



# Making Invisible Visible

Taking action for persons with invisible disabilities
Mental health, well-being and disability: A new global priority in SDGs
United Nations, United Nations University, The Nippon Foundation, The University of Tokyo

© The University of Tokyo Komaba Organization for Educational Excellence (KOMEX), 2016.



Editors: Takashi Izutsu (The University of Tokyo)

Atsuro Tsutsumi (UNU)

Robert Venne (United Nations)

Liza Haslan Tan (UNU)

Akiko Ito (United Nations)

Art Direction: Takashi Izutsu Photographs: Hironori Sakunaga

Cover: Model: Maki Kiriyama, Hair/Makeup: KANA OGUCHI, Styling: Waka

Design/Layout: Tamaki Sono (Psilocybe Inc.)



## Making Invisible Visible

Taking action for persons with invisible disabilities Mental health, well-being and disability: A new global priority in SDGs

Report of the Panel Discussion:

Taking action for persons with invisible disabilities: Mental health and well-being: A new global priority in SDGs

The International Day of Persons with Disabilities 2015:

Inclusive 2030 Development Agenda "Inclusion matters: Access and empowerment for people of all abilities"

Conference Room 4, United Nations Headquarters, New York 3 December  $2015\,$ 

#### Contents

	introduction
6	Opening Remarks for the International Day of Persons with Disabilities 2015: Ban Ki-Moon, Secretary-General, United Nations
	Moderator
8	H.E. Ambassador Luis Gallegos, Special Advisor, The Nippon Foundation (ex-Chair, Ad hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities)
	Remarks
10	H.E. Ambassador Mateo Estrémé, Charge d'affaires a.i., Permanent Mission of Argentina to the United Nations
12	Akiko Ito, Chief, Secretariat for the Convention on the Rights of Persons with Disabilities, Division for Social Policy and Development, Department of Economic and Social Affairs, United Nations
	Presenters
14	Presenters  Takashi Izutsu, Project Associate Professor, Komaba Organization for Educational Excellence, The University of Tokyo (ex-Chief, Mental Health and Psychosocial Support, United Nations)
14 16	Takashi Izutsu, Project Associate Professor, Komaba Organization for Educational Excellence, The University of Tokyo (ex-Chief, Mental
	Takashi Izutsu, Project Associate Professor, Komaba Organization for Educational Excellence, The University of Tokyo (ex-Chief, Mental Health and Psychosocial Support, United Nations)
16	Takashi Izutsu, Project Associate Professor, Komaba Organization for Educational Excellence, The University of Tokyo (ex-Chief, Mental Health and Psychosocial Support, United Nations)  Atsuro Tsutsumi, Coordinator, United Nations University International Institute for Global Health
16 20	Takashi Izutsu, Project Associate Professor, Komaba Organization for Educational Excellence, The University of Tokyo (ex-Chief, Mental Health and Psychosocial Support, United Nations)  Atsuro Tsutsumi, Coordinator, United Nations University International Institute for Global Health  Mark van Ommeren, Public Mental Health Adviser, Department of Mental Health and Substance Abuse, World Health Organization

#### Introduction

The International Day of Persons with Disabilities is celebrated worldwide annually on 3 December to promote awareness and mobilize support on critical issues pertaining to the inclusion of persons with disabilities in society and development.

The theme for the International Day 2015 was "Inclusion matters: Access and empowerment for people of all abilities".

The event was co-organized by the United Nations Department of Economic and Social Affairs and the Permanent Missions to the United Nations, and co-sponsored by civil society organizations.

As part of the International Day of Persons with Disabilities programme at the United Nations Headquarters in New York, the panel discussion was held under the theme "Taking action for persons with invisible disabilities: Mental health and wellbeing: A new global priority in SDGs". The panel was coorganized by the United Nations Secretariat for the Convention on the Rights of Persons with Disabilities, The University of Tokyo Komaba Organization for Educational Excellence, United Nations University International Institute for Global Health, and the Nippon Foundation, co-sponsored by the Permanent Mission of Argentina to the United Nations.

The year 2015 marked a historic transition in the focus on global mental health and well-being as well as mental, intellectual or psychosocial disabilities. Mental health and well-being, in addition to the rights of persons with disabilities, have been included in the 2030 Agenda for Sustainable Development and the Sustainable Development Goals (SDGs) as new global priorities. In addition, the Third United Nations World Conference on Disaster Risk Reduction (WCDRR) integrated aspects of psychosocial support and mental health services as well as disability-inclusive disaster risk reduction in the Sendai

Framework for Disaster Risk Reduction 2015 - 2030.

An estimated one in four people worldwide experience a mental health condition in their lifetime. Suicide is a leading cause of death among young girls, and depression is the leading cause of disability. However, 80 per cent of persons with serious mental health conditions in developing countries do not receive any appropriate interventions. Many persons with mental, intellectual or psychosocial disabilities face grave human rights violations based on severe stigma and discrimination, which can result in torture and murder. Economic losses related to mental health issues exceed 4 per cent of GDP according to the Organisation for Economic Co-operation and Development (OECD).

The economic, social and health impact of poor mental well-being and disability is pervasive and far-reaching, leading to poverty, high unemployment rates, poor educational and health outcomes, and human rights violations. Mental well-being represents a critical indicator and a key determinant of well-being, quality of life, sustainable development and peace. The inclusion of mental well-being and disability in the SDGs provides unprecedented opportunity to realize respect, protection and promotion of rights of persons with mental, intellectual or psychosocial disabilities, as well as mental health and well-being of persons with all abilities.

The panel discussion aimed to bring attention to action points for implementing SDGs for persons with mental, intellectual or psychosocial disabilities. Panellists shared good practices and lessons learned regarding integrating mental well-being and disability in development efforts with a particular focus on experiences and expertise on improving accessibility for persons with mental, intellectual or psychosocial disabilities. Updates on global mental well-being and disability were also shared.

## The 2030 Agenda for Sustainable Development and the Sustainable Development Goals (United Nations, 2015)

The 2030 Agenda for Sustainable Development and the SDGs were adopted in September 2015 at the United Nations Summit and included mental health and well-being as new key targets. The Millennium Declaration and the MDGs did not mention mental health and disability; therefore, this inclusion is ground-breaking.

Among the 17 SDGs, mental health and well-being are included in Goal 3 in addition to Our vision and The new Agenda sections of the 2030 Agenda.

#### Ourvision

7. In these goals and targets, we are setting out a supremely ambitious and transformational vision. We envisage a world free of poverty, hunger, disease and want, where all life can thrive. We envisage a world free of fear and violence. A world with equitable universal access to quality education at all levels, to health care and social protection, where physical, **mental** and social **well-being** are assured...

#### The new Agenda

26. To promote physical and mental health and well-being, and to extend life expectancy for all, we must achieve universal health coverage and access to quality health care.

## Goal 3. Ensure healthy lives and promote well-being for all at all ages

- 3.4 By 2030, reduce by one third premature mortality from noncommunicable diseases through prevention and treatment and promote mental health and well-being
- ${\bf 3.5}\ {\bf Strengthen}\ {\bf the}\ prevention\ and\ treatment\ of\ {\bf substance\ abuse,}$  including narcotic drug abuse and harmful use of alcohol

The paragraphs below include disability and this is relevant to efforts to protect and promote the rights of persons with mental, intellectual or psychosocial disabilities.

#### The new Agenda

- 19. We emphasize the responsibilities of all States, in conformity with the Charter of the United Nations, to respect, protect and promote human rights and fundamental freedoms for all, without distinction of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, disability or other status.
- 23. People who are vulnerable must be empowered. Those whose needs are reflected in the Agenda include all children, youth, **persons with disabilities** (of whom more than 80 per cent live in poverty), people living with HIV/AIDS, older persons, indigenous peoples, refugees and internally displaced persons and migrants.
- **25**. We commit to providing inclusive and equitable quality education at all levels —early childhood, primary, secondary, tertiary, technical and vocational training. All people, irrespective of sex, age,

race or ethnicity, and **persons with disabilities**, migrants, indigenous peoples, children and youth, especially those in vulnerable situations, should have access to life-long learning opportunities that help them to acquire the knowledge and skills needed to exploit opportunities and to participate fully in society.

## Goal 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all

- 4.5 By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations
- 4.a Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all

## Goal 8. Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all

**8.5** By 2030, achieve full and productive employment and decent work for all women and men, including for young people and **persons** with disabilities, and equal pay for work of equal value

#### Goal 10. Reduce inequality within and among countries

10.2 By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status

## Goal 11. Make cities and human settlements inclusive, safe, resilient and sustainable

- 11.2 By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons
- 11.7 By 2030, provide universal access to safe, inclusive and accessible, green and public spaces, in particular for women and children, older persons and persons with disabilities

## Goal 17. Strengthen the means of implementation and revitalize the Global Partnership for Sustainable Development

17.18 By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing States, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts

Extracted from Mental Health, Well-being and Disablity: A New Global Priority: Key United Nations Resolutions and Documents (UTokyo, 2015)

#### Opening Remarks for the International Day of Persons with Disabilities 2015

#### Ban Ki-Moon

#### Secretary-General, United Nations

Three months ago, the international community adopted the 2030 Agenda for Sustainable Development. Together, world leaders agreed that we must leave no one behind.

The Agenda is built on 17 inspiring Sustainable Development Goals.

We have set our sights high with a clear aim to empower and promote the social, economic and political inclusion of all persons, including persons with disabilities.

The United Nations Convention on the Rights of Persons with Disabilities and the outcome of the General Assembly High Level Meeting on Disability and Development both emphasize the important role of persons with disabilities in all aspects of society and development, respecting their rights and their dignity.

As the world sets out to implement the 2030 Agenda, persons with disabilities must be recognized for what they are - effective agents of change whose contributions bring enormous benefit.

More and more countries get it. They are developing a better understanding of the importance of empowerment and equality for persons with disabilities in sustainable development. They are taking action in partnership with civil society and international organizations.

We are making incredible progress - yet there is much more to be done.

Earlier this year in Sendai, Japan, the United Nations Third World Conference on Disaster Risk Reduction advanced the "disability-inclusive disaster risk reduction" agenda - sending a clear message that persons with disabilities are an essential resource for implementation of the Sendai Framework.

International efforts are under way to bring the vision and success of Sendai to the World Humanitarian Summit in Istanbul, Turkey in May 2016.

At the Third International Conference on Human Settlements, UN HABITAT III, in Quito, Ecuador in October, the voice of persons with disabilities will be critical to ensuring a new inclusive, accessible and sustainable urban development agenda.

As we move forward, we need to strengthen development policies and practice to ensure that accessibility is a part of inclusive and sustainable development.

We also need to account for persons with "invisible" disabilities whose needs and voice are often left unconsidered and unheard.

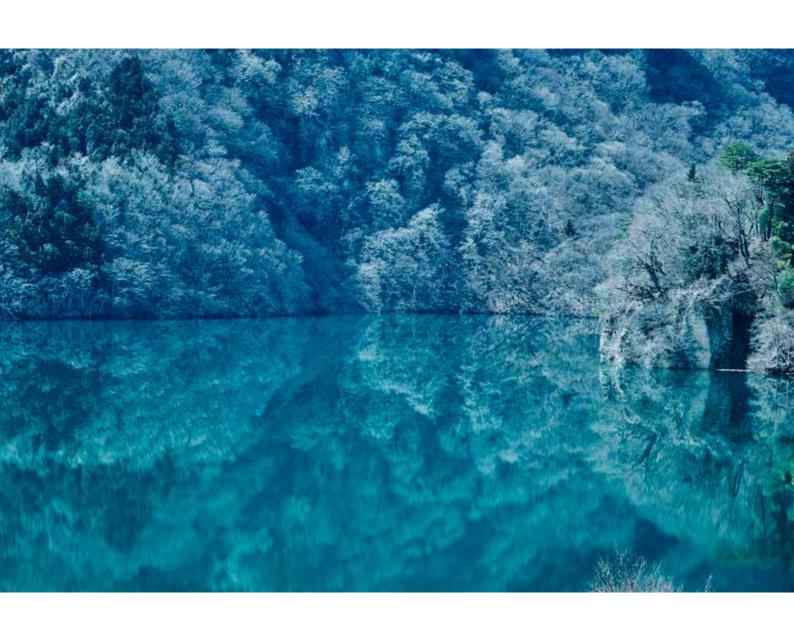
The theme for this day says it all: Inclusion matters.

Let the message from the international community be clear: Together, with persons with disabilities, we can achieve an inclusive, accessible and sustainable future for all.

Thank you for your commitment and resolve.

We also need to account for persons with "invisible" disabilities whose needs and voice are often left unconsidered and unheard.

Ban Ki-Moon, Secretary-General, United Nations



### H.E. Ambassador Luis Gallegos

Special Advisor, The Nippon Foundation

(ex-Chair, Ad hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, United Nations)

Persons with invisible disabilities such as mental, intellectual or psychosocial disabilities have long been marginalized in global development discourses, and even in disability-related policies and programmes.

Of course, the United Nations Convention on the Rights of Persons with Disabilities, which was adopted in 2006, refers to "physical, mental, intellectual and sensory" impairments. Therefore, persons with mental or intellectual disabilities are explicitly included in the Convention, which is a legally binding tool for those countries that ratified it.

Disability is now finally included in five of the SDGs, which were adopted in the United Nations Sustainable Development Summit in September 2015. In addition, mental health and

well-being is included for the first time in the 2030 Agenda for Sustainable Development and the SDGs.

This gives unprecedented opportunities and mandates to all the Member States, United Nations entities, civil society organizations and all of the other development stakeholders to realize the mental health and well-being as well as universal access and inclusion of persons with mental, intellectual or psychosocial disabilities in all societies.

I thank all stakeholders, including these global leaders attending this panel who worked successfully for this significant commitment with their tireless and persistent efforts, and who will be leading the long-awaited actions to make this commitment a visible reality.



#### H.E. Ambassador Mateo Estrémé

#### Charge d'affaires a.i., Permanent Mission of Argentina to the United Nations

It is with great pleasure that Argentina is once again joining as a co-sponsor of this event on the occasion of the International Day of Persons with Disabilities, and in particular, it is a high honour for me to do some opening remarks on such a key issue.

Last September, the Member States of the United Nations adopted an ambitious document which was considered "a historic turning point in our world" by the Secretary-General of this organization. Constituting a very detailed programme, the 2030 Agenda for Sustainable Development features several goals and targets aimed to specifically end poverty and promote prosperity among human beings.

The whole document was negotiated and agreed with an underlying principle: The idea that no one should be left behind. In this regard, the agenda highlights the need for the organization and the Member States to focus on the vulnerable people, the excluded and marginalized, while moving forward to reach a more developed world. Besides, the agenda calls for respecting, protecting and promoting human rights and fundamental freedoms for all, without distinction of any kind. Therefore, only by addressing the problem of discrimination in all its forms will we be able to achieve its full realization.

The question of disability is included expressly in five of the seventeen goals of the Agenda, in particular in relation with guaranteeing equal and accessible education; promoting inclusive economic growth; reducing inequality; making cities more inclusive; and collecting disaggregated data. Some of them have been already addressed in previous interventions, and therefore, there is no reason to go deeper at this stage.

Nevertheless, I would like to point out that in addition to the above-referred specific mentions, the whole 2030 Agenda is embodied with the idea of the importance of mainstreaming disability issues as an integral part of development strategies, encouraging States to apply a human rights-based approach to the question, as established in the Convention on the Rights of Persons with Disabilities (CRPD) and other human rights treaties, while intensifying efforts to advance the rights of persons with disabilities.

However, today's panel is centred in a specific situation, socalled invisible disabilities. The CRPD establishes in Article 1 that persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. Therefore, even if there is no agreed international definition on the concept of "invisible disability" and the cases that it involves, we could on preliminary basis understand it as those referred to mental and intellectual impairments for the purpose of this panel.

The question of the invisibility of certain disabilities presents an intricate challenge for the proper implementation of the 2030 Agenda, due to the fact that in order to achieve the full enjoyment of human rights by all persons with disabilities, throughout the world, the first step is to identify them by collecting high quality, accessible, timely, reliable and disaggregated data.

Invisible disabilities usually mean invisible vulnerabilities; and people tend to ignore those specificities that they cannot see. In fact, people often judge others by how they look; concluding that someone can or cannot do something just based on what they perceive.

Therefore, in order to establish disability-specific indicators, sensitive to all type of disabilities and in order to focus on addressing inequality gaps, the first step is to advance the discussion on what we understand for invisible disability and how it interrelates with the idea of promoting mental health and well-being as included in the 2030 Agenda.

The follow-up and full implementation of the SDGs should seek to identify also the existence of invisible inequalities with a view to promote the enjoyment by all persons with disabilities of their civil, political, economic, social and cultural rights.

The Member States, the United Nations, its agencies and civil society should be ready to work together in order to create structural conditions that do not hinder the enjoyment of the rights of persons with invisible disabilities, respecting their inherent dignity, independence and individual autonomy.

More human and financial resources should be allocated to build capacities at national, regional and international levels to further understand the challenges posed by the invisible disabilities taking into account that we have committed ourselves to leave no one behind.



П

#### Akiko Ito

Chief, Secretariat for the Convention on the Rights of Persons with Disabilities, Division for Social Policy and Development, Department of Economic and Social Affairs, United Nations

The international community has developed and implemented key global instruments for the protection and promotion of the rights of persons with disabilities, such as the World Programme of Action concerning Disabled Persons (1982), the Standard Rules on Equalization of Opportunities for Persons with Disabilities (1994) and the Convention on the Rights of Persons with Disabilities, which was adopted by the United Nations General Assembly in 2006. The Convention, which is legally binding for its state parties, includes persons with physical, mental, intellectual and sensory impairments.

Persons with mental and intellectual disabilities have been one of the most marginalized and neglected people in efforts related to peace and security, sustainable development, human rights, as well as humanitarian action. In other words, mental and intellectual disabilities have been "invisible" on too many occasions in international discourse. Given the huge impact and gaps related to mental and intellectual disabilities and the importance of mental health and well-being for individuals and societies, the United Nations has frequently adopted resolutions on mental well-being and disability, especially after the Convention. These include the 2030 Development Agenda for Sustainable Development and the SDGs, which make specific references to this "invisible" mental well-being and disability in their targets. This marks a significant step in making the invisible visible. Now, various global and local stakeholders are trying to bring more light to this area, and to make mental well-being and disability a central priority in sustainable development. To achieve these global goals, we have to ensure no one is left behind, including persons with mental and intellectual disabilities.

In this context, the United Nations has engaged in a number of collaborative efforts, including holding expert group meetings and public forums, as well as publishing various policy and programme tools related to mental well-being and disability with key partners, such as the United Nations programmes and funds, the WHO, the World Bank Group, The University of Tokyo, the Nippon Foundation, non-governmental organizations and organizations of persons with disabilities, among others. This was done to include the rich expertise and experiences of all of the stakeholders so that the United Nations can advance their issues. I am pleased to mention that we are in the process of seeing how best we can build a new and strengthened partnership with policy makers, experts and practitioners, organizations of persons with disabilities and academia.

It is high time to get together and take action to finally realize improvements in mental health and well-being as well as protection and promotion of rights of persons with mental and intellectual disabilities as an indispensable priority worldwide, and make visible and concrete progress.

Ľ



#### Takashi Izutsu

Project Associate Professor, Komaba Organization for Educational Excellence, The University of Tokyo (ex-Chief, Mental Health and Psychosocial Support, United Nations)

According to the WHO, about 800,000 people die by suicide annually. This is equivalent to the number of deaths from wars and murders combined. Suicide is the third leading cause of death among adolescents and is the leading cause of death among adolescent girls. The world has the Security Council and peacekeeping operations for wars, and police and judicial systems for murder. However, many countries face extremely limited resources and systems to respond to suicide and other mental health issues.

Mental health conditions might be "invisible", but one in four people will experience a mental health condition at least once in their lifetime. In developing countries, 80 per cent of persons with severe mental illness do not receive appropriate treatment. Though there may be a misunderstanding that mental health is not related to death, persons with severe mental illness die 20 years earlier than average according to the OECD. The Global Burden of Disease Study shows that depression is the leading cause of disability in the years lived with disability indicator. The economic cost is also huge. Direct and indirect costs of mental illness are estimated to exceed 4 per cent of GDP.

Despite these facts, the situation around mental well-being and disability has been quite challenging. For example, the budget allocation for mental health in national health budgets has been quite low. Among low-income countries, only 0.5 per cent of the health budget is assigned to mental health. Human resources for mental well-being and disability have been also extremely limited. Taking psychiatrists as an example, the WHO states that about 40 countries do not have any psychiatrists. There is also a lack of social workers, nurses, psychologists, community workers and human rights advocates.

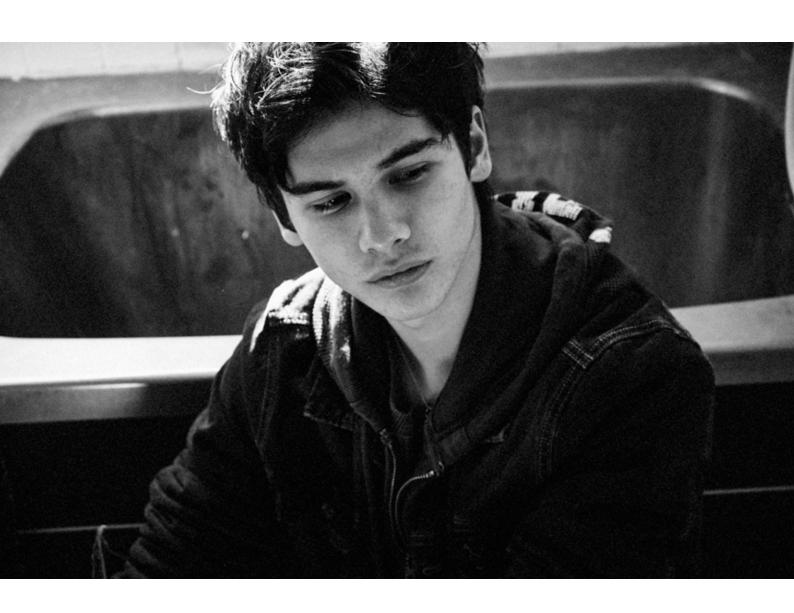
Although mental health, well-being and disability have long been marginalized or ostracized in the international community despite its huge impact on our lives, since 2015, this has been changing drastically because of the inclusion of mental health and disability in the SDGs. This big achievement was accomplished by persistent and strong efforts by the Member States, the United Nations system, non-governmental organizations, academia, many persons with disabilities and their families worldwide, and many "invisible" pioneers and heroes who have devoted themselves with courageous and selfless hard work and many sacrifices.

Mental health and well-being is included in Goal 3 of the SDGs, which is about good health. Among nine health targets, Target 3.4 concerns "Reducing mortality from noncommunicable diseases and promote mental health and wellbeing". In addition, prevention and treatment of substance abuse is included in Target 3.5. Furthermore, disability is included in five of the SDGs.

In 2015, mental health and disability were also integrated into another important global framework, the Sendai Framework for Disaster Risk Reduction 2015-2030 adopted at the Third United Nations WCDRR. The Sendai Framework includes "provision of psychosocial support and mental health service for all people in need" as part of its priorities.

The SDGs and the Sendai Framework, together with the Convention on the Rights of Persons with Disabilities, have finally shed light on this neglected, but critically important area at the global level. Various stakeholders are now coming together to take action to realize mental well-being and inclusion for everyone, including persons with mental and intellectual disabilities.

Useful tools and guidelines that can be utilized for action have been developed by the United Nations system, including the WHO and others. They are all available on the Internet. Finally, mental health, well-being and disability have become a global priority. I hope we can continue our collective efforts, hand in hand, to achieve our common goal of well-being, accessibility and inclusion. In addition to the implementation and realization of mental health, well-being and disability related targets in the SDGs, the next step should include: (1) inclusion of mental well-being and disability as a key indicator for all the development efforts beyond the health goal because human beings are emotional beings who are greatly affected by psychosocial factors; and (2) integration of perspectives of mental well-being and disability in the global discourses related to peace and security because emotional reactions such as anxiety, fear and hatred tend to be the root causes for conflicts and wars, while psychosocial perspectives might be able to play an innovative role in reconciliation, mutual understanding, and peace building.



#### Atsuro Tsutsumi

#### Coordinator, United Nations University International Institute for Global Health

The United Nations University, the United Nations, and The University of Tokyo, in close collaboration with the WHO and the World Bank Group, have released a new publication, "Mental Health, Well-being and Disability: A New Global Priority: Key United Nations Resolutions and Documents". This new tool was developed through unprecedented partnership among key global stakeholders to provide a useful foundation for the new era of mental health and well-being as well as disability, which is integrated in the 2030 Agenda for Sustainable Development and the SDGs.

This publication aims to: (1) provide an overview of the history of mental well-being and disability in the United Nations; and (2) list key resolutions of the United Nations General Assembly, the Security Council, and the Economic and Social Council, as well as other important tools and guidelines produced by the United Nations system. This publication was developed with the purpose of providing a key reference for future efforts to realize mental health and well-being as well as inclusion of persons with mental and intellectual disabilities. The publication is available online in both text and PDF files.

For this publication, a comprehensive document search of the United Nations resolutions that refer to mental well-being and disability for the period from 1994 to 2015 was employed utilizing the United Nations Official Document System. As a result, 371 General Assembly resolutions were found. Of these, one-third discusses issues of mental well-being and disability among children and women. There were also a large number of resolutions concerning mental health and human rights. Seven resolutions included concepts related to mental well-being and disability among the Security Council resolutions as well as in the Economic and Social Council. This shows that although mental well-being and disability tend to have been neglected in

the global community, there are solid global-level foundations to realize mental health and well-being for all, including persons with mental and intellectual disabilities.

The United Nations Conventions are of great importance because they are legally binding among those states that ratified them. Ten Conventions and eight Optional Protocols include concepts related to mental well-being and disability. For example, the International Covenant on Economic, Social and Cultural Rights adopted in 1966 mentions "the right to health", which includes a specific reference to the right to mental health. The Convention on the Elimination of All Forms of Discrimination against Women in 1979, and the Convention on the Rights of the Child adopted in 1989 have also included paragraphs on mental well-being and disability. The Convention on the Rights of Persons with Disabilities in 2006 includes persons with physical, mental, intellectual and sensory impairments.

Regarding the key outcome documents from major United Nations global conferences, many outcome documents have indeed included mental well-being and disability, such as the International Conference on Population and Development Programme of Action (1994), and the Beijing Platform for Action produced by the World Conference of Women (1995). Last, as mentioned earlier, the United Nations Sustainable Development Summit and the Third United Nations WCDRR adopted the SDGs and the Sendai Framework, respectively, which included mental well-being and disability in their key priorities. Following these achievements, now is the time for the international community to get together, realize mental health and well-being for all, and promote the rights of persons with mental and intellectual disabilities at all levels to leave no one behind.







#### Mark van Ommeren

#### Public Mental Health Adviser, Department of Mental Health and Substance Abuse, World Health Organization

When we think of people with severe mental disorders living through war or natural disaster, one of the priorities that we need to consider is their protection. People with mental health conditions - whether they live in the community and or in an institution - require protection of their rights. In many countries, horrible events such as neglect, abandonment or murder have happened to persons with psychosocial disabilities in a war or disaster setting. Currently, an estimated 125 million people are affected by humanitarian emergencies, including four to six million people with severe mental disorders.

The vulnerability of people with these conditions increases in emergencies. This is because care systems break down after emergencies, and health care and social systems, support providers, and medicines often become unavailable. Family support might not be there in the same way after a crisis as it was before the crisis. People with these disabilities may even be shot by security forces when they do not understand instructions. Therefore, it is important to make sure they are protected and cared for throughout emergencies. Care for persons with psychosocial disabilities needs to be integrated in disability programmes, health care services, social services, and education systems in emergency settings.

Is there evidence for the care required by persons with psychosocial disabilities? Yes, there is much evidence. Do we have policy and tools that help persons with psychosocial disabilities in emergency setting? Yes, there are numerous tools, including the Inter-Agency Standing Committee Guidelines for Mental Health and Psychosocial Support in Emergency Settings, which were developed by the United Nations system, leading non-governmental organizations, Red Cross and Red Crescent movement, and other humanitarian agencies. Therefore, we know what to do according to evidence and best-practices compilations. Are there agencies to support persons with psychosocial disabilities during emergencies? There are not enough agencies, but this is changing. In recent years, we have seen a steep increase in number of agencies and programmes working on care for persons with severe mental disorders during emergencies. We have seen an increase in the number of programmes provided by various agencies, including by the WHO, the United Nations High Commissioner for Refugees, the International Federation of Red Cross and Red Crescent Societies, the International Medical Corps, Save the Children, Action Contre la Faim, Medicine sans Frontieres, the International Committee of the Red Cross and Doctors of the World (MdM) amongst others. This field has momentum.

Do we have all the answers? Do we know everything we need to know? No, not at all. We need to learn how to make care and protection more widely available, and we are learning. Some things are going well, and some are not going well enough. There is much more to learn. We know how to set-up and deliver small, high quality programmes. Yet, we need to

improve our knowledge on how to set-up large mental health programmes of quality that reach vast numbers of people. We need to know more about how to supervise staff who have been trained in providing care. We know how to supervise, but we do not know how to supervise on a larger scale. We need to make sure that medicines are available for those who need and would benefit from them. We know which medicines are useful. These are provided in interagency emergency health care kits (IEHK), but we struggle to ensure an uninterrupted supply. We also need to learn much more about balancing medical and psychosocial approaches.

There are hard lessons to be learned, but there are also many success stories. For example, in Syria, 130 health care centres out of 1,200 centres in the whole country have trained their health care staff how to use a mental health Gap Action Programme (mhGAP) tool for providing care for people with severe mental disorders. About 16 per cent of Syrians have access to mental health care at the primary health care level. This is certainly not enough, but it is a great improvement from the complete lack of access to care previously. There are many other examples. For example, in Afghanistan's Nangarhar province, one NGO trained general health workers over a sustained period of time and 100,000 people received mental health care over 10 years throughout the humanitarian emergency.

Sometimes services improve after the emergency. In Kosovo, there were six inpatient wards and one psychiatric asylum before its war. This situation has changed after the crisis. By 2010, the asylum was closed and various community services are now available across the country. After the tsunami in Sri Lanka, community mental health services became widely available across the country because of the increased interest in mental health due to this major disaster.

Policy frameworks for humanitarian action increasingly give clear guidance on important components of mental health and psychosocial support. These typically include clinical services in primary care or other community settings and holistic psychosocial supports. However, many countries focus only on hospital care. Investments should be more balanced. Emergencies can be a good opportunity to reorganize the existing mental health services into services that respond to the real needs of the community.

Many efforts have been devoted to and much more can be done for persons with psychosocial disabilities in humanitarian settings. It is important that this topic continues to gain attention. Indeed care for persons with psychosocial disabilities should be considered a priority during the United Nations World Humanitarian Summit this May.

© World Health Organization



#### Patricio V. Marquez

#### Lead Health Specialist, Health, Nutrition and Population Global Practice, World Bank Group

It is clear that the inclusion of people of all abilities has to be at the core of sustainable development. Billions of people across the globe are living with a disability, and some of those disabilities are obvious or not so obvious. As human beings, we all have the possibility to have disabilities in the future. The World Bank Group is committed to work on the social and moral imperative to remove barriers and promote inclusion to change attitudes about disabilities inside and outside our institution. Internally, at the World Bank, we strive to allow all our staff, with or without disabilities, to participate fully and equally in our mission of eliminating extreme poverty and increasing shared prosperity by the year 2030.

The World Bank Group also recognizes inclusion as a priority in our development work. In many places, persons with disabilities face barriers and lack of equal access to transport and employment as well as other essential services. Therefore, we all should be excited about and welcome the SDGs, which intend to ensure that all persons, including persons with disabilities, benefit from sustainable development efforts. In doing so, I would like to reiterate that we need to focus on and to attach a special priority to promote and bring forward the issue surrounding the invisible disabilities as a barrier to society, development, and more integrated and sustainable countries. This call is long overdue. Persons with mental and intellectual disabilities represent a significant proportion of the world's population. Different forms of mental disorders affect millions of people. One in four people worldwide will experience a mental disorder in their lifetime.

Unfortunately, our youth are leading the epidemic of suicides. Recent reports show that among young girls aged 15-19 years worldwide, suicide has become the leading cause of death, surpassing maternal mortality. In addition, apart from facing strong stigma and discrimination, and suffering from physical and sexual abuse in homes, hospitals, prisons, or on the street, persons affected by mental disorders are excluded from social, economic and political activities.

Challenges related to mental ill-health are not only experienced among persons with severe mental disorders confined to psychiatric hospitals but are also a widespread and often invisible phenomenon. Many of us, or our parents, our partners, sons and daughters, might have felt sense of loss. We also experience nervousness and anxiety during changes in our personal and professional lives. Real or imaginary fears or worries might distract, confuse or agitate us. Though these

episodes tend to be transitory in many occasions, some of these experiences might make us take frequent breaks from work owing to stress and depressed mood, or sometimes because the medication that we take to alleviate our mental disorders makes it difficult for us to get up early in the morning or concentrate at work. Sometimes, because of these disorders, some people might start to experience alcohol and/or substance abuse.

In West Africa, where I was co-ordinating the Ebola emergency response, mental disorders were sometimes triggered because of the massive social dislocation and other factors. For example, Ebola in Liberia, Guinea and Sierra Leone, as well as the financial crisis in 2008 in cities such as New York, or civil conflict in Central America, tend to precipitate these conditions. What can we do? It is clear that we cannot close our eyes to this invisible disability anymore. We have to make it visible. The best way to do that is by promoting the development and implementation of a multi-sectoral agenda for action.

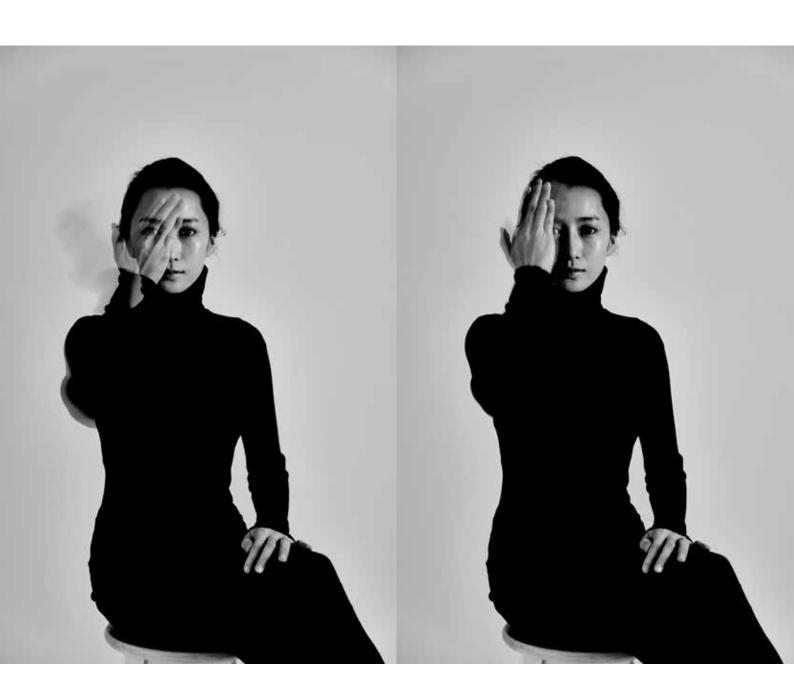
One point of entry is the progressive realization of universal health care coverage to ensure that people who need care can access essential services and do not have to spend a large amount of money to obtain those services or buy medications. We need to have financial protection from the negative impact of mental ill-health.

Mental health, well-being, and disability cannot be only seen from a biological perspective; a social perspective is necessary. There are multiple ways to deal with these phenomena and avoid medicalizing mental health. We have to find entry points in social protection, employment, and job markets to restore people as active members of their community so that they can live healthy, productive and happy lives.

The World Bank Group is committed to help move a multi-sectoral agenda forward. We are organizing a global event on mental health as part of the World Bank Group/International Monetary Fund Spring Meetings on 13-14 April 2016, to start operationalizing a broader multi-sectoral response worldwide in partnership with the WHO and institutions, including the United Nations, the Nippon Foundation and The University of Tokyo, among others. The goal of this meeting is to launch a broad movement of action to tackle this invisible disability by stressing the social and economic impact of inaction. We cannot continue to ignore this issue. The time has arrived to open our eyes and make this invisible disability visible.







#### Kathryn Goetzke

#### Founder, International Foundation for Research and Education on Depression (iFred)

I am pleased that we are respecting the one billion people globally with disabilities, including those with mental, intellectual or psychosocial disabilities.

It has been a year since I participated in the United Nations Panel Discussion on Mental Health, Well-being and Disability on the International Day of Persons with Disabilities in 2014. So much has happened in mental health advocacy since then. We have much to celebrate and give thanks for in regard to mental health. The inclusion of mental health in the SDGs seemed a daunting task when we met at the United Nations Headquarters last year. However, we succeeded in the inclusion of mental health in not just one, but multiple parts of the ambitious Agenda. I am grateful for this historic change.

I am here today on behalf of myself, my foundation, iFred, and FundaMentalSDG, which is a global group of mental health experts and advocates, and the 600 million persons with mental disabilities, to ask that you now add mental health indicators to the SDGs. As we all know, without measurements, it is very difficult, if not impossible, to see progress. Therefore, we must give countries recommendations on measurements using these indicators and hold them accountable.

Many colleagues in the panel gave facts for the 'why'. There is adequate research that including mental health helps us meet other SDGs, not to mention the US\$16 trillion projected cost to the economy for not taking action. The human rights crisis alone must be initiative for serious and immediate action. Therefore, I will take a more personal approach because I believe my story has relevance and insight to offer this meeting.

My father was one of my greatest mentors. He was energetic, brilliant, and committed to our family. He took us around the world to experience new cultures, ideas and people. He came from little and made an impressive life for himself, completing a Master's degree and becoming a Vice President at the First National Bank of Chicago. Everyone loved him, his generosity

to others and his passion for life.

He provided us with experiences that few had, including Wal-Mart annual meetings and learning from the great retailer, Sam Walton. On a float trip during one particular annual meeting, he even ensured I was the one that got to canoe with Sam's son Jim. We were caught in a rainstorm and Jim built a fire. Imagine that, Jim Walton! This experience is priceless to me, and it was all because of my dad's enthusiasm for life and his desire for my happiness.

Maybe you can imagine my total devastation when, as a freshman in college, I called my dad from my dorm room and instead of my father's voice, I heard the voice of a stranger on the other end. It was a policeman. My father had taken his life. In that one life-altering second, I lost my great hero; a person I admired, counted on, and loved more than anything in the world. I lost my dad.

I wish my story of depression and suicide ended there, tragic though it is. Unfortunately, because of my genetic heritage, I struggled with depression and spent years escaping with alcohol, smoking and other addictions. These are all societal burdens that come as a consequence of untreated depression. In my early 20s, even after losing my father and never wanting that pain for others, I attempted to take my own life. It is a miracle that I am here with you today.

That shocking wake-up call got me into treatment. This process gave me the health and focus to get an MBA in International Business, and the necessary energy to work for great Fortune 500 companies and become a productive contributor to the global economy. I then created my own successful company, The Mood Factory, with a consumer brand at Lowe's and over 5 million items sold to date.

Becoming mentally healthy also inspired me to start a foundation called iFred to eradicate stigma and rebrand

depression using celebrity engagement, the sunflower as the international symbol for hope, and a curriculum for 10-year-old children based on research that hope is a teachable skill. iFred and global mental health advocacy is my way of helping to counter something that has taken so much, and it is an understatement when I say I have been blessed by my access to mental health care.

Unfortunately, most do not have access to treatment or will not get it because of stigma. Four hundred million people worldwide have depression, yet less than 50 per cent are receiving treatment, and this number increases to 80-90 per cent in many countries, even though we have proven cost-effective and money-saving treatments. We lose almost 1 million people a year to suicide, which is more than war and homicides combined, and yet it is treatable.

I just learned yesterday that suicide is now the leading cause of death for adolescent girls. Our young girls, who are getting ready for a full life, are now choosing to end it early. In fact, one in nine children in the United States are self-reporting suicide attempts prior to graduating high school. This must change.

I believe that stigma is the reason my father is not here with me today, and why it took me so long to get my own help. Quite simply, stigma is a negative brand, a misperception, a lack of understanding and due to inadequate information. What we do not understand, we often fear. Stigma impacts everything: Funding, access to treatment, compliance and relationships. Working together to change stigma changes everything.

My late mentor, Paul Carter, continued my dad's traditions and took me to a few Saturday morning meetings at Wal-Mart. In the 1990s, I was lucky enough to see Nancy Brinker from the Susan G. Komen Foundation speak about breast cancer, which was also once a highly stigmatized disease. I then watched how she and others transformed the stigma of breast cancer through

policy, celebrity engagement, education and the iconic pink ribbon.

The United Nations also helped transform the stigma of AIDS with the Millennium Development Goals. The inclusion of AIDS meant fewer new HIV infections, increased access to treatment and reduction in stigma. I saw an estimate that over 6.6 million lives were saved. Amazing. This gives me great hope for the treatment of depression and mental health.

Not a day goes by that I do not think about what my dad would have done had he lived. I watched his colleagues do extraordinary things, becoming executives of large corporations, institutions and banks, and creating massive positive change in the world. I know that had he made it through his difficult times, he would have come out the other side ten times stronger.

I stand today in solidarity with depression survivors, those impacted by the loss of someone they love to suicide, and others needing mental health support, including those impacted by autism, Asperger's, Alzheimer's, schizophrenia, and post-traumatic stress disorder. I stand with the one billion impacted by disabilities globally. I stand in solidarity with those in chains in Africa and the one in nine children feeling so hopeless that they attempt to take their own life before even graduating from high school.

I am here to say that I believe creating specific indicators in the SDGs is the single most important thing we can do today to end stigma and ultimately provide access to care. I stand here to say that this is not a suggestion, it is necessary. These indicators send a clear message from our global leaders to the world that there is no shame in asking for help, that we matter, and that the United Nations believes in treatment, equality and human dignity for all.

#### Vivian Pender

#### Chair, NGO Committee on Mental Health; Special Advisor, American Psychiatric Association

hat we may call invisible disabilities may be in fact detectible by an informed, knowledgeable, careful observer. This knowledge will make the invisible visible.

The American Psychiatric Association (APA) finds that 50 per cent of all mental illness begins by age 14 and 75 per cent begins by age 24. There are early signs that if noticed by informed individuals can alter the course. Major mental illnesses such as schizophrenia or bipolar disorder rarely appear spontaneously without prodromal indicators. Most often family, friends, teachers or individuals themselves begin to recognize small changes or a feeling that "something is quite different" about their thinking, feelings or behaviour before one of these illnesses appears in its full-blown form. Learning about developing symptoms, or early signs, and taking action can help. Early intervention can help reduce the severity of an illness. It may even be possible to delay or prevent a major mental illness altogether.

The APA advises that if several of the following are occurring, it may be useful to follow up with a mental health professional.

- Withdrawal: Recent social withdrawal and loss of interest in others
- Drop in functioning: An unusual drop in functioning, at school, work or social activities, such as quitting sports, failing in school or difficulty performing familiar tasks
- Problems in thinking: Problems with concentration, memory or logical thought and speech that are hard to explain
- Increased sensitivity: Heightened sensitivity to sights, sounds, smells or touch; avoidance of over-stimulating situations
- Apathy: Loss of initiative or desire to participate in any activity
- Feeling disconnected: A vague feeling of being disconnected from oneself or one's surroundings; a sense of unreality
- Illogical thinking: Unusual or exaggerated beliefs about personal powers to understand meanings or influence events; illogical or "magical" thinking typical of childhood but seen in an adult

- Nervousness: Fear or suspiciousness of others or a strong nervous feeling - agitation
- Unusual behaviour: Odd, uncharacteristic or peculiar behaviour for that individual
- Sleep or appetite changes: Dramatic sleep and appetite changes or decline in personal care
- Mood changes: Rapid or dramatic shifts in feelings

One or two of these symptoms alone might not be able to predict a mental illness. But if a person is experiencing several at one time and the symptoms are causing serious problems in the ability to study, work or relate to others, he/she should be seen by a mental health professional. People with suicidal thoughts or intent, or thoughts of harming others need immediate attention.

More than a decade of research around the world has shown that early intervention can often minimize or delay symptoms, prevent hospitalization and improve prognosis. Even if a person does not yet show clear signs of a diagnosable mental illness, these early symptoms can be frightening and disruptive.

We advise family and friends to encourage the person to:

- Have an evaluation by a mental health or other health care professional.
- Learn about mental illness, including signs and symptoms.
- Receive supportive counselling about daily life and strategies for stress management.
- Be monitored closely for conditions requiring more intensive care.

Each individual's situation must be assessed carefully and treatment should be individualized. Comprehensive treatment to prevent early symptoms from progressing into serious illness can include ongoing individual and family counselling, vocational and educational support, participation in a multi-family problem-solving group, and medication when appropriate. Family members are valued partners and should be involved whenever possible. Learning about mental illness and what is happening in the brain can help individuals and

families understand the significance of symptoms, how an illness might develop and what can be done to help.

Early intervention programmes require education, awareness and funding for families, communities and professionals. The APA remains dedicated to making the invisible visible by providing training and education. Just as with other medical illnesses, early intervention can make a crucial difference in preventing severe symptoms.

As the 10th leading cause of death in the United States and the second leading cause of death for people aged 15 to 34, suicide is a serious public health problem. Each year in the United States, more than 40,000 people die by suicide (one every 15 minutes) and 1 million people attempt suicide, according to the Centers for Disease Control and Prevention. Men are nearly four times more likely than women to take their lives.

Yet, suicide can be preventable. Knowing the risk factors and recognizing the warning signs for suicide can help reduce the suicide rate.

Suicide is linked to and a possible outcome of mental illnesses, particularly depression and alcohol use disorders, and the strongest risk factor for suicide is a previous suicide attempt. The Suicide Prevention Resource Center defines risk and protective factors and warning signs:

#### Warning Signs of Suicide

- · Often talking or writing about death, dying or suicide
- Making comments about being hopeless, helpless or worthless
- Expressions of having no reason for living; no sense of purpose in life; saying things like "It would be better if I wasn't here" or "I want out"
- Increased alcohol and/or drug misuse
- Withdrawal from friends, family and community
- Reckless behaviour or more risky activities, seemingly without thinking
- Dramatic mood changes

Talking about feeling trapped or being a burden to others

In some cases, an immediate stressor or sudden catastrophic event, failure or humiliation such as a relationship breakup, legal problems, financial problems (e.g., home foreclosure or job loss) can leave people feeling desperate, unable to see a way out, and become a "tipping point" toward suicide. If someone indicates they are considering suicide, listen and take their concerns seriously, don't be afraid to ask questions about their plans. Let them know you care, and they are not alone. Encourage them to seek help immediately from a knowledgeable professional. Do not leave them alone.

#### Risk Factors for Suicide

- Previous suicide attempt(s)
- A history of suicide in the family
- Substance misuse
- Mood disorders (depression, bipolar disorder)
- Access to lethal means (e.g., keeping firearms in the home)
- Losses and other events (e.g., the break-up of a relationship or a death, academic failures, legal difficulties, financial difficulties, bullying)
- History of trauma or abuse
- Chronic physical illness, including chronic pain
- Exposure to the suicidal behaviour of others

#### Protective Factors

- Effective mental health care; easy access to a variety of clinical interventions
- Strong connections to individuals, family, community and social institutions
- Problem-solving and conflict resolution skills
- Contacts with health care providers (e.g., follow-up phone call from health care professional)

As with mental illness, one of the biggest barriers to preventing suicide is stigma, which prevents many people from seeking help.



#### Key Tools: Global Guidelines and Documents

#### 1. Key Frameworks for Action

- Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) http://www.un.org/disabilities/convention/conventionfull.shtml
- Comprehensive Mental Health Action Plan 2013-2020 (WHO, 2013) http://www.who.int/mental\_health/action\_plan\_2013/en/
- Geneva Convention relative to the Protection of Civilian Persons in Time of War of 12 August 1949 (ICRC, 1949) https://www.icrc.org/ihl/INTRO/305?OpenDocument
- Protocol Additional to the Geneva Conventions of 12 August 1949, and relating to the Protection of Victims of International Armed Conflicts (Protocol I) (ICRC, 1977)
   https://www.icrc.org/ihl/intro/470
- Protocol Additional to the Geneva Conventions of 12 August 1949, and relating to the Protection of Victims of Non-International Armed Conflicts (Protocol II) (ICRC, 1977)
   https://www.icrc.org/ihl/INTRO/475?OpenDocument

#### 2. United Nations Expert Meeting Outcome Documents & Policy Analysis

- United Nations-WHO Policy Analysis on Mental Health and Development: Integrating Mental Health into All Development Efforts including MDGs (United Nations & WHO, 2010) http://www.un.org/disabilities/documents/who\_desa\_mental\_health\_policy\_analysis.doc
- The UN Expert Group Meeting on Mental Well-being, Disability and Development: Conclusions and Recommendations for Inclusion of Mental Well-being and Disability into Key Goals and Outcomes of Upcoming International Conferences (United Nations & UNU, 2013) http://www.un.org/disabilities/documents/hlmdd/UNU\_EGM\_MWDD\_2013.pdf
- The UN Expert Group Meeting on Mental Well-being, Disability and Disaster Risk Reduction: Outcome Document (United Nations & UNU, 2014)
   http://www.un.org/disabilities/documents/egms/egm\_tokyo\_drr.docx

#### 3. Key Intervention Guidelines

- mhGAP Intervention Guide for Mental, Neurological and Substance Use Disorders in Non-Specialized Health Settings (WHO, 2010) http://www.who.int/mental\_health/publications/mhGAP\_intervention\_guide/en/
- IASC Guidelines for Mental Health and Psychosocial Support in Emergency Settings (IASC, 2006) http://mhpss.net/iasc-guidelines-on-mental-health-and-psychosocial-support-in-emergency-settings/
- Psychological First Aid: Guide for Field Workers (WHO, 2011) http://www.who.int/mental\_health/publications/guide\_field\_workers/en/
- The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response (The Sphere Project, 2011) http://www.sphereproject.org/handbook/

#### 4. Useful Resources

- Mental Health Atlas 2014 (WHO, 2014)
   http://www.who.int/mental\_health/evidence/atlas/mental\_health\_atlas\_2014/en/
- Making Mental Health Count: The Social and Economic Costs of Neglecting Mental Health Care (OECD, 2014) http://www.oecd.org/els/health-systems/Focus-on-Health-Making-Mental-Health-Count.pdf
- Mental Health, Well-being and Disability: A New Global Priority: Key United Nations Resolutions and Documents (UTokyo, 2015) http://i.unu.edu/media/iigh.unu.edu/news/3735/UN-MHWD-Book-2015.pdf







 $Making\ Invisible\ Visible: Taking\ action\ for\ persons\ with\ invisible\ disabilities:\ Mental\ health,\ well-being\ and\ disability:\ A\ new\ global\ priority\ in\ SDGs$ 









