest potential, enjoy equal rights within their communities and society and achieve physical, mental, social and spiritual well-being” **(Pupulin & Burke, 2008). The project was supported by a decree issued from the Prime Minister’s office and will be led by a national steering committee and working groups with a diverse set of community members to ensure an inclusive strategy and action plans are adopted.**

While the initial entry point for the UNICEF project was disabled children, the application of the *BIAS FREE* Framework helped to broaden thinking to overall social inclusion. Revamping school systems to be free of barriers so that all children may develop and learn to their fullest potential also will benefit other children from ethnic and religious minorities and impoverished circumstances. Seeing each disabled child as unique, special and of value will open the door to seeing all children that way. If successful, the project in Kyrgyzstan will serve as a model for other countries in the region and around the world, providing a pathway to social solidarity and human security.

## Conclusions

Nurturing healthy people and communities begins with their own visions, listening to disabled people, and to their understanding of what it will take to improve their overall development and well-being. Understanding the extent to which individuals, communities, and different populations are making progress along a path to healthy development that they define, and the extent to which they can make the interventions they know are essential to their well-being and their flourishing are key.

The *Dynamic Model* and the set of instruments derived from it have demonstrated their usefulness in exploring the situation of disabled children and assessing and informing the inclusivity of public policies, programs and services in a way that ensures the overall well-being and development of children, their families and communities.

The *BIAS FREE* Framework helps people to identify situations of structural violence within their own cultural and historical contexts. The Framework exposes the logic of domination faced by disabled peoples, and how it is the same for all disenfranchised communities. It thus shows the way to dismantle the machineries of oppression systematically so that societies can be transformed to be fully inclusive and ensure human rights, development and overall well-being.

Human security will always be at risk if structural violence remains embedded in our world. These are systemic problems perpetuated through the machineries of oppression that operate in research, policies, programs, service delivery and everyday practices. Dismantling these machineries will not be easy. The *Convention* provides a momentous opportunity to change the way we do business. The *BIAS FREE* Framework shows us the way. If we can "get it right" for disabled people we are well on the road to dismantling these machineries, given that the logic of oppression is the same for all social hierarchies. Ensuring human rights, health and well-being and social participation of disabled people lays the groundwork for social solidarity, peace, and improving human security more broadly.

 **Mary Anne Burke** has published widely in the areas of public policy, social conditions and human rights. She developed Gender-based Analysis (GBA) and social inclusion tools, including the "*BIAS FREE* Framework" with Margrit Eichler. She has extensive experience as Director of Research for The Roeher Institute, and as Senior Policy Analyst and Statistician in the Canadian government for Statistics Canada; Status of Women Canada; Health Canada; and Human Resources and Social Development Canada, and internationally for UNICEF and the Global Forum for Health Research. She is an International Consultant, President of the *BIAS FREE* Co-operative, Inc. and Assistant Professor at OISE/UT.

References

Allen, K. E., Cornell, A., Engel, M., & Paasche, C. L. (1998). *Exceptional children: Inclusion in early childhood programs* (2nd Canadian ed.)*.* International Thompson Publishing.

Amundson, R. (2000). Against normal function. *Studies in History and Philosophy of Biological and Biomedical Sciences, 31,* 33-53.

Arbour, L. *Statement by Louise Arbour, UN High Commissioner for Human Rights*

*General Assembly Ad Hoc Committee*. Presented at 7th session, New York. (2006, January 20). Retrieved October 12, 2007, from <http://www.un.org/esa/socdev/enable/rights/ahc7stathchr.htm>

Armstrong, T. (1994). *Multiple intelligences in the classroom*. VA: Association for Supervision and Curriculum Development.

Bach, M., & Burke, M. A. (2002). *Toward an inclusive approach to monitoring investments and outcomes in child development and learning*. North York, Canada: The Roeher Institute.

Benjamin, J. (1988). *The bonds of love: Psychoanalysis, feminism, and the problem of domination*. New York: Pantheon.

Bernhard, J. (2000, March). *Reconceptualizing ECE: Questioning theories and assumptions in human development.* Presentation at the Linking Research To Practice, Second Canadian Forum.

Bronfennbrenner, V. (1999). Environments in developmental perspective: Theoretical and operational models. In S. L. Friedman and T. D. Wachs (Eds.), *Measuring environments across lifespan: Emerging methods and concepts* (pp. 3-28). Washington, DC: American Psychological Association.

Bruner, J. (2000). Tot thought. *The New York Review*.

Burke, M. A., Bach, M., Colman, R., McKie, C., & Ward Stewart, G. (2000). *Dynamic Model of Health*. Retrieved (date), from<http://www.cwhn.ca/resources/health_model/Dmodel.pdf>.

Burke, M. A. (2002). *The construction of disability and risk in genetic counselling discourse.* North York, Canada: The Roeher Institute.

Burke, M. A., Bach, M., & Crawford, C. (2002). *Moving in unison into action: Towards a policy strategy for improving access to disability supports*. North York, Canada: The Roeher Institute.

Burke, M. A., Crawford, C., & Pegg, S. (2002a). *A tool for assessing child care/ECD programs*. North York, Canada: The Roeher Institute.

Burke, M. A., Crawford, C., & Pegg, S. (2002b). *Community profile tool: Measuring inclusivity of early childhood resources*. North York, Canada: The Roeher Institute.

Burke, M. A., Crawford, C., & Pegg, S. (2002c). *Early childhood development policy analysis tool.* North York, Canada: The Roeher Institute.

Burke, M. A., & Eichler, M. (2006). *The BIAS FREE framework. A practical tool for identifying and eliminating social biases in health research*. Global Forum for Health Research, Geneva, Switzerland.

Burke, M. A., & Pegg, S. (2003a). *Inclusivity of the Child Care Policy Environment in Canada: Much Work to Be Done*. North York, Canada: The Roeher Institute.

Burke, M. A., & Pegg, S. (2003b). *Analysis of special needs education policies in Canada using an inclusion lens.* North York, Canada: The Roeher Institute.

Burt, S. C. (1937). *The backward child*. London: University of London Press.

Canadian Association for Community Living (CACL). (1999). *Don't exclude our children: Include all Canada's children in the National Children's Agenda*. Toronto, Canada: Statement on the National Children's Agenda.

Case, S. (2000). Refocusing on the planet: What are the social issues of concern for parents of disabled children? *Disability & Society, 15,* 271-292.

Dahlgren, G., & Whitehead, M. (2006). Levelling up (part 1): a discussion paper on European strategies for tackling social inequities in health. WHO EURO.

Doherty, G. (1997). *Zero to six:* *The basis for school readiness*. Ottawa: Human Resources Development Canada, Applied Research Branch.

Eichler, M., & Burke, M. A. (2006). The BIAS FREE framework: A new analytical tool for global health research. *Canadian Journal of Public Health,* *97*(1), 63-68.

Epp, J. (1986). *Achieving health for all: A framework for health promotion.* Ottawa: Health and Welfare Canada.

Farmer, P. E., Nizeye, B., Stulac, S., & Keshavjee, S. (2006) Structural violence and clinical medicine. *PLoS Medicine* *3*(10): e449 doi:10.1371/journal.pmed.0030449

Gardner, H. (1978). *Developmental psychology: An Introduction*. London: Little, Brown, and Company.

Graue, M. E. (1992). Social interpretations of readiness for kindergarten. *Early Childhood Research Quarterly, 7,* 225-243.

Hanvey, L. (2002). Children with disabilities and their families in Canada: A discussion paper. *National Children's Alliance for the First National Roundtable on Children with Disabilities*. Retrieved (date), from <http://www.nationalchildrensalliance.com/nca/pubs/2002/hanvey02.pdf>

Haring, N. G., & , M. L. (1990). *Exceptional children and youth*. Columbus, OH: Merrill.

Health Canada. (1999). *Health Canada's women's health strategy*. Health Canada.

Jenson, J., & Stroick, S. M. (1999). *A policy blueprint for Canada's children*. Ottawa: Canadian Policy Research Networks.

Kagan, S. (September, 1999). Cracking the readiness myth. *Young Children*.

Kagan, S. L., Moore, E., & Bredekamp, S. (1995). *Reconsidering children's early development and learning: Towards common views and vocabulary* (Rep. 95(3)). Canada: National Education Goals Panel, Technical Planning Group.

Lalonde, M. (1974). *A new perspective on the health of Canadians.*  Ottawa, Ontario, Canada: Minister of Supply and Services.

Levine, S. (2000). The Tao and Talmud of adolescence and young adulthood: Being, belonging, believing, benevolence. In L. T. F. & A. H. Esman (Vol. Eds.), *Adolescent psychiatry: developmental and clinical studies: Vol. 25. The Annals of the American Society for Adolescent Psychiatry* (pp. 45-58). Hillsdale, NJ: The Analytic Press.

Lindemann-Nelson, H. (1997). *Stories and their limits: Narrative approaches to bioethics*. New York: Routledge.

Love, J. M., Abers, J. A., & Brooks-Gunn, J. (1999). *Ready or not, here they come: Strategies for Achieving School Success for All Kansas City Children*. Ewing Marion Kauffman Foundation, Kansas City, Missouri.

Mackelprang, R., & Salsgiver, R. (1999). *Disability: A diversity model approach in human services practice*. Brooks/Cole Publishing Company.

Marquis, R., & Jackson, R. (2000). Quality of life and quality of service relationships: Experiences of people with disabilities. *Disability & Society, 15,* 411-425.

McCain, M., & Mustard, F. (1999). *Reversing the real brain drain: Early years study*. Toronto: Canadian Institute of Advanced Research.

McIntyre, R. L. & Caplan, A. L. (1994). Mapping morality: ethics and the Human Genome Project. An interview with Arthur L. Caplan, Ph.D. *Trends in Health Care Law, & Ethics, 9,* 7-12, 32.

Mead, G. H. (1972). *Mind, self and society*. Chicago: University of Chicago Press.

Meisels, S. (1996). Using work sampling in authentic assessments. *Educational Leadership, 54,* 60-65.

Meisels, S. J. (1999). Assessing readiness. In M. J. Cox & R. C. Pianta (Eds.), *The transition to kindergarten.* Baltimore, MD: Paul H. Brookes.

Meisels, S. J. (2000). On the side of the child. *Young Children*.

Meisels, S. J., Atkins-Burnett, S., Xue, Y., Nicholson, J., & Bickel, D. (1998). *Turning teachers' judgments: A validity study of curriculum-embedded performance assessment in kindergarten to grade 3* (Technical Report)*.* Ann Arbor: University of Michigan.

Murray C. J. L. (1996). "Rethinking DALYs". In L. A. Murray & C. J. L. Murray (Series Ed.), *The global burden of disease. Global Burden of Disease and Injury Series* (pp. 1-98). Cambridge: Harvard University Press.

Murray, P. (2000). Disabled children, parents, and professionals: Partnership on whose terms? *Disability & Society, 15,* 683-698.

National Association for the Education of Young Children (1997). *Developmentally appropriate practice in early childhood programs serving children from birth through age 8*. Washington: NAEYC.

Nord, E., Menzel, P., & Richardson, J. (2003). The value of life: individual preferences and social choice. A comment to Magnus Johannesson. *Health Economics, 12*(10)*,* 873-877.

North Carolina Ready for School Goal Team (2000). *School readiness in North Carolina: strategies for defining, measuring, and promoting success for all children*. North Carolina: State Board of Education. Retrieved (date), from <http://www.fpg.unc.edu/~SchoolReadiness/SRFullReport.pdf>

Novick, M. (1997). *Prospects for children: Life chances and civic society*. Toronto: Laidlaw Foundation.

Odom, S. L. (2000). Preschool inclusion: What we know and where do we go from here. *Topics in Early Childhood Special Education, 20,* 20-27.

Odom, S. L., Wolery, R., Lieber, J., Sandall, S., Hanson, M. J., Beckman, P. et al. (2001). Preschool inclusion: A review of research forthcoming from an ecological systems perspective. In M. J. Guralnick (Ed.), *Early childhood inclusion*. Baltimore, MD: Paul H. Brookes.

Pianta, P. C., & Walsh, D. J. (1996). *High risk children in schools: Constructing and sustaining relationships.* New York: Routledge.

Polkinghorne, (1982). *Narrative knowing and the human sciences*. Albany: State University of New York Press.

Ricoeur, P. (1992). *Oneself as another [Soi-meme comme un autre]*. Chicago: University of Chicago Press.

Roberge, R., Berthelot, J. M., & Wolfson, M. (1995). *The health utility index: Measuring health differences in Ontario by socio-economic status*. *Health Reports, 17,* 25-32.

Roeher Institute (2000a). *Agenda for action: Policy directions for children with disabilities and families.* North York, Canada: Roeher Institute.

Roeher Institute (2000b). *Beyond the limits: Mothers caring for children with disabilities*. North York, Canada: Roeher Institute.

Roeher Institute (2000c). *Towards inclusion*. North York, Canada: Roeher Institute.

Roeher Institute (1999). *Towards an inclusive model for child well being and healthy development.* North York, Canada: Roeher Institute.

Roeher Institute (1998). *National evaluation of NSIPD Deinstitutionalization Initiative, final report* North York, Canada: Roeher Institute.

Roeher Institute (1993). *Social well-being*. North York, Canada: Roeher Institute.

Commission on the Future of Health Care in Canada. (2002). *Building on values: The future of health care in Canada – Final report*. Health Canada. Available at http://www.collectionscanada.gc.ca/webarchives/20071122004429/http://www.hc-sc.gc.ca/english/pdf/romanow/pdfs/hcc\_final\_report.pdf

Solar, O., & Irwin, A. (2007) *A conceptual framework for action on the social determinants of health*. Discussion Paper for the Commission on the Social Determinants of Health. p. 9.

Shore, R. (1997). *Rethinking the brain: New insights into early development*. New York: Families and Work Institute.

Skrtic, T. M. (1991). *Behind special education: A critical analysis of professional culture and school organization.* Denver, CO: Love Publishing Co.

Vygotsky, L. S. (1978). *Mind in society*. Cambridge, MA: Harvard University Press.

Wolbring, G. (2008) Why NBIC? Why human performance enhancement? European Journal of Social Science Research, *21*(1), 25-40.

World Health Organization. WHO definition of health, Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946. <http://www.who.int/about/definition/en/> .

World Health Organization. (2007). *Disability adjusted life years*. World Health Organization (WHO). Available at <http://www.who.int/healthinfo/boddaly/en/index.html>

UNICEF. (2009). *Assessment of the situation of children with disabilities in Kyrgyzstan.* Bishkek, Kyrgyzstan: UNICEF.

UNICEF. (2005) "Convention on the Rights of the Child: The human rights framework." Retrieved June 10, 2009, from http://www.unicef.org/crc/index\_framework.html

United Nations. (2006) *Convention on the Rights of Persons with Disabilities*. New York: United Nations. Available: http://www.un.org/disabilities/default.asp?navid=12&pid=150

United Nations. (2005). *One United Nations: Catalyst for progress and change - How the Millennium Declaration is changing the way the UN system works*. New York: United Nations. http://www.unsystemceb.org/oneun/2/p202

United Nations Human Rights Council (2007). *Implementation of General Assembly Resolution 60/251 of 15 March 2006 Entitled "Human Rights Council" Report of the United Nations High Commissioner for Human Rights on progress of the recommendations contained in the study on the human rights of persons with disabilities*. New York: United Nations.

Endnotes

1 The instruments of the international human rights framework are the *Universal Declaration of Human Rights* and the seven core human rights treaties: 1) *International Covenant on Civil and Political Rights*; 2) *International Covenant on Economic, Social and Cultural Rights*; 3) *Convention on the Rights of the Child*; 4) *Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment*; 5) *International Convention on the Elimination of All Forms of Racial Discrimination*; 6) *Convention on the Elimination of All Forms of Discrimination against Women*; and 7) *Convention on the Rights of Persons with Disabilities*.

2 Wolbring argues that social hierarchies of any type are constructed on the basis of ability, with those perceived as being “more able” at the top of each hierarchy, see: <http://journal.media-culture.org.au/index.php/mcjournal/article/viewArticle/46>

<http://journal.media-culture.org.au/index.php/mcjournal/article/viewArticle/57>

Wolbring (2008) Why NBIC? Why human performance enhancement? European Journal of Social Science Research, Vol 21,No.1,pp. 25-40

3 This section is largely excerpted from the *Dynamic Model of Health* at: <http://www.cwhn.ca/resources/health_model/Dmodel.pdf>.

4 The World Health Organization defines health as “a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity” (World Health Organization, 1946).

5 Throughout this article, equity is defined as the “*process* of being fair”. Equity leads to equality, not just of opportunity, but in outcomes. Equality is defined as the *outcome* reached through equity. Equality means that all people enjoy equal status in society and are able to realize their full human rights and their potential to contribute to political, economic, social, personal and cultural development within their communities, and to benefit equally from them. The concept of equality includes both equality in the law — de jure equality and actual equality — de facto equality. Achieving equality ultimately means that society values equally the similarities and differences among all people and their varying roles. Equality is a goal towards which one must constantly strive.