RI World Congress
27 October 2016
Parallel D Tinto
The WHO global disability action plan 2014-2021

Jan A Monskbakken: Welcome everybody. This was a strong strong voice through this microphone. Thank you to the organisers and welcome to this session. This should be a session for everyone, not a parallel session as we have distinguished speakers to talk on different items. I will push your expectations to the top. I would like to present my co moderator Asish Mukherjee from New Delhi, India who has been serving in IR for many years. He is very young! He has been a distinguished Indian person working with IR many years. I cannot go into details of his biography or we will lack time for the rest. I have an apology from Doctor Alarcos Cieza Moreno from Geneva should have been here talking of the WHO Action Plan but she is stuck. Her plane was cancelled but to replace her we have another person of extreme value for everyone interested in rehabilitation and been working many years in WHO but is much more than just a representative. We have Professor Jerome Bickenbach and I cannot go into what he has done in his life either but he is, from my point of view, one of the most distinguished rehabilitation and disability thinkers in the world and we are interested to hear from him. Please take the floor as a replacement for Doctor Alarcos Cieza Moreno. She is a little bit younger [LAUGHTER]. Jerome the floor is yours.

Professor Jerome Bickenbach: You will get to see her at 3.30 pm. Nothing is more disastrous than me replacing her! I will take us through a factual presentation and I want to set the stage for what WHO's agenda has been for almost 8 years now and this is the agenda that Doctor Alarcos Cieza Moreno's unit in disability and rehabilitation is committed and will organise their activities.

I will give a background and walk you through the sense of what WHO's agenda is. I will say it is disability and rehabilitation as WHO is in the health context but has interest in disability issues and inclusion and Human Rights but has a foot in rehabilitation and provision of services avoiding inequities and various delivering of services and scaling up rehabilitation in various parts of the world. This is the context here on the slide that is goldbricking and you should read this with care. There are several things going for the data

side of it. For the first time, world-wide prevalence off disability is evidence based in a methodology that is robust. If you look at point two on the slide the estimate here, as you can see, is significant for disability and where you make the cut of and significance that is vague is the criteria used. 15% of the world population or 1 billion of us or others would say 1000 million as said here have a disability - see slide. That information and the data behind it is in this document.

The second premise, and I have given chucks behind this, this is a call to arms in this document for education and employment. I am talking too quickly. The issue is that there is a question of removing barriers and accessibility which is at the forefront of Article 9. There are barriers but the optimistic point is that many of these barriers are removable and avoidable and those that understand accessibility we understand removing those. The availability is the message in this document, don't build them in the first place so think ahead when planning buildings. This document which is very difficult to summarise is the basis or informs the platform for the document I want to spend time on. The context is there which is the epidemiological reality which is because of the population ageing which is well established world-wide. Also, there is a shift from infectious to non-infectious disease in which we have the demographics of uncertainty of the next decades as those with disabilities will increase and they will have multi-morbidity and combinations of issues so the complexity of their services and accessibility will increase.

The world report on disability is foundationally based on the ICF. That means that the model of functioning and disability that informs this document is an interaction of features of the human body in the health domain and the physical human build, social and attitudinal.

This ICF model is about interaction and you have to understand the building not as a functioning issue but it is an interaction with the environment and is the source of the optimism as we can change the environment but there are conditions unchangeable such as age for functional limitations. That is what it is. The last component is we have a responsibility. You bring these things together and end top with a picture of disability characterised by these per the slide - reading. It is not the identification of a separate minority group and that disability is a social class minority group. We will have some function of decline as we get older - prick me and I bleed. We are all human and have the vulnerabilities of human beings and this is a human condition. We should moderate, mediate or eliminate disability but it is not the mark of a special group of people and is what it means to be human.

The understanding of disability in the WHO document and the consequence of this is that disability is not a biological phenomenon or a matter of social participation but complex and difficult to understand the

interaction between the two. The WHO says it is a global public health problem. That is the nature of disability. Some of which can be eliminated and prevented and some which cannot. It is a Human Rights issue as there are barriers we create. It is also given WHO focus on medium and low developmental issues on the world. This is a priority for development.

The Action Plan so we have the vision and the goal. The vision is that the vision of the action plan is a world in which all persons with disabilities and their families live in dignity, with equal rights and opportunities and are able to achieve their full potential.

The overall goal is to contribute to achieving optimal health, functioning, well-being and human rights for all persons with disabilities. That is say everyone.

There are three objectives. This is the focus of what I will say. I will go into them in more detail, not as much as Alarcos would have thought. I will go through them as it sets the WHO agenda with respect of disability for the next 8-10 years.

To remove barriers and improve access to health services and programmes. The UN agency is responsible for health and education but employment should also be accessible but the WHO is focussing on health services.

Secondly and more appropriately for us is to strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community based rehabilitation. So, this is the second major objective of the WHO Action Plan. In low and medium resourced countries, this is a scaling up exercise and what is the best way for those that have no form of rehabilitation to set the stage for progressive realisation of this right to move in a slow and progressive manner to scale up rehabilitation services.

Lastly because it is one of the WHO's mandates are to produce standards and data to strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services. These are the three. I could go and do the action agenda but I will just leave that on the screen for the sense of the fullness of the document. it is well worth looking at this to see how the WHO minds work. There are objectives and actions by stakeholder groups and policy groups, NGOs etc. You see actions as they play out. The WHO rationale is everyone has a stake in improving accessibility to health services and different stakeholders have different stakes to play.

The first thing is to remove barriers and improve access to health services which is removing the barriers but the world report on disability made clear they are not just physical but attitudinal barriers and the barriers you confront are more robust when they are attitudinal rather than physical but they are significant too. Alarcos would have talked of scaling up in a different context including her work on community based rehabilitation which you will hear at 3.30 pm today if she gets here on time. She will talk of CDR and what she now calls the disability inclusive community development and the steps she is taking. The issues for rehabilitation cover a wide spectrum of issues of great concern.

Lastly the data issue. Doctor Alarcos Cieza Moreno is an academic with experience in disability data but has moved on to the development of a model disability survey that she would have talked of in detail. The point of this is a different approach to understanding collection of information on disability. You collect information identifying people with health problems and then say because of your health do you have problems getting a job. It is a common survey technique but it has the fact of restricting the understanding of disability to the health condition and premise on that rather than the environment so you screen off the population in terms of their health condition and ask what they can and cannot do but the Model Disability Survey flips that to the environment restricting them. It is designed to identity the population restricted in participation of virtue of environmental issues rather than focussing on a health problem and then asking if they do or don't do but this survey asks people what they do in their lives and what environment modifications help and what environment barriers restrict them. The idea of the survey is to get a better and more accurate picture of prevalence. There is the statistical side but is phenomena of disability. I know it's time! Ok saving questions for later. I will leave you with this picture. Thanks very much. [APPLAUSE].

Jan A Monskbakken: Thank you Jerome for being such a beautiful stand in for Alarcos. I think we will take questions and discussions at the end so we don't run out of time for the other presenters. Can I mention two things. The WHO action plan Jerome spoke of was a product of the WHO new resolution on disability adapted in 2013. It is also important to mention that a letter was sent in 2012 to the Director of WHO and urged them to update the resolution. The government of Ecuador pushed the issue and the Action Plan is a result of that. Also, you mentioned the WHO is working to raise awareness of rehabilitation as a part of the health strategy and there will be a big stakeholder meeting in Geneva on 6th and 7th of February regarding this. That call has not gone out now but I am sure it will.

I will introduce Gerold Stucki, Director, Swiss Paraplegic Research, Notwill, Switzerland. He also been

running a rehabilitation department in Munich for many years and is president of international rehabilitation. I have not to mention what he will talk about. He is a very distinguished speaker and much involved person in rehabilitation both in his own country and at European and Global level. I introduce Gerold Stucki. Over to you.

Gerold Stucki: This is not my presentation. This was sent three months ago. I gave it to the room and it was all fine and in the sequence. This is not my presentation. Perhaps have someone else first. It was not uploaded. At the end of the day we need better data on functioning that we can use for different purpose including disability and all those issues. I will focus on rehabilitation. First I will introduce why we need functioning in rehabilitation and how to deal with this as the documentation is not a simple thing and is a challenge. They have been saying here at this conference that rehabilitation is a simple thing. What is that? From the rehabilitation medicine community, there has been a concept of rehabilitation based on ICF and we have to go forward and think internationally how to operate or conceptualise this. There are many definitions but we should have one for focussing on ICF. The WHO should resolve that and think about that. If we can apply this, we start at the clinical level of the person. I always wonder how we could practice rehabilitation without having functioning information at our fingertips. We have to have that information that we can use. So, I don't know how many of you that practice in rehabilitation have used ICF data for your clinical practice. A show of hands. That is more than I could expect. We have a challenge as that has not happened but has to for the diagnose of function and for trajectories to follow our patients over time and for the evaluation of individuals. If we don't do rehabilitation surveys, we are part of those, how can it be there are rehabilitation services in the world that have no measurement for improvement and don't feedback what they have for functioning improvements? Why not?

We are really behind in rehabilitation and that must change. We need a standard which is ICF. At a national level, we have rehabilitation programmes. We heard about the future of rehabilitation but we have to have integration of services across care. If we think of functioning out at a national level, we need information. I will skip this slide. We need functioning information to scale up rehabilitation and that is at the core. You can strengthen the strategy if it is only done across all the components. I mentioned clinical and we have case studies of you to look at which are on the web to see how to use functioning information in your practice.

We need rehabilitation services... [Unfinished Sentence]. This idea of the national level. We have to be very careful and need to know do our services product the functions we require and we need the data and benchmarks. We can only compare the UK with other countries from a health service perspective for

those outcomes. If we compare systems, we could learn from each other. Something that has been puzzling me for a long time, if we look at national outcomes from a programme then that is outcomes for people in the system but what is happening at the population level? We need population data and a model disability survey or spinal cord injury survey. Here we have to do a better job and level up policies.

It is not getting good function outcomes but getting them at all times for everyone. We need stakeholder dialogue that the WHO uses. We need to have a more formal approach for what evidence based medicine has done and we have to have a better way to deal with policy level.

How can we document functioning to fulfil those purposes as we can use it at all different levels? For this we need a standard and the ICF is the standard for the documentation of function. This slide is an old one but I really like it. You have these guys with different boxes and they use different measures. They don't agree what is in the box and what they can document. We have to resolve this. What you can see here is ICF coded data. Everyone knows what self-care is. It is in all langue and is defined. The boxes here are those boxes [demonstrating]. You can see the 0-100 scale and the population which is the medium which you can see on the slide.

This is a metric which is an interval scale metric so between 5 and 6 is the same as between 8 and 9 and you cannot say that with 99% out there as instruments. Only after transformation from the 0-100 scale can that happen. We have to define what needs to be reported. We have to report it using simple metric. It seems simple, this is not new. I learned this 20 years ago but we struggle to get it down. First you have to say what needs to be documented and we have ICF core sets, ICF rehabilitation sets and then decide what perspective to use as per the slide - reading. Then we have to decide on data collection tools but we don't have to use ICF tools. We need one type of reporting. There are many standards for documentation and there is a huge project mapping the tools we use in rehabilitation for ICF and what it looks like. You see examples of self-care and different instruments and they cover different types of the spectrum of self-care and continuum of self-care for a common metric for a specific number. You can call that technical but it is important to understand that. At the end, I don't know why we don't see these graphs in publications. We have to get the scientific community on board to advance this. There should be journal guidelines and no study should be published if it does not report in ICF. I got the news the Cochrane Field for Rehabilitation has been announced.

For quality management and registry, we need rehabilitation information systems and have to think about the National Rehabilitation Plans. We need a model coding scheme for functioning and be able to code

and money is flowing only if you code functioning. We have problems with this. Those are concrete approaches we should go for system wide implementation. ICF is fit for purpose but we have to implement it. Thanks.

Jan A Monskbakken: Thanks. I think we should open for two specific questions before we continue. If anyone has specific questions, please raise your hand. At the back. Be short.

New Speaker: Thanks for the presentation. How do we go about registration?

Gerold Stucki: Not one single society can do it but WHO have to come up with a model and then you can use it in your setting. At least then we have a model.

Jan A Monskbakken: One more question? No. It seems everything was clear. Then we will advance to the next speaker. It is Alessandro Giustini, Scientific Director at San Pancrazio Hospital, Arco Santo Stefano Rehabilitation Group, Israel.

Allesandro Giustini: Thanks. I am glad and proud to be a member of this think tank because in this session and in all the meetings we are trying rethink many aspects. I try to follow what the two previous speakers have said to show how it is possible to support the health system to learn and modify and concretise the services for the person of the older society that must learn from visibility problem. As has been said, it is not the problem only of health services but a problem for the person in the community and social and economical services must learn. I am a doctor and have to work and try to explain and to realise these learnings step by step to modify and implement. These projects are a sort of demonstration I think, a concrete demonstration, because the Action Plan is born after many years of work in the WHO team with many others co-operation. For the international perspective on spinal conditions, it is easy to define and see a sort of specifics which is relevant and easy to define disability for a not so big number of person so is possible to have an example to define the condition of this person and is possible to make a sort of ward point of view on this situation.

Spinal cord injury can be the table to measure, to support, to realise and to measure the learning advancing of the health services. I am repeating that we don't need only from the health services but we have to work on the health services to show that it is possible to modify. We can have the document international perspective of spinal injuries with its recommendations and go to the health services and communities in many countries to see how their health services can learn and modify itself. Also, to see

how this learning and this modification can realise a different quality of life, different health situation and individual situation of this person with a spinal cord injury and the outcomes can be connected with the recommendation of the IPSCI.

As the two speakers explained, we have to have work based on three blocks altogether working. We have underlined the evidence in cross-cultural situations as we need a world-wide perspective. We have to discuss and to support the stakeholders, the different stakeholders. Many are here today in the Congress. It is important to open this window in this session about this problem too and continue co-operation. At the end, we need the third block to verify something can be modified and we need to create a capacity to build a new programme in health services and new programme to modify the life condition of this person.

The cornerstone of this global activity is this article of the Convention of Rights of Disabled People to conduct statistical data. We require data, we cannot just have documents or books. We need data and with this we have the possibility to modify in some health services but not all.

SCI is a good example to show how actually this situation is really... I try to say useless. We can see there are criticism as many data arrives from a single centre hospital and in different countries standards are not the same and global data - at what level can describe many situations in this very specific health situation like SCI. So, we need to implement this data, apply ICF and apply the relation described in ICF from a spinal cord injury and the life of this person.

It is necessary to have an international point of view with the same standards and methodology to have this data and to discuss with the stakeholders.

The other point, which is very important, is to monitor in each country with similar standards so what is happening during the period in collecting this data and in explaining how this data can show how it is possible to change the life and quality of life and education for this person following the International Perspective on Spinal Cord Injury recommendations.

This survey you can see here on the slide with the countries all over the world. It is very different in social, economic, cultural and religious and any conditions. It is the possibility to realise what the actual plan is.

There is a survey in many countries which is starting next January and will be repeated every 5 years to monitor and collect new data after, we hope, bigger changes.

The objective is the same and similar of the Action Plan and World Report. The last point I have to underline repeating another idea that Gerold and the first speaker presented. We have to have two different points of view, to collect the data and monitor the situation from the person perspective, not only illness from the ICF perspective but also from the social perspective and how society describes the condition of the person with a spinal cord injury and economic and demographic aspects and quality of life. This is a brief summary on the slide of items of the survey - see slide.

At the end, we think and we hope to have elements to discuss all over the world in the WHO teams but also in society and together with rehabilitation international. To summarise what I have said - the survey and the monitoring of results of the data of the survey and in society and community and repeating every 5 years with new collection of data. This is the list on the slide of the most important collaborators on the WHO and international society table who creates these surveys and we think this session is an important moment to share and it will open other discussions also more than this big group but little groups in a world perspective. Thank you. [APPLAUSE].

Jan A Monskbakken: Thanks so much. I will open up for one or two questions? You need a microphone. Anyone have one?

New Speaker: Thanks I am from Israel. I think one of the principles that is important to pass on is the issue of measurement and evaluation and how important that is
As part of rehabilitation, I wonder if there is role to encourage and train and give information to NGOs as to how to operate ICF. We have a rehabilitation centre that work with ICFs but others don't use this but it is fantastic to use for the clinical work you are doing.

Allesandro Giustini: I agree with your critical point. Not everyone is familiar with this standard. I am a doctor and have to speak on my people that are not familiar to evaluate the person, not just the illness. For this group, we must make an education to apply in the world with these standards. If it is possible to have a co-operation with NGOs that could be important but in every team, every concrete team, we have to start from some point which is useful to open the medical situation regarding the condition of person more than illness. What you have said could be really useful for the quality of the results of the data and more and more of the quality of learning because health services can learn if all the communities push to these modifications because on the contrary we can have some countries or health services who have no interest to modify the traditions. So, the NGOs and community has to ask and push to go this way.

Jan A Monskbakken: One more but we have to leave it to afterwards due to the next presentation. I can respond to that last question. The number 1 International Perspective on Spinal Cord Injury is a model that can be looked at in other conditions. SPRM, WHO, RI and others should co-operate to make this a successful pilot or model for good results for the coming years. The Next speaker is from Germany and will speak about rehabilitation. This is Boya Nugraha, Department of Rehabilitation Medicine, Hannover Medical School, Germany.

Boys Nugraha: I would like to talks of this what we have done on behalf of WHO. I would like to give you the concrete product about strengthening rehabilitation.

This is the overview - reading slide.

We know this WHO Global Disability Action Plan was adapted in 2014 and it addresses health and functioning - reading slide.

This is a big issue.

You already heard before about objectives so I will not talk of this. I took example of the 2.4 objective that mentioned to expand and strengthen...reading from slide like Gerold Stucki mentioned before. 3.1 is to improve disability and data collection - reading from slide. We all know that this is redundant in many countries but the WHO mentions here what is clear.

I will talk of the WHO Collaboration Plan. ISPRM is an NGO with special relations with the WHO but we have to have a collaboration plan within a certain period and we would like the outcomes for this collaboration plan. We would like to have the collaboration plan that can be delivered and we would like to support this document.

This is the collaboration plan in detail as per the slide - reading slide. We negotiated with WHO and we have 28 countries world-wide. Number 2 - reading. We know sometimes that ICF is not easy. In Italy and China there are publications for this intuitive model already there.

Number 3 - reading slide

Number 4 - reading. One of our team is currently working with disaster relief in the other room.

You can see here GDAP objective number 1 - reading slide.

Now there is more focus on our collaboration number 2 - reading. DTO is technical officer. We also wish to provide matrix and checklists... reading slide. We need to establish readability services advisory team - reading.

The goal is as per the slide - reading. This consisted of 1-3 - reading. If one expert can understand the language and culture that is fruitful.

We apply principles... reading.

We collected data... reading.

The outcome... reading. We have some lists of recommendations and what has to be improved by the country.

Guiding principles - reading slide. The tools we use... reading. We developed the first two projects ourselves and in September we were invited by the WHO to review the tool. Then for the international classification... reading. We are working on development and refining of this classification - reading slide.

Recommendation - reading slide.

Here is the implementation strategy cycle - see slide. We would like to develop the national disability health and rehabilitation plan. The Ministry of Health should work with the countries and report to the WHO headquarters in Geneva. Request are asked and then we go and investigate and develop the recommendations in the country - as you can see on the slide.

This is how the strategy is done - reading slide. We use this RSAT tool and collect data - reading slide. For Egypt, we had two visits - reading slide.

Here is our recent situation - reading slide.

This is the Egypt Mission - reading slide. There are no clear definitions. Then in the Ministry of Health - reading slide. The other population groups are neglected - reading slide. Then we have the health insurance system - reading. For children with disabilities the Ministry of Health offer insurance for children to go to school but do not cover all population groups.

Recommendations - see slide - reading.

We also try to make project example of Egypt to translate relevant international documents... reading slide. Then to make feasible and culturally accepted tools... reading

Here in the Ukraine we found out the responsibilities - reading slide. The understanding of disability... - reading.

The rehabilitation professionals... reading.

The Ukraine Mission recommendations - reading slide. They already have services but not in line with international standards. We have to have the international standard - reading. For your information, the second one here now but last month this was under discussion with the Parliament of Ukraine.

The project for the Ukraine - reading slide. It is important not only from the side of the medical field but from the linguistic persons that understand the need and cultural issues in the Ukraine.

This is my talk. Thank you very much. [APPLAUSE].

Jan A Monskbakken: Thanks for presenting these specific and concrete examples of how we are working together around the world and is a good model you are creating that can be used in all countries with or without the WHO. We will open to questions for all presenters. The floor is open and Asish will take care of that part of the service.

New Speaker: Hello I am from Belgium and wish to ask that in Belgium for our Flemish speaking part there has been organised a train the trainer courses in ICF and we went to a centre that taught us in ICF and we spread the word in our country so everyone is educated in the same way and standards and how ICF is spread. Those courses have a lot of success. We have intervention groups so people of different disciplines come together to exchange knowledge and experience of working with ICF.

Professor Jerome Bickenbach: Is it translated in Flemish?

New Speaker: No to Dutch. We have the word 'running' in Flemish but it means 'walking' in Dutch! There is a problem with translations.

Dr Asish Mukherjee: Any questions? Back?

New Speaker: Somehow we need to come back to the issue of registration of the WHO on a world-wide basis so people in our country have access to what we talk of here. If we have 100 million people world-wide that is a big change to make things work world-wide. It has to be a situation so countries give their residents free issue to disability issues and care.

Jan A Monskbakken: Thanks. Maybe I should comment on that. It is totally true what you say. For disability and rehabilitation, we have to work on this on several levels and several arenas. I will use your input to summarise this session because we started out with the WHO Action Plan which is a document that relates on the UN Convention from 2006 which is the highest political document you can have in the world. This led to the World Report that led to the WHO resolution 2013 which led to the WHO Action Plan which is now leading to all several of those projects we have been presenting today. I think to achieve what you are looking for; we have to work politically and professionally in a collaborative way so that is why we are having a meeting on this to raise the importance of this. This session shows that it comes as results of documents and decisions made globally, it takes time. Some people ask why do you go to meetings and try to write good documents. It is not so pleasant to write good documents but we need those before going to make changes in the world. The process of changing the world starts politically but we have to work to make political change. I think all important stakeholders on rehabilitation should work together in the future to make sure we have better political documents to implement at grass root levels. Thank you very much.

Allesandro Giustini: Regarding my speech, it was previously prepared in the form of a poster so we have some copies and in the copy, it simplifies some replies. Another point, probably you and we know the document based on rehabilitation is not another field or point. It is a different tool to work together as the contents of ICF and the problem of global approach to the person is also in this field. We aim to have a specialised and qualified intervention in spinal cord injury and in all other conditions of disability but the other tool of community based must be and is very closely connected with this contest. In this field, what

are really important NGOs are activities such as health services and we all remember what the speakers said about poverty as that is a problem for disability and health services and we have to work together to overcome this common, very strong, problem.

Dr Asish Mukherjee: Thank you. I will stand up and talk. I am Director General for Health Services in India. It is hard to say anything else but thank you. I have read all the papers from the government and is the first-time rehabilitation has been focused on health services and is a great triumph.

There is no question out of the speakers that we need really which is evaluation. We have 62 countries that report national data which varies from 0.9% to 20% of the total population which says we are highly confused. It is recorded and that is all. The second area we need is in evaluation so that it is not questioned and there are permeations that have taken place. My issue with ICF is the that evaluation systems needs simplification. My submission is there is a need for simplification. The health system, I have looked into that a long time. Disability is another chapter in the health system. There is a need for introduction on disability for the health system programme.

My submission there is an early development for coming together of NGOs and training that is acceptable to the global community. [Applause].

Jan A Monskbakken: We conclude this parallel session. There is a coffee break.