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**RI World Congress**  
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**Parallel D Kilsyth**  
**Convention on the Right of People with Disabilities**

MODERATOR: I make it 1.30. We've been asked to finish this session earlier, which is a curtailed time for questions, but, hopefully, we shall still have a good opportunity. We've got a fantastic panel of speakers for this convention which on the convention of the rights for people with disabilities, so, very, very interesting speakers. We're going to start off with Eva who is a research fellow at the University of Innsbruck in Austria, and she will be gives us a brief overview of -

EVA NACHTSCHATT: Thank you very much. I have to correct you a little bit. At the moment, I'm a research fellow at the University of Kassel but I did a research project which I presented to in Innsbruck in Austria. Thank you very much for the opportunity to talk to to you, and to present our project, with the title of Observing Legislative Processes: Implementation of the CRPD. In this project, the University of Innsbruck observed ongoing legislative processes during the last few years, 2014 to 2016. The overarching aim of the project was to find out if and how the member states of the Convention fulfilled their obligations and how participation of people with disabilities is performed. So I will give you some brief information about the project. The project term was two years, with two research associates, and Professor Ganna as head of the team. The comparative countries: Austria, Germany, New Zealand, and Australia Australia. In a few minutes, I will tell you more about our choice. And, just as an additional basic information, we started with the provisions Article 4.3 and Article 33.3 of the convention. In Article 4.3, there is the obligation to closely consult with and actively involve persons with disabilities, including children with disabilities through their organisations in the development and implementation of the legislation, and policies could implement present convention, and, other decision-make processes concerning issues of relating to persons with disabilities.

In Article 33.3, there demands the establishment of a national focal point, a co-ordination mechanism, and a monitoring mechanism.

The decision on how and where the state's parties, established facilities was left to them. I'm now going to the reasons why these four countries - Austria and Germany - are the countries of the civil

law system, and Australia and New Zealand are representatives of the common law system, but, more specifically, New Zealand was one of the leading countries in terms of self-representation and participation of persons with disabilities during the development of this year. Their government decided to include representatives of persons with disabilities on its formal delegation to the UN. It was widely seen as a revolutionary decision. Even before that, New Zealand was known to have politically active disability community that had influenced mass politics since the 1980s.

Therefore, New Zealand was a clear choice to be included in the research. Austrian and Germany are very similar countries in regard to their legal and political systems. Both are federal states with closely related civil law systems. Due to the similarities with New Zealand's legal system, the common law, Australia was a natural choice to be included. However, Australia is also a federal state - states and territories, and it has its own legislative and administrative ...

To our empirical study relating to Article 4.3, we compared ongoing processes between the Austrian guardianship law, and the German process of the [German spoken], federal law on participation. In these comparisons, we looked specifically at the process itself, not on the content of these laws. We looked at participants, the number, the composition of individuals, persons with disabilities, and their representatives. We looked at the settings, the technical and spatial equipment. The invitation, who they have invited, and persons with disabilities are invited, and also the time frame, number of meetings, distance of time between the meetings, and also preparation time before those meetings. We also looked at the information material. To look at all our outcomes in detail would go far beyond the scope of this presentation, so I will just in brief present to you the main issues which came to light in our empirical studies. But now some quick words to the empirical procedure, and the outcomes regarding the two legislative processes. The Austrian [German spoken]. The empirical research in Austria focused on the process and amending the current regime of the legal guardianship law as it is one of the ongoing legislative projects in Austria prompted by the CRPD. Fortunately, the Federal Ministry of Justice agreed to enable and support the research. Therefore, it was possible to get a deep insight into the whole process. Regarding regular workshops and sessions were held throughout December 2013 to May 2016. These working groups were attended by project staff and were observed. On three occasions throughout the process, a standardised questionnaire was handed to all participants. The questions focused on the information policy of the ministry, the design of the legislative process as a whole, and the possibility for each participant to take part effectively in these working groups. Furthermore, structured interviews with selected group members were carried out, and through them, we got a more detailed insight from their point of view. Also, interviews with ministerial officials were conducted as well.

In Germany, law makers drafted a federal participation that aims to get Germany closer to an inclusive society by strengthening self-determination in persons with a disability, and to shift away from a paternalistic and patronising approach. The legislative processes - the legislative processes themselves were proceeded by an interdisciplinary working group. This working group held nine sessions from July 2014 to April 2015, and included persons with disabilities and their representative organisations. The final report of this working group was released in July 2015. An online survey was carried out by the project staff - by us - after the final session, and all attendees were invited to participate, but not all of them did. The online survey was similar in questions to the paper one from the guardian working reform group in Austria. Additionally, interviews with experts in the field of disability politics and law-makers of the federal Ministry of Labour and social affairs were conducted. On the basis of the differences between the civil and the common law system, we did not find legislative processes in New Zealand and Australia we could have observed, so we had to look for something else, and we found some information which I wanted to go into further detail.

As the research was carried out by two part-time researchers over the course of less than two years, there were certainly limitations to the research. Above all, there are organisations and persons of relevance to disability politics in countries which would not be included in our studies due to the limited resources. Therefore, the results are not trying to give a total insight into all aspects of that these politics. The outcomes are merely trying to give an overview of recent developments in these four countries. So, just in brief summary of the main results, our research showed that generally, very few people with cognitive impairments were involved in the legislative processes. Persons of different types of impairments are not equally represented, especially all the persons with mental disabilities at the end to be left out. In all observed countries, there is a lack of awareness of politicians and the general public regarding the issue of representation of disabled persons.

Service-providing organisations which may be included in the dict sector are not representative organisations of persons with disabilities. This is especially true for Austria and Germany where no clear distinction is made between DBOs and other organisations in the sector. Organisations with persons of disabilities are called upon by the CRPD to fulfil the representative role. There is a huge difference between organisations of persons with disabilities and for persons with disabilities. Politicians and representatives of public administrative bodies have yet to recognise the true value of participation of disabled persons and their organisations. Therefore, participation should be encouraged by at least reimbursing the expenses directly related to that process. There are calls for comprehensive regulations regarding compulsory involvement in legislative and other

policy-making processes. Pieces of legislations which are an accomplishment of combined efforts by legislators and the civil society is viewed as a joint product. This increases the degree of acceptance for regulations in civil society. An equal partnership of law-makers and experts acting in their own interest provides benefit for both sides. Not only are they able to exchange information but also build confidence. Their co-operation and likely open discussion encouraged a better understanding for the other party and can benefit the future processes.

Authorities and law-makers on the government side are responsible for providing clear and transparent guidance, especially for persons with disabilities.

Structures, competencies and expectations, and also the limitations have to be defined this advance in order to prevent unrealistic expectations. Co-operation processes with effect - with effective representatives from civil society should be arranged in a thoughtful, sincere, transparent and well-structured way. In these processes, disabled persons should have an adequate time frame and easily comprehensible information material for appropriate preparation. Clear structures within the disability sector, and within organisation is important as well, so that government officials who they contact for certain matters. In regard to financial aspects playing an essential role in education work. Without additional financial resources provided by government, participation is hardly possible. This is especially true for organisations in the disability sector as they are usually underfunded. However, some organisations' financial dependence on government raises fundamental issues, because don't bite the hand which feeds you. Civil society organisations are called upon to provide crucial voices. Their independence from government is important to fulfil this role.

As a final conclusion, it can be said that participation and involvement of persons with disabilities in legislative processes and other policy-making processes require great emphasis of both sides. Law-makers as well as persons can disabilities and their organisations have to show mutual appreciation and acceptance for problems of the opposite side. All participants of our research showed great openness and sincerity in their dealings with disabled persons. The true value of involving persons with disabilities in the process was recognised and praised by all participants. Nevertheless, some officials in their paternalistic attitudes seemed to be unaware of this enrichment. In Austria, representatives of the ministry of justice have recognised opportunities to gain experience and deep insight through the input of persons with disabilities in order for our laws to be a bit for equitable.

This is the cover of our final report. I hope I could give you a sufficient overview of our project, and what we did the last two years. If you want to know more, don't hesitate to come up to me and ask

me. Or you can also use the Open Access Link to read the whole report. Thank you very much for your attention.

[APPLAUSE].

MODERATOR: Thank you very much for that, Eva. We're now going to move on to Kirsten Vollmel, scientific staff Federal Institute of Education and Training, Germany. We're going to hear a presentation on training and education in Germany, and the UNCRPD.

KIRSTEN VOLLMEL: Ladies and gentlemen, it is an honour and a pleasure to speak to you in this audience in the historic and beautiful down of Edinburgh. - exchange with the key sector much participation and inclusion, about patient education and training. Let me quote, "States parties' recognise the rights of persons with disabilities to education with a view to realising this right without discrimination and on the basis of equal opportunity, states parties shall ensure an inclusive education system at all levels, and life long learning directed to the development by persons with disabilities of that personality, talents, and creativity as well as our mental and physical abilities to the fullest potential." So far, the convention of the United Nations on the rights of persons with disabilities.

Do these sentences describe reality? Do they describe vision? Paint a dream? Are they sentences expressing a promise? Established rights? Since Germany signed the UN Convention as one of the first countries, these sentences are intensely discussed. Often rather controversial, mostly very emotional, sometimes ideological. Interesting, and maybe somehow specific German is that while the word "participation" is much more often used in the Convention, it is a term "inclusion" that made an astonishing career as a key word when we first was with the interpretation and implementation of the Convention. Inclusion is a term that has been increasingly familiar in professional circles as well as the media, since the enactment of the United Nations convention on the rights of persons with disabilities, and its adoption in the Federal Republic of Germany in March 2009. But what does it actually mean?

To what what extent does an inclusive approach substantively move beyond the philosophy of participation? In other words, it is not the case that the German social security code number 1 represents the real quantum leap in this direction. After all, the much-quoted paradigm shift away from self- - is attributed to the social law enacted in 2001. While these issues continue to provoke controversial response from experts, the implementation process of the UN Convention in Germany has begun several years ago, and the focus has shifted to specific not only structural questions.

The quoted article 24 of the UN Convention deals with the right of education and demands that countries shall ensure that, and I quote again, "Persons with disabilities receive the support required within the general education system to facilitate their effective education."

"Effective individualised support measures are provided and environments that maximise academic and social development consistent with a goal of full inclusion."

"Persons with disabilities are able to access general tertiary education, vocational training, and adult education, and life long learning without discrimination, and on an equal basis with others."

My specific focus is vocational education and training. Vocational education and training can mean very different things to different people. In some countries, it refers to education and training provided by and in schools, with no or limited exposure to real-work situations. What is meant when talking about education and training in Germany? The system is at the core of education and training in Germany. It's referred to as Dual because training takes place in two different learning venues: in a company, and in a part-time vocational school. The Dual system is based on the Vocational Training Act of 1969 and on the Crafts and Trades Regulation Code and is still the main pathway for the young into employment, including in recent years academic education. Companies sign contracts with the applicant under private law and train them with binding provisions which guarantee national standards. This is monitored by the so-called Competent Bodies, namely the Chambers of Industry, craft, agriculture, doctors, lawyers. The Dual system provides broad vocational training and competences for 129 recognised occupations. The programmes, and the Dual system usually take three years. What about vocational training of people with disabilities and the quoted UN Convention? In Germany, legal guidelines which consider these demands have been in place in many years in the form of - these include arrangements of compensations for disadvantages with regular training and testing. Furthermore, they include training arrangements exclusively available to persons with severe disabilities which stop them from the regular qualifications. At least regionally, however, still a degree of uncertainty exists about the possible forms of arrangements about how to practise these arrangements concretely, and, after all, about how to practise them without offering unjustified advantages with respect to people without disabilities. As a result, that is part of the self-evident use of these instruments. However, highly provoked by the UN Convention and the national agenda of implementing it, a big push forward has taken place. The institutions responsibility for vocational education and training, especially the so-called National Competent Body, are realising the need to take up more engagement concerning the task to include people with disabilities and vocational training in work. In addition, parallel discussions about demographic change and shortage of skilled persons contribute to consider people with disabilities as so-called "human resource", and

"human potential". What does it mean, compensation for disadvantages caused by disability? This states special circumstances of disabled persons shall be taken into account and, I quote law now, "This shall apply in particular to the timetable did the initial training, the duration of the examination periods, permission to use utilisation of the existence of third parties such as sign language for the hearing impaired." "In particular means" allowing longer examination periods is an example. More and other compensation arrangements are possible, and should be practised according to the individual case. In requiring these particular circumstances to be taken into account, legislation transfers to the competent bodies a task which is judged just as challenging as it is crucial to the disabled persons affected and to their opportunity to undergo training in a recognised regular training qualification. We, the Federal Institute of Vocation Training and Education have worked out with a circle of experts for different kind of difficulties, a handbook which offers practical information for all dealing with compensating disability, cause disadvantages in vocational training. This guide offers orientation and support for the Chambers for trainers and companies, and for vocational training centres, and for teachers in part-time vocational schools. With the publication, we intend to prove the application of compensation for disadvantage, and thereby aim include disabilities in general vocational training and afterwards in employment in the general market. What about the training arrangements for persons with very severe disabilities not able to be trained in recognised regular operations at all? The two basic laws dealing with vocational training make provision for the competent bodies to act on an application made by disabled persons or their legal representatives, to issue training regulations. These special training regulations shall be in accordance with the recommendations of the board of the federal Institute of Publication and training. Professional assessments regarding the nature and severity of disability are made by the regional employment agency which in turn is required to include the specialist services of the Federal Employment Agency. The special qualifications in respect to severe disabilities shall be developed from the contents of training occupations according to the statutes and development of the general labour market. Because training arrangements ... are issued by the regional competent bodies, many different training arrangements have been issued over the course of the years. Starting from the finding that the number of training arrangements have grown to just 1,000 by 2006, framework guidelines were adopted in the same year. This training arrangement framework constitutes a further step in the process to provide a guarantee that disabled persons will be trained in accordance with national equality standards. The core elements of the training arrangement framework are as follows: the opportunity to change to get trained in a recognised occupation, to upgrade, a personal support plan, the co-responsibility of the vocational school, adopting people with learning disabilities as they are the main target in

these special way of getting trained, suitability of the training venue, specific additional qualifications for trainers in the field of rehabilitation, periods of company-based training, unified non-discriminatory qualification title. Vocational competence as the aim of the initial training, this is very crucial as it is the aim of our regular initial training on the basis of German law. As well as forming the binding basis for the enactment of all training arrangements by the regional competent bodies, the training arrangement framework also constitutes the basis for the activities of working groups which draw up an occupation-specific set of regulations. The working groups operate under the federal Institute of Education and training, and include experts from the social partners, the federal government, the conference of the ministers of education and culture from institutions for the vocational training of disabled persons. The first working groups produce pioneering work for all - the factors where classic regulatory work for the introduction and updating of recognised training occupations enjoys the support of a standardised procedure which has been tried and tested for decades, these working groups have broken new ground. Forthcoming task in the field efficient training arrangements enable to the participation of disabled persons within the meaning of the prohibition of discrimination statement in German law and in the UN Convention will include both the nationwide and cross-branch implementation of the training regulation framework and the sample regulation, and the medium term evaluation. In addition to this, a particular focus needs to be placed on expanding the rather limited spectrum of educational areas which offer disabled persons vocational training on the basis of training arrangements. Here, the developing alternative to the developing - sample arrangements can create a simple effect and encourage companies and vocational training institutions to develop training provision at later market-orientated areas which are suitable for this group of persons. Vocational training according to training arrangements leads to certificates as [German spoken], which can be translated as "practical skills worker". Often this training takes place in occupational training centres for disabled persons, not in companies. The UN Convention put into focus the important task to improve the participation and inclusion of people with disabilities in general vocational training, and in general by the market. The discussion about how to achieve this, about how to reduce extra company training, about how to motivate small companies to train and employ people with disabilities, and about how to find and create approaches for the different kinds of disabilities, and especially the growing number of people with psychiatric disabilities is ongoing. Let's have a look to the vocational training of disabled persons beyond the legal conditions and umbrellas of the two basic vocational laws. An important feel to be - the workshops highly relevant in quantitative terms: almost 300,000 persons are either getting training there or already included in working processes. Right now, we are enacting a new advanced qualification for those persons who trained disabled employees. While

working out a modernised qualification profile, we could specially emphasise on increasing the number of transitions from the workshops to general labour market, according to the demands of the UN Convention. The related supported employment is another instrument to be looked at. It aims at integrating persons not able to undergo regular vocational training in employment by training on the job, accompanied by job coaches. In general, connectivity and - for these reasons, bridges need to be built and pre-conditions for the specific implementation put in place. One example of how this could be done would be to align vocational training workshops for the disabled persons to Dual training on the basis of vocational training act and the casts and training regulation code, and to make specific credit transfer available. Life chances no longer culminate their ends as a result of various legal circles, and areas of - and it is the spirit and the letter of the UN Convention can be upheld, and accessibility achieved, disabled persons will actually enjoy equal participation, both in vocational training, and via vocational training. The UN Convention can serve as an excellent compass for investigating both framework conditions and the institutional landscape as it has developed over decades with regard to the guidelines of participation and inclusion. It is within the interests of those affected and completely within the spirit of the UN Convention with regard to its emphasis on the dignity of every single individual person not to set out any concept in absolute terms, and not to defend structures and rights simply for their own sake. Instead of this, the focus needs to be on identifying and shaping pathways for optimisation which does justice to the provision of the US Convention. Ladies and gentlemen, thank you for your attention.

[APPLAUSE].

MODERATOR: I very pleased to welcome Jim Gosney.

We have a lot to learn but it's wonderful for me to take some of the lessons back to my organisation as we kind of, erm, scramble further, so thank you.

JIM GOSNEY: So I will talk with you about - can everybody hear me - am a projecting well enough? Thanks. I will talk to you about disability inclusion from a different perspective, that of physical rehabilitation across the disaster continuum and look at an international perspective, not a country-wide one, but to share with what has been done and what is evolving in this field.

My interest is at the co-ordination of our preparedness and recovery work in the international umbrella organisation for physical medical physicians. We have about 90 different societies spread throughout the world, and we work primarily through our national societies to share lessons learned and develop policies.

So the UNCRPD Article 11 on situations of risk and humanitarian emergencies, it reads as follows: (read from main screen).

When you analyse this statement in the spirit that medical rehabilitation tries to address, most of the philosophy of medical treatment medicine is treated from a bio-psychosocial model which is out-moded and outdated thanks to the UNCRPD among another framework document.

Looking for a Human Rights perspective which is how medical officials treat disability, or should, it becomes very clear that inclusion in every aspect of disaster responses is very important and intrinsic to overall health and continuation to commune based rehabilitation, education and other education.

Another framework document that you may be aware of is the UNDAI framework for disaster risk reduction that looks for inclusion of all organisations is involved, Member States and international organisations to include professional societies of rehabilitation and therapists and beyond that also NGOs that work with rehabilitation in the field of disaster response.

If you look the WHO global disability, the action plan objective 1... (as read)

Basically is to integrate disability across the whole continuum and in the disability community to look at risk management.

So this is the classic disaster management cycle, started in the US about 1980 but has great international relevance and establishes the framework for emergency response in terms of responding to a disaster. Like any cycle you could start where you wish.

As a committee with ISPRM, it has been on response that is where we have the human resource capital, physicians with skill sets to look at relieve with external support after persons have been evacuated to facilities to care for them.

If you look from the person's point of view if say you start the cycle with prevention and mitigation because you really want to have up-front ongoing processes to lesson the severity of the hazard.

If you look at the upper left you will see at the point of impact that the hazard is the event itself: so the earthquake in Nepal, and recently in Haiti, and the tropical storm there, that is the incident itself or the hazard, but contributing to risk as well is the vulnerability factors and that is where Persons with Disabilities, as you look at the data suffer more than their normal counterparts.

So the World Health Organisation is taking a leading role in 2013 with public partners who published this guidance note. It talks about the needs of Persons with Disabilities across the rehab cycle and the idea is to help educate all those participate especially international organisations but, as you know, not every organisation is as professional as the IFRC, or UNICEF,

for example. There is to the profession improving the accountability and standards for a response to including Persons with Disabilities in all aspect of the response.

So, in terms of the response, the emergency medical team started and it was the Haiti earthquake in 2010, in which it was said that we have so many things that we should do in terms of our professionalism and our response. Out of that, the Secretary General really emphasised the EMT movement, and the next move in Hong Kong is the second global meeting where we meet to talk about training and inclusion and other aspects as well.

Who are EMTs?

They are basically teams or groups of health professionals and colleagues who respond to disasters and outbreaks. We have learnt a great deal from the Ebola response and looked at the lessons from the cyclone response in addition to other disasters.

The mission is to reduce the lives and prevent long term disabilities in disasters and outbreaks, and the research shows that early rehabilitation with physical intervention measures reduces mortality and morbidity and increases functional outcomes.

So as foundation for this, the blue book outlines the classification of teams by capacity, the levels of teams as well as specialised rehabilitation teams, and outlines minimum standards for competency. Most recently these have been outlined for rehabilitation, and this is the first group to really look at the blue book and to flesh-out standards that are global recommendations.

I participate on this work group, and the work group still stands. A consultant was hired - this will be published on the website if you go to the website. It includes recommendations for all standards to follow and if you are a surgical response team you have to demonstrate some rehab and inclusion because there is a conflict of interest perceived from many response organisations and it's been demonstrated they are more concerned about how to re-look at rehabilitation, and the population they are working with in terms of disabilities.

So this is just to show you a group of organisations, professional organisations, that share the work with ISPRM and some of these groups look at advocacy at a high level such as rehabilitation international and others are more operationally-focused. For example the International Spinal Cord Society focuses more on education and training. But I would like to look at the WCPT, and comment in their report that came out last year. If you look at one document to understand the role of rehabilitation across response and inclusion I would say this is the key document to look at: it's really quite well written and basically expands on what I am showing you here today.

So, again if we look at this disaster management cycle: the question we really want to look at and we are looking at internally with our sister and brother societies: what role do we have

rehabilitation professionals have? How can we reduce risks for Persons with Disabilities in terms of disaster, looking at the recovery aspect as well, and for example I submitted a grant earlier this week to my organisation on behalf of a group in Haiti who had lost their prosthetic and fabrication clinic so I co-ordinated with them to an assessment, with the concept of building better infrastructure, and in this case it's a prosthetics lab. For those that understand Haiti, you know it's a challenge, so this grant hopefully will allow them to increase their foot print on the community because of course they will be able to work at more full capacity.

So I have alluded to this before, but in terms of health risks and Persons with Disabilities, there is research documenting this that Persons with Disabilities have reduced access to information and to services for a variety of reasons and their social support networks are certainly disrupted and they have high incidence of medical complications and this was demonstrated with Katrina etc, and where diabetes and cancer rates spiked later, and it was able to be demonstrated, and this was the result of a neglected population initially being effected by disaster.

In terms of being separated from medical equipment, that is a significant issue, not just wheelchairs but hearing-aids and other devices.

So looking at the cycle, I have talked about responsiveness and it's good to do a good vulnerability assessment. In other words before allocated resources, you want to identify the population and the specific need in that population and specifically focus on Persons with Disabilities because often historically they are neglected because it takes more effort come to the clinic because the warning systems etc may not reach all the members, so it's looking at house to house patrolling etc. More invasive measures need to be taken to ensure all the persons are potentially reached.

In terms of recovery: it's very important to document lessons learned in the field and disseminate the results widely and in keeping with WHO emphasis on creating a body of research to document our efforts and we want to look systematically at impacts with disaggregated data because it's very important to indicate which losses were averted. It's difficult to quantify because it's largely public health. How can we quantify or value the results, the inclusion in a disaster so that other community agencies, local federal and international agencies will fund these programmes in times of disaster.

In terms of preparedness and mitigation, obviously a registry system, where I am in Virginia, is a more sophisticated level for Persons with Disabilities and it's proven they can work. They are intensive but they work, and evacuation measures and inclusive sheltering as well. I think the Japanese and nuclear and Tsunami incident looked at this and it was very important how the patients were adapted physically to minimise the physical disabilities they suffered.

So I focused somewhat on what we can we do as rehabilitation professionals, all of us? How can we work with emergency risk management across the disaster continuum?

This is a very busy slide but it's a concept that we recently published in a emergency medicine text book, in 2009, drawing-off lessons at that time, but actually it was 2012 and you can the response and from the physical rehabilitation point of view.

Long-term rehabilitation is critical for spinal cord injury patients but with fracture, like Haiti being a disaster of fractures, and it's very important to have very good clinical processes set up in emergency medical teams, but also the non-clinical aspects are very important as well, decisions on evacuation and transfer and documentation on looking at a baseline for data and clinical tracking.

As you can see in terms of the long-term and looking at the community integration, it's where we intersect with other programmes, with goals not being able to compete but to support hosts' local programing. You are looking at community-based rehabilitation, education and social rehabilitation as well.

This simply breaks the chart down. Actually I was not sure the chart would show as clearly as it did.

In terms of future directions: thank you for listening to my colleagues talk, ISPRM, and all the societies need to co-ordinate to see which each of us is doing in our own countries because the country dynamics are different with physical definition and there is no good definition of what good physical rehabilitation is, you have the European model that is codified in the white book and that is excellent, but it's looking at high income country model.

One thing for emergency response is to help build the system and train using your providers so that on departure, where it occurs over a long period of time and where Hand international etc do development work to compensate their work, to build the local system as it's happening in Nepal for example, and that his a silver lining if we look at Nepal and Haiti and looking at the robust six test and where inclusion is critical to this and from a Human Rights points perspective as well as the UNCRPD.

Thank you for your time (Applause).

MODERATOR: Our last speaker, we are delighted to welcome; thank you, Professor.

PROF ERROL COCKS: Briefly, I have been involved in disabilities in the UK and Middle East, Australia and in south-east Asia around training and various kinds.

I have been back in-house in Australia for ten/twelve years now and my research is in intellectual, developmental and learning disability and focussing on employment and health.

The project I want to talk about today which is individual supported living.

I wondered why I was put in this particular session because this is not about the UN Convention but whoever reads this, thought it was Article 19 of the Convention as the starting point for this particular project. It's hard to over estimate the challenges that section, Article 19 presents.

The idea that a Persons with Disabilities particularly the three types of disability I mention is able to choose where they live and with whom they live is many parts of the world absolute pie in the sky because we still have a very high reliance on institutional care. In fact after World War 2 we had a burgeoning of building of new large institutions in most Western countries and the social political and economic capital has been put into large-scale concrete clear options in Western countries is phenomenal, and it means any reform of change is particularly challenging.

Article 19 really is extremely challenging to think that Persons with Disabilities can actually choose with whom and where they live, because most of the time that is already decided for them.

In Australia, it's moving from large-scale options to small groups, places called group homes where an individual with a disability can live in their own home adequately supported and it's and it's an issue in Australia as I see it in the US and other Western countries.

You will see there that Australia spends a lot of money, in fact over £8 billion a year to provide funding to non-governmental organisations and directly to families and people with disabilities which is an essential element, if we want to move towards individual Supported Living situations. Unless a person with a disability and/or a family has some degree and control over the incidence that occurs, the money goes to the NGOs that have heavy commitment around local, social capital in maintaining large institutions.

You will see the bottom part there that in Australia we have a large proportion of people with disabilities in various form of congregate care.

So this is a project about trying to challenge some of those issues and the way we want to do that, or in terms of developing the study that we are doing is to challenge the common assumptions that are made about Persons with Disabilities.

So our stance is that all people with disability, as long as they are provided with right individualised support, can and perhaps should, but certainly can live in their own homes.

Secondly they don't have to be independent in order to live in their own home.

We use the term individualised supported rather than independent support because we know that if you have a disability, you are not seen as being capable of being independent, mind you none of

us is independent in the sense we impose that label or that requirement of Persons with Disabilities themselves.

The third point: people with disability don't have to live together. They may choose to do so but they don't have to.

And yet most of the way in which we provide living support for Persons with Disabilities requires that they live with other people with disability. That of course runs counter to Article 19.

The project that we have developed since 2007 is what I see as an action strategy to try to implement Article 19, or at least encourage its implementation. My own feeling is about - no I will not say that - I was going to make a critical comment about the Convention and how distant it is from real practical down-to-earth attempt to change. It's working directly with Persons with Disabilities and directly with families, and tend to work at the bureaucratic level and what we are trying to do in this project is to burrow down to people that are primarily concerned: Persons with Disabilities themselves and their families.

So our action, strategy, if you like, is that a Person with Disabilities should be provided support they need. The support should be one person at a time. So we are not planning a group of 6 or 7 people where you have all the compromises in order to have strangers live together. It's about one person at a time.

It's also about having a deep understanding of what we mean by home. It's actually a universal concept and we would all agree on many of the element what a home is and it's not often reflected in a large institution or a group home.

Similarly we need a clear understanding of what we mean by so called good life.

Okay, so is this research project about? It started in 2007. The first two stages of the project goes through to 2013.

What do we do and aim in the we were aiming to establish a clear evidence base for what individual supported living actually is, and what are the particular qualities that can be conveyed into the life of a person with a disability and their families, if they are living in individual supported living arrangement.

We carried out 3 literature reviews and literature deals with institutions: movements other of people out of institutions and we found 20 Articles in literature that addressed issues around individual supported living and then we set about developing what we called a fidelity measure which I am sure many of you will be aware. But that measure is essentially a measure of a match between the stated purposes or principles if that you are trying to embed and what you actually

do. So it's an evaluating process so it looks at how success you are doing it, and I think they should be a lot of those measures around convention.

How did we do this? We followed about 6 people in the ISL arrangements over 18 and what is ISL? And the best way to found that out is to go and talk and spend time with people who were actually doing it.

We also consulted broadly with a group of people who actually were involved in ISL arrangement: family members, Persons with Disabilities, people from NGOs who were supporting these arrangements.

The outcome was a descriptive framework for ISL that we now intended to use as an evaluation instrument, to measure the quality and the extent to which what is happening in ISL arrangements reflects the assumptions that underpin them.

We distributed some pilot studies and developed the measure which eventually looks like this (Indicates). This is the actual manual we used in evaluations.

What I will do very briefly is run through the different themes. This could take longer than the whole time I have been allocated here.

But, very quickly, leadership was a very key thing. If you didn't have leadership these things didn't have. Often people had to struggle to get individualised support because everybody around them told them you can't do that, it will not work, he or she is to a disabled and so on.

So you needed leadership.

Secondly, you need a clear indication of the elements of a home which involve security and tenure and so on.

One person at a time meant that the arrangement had to focus on an individual person, not on a group of people.

Planning was a very important element of the evaluations so you needed planning especially medium to long term planning, if you like life long planning, we found to be a really important element here.

The issue of control is a key one. Who controls elements of the person's life? And how much control they have and all the way down to the actual arrangement itself. How much influence does a Persons with Disabilities, family members have etc, influence in the way supports are delivered Approaches needed to be flexible and responsive and a strong informal or unpaid involvement in the arrangement.

Most of the arrangements are supported by paid. We were looking for ways in which friends, relatives family members and advocates also became involved in the actual arrangement.

The issue of thriving was important. You want to show that people are living better lives as a result of it, and obviously, social inclusion was a very important part as well.

(Five more minutes).

All right, where is the projection at the moment? We have some funding from the Australian research council and we are at the process of looking at 150 ISL arrangement across three Australian states and we are getting a lot of information about what ISL is and what sort of outcomes is presenting. And we have provided a lot of training: many more than 300 people. We talk often - I was in Ireland a few weeks ago, at Inclusion Ireland, where they were talking for a half day around these sorts of issues, so people were interested to know about individual supported living.

We partnered with two other Australian Universities and 17 NGOs and we gather additional information, not just the actual manual itself but we gather other information as well, and we are interested for example how long people have been in an arrangement and we are also interested in the support level of the person and I have some data I will show you in a moment.

So far we finished about 130 evaluations equally, almost, male and females and age range you can see, so we have 5% of the people over 60 and some of them if you look at 3 they have been in the arrangement for over 20 years so individual supported living ain't new. But it's been around for a long time. However it's not been taken up in the way that perhaps we would argue it should.

In terms of support needs: you will see nearly a quarter of people have assessed high support needs. These are the people that would be considered not to be suitable to live in an individualised arrangement. They just need too much help. The answer is if you can provide, the right sort of support, it's perfectly appropriate for them.

What are some of the initial findings?

We are researchers, we want to make sure the measure has content and reliability and it does and we have identified different ways that individual supported living can occur, and there are ways that an (acronym...) can be supported in their own home.

What are some of the key elements of ISL?

Crucially the way in which support is provided is obviously extremely important. It's interesting that where I would argue that certainly in Australia, we are experiencing a second parent or family movement in disability which is wonderful: families are getting engaged again in the way they were

in the 50s and 60s when they set up NGOs that became large and bureaucratic and the parent or family faded.

Issues of management: the person with the disability may manage their own arrangement, the family may arrange it or there may be a shared arrangement with an agency that will look after the finances for the family.

Of course all these approaches require individualised funding.

I don't have time to explore that issue but it's crucial. If you don't have a process of being able to fund people directly, rather than through an NGO, then this becomes extremely difficult if not impossible to carry out.

Some of the other key elements, I mentioned individualised funding, and security of tenure is crucial and there is a number of ways that security will differ depending where the person lives. We are struggling with cultures, where a Person with Disabilities would not leave home because of the culture the person would remain in the home.

Okay. We're now planning a second large-scale project. This time we want to focus on Persons with Disabilities who are still with their families and Persons with Disabilities who are in group homes run by a NGOs and we want to use evaluation and training and educational processes, we want to see if we can shift both families and NGOs in the direction of individual supported living so we are hopeful we can get funding for that and then we can really take a major next step because at the moment our focus is entirely on people in individualised arrangements.

Finally, there are some references there. The first two references describe the development of the project and the others some of the early findings for them. Thank you.

MODERATOR: Yes thank you very much (Applause).

Thank you. I promised we would finish at 2.45 and I make it 2.46 so I think our transcriber may have to run to the next session.

So thank you to our speakers; it's an awful lot for us to take away, so can we share our appreciation for the four speakers. (Applause).