HOUSE OF COMMONS

International Development Committee

Oral evidence: Disability and Development, HC 947-ii

Tuesday 21 January 2014

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Written evidence from witnesses:

- Bond Disability and Development Group
- Handicap International
- WaterAid
- Leonard Cheshire Disability

Watch the meeting Tuesday 21 January 2014

Members present: Rt Hon Sir Malcolm Bruce (Chair); Hugh Bayley; Fabian Hamilton; Pauline Latham; Jeremy Lefroy; Fiona O'Donnell; Mr Michael McCann; Chris White

Questions 46-108

Witnesses: Tim Wainwright, Co-chair, Bond Disability and Development Group, Aleema Shivji, Director, Handicap International and Barbara Frost, Chief Executive, Chief Executive, WaterAid gave evidence.

Q46 Chair: Good morning and thank you very much for coming in to give evidence to us. You may know that this is the second formal oral session that we have had on this issue of disability and development. I wonder if you could, first of all, introduce yourselves for the record.

Tim Wainwright: Good morning, everybody. My name is Tim Wainwright. I have two hats for this. I am the Chief Executive of ADD International, which is a PPA holder. Just very briefly, we work in Africa and Asia with disabled people, particularly working with disabled people's organisations to develop their capacity. Right now, today, I am here as Co-chair of the Bond Disability and Development Group, which is one of the working groups of Bond. It has 74 members and is representative broadly of organisations within Bond that are working specifically with disabled people or have a particular interest in this area.

Aleema Shivji: My name is Aleema Shivji. I am the Director of Handicap International in the UK. As an international organisation, we operate in about 60 countries worldwide,

supporting disabled and other vulnerable people in the context of poverty, conflict and disaster with humanitarian and long-term development programmes.

Barbara Frost: Good morning, everybody. I am delighted to be here. I am Barbara Frost; I am the Chief Executive of WaterAid. WaterAid is working in sub-Saharan Africa and South Asia, investing in local organisations to help poor communities get safe water to drink, improved hygiene and decent toilets. In our strategy that we are operating, we have stated a commitment to equity and inclusion. Therefore, we have done a lot of work on disabled people's access, working both with disabled people's organisations and others, in terms of effective design.

Q47 Chair: Thank you very much. You will be aware that the Committee made a decision to do this inquiry quite some time ago, so we are pleased to have it in process right now. In the time since we made the decision, the High Level Panel has met and reported, with David Cameron as one of the Co-chairs. The Panel said, "No one should be left behind." The evidence we have received to date points out that something like 15% of the world's poor, or perhaps more than 15%, are disabled. Obviously, we are interested in the role for the UK. How do you think the UK can and should pursue policies? Indeed, can it live up to that rather ambitious challenge that no one should be left behind, and how should it do it in terms of prioritising disability?

Tim Wainwright: Maybe I will just kick off with a few thoughts. The "leave nobody behind" phrase was a very important one in that report of last May of the High Level Panel. We should be grateful to the UK, which played a very supportive role, under the Prime Minister's leadership, in achieving that very helpful mention of disabled people in that report. One of the most important things that that report says is that no development intervention should be judged as successful unless disabled people are fully included in it, so it is setting a high but appropriate benchmark for future development action and I very much hope that is reflected in the final settlement post-2015, which is another 18 months or so away.

In terms of how that should be done, I would suggest a few basic principles. One, which has been very well established both in the field of disability but also in other areas of mainstreaming, such as gender, is the twin-track approach of both investing specifically in disability-related initiatives, but also critically focusing on including disabled people in the whole range of activities that, in the case of DFID, the UK is engaged in, in terms of development. To make a start on that, I would propose a strong public statement developing a clear strategy, a theory of change and picking some clear areas to begin with, for instance a country, a sector or a region of the world, to really demonstrate how this can be done within the organisation. Those would be a few thoughts on how to start.

Aleema Shivji: I would probably support everything that Tim has said and would add that, certainly having gone through a very recent process of building a theory of change or contributing towards DFID's Theory of Change online action, it was such a key process to launch thought and engage stakeholders. What DFID needs to do is to work on that theory of change, but bring in stakeholders. Bring in the multilaterals to which DFID is a major donor and to which most of DFID's funding goes. Get them on board because, if we really want to make change, we need to do it at all levels.

It is also doing things concretely, for example looking at requirements implementing partners, whether they are multilaterals or NGOs like us, have to fulfil to get DFID funding. It can be very concrete and as simple as putting guidance into proposals. Getting people to think about it at all levels and making sure that DFID advisers are trained on disability and know how to review programme frameworks from a disability perspective would also be very helpful.

Q48 Chair: DFID, our evidence has said, is not currently a leader in this area, but it has set out that framework. I just want to pick up that point: you think it is ahead of the multilaterals and you think they really do need to be pressed. Obviously, as a major donor, we do have influence in that.

Aleema Shivji: On the multilaterals front, I will give you a couple of very concrete examples. We do a lot of work with UNHCR and, at the global level, UNHCR came to Handicap International and HelpAge a couple of years ago, asking us to support them to write an advocacy statement on disabled and older person inclusion in emergencies. There was buy-in in Geneva but, if you talk to UNHCR colleagues on the ground, they might not even know that statement exists and, when they do, they do not know what to do with it. There is nothing forcing them or requiring them to make sure disabled people are included. There is a huge challenge there, and DFID, as a world leader and as a major donor, has a huge role to play to influence multilaterals.

Secondly, very concretely on the Syrian crisis, we have just completed a study that will be coming out quite soon on the situation for disabled, elderly and injured refugees in Jordan and Lebanon. A lot of our data came from UNHCR, and the challenge we face is that they do not have the right data set. We cannot get a clear picture. We did our own door-to-door survey as well, but what we found is that, where we should be able to get the data, we are not able to get it today. Again, the multilaterals do have a long way to go, and DFID has a really strong role to play as a global leader to influence that.

Barbara Frost: I absolutely agree with everything that has been said before and also reading the evidence that has been given before. There is plenty of evidence out there in terms of data and there is plenty of information about how to do it, but somehow it is not happening. DFID is well placed to take that "everyone everywhere" by 2030 and really do something about it.

Reflecting back, before I worked for WaterAid I worked for Action on Disability and Development and, in the late 1990s, was part of the group that had a similar discussion with MPs talking about disability, poverty and development then. This document was released in 2000 by the Department, which talks about the twin-track approach; it talks about mainstreaming; it talks about requiring that disabilities should be included, yet it has not happened. There is a real opportunity for DFID to be a leader in this and to take it forward.

It would be so important in terms of the outcomes with the existing MDGs, but also the post-2015 SDGs. The sorts of actions that we would support are as set out in the Bond submission, which my colleagues have already touched on as well, in terms of making it a requirement of funding, whether that is NGO, multilateral or bilateral, that disability inclusion must be part of all the work that is undertaken and ensuring that there is decent

reporting-back about how that has happened—how disabled people have been included—and information is disaggregated.

We would also say, from a water and sanitation point of view, that there are some very concrete ways that change could happen and they do not have to be costly. Ensuring facilities are accessible when they are designed by including disabled people in that and then making sure they are simple accessible designs, like this model I have brought, can really ensure that the whole community can access toilets, for instance. Disabled access facilities are also really good for older people as well, so they have a really positive benefit. I would encourage the Department to take this forward.

Q49 Hugh Bayley: You have touched on something very important, Barbara, and that is the gap between intellectual understanding of a problem and actually doing something about it—the gap between words and action. Why do you think 15 years or whatever it is have gone since DFID signed up to mainstream disability without their working practice changing? What needs to happen to make sure that the right words that the UK got in the High Level Panel report result in action rather than going the same way?

Barbara Frost: We have been asking ourselves that as well, because there are a number of elements to that. One of them is clearly about leadership and championing it across the organisation, making sure that disability inclusion is talked about in all programmes, so in education, health, and water and sanitation. It is not on one side; it is central to the work of the Department; it is central to their investments in others as well. That championing, though, needs to be at the highest level.

It is kind of carrots and sticks, I feel. There needs to be a requirement, and that is why, under funding agreements, proposals, multilateral and bilateral agreements, it needs to state, "This is actually necessary. This is about making sure the whole community, and particularly the poorest people, are included." There are some really practical things that could be done. There is also something about how this is led across the organisation and across all departments, and in-country programmes, because I do recall, when this was in its first five years, travelling to country programmes and taking it as the representative of ADD. People did not know it existed in the Department, so it is how to get that information properly disseminated.

Q50 Hugh Bayley: When we as a Committee put in our evidence to the High Level Panel, we stressed very strongly indeed the need for the Government not just intellectually to come to a good development concept, but for leadership—to use your words—at the highest level to drive it forward. To be blunt, it is for the Prime Minister to get on the phone to other presidents and heads of state and say, "This is what we are signed up to. Are you?" That is exactly what Blair did following the Africa report, which resulted in the G8 agreeing to double aid to Africa. Do you see that happening from Downing Street and/or from DFID? If not, what might provoke more real commitment to drive forward the agenda that the High Level Panel set out?

Tim Wainwright: I want to make a couple of points on your first question and then I will come on to the one you have just asked. I think it is a very interesting one. Just to add to what Barbara said, which I completely agree with, one of the critical reasons that more action has not been taken is the absence of a mention of disability in the original set of

MDGs. The Department for International Development has, quite rightly—one could really strongly argue for this—focussed on delivering the MDGs over a long period of time, but they were imperfect in their coverage of disabled people. It is not just about leadership. That global structure was highly popular. Many agencies did the same thing and focussed on them, so that is also part of the reason.

More recently, over the last seven or eight years, there is also the UN Convention on the Rights of Persons with Disabilities, which is an extremely successful convention. It has been ratified by over 130 countries, including the UK, so you would think that would have maybe exercised more influence, but it is not very well known in mainstream development. It is seen as more of a separate disability thing, and it needs to be integrated into people's thinking about how disability is handled.

Also, my personal view on this—and what I see over and over again—is that if in high-level discussions or those discussions that take place at the beginning of the development of work, when you are first scoping out a major programme of work—say developing a strategy for how the Department for International Development is going to work in a particular country—disabled people are not in the room at that moment, represented well, articulately, then for some reason what you get seems to forget disabled people. It is a bit like building a latrine that is not, to start with, accessible. Trying to build it in later is really difficult.

Q51 Hugh Bayley: Can we go back to Aleema with the second question, which is what difference political leadership of DFID and Number 10 can make to implementation of this kind of agenda, which has been on the table for a decade and a half but has not happened. For instance, the eighth session of the Open Working Group on Sustainable Development Goals takes place next month, with social equity as one of its key themes. What leadership should the UK give on disability and how should it drive forward the agenda to get others to commit, so that the convention is not another document like this one, which everybody says is fine and they are behind, but nobody remembers when they are designing a schools programme or a sanitation programme?

Aleema Shivji: Two points on that. First, following on from what Tim said earlier, the key thing is continuing in the same vein that the UK Government has been in since the beginning of the post-2015 process and making sure that the message of leaving no one behind stays disaggregated. One of the risks is, along the lines of what Tim was just mentioning, if we talk about social inclusion, often what happens is people focus on the most obvious marginalised, so women and children are always talked about.

Even with DFID, if I speak specifically on the humanitarian policy, the humanitarian policy from 2011 clearly talks about women, children, older people and people with disabilities, yet rhetoric within the Department is often about women and children, so it is about disaggregating that and making sure that message is not lost. That is one concrete way, moving into the Open Working Group and then the work that will follow on from that, of making sure that we talk about the different types of marginalised groups and are not just lumping it all in under "marginalised groups".

Secondly, another very concrete action, as I think Tim mentioned at the beginning, is having a public statement. If we look back to about three months ago, the Secretary of State held a global event here in London on violence against women and girls. It was a

call to action. It was a very concrete high-level event attended by political leaders from around the world that came out with very concrete commitments on violence against women and girls. In that particular process, I am quite proud that we managed to get disability into it. Part of it was because we happened to have a champion in the Department who worked on violence against women and girls who was very sensitive to the impact on disabled and older women, but it was not a systematic thought process; it was because one person thought about it, called us and said, "Can you contribute?"

The process itself for having this call to action was very powerful. Today, the US has now taken over the leadership for the call to action in 2014 and there is a whole process being set up, which I hope will come to fruition, about making sure that the concrete commitments that were made by all the Governments will actually happen. Those are potentially two ways. One would be making sure that we maintain the disaggregation or specificities of different marginalised groups, and the second would be having a very public concrete call to action or some sort of public statement.

Tim Wainwright: If I could just add something, my understanding, going back to your question about very senior political leadership—I was not there when it happened—is that Number 10 has delivered quite a significant amount of leadership on this issue to take us to where we are today. The "leave nobody behind" and its inclusion in that report is due in part, if not in full, to the intervention of the UK.

Hugh Bayley: I think that is true. It is taking it to the next step up the staircase.

Tim Wainwright: I agree completely with you that sustaining it and turning that into action, and for the UK's development arm, the Department for International Development, to role-model that and lead in that area, is the obvious next step. That is what they should do; I agree.

Q52 Mr McCann: Perhaps I could direct my question to Tim and Aleema. As well as the post-2015 development agenda, there are other global frameworks that have an impact on disabled people. For example, the national development planning process is established by the World Bank. Given that DFID is a significant player, what influence can it bring to bear to ensure that the needs of disabled people are properly considered? Perhaps Tim could kick off.

Tim Wainwright: I think the two most important things that this inquiry should be considering are both the support that DFID implements via multilateral agreements, such as the World Bank and other players, and its bilateral programme. That represents the vast majority of UK aid programmes and that is where the focus should lie. To take the multilateral example that you raise, I will give you an example first of all, just to illustrate the problem that exists here.

Very recently, earlier last year, a review was conducted by NUDIPU, one of the best known DPOs in the world, the National Union of Disabled Persons of Uganda. They looked at a very large World Bank programme in Uganda, which is supported by around £100 million of UK funding. They looked at the way that disabled people had been included or not in that programme. It is an interesting report. I will send a copy to the Committee after this hearing, but basically it goes through and, at the very highest level, the very high-level rules say, "You have to think about disabled people." The moment

they looked a little bit deeper, that got lost. In essence, what the report says is there is no serious attempt being made to ensure that what is delivered is accessible.

This is very well illustrated by the example of a bore hole, going back to the importance of water, that has been built with steps leading up to it, making it inaccessible to a range of disabled people, older people and so on. It is big money; this is not a small amount of money. It illustrates the importance of DFID bringing this into the discussions at the design stage of these kinds of programmes.

I also had a conversation with a DFID official in Bangladesh a couple of years ago, where they were at that same design stage of two programmes. One was health; one was education. One is managed by the Asian Development Bank; one is managed by the World Bank. They are complex long-term programmes, with a very long period of design where you are negotiating with lots of other government programmes. When I asked him, "What are you doing to ensure that women and girls are included in these programmes?" he said, "We've got lots in there: we've got this; we've got this cheque, we've got this cheque and we've got this cheque." My second question was, "What about disabled people?" He agreed with me there was nothing and that was a problem.

This emphasises the importance of acting now, because with these things, once they are negotiated, it is very hard to retrofit inclusion, so I would call on you and the Department to look again at the very beginning of these things. I think the Parliamentary Under-Secretary of State, Lynne Featherstone, has started to ask some of these same questions. I am unconvinced as to whether the Department is systematising that.

Aleema Shivji: What I would add to that is agreeing that there are lots of other frameworks, and post-2015 is one of them—a very significant one—but there are other things happening. The Hyogo Framework for Disaster Risk Reduction is another one that is being renegotiated as well right now, for post-2015. At the moment, disability is very much included in the initial phases. Coming back to the question of what the UK can do, it is making sure that message continues to be pushed.

It is going to be very hard for the UK Government to continue to push that message without making an example of itself, making its own commitments and saying, "Okay, we are going to influence the Hyogo Framework for DRR, but that means our own disaster risk reduction work needs to be disability-inclusive first, so we need to make concrete commitments." I would come back to very concrete things, like we need to make sure that, in proposal guidance, we have a section on resilience; we have a section on gender. We require all of our implementing partners to explain how they are going to implement resilience and gender. They need to ask the question of how they are going to integrate disability as well.

Q53 Mr McCann: This is perhaps for everyone, but Tim mentioned bilateral programmes, and I was wondering, in terms of our partnerships with countries across the globe, should we be ensuring that disabled people being included in other governments' economic policies is a condition of giving aid in the first place, or do you think it should be more of a carrot, an encouragement, rather than a stick?

Tim Wainwright: I will make a quick comment on that. I am sure my colleagues may also want to say something. The country level is a very interesting level because, in my

discussions with leaders of the disability movement in Africa, what they are saying is, actually, at the policy level things are looking good because, over the last few years, many governments have ratified the UN Convention on the Rights of Persons with Disabilities. In Africa, this is taken seriously. Frankly, it gets a higher profile than it does in this country. It is a big deal. In my recent visits, I have heard about modification of legislation taking place, and not just at national level; in Sudan for instance, they are modifying state-level legislation to make sure that it is compliant with the Convention. The policy environment is looking good. What the leaders of the disability movement in Africa are saying is, "It's budgets." It is also about political leadership because, quite often, the leadership is coming from weaker departments within the African Governments.

If you look at the role of an actor like DFID, they are extremely well placed to go into that environment and put the inclusion of disabled people on the table in the developing of country plans. It should be a receptive environment. It is not politically sensitive. Disabled people, as far as I am aware, are not linked to any independence movements around the world. It is not a difficult thing to do and the policy environment is there but, again, it is this thing of turning words into action.

Barbara Frost: It is an interesting question, because it is conditionality, is it not? On one level, we often argue against conditionality, because governments need to own things themselves and want to take forward a particular policy or practice. However, because of the marginalisation of disabled people and because they are so excluded, this is positive conditionality and I do think it would be the way forward. As we were saying, 15 years on from other policy documents, things have not changed. It feels to me as if there needs to be something somewhat harder about requiring inclusion.

Q54 Mr McCann: Finally, the World Bank has a Safeguards policy to ensure that any unintended consequences of the policies do not harm vulnerable groups like disabled people. They are currently reviewing that, and I was wondering whether you think the outcome of that review will shed new light on the subject.

Tim Wainwright: I have met with them on it and it is very encouraging that the World Bank, at their July board meeting last year, voted formally to include disabled people in their Safeguards review. I am not clear where that process has got to, though, because, as you are aware, the World Bank is reviewing many things. One of my concerns is that the inclusion of disabled people is there in the Safeguards review but I am less clear whether it is included in other elements of that strategic review, which are less open to public scrutiny. The inclusion in the Safeguards review is certainly encouraging; however, we wait to see what that actually turns into.

Q55 Jeremy Lefroy: Just briefly to follow up on that, in my work with the Parliamentary Network on the World Bank and the IMF, we are constantly asking whether the World Bank is engaging with parliamentarians in the areas where the development projects are being implemented. For instance, Tim, you referred to this more than £100 million UK funding programme through the World Bank, and yet it was only at the policy level that disabled people were included.

The question I would ask always is: where are the parliamentarians in this? If you look at the changes made in this country, it is often through parliamentarians, particularly

parliamentarians with disabilities, who together with civil society groups achieved a huge amount, not just in law but also in the implementation of that law. Where are you working with parliamentarians? It is all very well for us to say, "DFID should do this and the UK Government should do that." We are not responsible in those countries; the parliaments are responsible. They make the laws. Surely, it should be up to them to challenge their governments and say, "You have signed up to this, but you have not actually implemented it. Your budgets are not there; your action is not there. Your leadership is not there."

Barbara Frost: I agree entirely. That is why the approach many NGOs take is investing in citizens' awareness and citizens' actions, so they can actually call on their own MPs. When we are looking at water and sanitation, it is making sure that the poorest people get access to toilets and safe water, and that includes disabled people. Our role as civil society is very much in raising awareness in communities about people's rights, so that they themselves can engage with their own local governments or their own MPs to make sure that those rights are realised. In much of WaterAid's work, it is both about investing in organisations to supply services and to help develop the capacity to do that, but it is also very much investing in community organisations to raise their voice and to be able to influence decisions at a local level.

Q56 Jeremy Lefroy: Just a quick follow-up on that: have you ever challenged the World Bank and other multilaterals as to whether they had involved parliamentarians, at a regional or national level?

Barbara Frost: We have done some research actually, not specifically on disabled people but more on whether the large World Bank water and sanitation projects reached out to the most marginalised and poorest people whom they are meant to reach, and worked closely with the Bank on that, in a very collaborative way, because we have not done it to name and shame but to say, "Practice needs to improve and guidance needs to improve." Part of this has been being more responsive to local community needs and making sure that local decision-makers are part of that, so yes.

Tim Wainwright: I am thinking about the Uganda example and I do not know whether there was engagement with parliamentarians or not. Given that Uganda is actually one of the best examples of the inclusion of disabled people in the parliamentary system, if they did engage parliamentarians, they did not engage with—I would assume, but I can check and submit something to you after the event.

Jeremy Lefroy: It would be interesting to know.

Tim Wainwright: Let me get back to you on that.

Q57 Chris White: My question is to you, Aleema. Going back to a bit more of the general scope, what do you think are the main barriers that prevent disabled people from accessing humanitarian support and what do you think can be done to overcome some of these barriers?

Aleema Shivji: At the implementation level, the barriers are often really simple. It is non-accessible latrines, so totally the opposite of what WaterAid has here in front of us. It is aid that does not reach people. If I give you the example of Syria today, and you can take the same example in the Philippines, Haiti or anywhere where you have dispersed

communities of affected people, whether they are refugees are displaced within their own countries, today one of the challenges is making sure that the most marginalised, and not only the disabled but the disabled elderly people from isolated communities, know that there is aid and where to access it. Because of the way people are living, for example in Jordan and Lebanon, you cannot expect them all to be able to come to you. You need to be able to go to them.

One of the challenges of the aid programme today, DFID included but not just them, is that it is funding very large-scale programmes that have fixed points. It is something as simple as having an outreach team and having people who go into communities. We are very grateful DFID is funding us to do part of that in Jordan and Lebanon, and there are a few agencies that are being funded by different donors, but very few of us. We have all been able to show that is how you reach the most marginalised, and they are the ones who cannot come to fixed points. Sometimes it is something as simple as that, but there is a cost implication obviously. It costs more money to set up teams that are going to go into communities but, ultimately, your aid is much more effective, because you are reaching those who need the aid the most.

Barriers can also be things like people not knowing how to make their work inclusive. That is one of the things we see. In the Philippines, DFID has identified us and HelpAge as inclusion focal points for all the partners of the rapid-response facility. A lot of those partners we engage with collectively here in the UK. Tim and I facilitated a workshop with the humanitarian directors of the Disasters Emergency Committee in 2012, and they were very forthcoming in saying, "Help us; we would like to have support."

That sits at lots of levels. There are donors that do not know what to do. There are implementing organisations. I spoke about UNHCR earlier, which asked for our help to guide them. The barriers are at lots of different levels, but some of them are very basic. It is about building accessible latrines. It is about looking at your programmes and saying, "If we want to reach the most marginalised, we need to think about outreach." It is about making sure that, when we do assessments in a humanitarian context, you engage with disabled persons' organisations so that there are disabled people in the assessment teams, and you collect data so that you know where the issues are.

Q58 Chris White: Thank you. It is a very sad fact that people with disabilities have lower survival rates when disaster strikes. How can donors help to change this?

Aleema Shivji: Some of it is upstream. Coming back to the work on the Hyogo Framework for Disaster Risk Reduction, it is looking at how we can make communities more disaster-resilient and better prepared. A global study has been done quite recently by the UN Office for Disaster Risk Reduction that basically showed that, if people with disabilities were better prepared, there was almost double the likelihood of them being able to escape quickly and safely. Something like only 20% of disabled people felt they could safely and quickly escape when a disaster was coming. If they had been prepared—if there had been training and if there had been support, and the strategies implemented in the community were inclusive—it increased to 38%. Some of the work is upstream. It is looking at disaster risk reduction and it is looking at preparedness.

In the implementation phase, it is very much about implementing actions that are going to reach them at the very beginning. It is making sure that those actors that are implementing

food distribution think, "We do it already for women—a separate queue for women. Maybe we need a separate queue for disabled people in certain contexts." Maybe it is about targeting and again going into outreach very early. If there are lots of injuries, it is about making sure the health response has a rehabilitation component integrated, so that people do not die of the secondary complications that are quite prevalent after a crisis.

Tim Wainwright: I have just a couple of very quick points on this. I think Aleema has illustrated this very well with her detailed knowledge. On the points she made earlier about the importance of collection of data, I had a very interesting conversation at that workshop Aleema mentioned with the head of humanitarian for one of the major DEC agencies, who was reflecting on how dependent his organisation was on assessments that are based on collecting information very quickly with the head of the household. Unfortunately, one of the weakness of this is, if you knock on the door of somebody in a developing country and you ask a mother how many children they have, it is sometimes common not to give an accurate answer. The answer will omit the existence of a disabled child. This goes down to a very fundamental low-level detailed data-collection issue, but it reflects that this is quite a complex issue and it needs quite careful thought. You cannot assume that what you see is the real situation.

Also, on Aleema's answer, just finally, the point she was making about a measurable change—a significant change if action is taken—is a wider illustration of the point that there is sometimes an assumption that this is too difficult as an area to go to. That is a great example of how, if some careful, thoughtful work is done, you can make a major change.

Q59 Chris White: Thank you. This question may be a bit naïve, but you talked about the challenges if you are speaking to mothers or heads of households to obtain this data. Do you use hospital information as well—information obtained from hospitals at birth?

Aleema Shivji: It is a mix of different things. It is accessing data from different avenues. I talked already about, in a crisis, getting data from UNHCR, hospitals and so on, definitely. The key thing, though, is coming back to training and it is making sure that the people who are collecting the data are trained. If we take this back to what DFID can do, one of the welcome announcements that came quite recently from Lynne Featherstone was that any census that DFID will be funding will include the Washington Group questions, which are questions to help identify disabled people. It comes back to conditionality and asking questions, in saying, "If we are going to be doing data collection, are you training your enumerators to make sure they know how to ask the questions correctly?"

Barbara Frost: Just to add to the point that Tim made, going back to some of the evidence you heard last week, fundamentally, this is about discrimination and it is about attitude as well. Families might not talk about their disabled children; I know when you opened the inquiry you talked about when you visit you do not necessarily see disabled people. That is a real challenge. I know that, when sometimes I visit a community and I ask about the disabled people, the wider school does not have a disabled toilet. I am told, "Well, we don't have disabled children in our community." We know that is not the case. There is the thinking behind asking the right questions and being aware that, if 15% of the population are disabled, they should be represented and facilities should be accessible.

Picking up on the example around schools, having accessible toilets makes all the difference for disabled girls, because girls drop out of schools at puberty if there are no

toilets there. If they are inaccessible, of course disabled girls drop out. There are some real fundamental questions to be asked, which are about design, but it is also about asking the questions and about attitude as well.

Q60 Fabian Hamilton: A lot of DFID's humanitarian work is delivered through partner organisations. Apart from specialists like Handicap International, how well do you think these organisations include disabled people in their work and how do you think DFID could encourage them to do more?

Aleema Shivji: I can start on that one. It really depends on the crisis. What we find really interesting is, in one context, you might have an organisation—I will take Oxfam as an example—that has an amazing approach to disability in one country and, in another, they will not. They are very aware of that, because it is not a systematic approach at all levels.

As both Tim and I mentioned, when we spoke to the humanitarian directors of the Disaster Emergency Committee, they were looking for support; they are looking for ways to do it. In the Philippines today, we are conducting training with Save the Children, with Plan and with World Vision. The list goes on and on, and they are all asking for support. People are open to the idea of it. In a context where we are able to show them that there are needs, which is everywhere but it is a matter of having the right data to show them, they are willing to do it, but it depends a lot today on who is on the ground. Because it is not systematic, because there is no accountability around it, people do it if they have the sense that they want to, but there is not really a systematic coverage of it.

In the Philippines, one of the things that I was quite pleased with is DFID took a very clear stance in saying, "We will fund HelpAge and Handicap International to support the mainstream RRF partners to work on inclusion." However, we need to now take a step back and say, "Okay, that was a great one-off, but what is going to happen in the next crisis?" It does not need to be funding us necessarily, but it needs to be some sort of systematic approach so that the actors know, in every crisis, they need to be thinking about disability and age inclusion.

Tim Wainwright: It is a bit like the issue we discussed earlier about bilateral and multilateral aid. Is there a role for conditionality? It is certainly requiring a certain amount of reporting so that, as a donor, DFID can exercise pressure on a system. Having said that, given that around 80% of DFID's overall budget is in bilateral and multilateral aid, that is where I would start.

Q61 Fabian Hamilton: DFID has committed £600 million to the humanitarian crisis in Syria. How well are disabled people included in this response, do you think, and what could be improved?

Aleema Shivji: I have a couple of thoughts on that. It is a bit of a difficult one; it is such a large and complex crisis. I think, though, because it is so large, what is happening is the focus is on very large projects, because they are obviously easier to manage and the coverage is bigger; there is very much an emphasis on big. It comes back to my example of outreach. That is something that DFID and other donors are really struggling with. How do you find that balance between really reaching the most marginalised and being

able to implement something that is going to have an impact at scale—the scale that is required for a crisis like this?

Also, because we are in this phase where, coming back to your previous question, a lot of the agencies do not quite know what to do, one of the key things that needs to be done today is to continue to train agencies to know what to do. Sometimes that seems very soft, so we have had very different conversations, going from one extreme to the other with DFID advisers in the region, where some of them are very much on board with inclusion and the importance of making sure disabled people, older people and injured persons are being taken care of and supported in this crisis. Others are looking for very hard, concrete measures but, to get to those hard, tangible measures, you need to actually train the agencies. That is an area where DFID could certainly be doing a lot better, in Syria and in crises in general. They have supported us in different places to be able to do that, Haiti being one of them and the Philippines being another current one. Certainly, in the Syrian crisis, one of the challenges is trying to convince donors, when they want to fund very big projects, to also support that soft component of working on inclusion with the agencies. If they can do that, they will then have better tangible results.

Q62 Fabian Hamilton: How far does the design of the Syrian refugee camp take into account people with disabilities or the needs of the disabled, do you think?

Aleema Shivji: It depends on the camp. With Zaatari camp, which is the most visible and obvious camp in Jordan, it was not thought about in the initial design, definitely, but since then we have got an accessibility team working in there, along with other actors, trying, as things need to be retrofitted and as the camp needs to grow, to make changes to make it more accessible. There are a couple of smaller camps, one of which has been waiting to be opened for a long time. That one has been designed in a much more accessible way.

Again for me, it comes back to being good for business for us, but it is not good for making it systematic, because it is waiting for actors like us to be there to show others how to do it. There is no requirement. For example, if DFID said, "If we are funding this camp, we need to know that 10% or 12% of the latrines must be accessible, and it must be in the design of whoever is implementing the camp," that is a way of making it more systematic. I gave that percentage as an example.

Q63 Fabian Hamilton: Barbara, is WaterAid involved in the design of these camps at all?

Barbara Frost: We are not, because WaterAid's work is all about long-term sustainable development, so I am not an expert on this topic.

Tim Wainwright: I may make a short comment. Again, my current work does not involve humanitarian response. I did work in the field when I worked for a larger mainstream NGO in the past and, in general terms, my picture of large-scale responses is the way they are meant to work is you should have a UN agency in the lead and then other UN agencies playing central roles leading in different areas. Then you have a range of actors—sometimes a lot of people, a lot of different organisations. The idea is to try to get specialists focusing in different areas. Now, regarding the inclusion of disabled people, in my view it is great having a specialist like Handicap International on the ground, covering

that area as a specialist, but you need them all to think about it. That requires leadership from the big donors and the UN agencies.

Q64 Pauline Latham: If I could just follow on briefly on that point, Aleema, in the camps that you have seen or you know about in Syria or near Syria, you have talked about the disabled. Are the girls' latrines separated from the boys' latrines all the time?

Aleema Shivji: Yes. That is something we need to learn from for disabilities—the huge steps that have been made on gender. DFID has also been a leader on that. Talking about women and girl's issues, DFID is a global leader on that. That is an area where there is a lot of learning to be taken. Yes, today it is very rare—it still happens, but it is quite rare—that you come across a camp that has been supported through the multilateral system that will not have that very basic notion of separation of female and male wash facilities. Pulling from that, it is just saying, "We know we can do it, because we can do it for gender. How do we take it to the next step?"

Q65 Pauline Latham: That is progress. Barbara, could I ask you about water, sanitation and hygiene? DFID is funding a number of accessible schemes. I think these pictures are an example of some of them. How can it build on those projects to ensure that all the WASH work is accessible to disabled people? It seems to me cost is an issue. How much extra does it cost? If you look at the middle one, the concrete static toilet seat and handrails, that is obviously going to be quite a significantly more costly latrine than just a long drop. Also, the movable wooden toilet seat is going to cost more. Obviously the rope is not hugely expensive and the T-bar handle on the hand pump, making it easier to pump, is not a huge cost. I guess also, of these examples, the ramp is going to be costlier. Do you see that as a big barrier? What would it cost on average to make the facilities more inclusive?

Barbara Frost: It depends a lot on which of those accessible solutions we are looking at, of course. Some of them are very low-cost, as you said, like the rope. Those examples all came from WaterAid's work. Yes, it is true that the seat would be a more expensive option, but the seat not only allows disabled people to access the toilet but, as I have mentioned before, older people, pregnant women, etc.

We have to look at it the other way around: what is the cost of excluding those people? What is the cost of excluding girls from using toilets? Going back to the education example, if girls drop out of school because they cannot use the facilities at puberty, their ability to go on, earn their livelihoods and be part of a community is affected. It is the other side of it. What we were trying to show with those diagrams and by the little model I have here is that these are not high-tech high-cost solutions. They are ones that local communities themselves can modify and innovate. It is really thinking about it at the design stage, so that it is built in.

When you read the stories from people who now are able to use a toilet with dignity, it can be completely transformative for their lives and obviously for the lives of the communities. Previously, particularly say for a physically disabled person, if they are having to crawl to a toilet and they are not able to use a pit latrine properly, it is so undignified. As we know, a large percentage of poorer people in some countries still defecate in the open as well. For a disabled person, that is particularly difficult. I would

argue there is an additional cost, but it is certainly worthwhile in terms of what it then allows the community to do.

We have a lovely story in one of our publications where somebody is talking about how, once the facilities in their village were accessible, the whole community became more prosperous, felt more empowered and was able to do more. I think it is the cost of exclusion we should be looking at, not the cost of inclusion.

Q66 Pauline Latham: DFID says it works to ensure its bilateral, multilateral and non-government partners also implement disability-inclusive WASH programmes. Have you seen evidence of this and what more do you think DFID can do?

Barbara Frost: We were trying to have a look at this in preparation for the inquiry, and obviously there were some anecdotes and some stories. It goes back to what we were saying at the beginning because, unless it is a requirement—unless it is a condition of putting in these facilities—it is not necessarily happening. When DFID through its bilateral programme and multilateral programme is investing in water and sanitation, access by disabled people should be a requirement. Then there needs to be the reporting back to show that actually has happened. Until that is there, we are not going to see enough change. As Aleema said, there will be pockets of good practice where people are aware and are trying to do something about the issue, but there will be others that miss out unless it is required.

Pauline Latham: Unless there is reporting back, we are never going to know what the coverage is.

Barbara Frost: Exactly.

Q67 Pauline Latham: In terms of girls, you talk about girls dropping out of school because of unsuitable latrines. It is also the case that they do not have suitable sanitary protection. Unless they have that, they are not going to leave home, so that is a huge issue.

Barbara Frost: Exactly, it is a huge issue. The whole issue about menstrual hygiene management, one affecting all girls if there are no places for washing during their periods, for disabled girls again is about hygiene; it is about indignity and it is about equal opportunities.

Q68 Jeremy Lefroy: Just really following up from what Pauline was asking about, particularly to Barbara, based on your experience, how do you think that DFID can encourage NGOs, mainstream NGOs in particular, to make more of their work disability-inclusive as you do?

Barbara Frost: I am delighted that Lynne Featherstone is hosting a meeting on Thursday to talk just about that topic and, because there are a number of us, the Chief Executive of Oxfam, Plan and I, who all came from a disability background, we are all very keen to see mainstreaming of disability inclusion in our mainstream work. There is a lot of guidance out there. Regarding sharing that, making sure there is good practice and learning, we have been doing some work with Loughborough University on simple designs and making sure that is shared. Again, it goes back to requirements, in terms of requiring all of us to

do it. It is not an optional extra to reach disabled people. It should be a requirement, but then making sure that, between us, we are sharing good practice.

Q69 Jeremy Lefroy: Thank you. Perhaps I could widen it to the other members of the panel. Do you agree with what I understand Barbara to be saying—that disability inclusion should be an explicit requirement of DFID funding?

Tim Wainwright: Absolutely yes. I run an organisation that is funded by DFID and there are many things you have to do if you are funded by DFID that contribute to the assessment of your work, or to future funding decisions, but one of these compulsory questions I am never asked is, "Am I including disabled people in my work?" Of course, that is the only thing we do.

Chair: You said you are never asked.

Tim Wainwright: In a way that contributes to how success is measured or funding decisions made. I am asked whether we include women; I am asked about our environmental impact, etc., I am never asked that question. It is just an example of the fact that, within DFID and, indeed, I should add, within most major governmental donors at the moment, this is not systematised. It is not a reflex to check that disabled people are included. It is something that happens on more of an exceptional basis, so of course I believe it is a good idea.

The only thing I would say is to bear in mind that approximately 80% of DFID's overall budget is going to bilaterals and multilaterals. That to me is a bigger issue. I was talking to one of your witnesses last week, Bob McMullan, about this issue, and he was saying that, in Australia, his experience was, when AusAID put a focus on their main funding, their bilateral/multilateral funding, the Australian INGOs started to show much more interest. That will probably happen. That is an easier thing to achieve. The more important and larger issue is bilateral and multilateral funding—the really large-scale support to countries. I also agree with you it is a good idea.

Q70 Jeremy Lefroy: Just given that, increasingly and rightly, we believe, DFID is working with the private sector—it has a large private-sector department, because it is such an important part of development—would you see the same criteria being applied to that work, given that in this country we have often seen that certain parts of the private sector have taken a leading role in making sure that what they do is accessible to disabled people? Not exclusively, there are some exceptions, but the private sector has been involved in that. It is not just education, health and the government sector.

Aleema Shivji: I would maybe bring it back to the Convention on the Rights of Persons with Disabilities and Article 32, which talks about international co-operation. For me, the fact that the UK has ratified the Convention and has signed it means there is an obligation around there about commitment to making sure international co-operation, the money that goes directly or through partners, no matter what type of partner it is—whether it is private sector, multilateral, bilateral, NGO or a civil society organisation—should be the same. For me, the same commitment should be required.

Q71 Mr McCann: In some of the written evidence that we received, some concern has been expressed about donors facing difficult decisions by helping a small number of disabled people as against a larger number of non-disabled people. Have you ever faced such a dilemma and what decision have you arrived at?

Barbara Frost: From our perspective, we have been trying to promote that we work with communities, and communities are made up of disabled people, older people, women, girls, etc. Therefore, if we are really going to help that community through the investment in local organisations, they need to be reaching everybody. As we talked about earlier, there are some cost implications of access but helping the whole community, investing in the whole community, is the way forward.

Q72 Mr McCann: I know that is a nice answer to give, but let me give you an emergency situation where you have a crisis and you have a decision to make. You could have been a politician given that answer, because you will want to help everybody, but we know that we do not have the resources to go everywhere we want and do everything we want to do.

Barbara Frost: We do not do emergencies, but we have to make those tough decisions, of course. We talk about working in geographical areas and we focus on whole communities, so we do not focus on parts of that community. We do not leave out 15%, the disabled people, so the focus is on the community.

Tim Wainwright: I would agree with that. The way you are posing the question makes it sounds like you have disabled people over here and you have everyone else over there, but of course disabled people are part of households; they are part of a community. I would agree with Barbara; what is needed is an inclusive approach.

There is an interesting submission that you got from the ILO, which talks about the 3% to 5% impact on GDP. That is only looking at the cost of exclusion from the workplace; that is not looking at wider issues. Also, the overall understanding of the cost of excluding disabled people is often overlooked in these arguments. If you implement an education programme that is actually widening the gap between disabled and non-disabled people, because the vast number of disabled children are not attending school, is that really what we should be about? What is the long-term societal impact of that type of intervention?

Q73 Mr McCann: The question is specifically about a situation where there is an emergency, and respondents have given us evidence that they have to make tough choices. I understand that there is a long term and there is a short term. When you are faced with an immediate crisis, what do you do?

Aleema Shivji: Let me try to answer that, because a lot of what we do is humanitarian response. I put some preliminary data in our written evidence, but we now have more complete data. We have seen in a study amongst the refugees in Jordan and Lebanon that 29% of them are older, disabled, living with a chronic disease or injured. 17% of them have difficulties with their daily activities, so you are not talking about a small part of the community. For me, again, there is not really a choice to be made. It is to say, "We are going to implement a very large-scale food distribution programme or water and sanitation programme, because there is no clean drinking water. We need to make sure that, when

that is being done, it is inclusive," because otherwise, in a context like here, you have 17% of the population that is not going to access it and so, therefore, are not actually accessing aid.

For me, it is not really an and/or question, even in a crisis question. It is about saying, "There is an emergency. As the British Government, we are going to respond. We need to make sure that every penny in every pound is going to the most vulnerable." We know from past experience that disabled people are amongst the most excluded in humanitarian aid, no matter what type of crisis we are talking about. It is making sure that the aid includes them.

Q74 Mr McCann: In terms of NGOs, there is evidence that they are suggesting that DFID should have a centralised response to ensuring that disabled people are included. DFID has a very decentralised structure in terms of how it operates and suggests that priority should be set at local-office level rather than having a central strategy. How would you respond to that? Do you believe it should be a mix? Do you think it should be local offices that decide or do you think it should be a central policy within DFID?

Aleema Shivji: It depends on whether we are talking about humanitarian or development. Our own experience, working with both the civil society and the humanitarian teams, is that, yes, civil society is very decentralised. There needs to be an engagement at the country level. We have seen big gaps and we have great examples in Rwanda where the country programme is completely on board with disability. They have a focus within their programme on education for disabled children. Then you have countries like the DRC, where the head of the health programme was a bit sheepish when he said they did not even think about it, because it was not in their priorities.

Yes, there needs to be engagement at country level. From my experience of the humanitarian programme, though, it is very central. Even when it becomes country level, it is people from central that are going to the country programmes. Today, most of the people we are speaking with in the Philippines are people who are normally based in London, so I think there needs to be both.

Q75 Mr McCann: Is it central themes but flexibility within to be able to take account of country issues?

Tim Wainwright: It is also to do with the spectrum between humanitarian fragile states going through to longer-term development. The more you are in a longer-term development relatively stable situation, the more, in my view, you should be delegating to the country office and making sure the country office is engaging with the government. My view on this generally is I think a certain amount of central leadership is called for in this situation, particularly as it appears that it is not something that is well understood, not just within DFID but across the whole of the sector, so a certain amount of centralised leadership.

As I was saying earlier in answer to another question, disabled people live in society; this is not a group of people who are separate somehow. They are part of all of our lives. Therefore, you need to integrate this into the mainstream of what you are doing. If most of what you are doing is at a country level, it needs to be at the country level, but maybe with some support from a centralised unit or some leadership, oversight, governance and

so on. It would be a mistake to take the whole thing and make it a separate thing. I would be concerned about that.

Q76 Hugh Bayley: I am persuaded by your arguments in relation to water and sanitation and, indeed, to education, but in the health sector some health interventions are very cost-effective and then some are cost-ineffective. You think of immunisations, which are there very often to avoid disability; they are relatively cheap and they are something that has been done for decades. One would seek to do that and carry on trying to eradicate polio in Pakistan, for instance. Perhaps you would not argue, if you have to make choices, for an iron lung for somebody who is a polio victim who can only survive with an iron lung. Triage in medicine is something that is practised in this country at one tier and is practised perhaps at a lower tier with a shorter, smaller formulary of drugs in district hospitals in developing countries, so choices are being made about where the opportunity cost of an intervention is too great. Yes, you could provide an elbow replacement to a patient who needed an elbow replacement to continue working in India, but you might say a hip replacement is the highest level of orthopaedic intervention, so how do you make these choices, which are very often choices about the quality of life for disabled people?

Tim Wainwright: My instinctive response to this is that what you need to do is, as far as possible, make the status of somebody, whether they are disabled or non-disabled, irrelevant to the decision.

Hugh Bayley: By definition, if you are doing a joint replacement, the person will suffer a level of disability. It is only disabled people who get hip replacements.

Tim Wainwright: A lot of the issues that are around provision of health are that disabled people are not able to access healthcare in the same way that non-disabled people can. For instance, if you take the example you gave of the elbow versus the hip, if the individual happens to be blind, my expectation would be that the same decision was taken as it would be for somebody who had normal sight.

Q77 Hugh Bayley: You are saying that there are some areas where you do have to look at effectiveness and cost-effectiveness in relation to interventions to deal with a disability. You are just saying that one should not set the bar at a different place for disabled and able-bodied people.

Barbara Frost: Exactly. Given that the mission of the Department is poverty eradication, the focus, as I see it, is on basic services being equally accessible to all. The decisions around investing in health, in my view, are about making sure that those basic primary health services are accessible to disabled people. In terms of water and sanitation, investment in sanitation has an enormous impact on girls' health, disabled girls' health and women's health, so it is looking at really where the best value for money can be had in terms of where the investments are made. I would doubt that DFID is investing in high-end surgery through its development programme, but it is investing in basic services, and those basic services need to be accessible to all.

Q78 Hugh Bayley: Can I come in with a further question? I have told you that you have persuaded me in relation to primary schooling that you should provide the toilets, the ramps, the desks and so on that enable access for children with disabilities. Now, I accept

that, but you do have to put cut-offs, do you not? You are accepting this in relation to health; you are doing immunisation to stop people getting a disabling disease, but you will not necessarily have the resources to provide Western standards of care to somebody with that disability. You perhaps ought to provide a hearing aid; perhaps that is affordable. A cochlear implant might not be affordable. What I am really saying is: how do you make those difficult choices, also in the education field, I suppose?

Aleema Shivji: One of the things to look at as well is there is a big gap between doing immunisations and providing Western medicine for people with disabilities. There are lots of things in between that. It is looking at the impact on the community. There are statistics on diabetes; every 20 seconds, somebody has an amputation around the world for diabetes. If we do not do something to support those people who are having amputations, the cost to their communities is huge. We need to look at not just the immediate health impact but the impact on the whole family.

Maybe an amputation is more of a simple measure, because you can get a prosthetic and you can potentially reach the same functioning you had before but, if you look at the impact of various different tropical diseases or non-communicable diseases, the morbidity management is a really important component, because those people are living in communities and there is a cost to the community. They are also equal members of the community as well.

It is the same here: yes, there is triage, but it does not mean that different levels of services are not provided in the UK. It is making sure that there is a range of services provided, yes, with the baseline of trying to prevent, in the first place, these diseases from even happening, absolutely. That is a really important focus that needs to be looked at in terms of prevention of disabling diseases, but we should also be very realistic: not everything will be preventable. Therefore, we need to look at what we can do to support that. Maybe somebody who is going to be able to answer even more on that question is Tom Shakespeare, who is on the next panel, with his extremely long experience with the WHO. I really encourage you to ask him as well, because I think he has written about that. Nora has as well.

Q79 Chair: It derives from that. When we got evidence last week from the Australian example, they said they prioritised certain sectors rather than cover the whole piece, which is not quite the same point that Hugh Bayley is making but, nevertheless, is about how you actually build up a programme. First of all, do you agree that that approach from a donor's point of view makes sense and, if you do agree, how should DFID make its choices?

Tim Wainwright: It is a sensible approach if you are wanting to transform a large complex organisation. It is a sensible thing to pick off certain areas, such as a region of the world or a collection of countries and a sector maybe, to start somewhere. There are certain things that could be done across the board. There may be simple things that could be done for everybody. I suppose, if I heard that DFID were planning to implement full inclusion of disabled people in six months, I would be concerned that would not be done very well. It has taken 20 years to get us to where we are on the inclusion of women in aid, and many people would argue that there is still some way to go in that area. The inclusion of disabled people is starting from a lower base.

I suppose I think it is a good idea, just from the point of organisational change, not to try to change the entire organisation in one go, but it is very important that it begins with major, important areas, and that it is not treated as a small-scale initiative. It should be a whole country, a whole sector or a region of the world. That mirrors what Bob was saying last week about Australia.

Q80 Chair: It would appear from the evidence we have had from DFID so far, for example, that one of the sectors they are prioritising is education. Should they then be looking at how that links? The obvious one they talk about is toilets, but then people might raise issues like nutrition—we have seen that in some countries, where you are providing food or providing a meal—or indeed linkages to the health sector. What is the point of having schools with disability access if the clinic does not? I do not know whether you have a view on that. If you have sectoral priorities, how do you also ensure there are proper linkages between them?

Barbara Frost: I can see the dilemmas. I do think disability needs to be championed across and then some focus made on which areas initially are going to be looked at, as Tim said. In terms of the focus though, again, I want to pick up on what my colleagues said. It is not about having discrete programmes of work for disabled people; it is how the mainstream programmes are including and allowing disabled people to access them. That really could be pushed forward across the board, because there is a lot of material out there about access to schools, to education and to water and sanitation. It is a bit like the twin-track again, going back to the original document in 2000—some focus on the mainstream, but also on some specific areas as well.

Aleema Shivji: When DFID is making these difficult choices, it is really important to have multiple avenues, because that is the only way to see if it is really going to work. Yes, maybe focus on education, humanitarian and whatever the choice is, but also focus on regions, because otherwise the risk is that it will only get implemented in one way and it will not get filtered out through the organisation. If you look at a region of the world, it will have not only a sectoral focus but a country-level focus, and it will reach both the decentralisation and the central objectives, so it is really important to do both.

Again, I think what Barbara said is true: there are things that can be done across the board. Again coming back to something like proposals, guidance saying all projects need to talk about how they are including disabled people is already a huge concrete step. The answers might not be there by the different agencies, whether they are multilaterals, NGOs or whatever they are, in the first few years, but by DFID making that a requirement it starts the engagement and conversation on how to take that further.

Barbara Frost: I saw, in the earlier evidence that you got, I think Lorraine saying, "What about picking up where there are some really good areas of good practice and then really using them to promote across the Department, as an example of what can be done?" That was a good strategy as well.

Tim Wainwright: One of the most important things in taking this forward is ensuring meaningful inclusion of disabled people at all levels, so in the leadership process and governance processes, but also country level, where DFID is inviting disabled people into conversations before it is too late. Actually, Mr White, you asked a very good question last week. Are disabled people being included early on enough to challenge bad practice

or is it just: "Oh, it's so expensive to change that now; I'm really sorry"? I think that is so important. If you reflect on gender, no one would be questioning why it is important to have women in the room when key decisions get made.

Q81 Hugh Bayley: One of the attractions of the slogan "leave no one behind" is that it addresses the needs of women and children, people of disabilities, LGBT agendas, the exclusion faced by Dalits in India, ethnic minorities and so on. The question is: should DFID have a policy to address social exclusion or should it have a policy to address disability, with the consequence that you might be fighting with some of these other minority groups, because your gain would be at the expense of action on the untouchables?

Aleema Shivji: There needs to be both. I know that is difficult. I think we are all going to echo each other on that one, but what we have seen is that, when there is a focus on marginalisation—I think I brought it up at the very beginning—the risk is all the different groups inside that get lost. Today, if I take the example of the same multilateral I keep giving examples from, UNHCR has an age, gender and diversity framework. It is very clear that they are looking at age, which at the moment is very much focussed just on children and women, and the older component is quite weak. Everything else is lumped under "diversity", and what happens is it gets lost. It is really important to find that balance, where there needs to be a specific focus on disability, as there needs to be a specific focus on how to reach ethnic minorities and how to reach older people.

Q82 Hugh Bayley: We are short of time, so can I put in one brief supplementary on age and diversity? Some of the problems faced by disabled people we have touched on before are problems also faced by older people, so would it make sense to have a focus on ageing and disability?

Aleema Shivji: I certainly think so. When we look at the different groups, a lot of the issues faced by older and disabled people are quite overlapping, so that could be one way of moving forward: to look at age and disability together. However, they need to be looked at as interlinked, because they are overlapping, and we need to look at how DFID is making an approach to all of them. Having one social inclusion policy, the risk is that the focus on the country programmes and on the different implementation will be on the most visible group, so there needs to be a way to make sure that there is a specific focus on disabled people, older people and ethnic minorities.

Q83 Hugh Bayley: Perhaps you are saying you have one overall policy but you keep reminding people who it includes, and it includes disabled people.

Aleema Shivji: Absolutely.

Tim Wainwright: More than reminding, I would say—requiring. The words of "social exclusion" or "social inclusion" are not new to DFID, and yet this inquiry would not be taking place if there was not a question mark here. That is the danger, but I would echo Aleema's comments that, actually, there is nothing wrong with the idea of saying, "Let's look at social inclusion and let's look at disabled people in the round." I have met no representatives of the disability movement who are arguing for something special. The arguments are all about treating disabled people as you would anyone else, with

reasonable adjustments, but basically equality is being argued for, not something special. That should mean a good-quality analysis that enables you to prioritise between different groups. The problem is just forgetting it—giving an overarching term but actually not paying attention to the issue.

Q84 Fiona O'Donnell: Incredibly quickly, I just wanted to say that, from the lessons we have learned in this country, often pushing together people with disabilities and older people, you end up with services that are not age-appropriate and actually limit the aspirations. I hope that would not be part of it absolutely in the round, but recognising at each of the stages that needs change.

Aleema Shivji: Absolutely. I think that is the case even amongst people with disabilities. We need to make sure it is a mix of very different types of issues. You have people with intellectual impairments, who have very different needs from people with physical impairments, and at different stages of their life as well—children with disabilities and older people. I agree there needs to be a very disaggregated look at the different sub-components within that.

Chair: Thank you very much. I think we need to give our second panel a fair engagement as well. Can I thank all three of you for taking part? I think we are finding it very helpful and very interesting, and I sincerely hope we will be able to come forward with useful recommendations that might take the thing forward, both in terms of the Department and indeed your point about how the Department can engage with multilateral organisations to raise their profile on disability and development. Thank you both for your written submissions and for coming here today.

Examination of Witnesses

Witnesses: **Professor Nora Groce**, Director, Leonard Cheshire Disability and Inclusive Development Centre, University College London, **Dr Tom Shakespeare**, Senior Lecturer, Norwich Medical School, and former disability specialist, the World Health Organization, and **Professor Graham Thornicroft**, Professor of Community Psychiatry, King's College London, gave evidence.

Q85 Chair: Thank you for coming in this morning. We do appreciate it and I hope those of you whom we have engaged with are pleased that we are finally getting to grips with this. Again, as I did for the last group, for the record, please introduce yourselves.

Dr Shakespeare: My name is Tom Shakespeare. I am a Senior Lecturer in medical sociology at the University of East Anglia Medical School, and previously was a Technical Officer at the World Health Organization Disability and Rehabilitation team.

Professor Groce: Hello. I am Professor Nora Groce. I am the Director and Chair at the Leonard Cheshire Centre for Disability and Inclusive Development at University College London. Our centre is one of the few in the world that specialises in applied research related to persons with disabilities in low- and middle-income countries, and it is a

collaboration between Leonard Cheshire Disability International, which is in 57 countries, and University College London.

Professor Thornicroft: Good morning. My name is Graham Thornicroft. I am Professor of Community Psychiatry at King's College London, and I am also a Member of the Centre for Global Mental Health, which is a partnership between King's and the London School of Hygiene and Tropical Medicine.

Q86 Chair: I can certainly say that you are a high-powered academic panel. You have obviously been in on the previous discussions and you know where we have got to, so, just to pick up, it is ambition, I suppose. The World Health Organization says it wants a world where people with disabilities can enjoy the best and highest standards of health available, but frankly in low- and middle-income countries many of them get no healthcare at all. The first question is: how can DFID help tackle that? Perhaps also, because we have not specifically talked about it, although it was made reference to, mental health is a major problem and yet people tend to talk about physical disabilities and almost do not even talk about mental health. I just wondered if you could address whether or not it should be incorporated right at the beginning and, if so, how. Who is going to start?

Dr Shakespeare: You started in the last conversation to talk about expensive healthcare. Certainly, what the *World report on disability* was talking about, in particular, was access to ordinary healthcare—healthcare on an equal basis to others. So many people in low-income countries die because they develop an impairment that, in the West, would be easily remediable or survivable but, in a low-income setting, is not. For example, I became spinal-cord-injured in 2008. In a low-income country, I would most likely be dead by now, not because I needed life-saving surgery or anything, but because I needed catheters and I needed to avoid pressure sores. It is those very basic things from which many, many people die and which reduce life expectancy.

It is about valuing disabled people, understanding that with often fairly minor healthcare interventions they can survive, thrive and contribute, that we are looking to. If you look to the *World report*, one of the startling statistics was that disabled people were twice as likely to find healthcare providers, skills and equipment inadequate to meet their needs, three times as likely to be denied care and four times as likely to be treated badly. One of the things that I think is very important is training of healthcare providers. We are not talking about consultants at the top level; we are talking about basic health workers in the field treating disabled people as people worthy of services, worthy of inclusion, and meeting those basic needs.

Professor Groce: Let me just build on what Tom has said. We often have it in terms of disability prevention versus access to care but, in terms of overall programming, basic healthcare programmes, for example vaccination programmes for children, there is no reason why a deaf child should not be vaccinated or an intellectually disabled child should not be vaccinated. Too often, these children are not included in these simple preventive medicine projects that are out there that should include all children. It is the same thing with AIDS—AIDS information for people with disabilities, access to basic healthcare if you are disabled and you become infected with AIDS. Those sorts of things where there is an overlap are things that we do not think about and are very important that we include in

just the basic programming that is available and funded by DFID in many communities around the world.

I should also say that disability is a cross-cutting issue. People with other types of disabilities also have mental health concerns. Sometimes when there is the cross between a physical disability and a mental health concern, the options available are even more limited, so we should think of these not in silos, but as a cross-cutting issue that really can be addressed often at very little extra expense or no extra expense, as part of the programmes you already have and support in the field.

Professor Thornicroft: In terms of setting the scene further to what my colleagues have said, it is important to recognise that about a quarter of us across the world this year will have a mental health problem that could be diagnosed. That comes to 600 million people across the world and it means that, of a total DALY count, it is about 7%. If you look at years of lived-with disability, it is actually much greater; it is actually 22.9% attributable to mental disorders.

To take one condition, depression is the second-biggest contributor towards disability across the world as a whole. Indeed, every day about 3,000 people commit suicide. Given the scale of that challenge, how far are we responding? Virtually not at all in global terms. In low-income countries, about 0.5% of health budgets are spent on people with mental illness. In middle-income countries, about 2%. The net result is what the World Health Organization described as "the mental health gap", namely the distance between the need and the provision. The gap is across low- and middle-income countries 90%. That means only about one in 10 people with mental illness actually get any treatment and, in some countries, as shown by data from Nigeria, only 2% of people with mental illness get any treatment at all. Mental illness has a huge way to go, in terms of people disabled by mental illness, bearing in mind that many have comorbid physical disabilities or physical illnesses at the same time.

Q87 Chair: In addition to that, David Cameron specifically identified dementia and said that he wanted this to be put at the heart of the future development agenda. It is a major problem everywhere. I suspect it is as much of if not a bigger problem in developing countries and possibly gets even lower priority. Does what you have just said apply to that or are there specific things for dementia?

Professor Thornicroft: At least as much so. Estimates are that the number of people across the world who are aged 60 years or over, from 2010 to 2050, will increase by 224%. That means an increase from 490 million to 1.59 billion people, among whom in that ageing population we will have increasing numbers of people with dementia, and they have their disability needs as well as their family members, so that is absolutely correct.

Q88 Chris White: My question is to Dr Shakespeare. At the WHO you worked to bring disability much more into their programmes. This might seem a strange question, but did you ever encounter something that was important but not cost-effective? How did you respond to such arguments?

Dr Shakespeare: Yes. I went round and spoke to as many of the Directors of WHO as I could. I was working for the task force on disability, which was set up by the Director General for this purpose: to include disability and cross-cutting in all of the programmes.

The question that most directors asked me straight away was: "How many people? Why should I care?" They did not mean that because they were unkind; they meant that because they were fighting to meet all the different priorities they had at their disposal. Too often, I did not have enough data to persuade them that it was important.

Yes, at WHO level, for example, you are dealing with the major common diseases, the major causes of death. For example, when I was previously an academic I was very interested in genetics in prenatal diagnosis and all the rest of it. That is not important at WHO, because these are vanishingly rare conditions. So many babies are dying of diarrhoeal infection and pneumonia, and so forth, so the idea of cystic fibrosis, muscular dystrophy or whatever I was interested in was not pertaining. Ironically, as countries rise up the development spectre, and fewer and fewer babies are dying of those preventable conditions, so the burden of genetic disease might increase and they will begin to have to deal with these questions. Of course, as you were highlighting previously in your questioning, there are matters of priorities. You cannot do everything.

Just to take one statistic, I want to stress the importance of rehabilitation, for example. We want to prevent people getting injured from landmines, from road traffic injury or whatever else it is but, when they are injured, and inevitably they will be injured, we want them to get back on their feet, get the wheelchair they need, get the artificial limb they need and become productive again, which they can and do when they get that access.

In a high-income country, there is something like 14 or 15 rehabilitation therapists per 10,000. In a middle-income country, it is four. In a low-income country, it is less than one. There are many, for example, African countries where there is one occupational therapist for the whole country; one physiotherapist for the whole country. To up-skill and to train mid-level therapists to get very basic remedies to people to enable them to be productive is a good investment. It is not aiming for the moon; it is aiming for very everyday solutions to very common problems.

Q89 Chris White: Thank you. Do you think that, if you were able to gather better data, your and others' arguments would be made stronger?

Dr Shakespeare: Yes and no. I think that everybody who has given evidence today would say, "We do not know enough; we need better evidence," and so forth, but we do know enough to know what is not there. We do know enough to know what we need to do. It is often the case that people wait and say, "Let's invest in an expensive survey" or "Let's do some more research." We can start. We can make a good start and we should evaluate what we do to see what its impact is. It stands to reason we should not invest in things that are not giving us bang for our buck and not giving us a return. We should rigorously evaluate what we are trying to do.

We know what the problems are; there is no doubt that we know what the problems are, but we do not know what all the solutions are. If you look to the *World report on disability*, the conclusions, the recommendations of that, were very broad. We would have loved to have said, "Exactly do this. Exactly do that." We could not; we lacked the information. I mean, we do have the information about certain things—of course we do—but, in general, the only way we are going to get that information is to try it, to evaluate it rigorously and to make decisions on the basis of that experience.

Q90 Hugh Bayley: I think it is important to base policy on data, but not to keep reinventing the wheel. 20 years ago, I wrote a proposal to create NICE. The idea was not just to exclude expensive and ineffective treatments, but to guarantee to the public that 90% of their health needs would be met. If you were looking at medication in a developing country, you would probably build a stock national formulary of 200 medicines, rather than the 900 you would have in the UK. Do you think the WHO could do a useful job listing a series of health interventions across the board that includes interventions to cope with disability that are cost-effective? I would like to ask Dr Shakespeare and, perhaps in the mental health field, Professor Thornicroft.

Dr Shakespeare: I am bowing to my colleagues who have greater knowledge, but I do know from WHO that there is an essential medicines list and an essential health technologies list.

Q91 Hugh Bayley: I did not make myself clear. Should we go beyond that and have an approved therapies list, which may or may not be medicinal interventions?

Dr Shakespeare: Yes. I think we should expand our idea of essential medicines and essential technologies to include essential therapies. Yes, I do, but the evidence on rehabilitation is very poor. As everybody who is involved in medicine knows, it is the poor relation of medicine, even poorer than psychiatry, I think. We do need more research on exactly what works most effectively.

Professor Groce: We need to think of more information and data as a process. The more we do, the more we get out there, the more information we collect, the more informed we can be. The first example I know of of a global body trying to get data on disability was a petition for a centre on disability statistics that came before the League of Nations in 1931. They did not actually get around to doing anything, but that could be said for a lot of things related to disability; on paper it looks much better than it is in practice.

We cannot wait until we get more data to begin acting now. We know what many of the key issues are. As we start crafting services, as we start including disability in development, we need to set up mechanisms such that we continue to bring in information while we are crafting these interventions, such that we become increasingly well informed and we see what does and does not work. Waiting to get the perfect list is going to be an excuse for inaction that is not warranted.

Professor Thornicroft: The head of the Mental Health Division at WHO Geneva is called Dr Shekhar Saxena. A couple of years ago, he and I led a committee to do exactly what you have just mentioned, which are the NICE equivalents. It is now published; it is called the *Mental Health Gap Intervention Guide*. This is now being translated into about a dozen languages and adapted for about 25 countries worldwide. It is intended precisely not for specialist mental health staff but for primary care stuff, nurses, healthcare assistants, community health workers and other doctors in low-income and middle-income countries, based upon all the best international evidence that is relevant to those settings, taking into account the health economic data as well as the outcomes. A lot of it is very basic, not just pharmacological but psychological and social interventions as well, in terms of what is possible, in a few minutes, for example among 400 people queuing at a primary care centre in Pakistan. It is exactly as you have said.

Chair: I take it that is a copy for the Committee.

Professor Thornicroft: Yes, it is.

Q92 Fiona O'Donnell: We are at the stage where we have the broad intention to include everyone. Dr Shakespeare, you spoke about the need for rigorous evaluation of the steps we were taking, but some experts have suggested that moving forward we should focus on a couple of sectors. First of all, do you think that is an idea? Would you make health one of those sectors or do you think that, possibly, by just focusing on a couple of sectors you miss out the link between nutrition, health, employment and training? Maybe by starting with one sector like education, a child may then through their teacher access health and is more likely to access employment because they have had education. It is a quite long question, but I thought I would just do the whole question and it would save people coming back in. Also, some of our written submissions suggested that DFID has given too much emphasis to advocacy. Dr Shakespeare, again you talked about getting people practical aids so that they can get on with their lives and start being included, so do you think the balance has been wrong between advocacy and practical interventions? Finally, in all of this, where are people with disabilities? Are they being asked this question at any point or are very clever people in the room making these decisions for them?

Dr Shakespeare: I do not need to start, but I am nearest to you, so I will. To start with where you finished, we should talk to people with disabilities in southern countries, wherever we can and as far as we can, to get their feedback on what is a priority. If you are asking me what is a priority for DFID in disability and development, I could put it back and say, "Let's go out and ask. Let's see what folks are wanting." That is the first point.

The second point is that, if you see different agencies around the world, they do focus on different areas and I think that is right, because they have their understanding of priorities. We have in Britain particular skills and offers that we can make to the world, from our own experience nationally, and presumably DFID would then develop a particular strength, say in education, say in employment, say in health, which it can bring to the global table. When I was at WHO, I was very sad that in a lot of the multilateral gatherings, the conferences, state parties to the convention and all of these things, there was no DFID at the table, and I know that DFID has huge strengths to bring to the conversation about disability, maybe from other areas of DFID work, like governance, economics or whatever. Bring that strength to disability and focus on that.

If we need to know what it is that we do, we should look at what other bilaterals are doing, what our strengths are, what our track record is and specialise. I know from a disability rights perspective that to speak continually about health disturbs people because, rightly, they say disability is a multi-dimensional issue, from education, employment and all the rest of it. Having said that, if you cannot survive, you cannot enjoy your other rights, so we have to have that balance, not put all our eggs in one basket, but take maybe two or three things to major in.

Professor Groce: Just echoing what Tom says, it does not have to be an either/or situation. We do not ask that of things like women or children. We are not saying, "We either specialise or we go broadly." I think that disability needs to be a component in everything that DFID does, but there are arenas. I believe last week Lorraine made an excellent point

when she said, "Pick what the strengths are and use them as the way going forward, so really concentrate." However, it does not have to be either/or.

I should also note that, AusAID is held as an example and they do very good work, but there is not a lot of pre-eminence in this field. With not that much—I would say "not that much effort"—but with a commitment on DFID's part, DFID could quickly become the leader or as much a leader in the field as AusAID.

Chair: You are saying we are a role model because everybody else is too far behind.

Professor Groce: There are several reasons. Certainly, it is not a highly competitive field. You could quickly take leadership and be a role model by showing a commitment to inclusion, and that means, among other things that were mentioned in the previous session, it is very important to hold people accountable. It has to be part of monitoring and evaluation, as you do with gender. You never set up an agricultural programme, put in a transportation system or set up a school system without asking how girls are included or how women are included. In the same way, there should be accountability at the end of the day where you say, just as to anybody you fund, "Give us the specifics of how you have included people with disabilities in this."

On top of that, you can have pre-eminence in the field by selecting what you are already good at and using it as a framework within which to put disability to show how disability can really be significantly increased, often by just building on what is already there in good programming.

Q93 Fiona O'Donnell: You said in our approach to gender we will just do one thing for women. Very much the emphasis has been on education for girls. That improves their health because they do not end up getting married so young and having so many children. They are more likely to get independent employment and escape poverty. Is it similar? Do you have a priority for disability? Is there a vision of that in the same way? Is it health because of what you say—that if you do not survive the first few years—?

Dr Shakespeare: I am going to get another crack at this then. Personally from where I am coming from, I would say rehabilitation. Disability education is vitally important. There is very good work going on about it but, remember, disabled children are something like 5% of each age group. When you are getting into the older age groups, it is 10% probably of working age people and obviously up to 15% or more of older people. If we want to help people, it may be, given what other people are doing, that we could make a really good contribution in terms of rehabilitation and getting people into productive work.

Professor Thornicroft: Could I perhaps pick up your participation point please? I am working with colleagues in six Asian and sub-Saharan African countries in a project funded by the European Union called EMERALD, part of which is strengthening mental health systems, for example through greater participation of people with mental-illness-related disabilities.

There are huge variations. Across Uganda, there are about 17,000 people with mental illness disabilities actively involved in advocacy groups. In Ethiopia, there is virtually nothing, nobody involved, because it has just not been organised so far. DFID here might helpfully take a steer from the Department of Health in this country. I will tell you why.

A couple of years ago, under the leadership of Dame Professor Sally Davies, now CMO, they did a wonderful thing in applications for funding from the National Institute of Health Research. They put in a box and they said, "Tell us the contributions to this bid by service users," meaning patients—people with mental illness. The second box said, "If none, why not?" This has transformed the field, because now it is mainstream business for people like me bidding for grants to do mental health research—to have to talk meaningfully to people with the actual condition and for them to be partners in the bid. Basically, you do not get the grant if there is no real partnership—not tokenistic but substantial. DFID might helpfully have something parallel saying, "What partnership arrangements have you made with disabled people in this proposal. If not, why not?"

Professor Groce: Could I add just one more thing? We have been talking about individual level here, but it is important to think on a number of different levels. If there is a large grant going to a country to set up a new transportation system and you are paying for buses that are not disability-accessible, you have missed a trick. It is not just the individual. It is easy to focus on the individual, but you should also be thinking in terms of systems—communication systems, new transportation systems. You put a lot of funding into that. It is just a tick box as people are applying or countries are applying: "Tell us exactly how people with disabilities and different types of disabilities are considered and will be full participants and full beneficiaries of this programme." That would be a major step forward and it is not being done.

Q94 Jeremy Lefroy: Good morning. We have referred already to the fact that, in some cases, people with mental health conditions are particularly prone to stigma and marginalisation. How far do you think that some disabilities may be more marginalised than others in international development programmes and perhaps more generally? Perhaps you could suggest how that balance could be redressed.

Professor Thornicroft: It might be invidious to compare, but I could give you some perhaps helpful statistics. Recently working with colleagues in 41 countries around the world, we have carried out research on the extent of stigma discrimination against people with mental illness. We know that 95% of people with schizophrenia in many countries do report being discriminated against. We know that for about 90% of people with depression. This has a number of implications. It means exclusion from the job market. It often means exclusion from marital prospects. It can have knock-on for family members, who may also be tainted by association and have their marital prospects harmed, but it also means that people who understand the discrimination, which is actually endemic in all our communities, may actively seek not to go for help, because they really do not want to gain a reputation of a diagnosis of mental illness.

I recently visited a low-income country where many people go to see a neurologist if they are depressed, not a psychiatrist, for example. In fact, I recently heard about colleagues in China where community mental health team staff prefer to talk to patients by telephone, not to visit them at home or in the clinic, for fear of direct proximity. We have a major problem here. We do have a commitment from the World Health Organization in their new Global Action Programme to tackle this, and we have some emerging evidence about how to do it, which is actually using people disabled by mental illness as the active change agents through social contact. That means by getting close, teaching for example primary

care staff, working with policymakers. That is the best known active ingredient to reduce stigma, with the participants as the consumers.

Professor Groce: It depends on the country and the programme, as people with different types of disabilities face different types of marginalisation or stigma, depending on what the project is and what the programme is. People with intellectual disabilities, for example, are often not included in outreach efforts around issues like family planning, although they are as much in need as anyone else of family planning information. It really will depend on the type of disability and how the people who are running the programme, either through DFID or at a local or national level, conceptualise disability, which also goes back to discussions earlier this morning and some of what Tom says. The issue is that we often view administrators, decision-makers and policymakers, both at DFID's level and at the national level, as kind of a black box: "We do not have opinions; we are just looking at it as professionals."

In fact, we also need to question the amount of knowledge, training and insight that people who are making these decisions have within the system themselves and to better educate DFID staff at all levels and also people in-country at all levels, who will get the funding, about the complexities of disability. It is not rocket science; it is understandable, but we need to do a much better job of ensuring that the burden is just not on people with disabilities or disabled people's organisations that have to come and explain themselves. We need to think about this as a fairly nuanced issue. If it was easily solvable, we would have solved it already. The question is how to unpack and disaggregate some of this information such that we can promote and fund, and then provide monitoring and oversight, for effective policy and programmes.

Dr Shakespeare: We talked about WASH in the last session. For people who have faecal or urinary incontinence, or who have not but cannot get to the toilet and are left are in their own faeces or urine, there is obviously a lot of stigma and a lot of negative consequences from that for their whole social participation, and for women with fistula for example also. These groups face particular stigma.

Stigma translates into something else sometimes, which is violence. You need to understand violence against disabled people, including people with mental health conditions, as a really important priority, both domestically but also globally. We did systematic reviews for *The Lancet*. People with disabilities had a 50% higher experience of violence in the past year. People with mental health conditions had a three times higher experience of violence in the past year. Children had three times higher rates of violence in their lifetimes, so there are some real issues there that we have not begun adequately to consider and face. A lot of that comes out of stigma and these negative attitudes.

Q95 Jeremy Lefroy: I return to the question that I posed to the last panel, which is the importance of engaging with representatives, particularly parliamentarians, and seeing this as not just a matter where DFID has to sort itself out, or the World Health Organization, the Global Fund or these other multilateral organisations and bilateral organisations. It is a question of parliamentarians and civil society governments in the countries in which we are operating taking responsibility and showing leadership against the stigma and discrimination that occurs, not just to the extent of passing laws, which as we have said we can all do, but actually showing leadership in their communities in support of disabled people. Perhaps you

would like to comment on that and whether you have seen some good examples of that in your work.

Dr Shakespeare: On taking a leadership position, we launched the *World report on disability*. It has now been launched in something like 50 different countries, and I was at various of those launches. It was very encouraging to see governments. To single out one, obviously not a low-income country, Turkey for example has really prioritised disability. It has been one of the themes of their work, and that makes a difference. When the big man says disabled people are important, people jump into line and listen a bit more closely. You are absolutely right.

Graham can talk about the Prime Minister of Norway, who came out, as it were, as having had depression. When people say, "Yes, my brother is disabled. My son is disabled. I have had a mental health condition," or whatever, it brings it out of the shadows and it helps destigmatise it, because universally disability is associated with being rubbish. When leaders in society show that they are also, both in their families and in their own selves, affected by disability or that they know how you should better deal with disabled people, that is very important.

I also say that—obviously you are not denying this—at the grassroots something like a CBR programme, community-based rehabilitation, which is really about community development and social inclusion, may not actually need to spend very much money to be there, to bring disabled people to the village meeting, to bring disabled women out from the huts to actually participate, and to make sure that parents care for their children with spina bifida.

There is a great study by Warf et al. from Uganda comparing districts that had a CBR programme with districts that did not. Where there was no CBR programme, children with spina bifida died at twice the rate of other non-disabled children. Where there was a CBR programme, they had the same mortality as other children. That is not because CBR brought great healthcare; it was because it prioritised attention to, care for and inclusion of these kids. Both at the top and at the grassroots, we need to have this change of attitudes in society.

Q96 Mr McCann: Can I just ask a quick question on that? We have recently returned from Burma and we visited a displaced person's camp, which was related to the violence between Christians and Muslims in the country. We are meeting the Minister later this week. Hugh and I were walking around one of the camps and there was a young man who was mentally disabled, and he was tied, handcuff-style with string, to a piece of root on the ground. We asked his mother what was going on and it was to prevent him hurting himself. In terms of practical intervention, in terms of DFID's operations in that country, if we had a mainstreaming of disability issues in terms of a development programme, what action would you propose to deal with that practical grassroots problem that we identified? Quite frankly, I was pretty heartbroken walking away from that situation knowing that we were leaving a young man, without even giving any advice or help to that family in terms of how they could deal with those particular difficulties.

Dr Shakespeare: Graham can speak to mhGAP, which has a component about intellectual disability. CBR programmes work in the area of intellectual disability. A lot of parents of disabled children, whether it cerebral palsy, Down's syndrome or whatever it is, are

stigmatised and they just do not know what to do. Like in Britain, it is meeting other parents, having that mutual support, or having a self-help group so that the mother is not alone—and perhaps a number of mothers can take it in turn to care for their children and so forth and so on—and can learn better how perhaps to educate him or to help him with his self-care needs or whatever else it is; it is mutual help and mutual support. There are no extensive services, but there are options when communities understand that they can make a difference to these kids and it is not just a matter of leaving them to die.

Professor Thornicroft: Could I respond to that point in particular, please? A similar example is from when I visited a place in south-eastern Nigeria called Enugu province. I was shown a man who had thick scars from having been shackled for many years; he was a young man with a psychotic disorder. In this place, a charity, an NGO called CBM, had put in place something called a community health worker, who had gone to his village and said, "Do you realise just a mile away is a primary care centre where you can get assessment and treatment?" They did not know that, so they took him there and he was given antipsychotic medication. He improved a lot and now he is helping the family by working in the fields. Similar projects are run by BasicNeeds, by GIP and by a series of other NGOs in the field, so you can do a lot in terms of the reduction of human rights violations—chaining and caging and so on—just by connecting people if basic services are available.

Can I answer the parliamentarian question as well? In the mental health field, it is relatively straightforward to engage senior officials in ministries of health. For example, I am working with colleagues at the moment in Ethiopia, India, Nepal, South Africa and Uganda in a programme that is actually DFID-funded. It is called PRIME. We have the senior ministry officials responsible for mental health in countries directly on the steering committee coming to meetings, talking about policy change.

Actually involving parliamentarians is a separate question. In this respect, we are probably in the lead in this country in the world at the moment. You will know from the Health and Social Care Bill recently, when we had these six colleagues speaking out actively about this, that was a tremendous step forward. We know that, on average, a quarter of parliamentarians will have a mental illness like everybody else but, as Tom mentioned, there is only one really prominent example in the world of this, who was the Prime Minister of Norway, Kjell Bondevik, who had a period of depression while he was prime minister, got treatment, spoke openly about it, came back in 2000 and was re-elected. Certainly, in low- and middle-income countries it would be seen as political death to be open about having a mental health disability in a politician, let alone in a minister.

Professor Groce: Could I just follow up on that parliamentary question as well? In my experience, we have worked in about 15 countries, primarily in Africa, over the past four years and certainly, repeatedly, I come across parliamentarians who are very involved and have very strong links often with the local disabled people's organisations. They understand. They themselves may be disabled; they may have disabled members of their families. They have often been taking real leadership, so it is not an absence. It is often a lack of connection within the parliamentary systems that they work in.

I do not know of many parliamentarians who have been active in specific countries who connect regionally or internationally with other parliamentarians interested in this. It

would be great if there was some sort of international way that parliamentarians themselves who are passionate about this and who have a history and often great experience could share their expertise and their insights. I do not know of anything where there has been this cross-national approach, but if one of you would like to, in your spare time, take the lead, there is a great deal of experience among parliamentarians on disability that is not being mined.

Q97 Fabian Hamilton: Can I suggest a former Member of this Committee and a former Member of Parliament who took up these issues, John Battle, who used to be the MP for West Leeds and is now retired? He has got a little bit more time, but he is an absolute expert on this and he was on this Committee for two terms, I think. He would be somebody you should contact and I can put you in touch with him.

Picking up what Professor Thornicroft said earlier about parliamentarians, a watershed moment, as you rightly said, in this place was when we had that debate on mental health and a number of MPs stood up and said, "I have had mental health problems." I thought it was very brave of them, but it was a watershed moment about the stigma attached to mental health issues, as we have all been discussing. I am glad also, Dr Shakespeare, you mentioned Turkey and the approach that they have had. I have an involvement as Chair of the All-Party Group for Turkey. I go there regularly and I see the progress they are making. There are lots of criticisms maybe of what is happening there, but this is one area where they are really showing the rest of the world what can be done in a middle-income country.

I wanted to just continue the discussion about the stigma attached to people with mental health conditions and ask what you think can be done about the fact that so many are excluded from the disability movement itself. How can we actually counter that? Yes, we can show by example, but what can be done to make sure that those people are not stigmatised by the very movement that tries to help disabled persons?

Professor Thornicroft: I feel like a bit of a late arrival at the ball here. You will know that, a couple of years ago at the United Nations high-level meeting on non-communicable diseases, mental health was essentially absent. You will know that from the Millennium Development Goals, mental health is essentially absent, so it is only recently that we have actually been making the case strongly enough to be invited, for example, to meetings like this. We have now been included in the United Nations Statement 'A Life of Dignity for All', which includes an explicit reference to mental illness. There is now a WHO General Assembly Resolution this year, which supports a new global mental health action plan.

The case is now being made increasingly, but the major difficulty of the challenge is the investment in mental health resource on the ground. As I mentioned, 0.5% on average in low-income countries of the health budget goes towards mental health. It is clear systemic or structural discrimination before your very eyes.

What can you do? One clear thing is not to say we have to completely transform mental health services, because often in sub-Saharan countries there is no psychiatrist—not one. The key is at a primary care level. For example, recently I heard about a nurse in a clinic in rural Ethiopia who did not want to touch the case notes of a person with mental illness in case he got contaminated by just touching the case record. That is the degree of stigma we are talking about, so it is a very substantial challenge for us, first of all to think about educating primary care staff to recognise and treat people with mental illness. Having a

separate vertical programme in most countries just will not work; there is no political willingness to do that.

A more helpful approach is an integrated one, where you teach people in primary care to look after people with non-communicable and chronic disorders, mental and physical. Of course, a lot of people have both at the same time. A very good example of this is in South Africa. This mental health set of guidelines has now been incorporated into generic non-communicable disease guidelines, called PC 101, led by Dr Fairall and colleagues, and Professor Lund, which is now being taught to all primary care staff across the whole country. That is a very helpful development.

Dr Shakespeare: Could I just respond to Mr Hamilton's comment about the disability movement? Anybody who has spent time in the disability world knows that the disability movement is not perfect. It is in fact a lot better than many movements in its efforts to make itself inclusive and representative, but disabled people are like everybody else and, if they have not personally experienced mental health conditions themselves or in their family, they will be fearful; they will wish to avoid. They will perhaps feel that, if their group is involved with these people, the whole group will be marginalised, so we need to educate folks with and without disabilities.

When we work with the disability movement as DFID, we should be holding it to account, in terms of not just whether you are including people with mental illness and intellectual disability, but also are you including women? Are you including the poorest of the poor, the rural folk and all the rest of it? The disability movement rightly challenges DFID, and DFID in its own way also needs to ask questions of the disability movement to ensure that it maintains that representativeness, because disability is hugely diverse. A large proportion of disabled people are older people, and it seems to me that older people are under-represented in the movement. I heard you talking in your previous discussion about, as it were, the alliances, the partnership, the synergies between older people and disabled people; this is a no-brainer—this has to be the way forward. We are living in an ageing world and this is a real win-win. If we can make places accessible for older people, they are accessible for disabled people.

In terms of the International Disability Alliance, which is a global representative network of disabled people's organisations, the World Network of Users and Survivors of Psychiatry is an honoured and valued member of that group. They have taken a leadership role in that group, so has Inclusion International, which is working with people with intellectual disability. At least formally, at the top level, those groups are at the table. You are right; in individual groups and wherever, there may be instances of prejudice, and we need to work with that or against that.

Professor Groce: It varies both by country and region, and often on a local basis as well. Again, there is a complexity to it but, just to re-emphasise what Tom said, we should hold everyone to account for inclusion for all.

Q98 Hugh Bayley: I have two supplementary questions, not related. One follows the stigma discussion we had and the most extreme cases, where I believe a young man tied up, day after day, is a gross human rights abuse, but it was not seen that way in this camp. It

was seen as a necessary response. I have seen some orphans who had been deemed child witches in the Congo being rehabilitated.

The question is: amongst the other tools that we should ask DFID to work on, should we be asking them to strengthen human rights law? That is the first question. The second question, Professor Thornicroft, is you say many sub-Saharan countries have no psychiatrists at all. You have mentioned this case, I think you said in Nigeria, where antipsychotic drugs made a huge difference to somebody's life. Can you give us two or three examples of—how can I put it?—affordable and cost-effective mental health interventions, not necessarily drug therapies—Dr Shakespeare has been talking about community responses—that you would draw out of your best practice guide there? Just give us some examples. There are two different questions.

Dr Shakespeare: Shall I go first? As we are all well aware around this room, the Convention on the Rights of Persons with Disabilities, which so many countries have ratified, means that they have to revise their laws in line with that. It is very easy to ratify; you could see on the day that it was first tabled not everybody but a large number of people ratified it straight away. Of course, they are not complying. They were not then and they are not now. DFID working with countries to say, "Look, you have ratified; how are you going to revise your laws? How are you going to revise your practices? How are you going to meet your obligations?" is really important. If we are going to do that, people are going to turn around and say, "United Kingdom, what are you doing and how are you meeting it?" We have to be very careful.

However, there are lots of things that we have succeeded in that we can begin to export. Transport came up earlier. I got an accessible taxi here today. I could have got an accessible bus. I know that there are limitations and problems, but Britain has shown that you can have an accessible transport system and we can help particularly low- and middle-income countries get that right from our experience and, therefore, meet their human rights obligations. We can share our knowledge. We can support their parliaments and their policymakers to work out what it means and how it can be delivered, but we need to do so in humility, realising that, in our own domestic situation, when we come up before the Committee on the Rights of Persons with Disabilities, they will have lots of criticisms of us.

Professor Thornicroft: Do we need a new law? No. The CRPD is a good enough framework at the moment. What is the problem? We are not implementing it, so there is no practical monitoring. Section 33 does lay down requirements for monitoring, which many countries do not actually do. The right to health is included there, covering a whole range of the issues we are talking about today, but it is actually not put into practice. Many organisations, for example in my field one called the Global Initiative on Psychiatry, are doing work exactly on the intersection of human rights and mental illness, but this is not yet sufficiently developed to have purchase at country level with governments. The framework is there; it is the question of implementation. DFID may have a role to play in developing that.

On your second point about examples, we do have some. The key concept here is called task sharing so, if you do not have doctors, you cannot wait till the doctor prescribes; you give those responsibilities to nurses. If you do not have any nurses, you create a new cadre of people called community health workers, for example, and they do the basic

interventions. Recently that has been tried, led by my colleague Professor Patel in India, for people with depression. We have shown that community health worker interventions for people with depression in the community are cost-effective. Also working with him, I have led recently a trial called COPSI of people with schizophrenia in India. We are about to publish the data in *The Lancet*.

Q99 Hugh Bayley: What are one or two examples of the typical interventions?
Professor Thornicroft: They are a mixture of getting simple cheap medications to people, psychoeducation, which is telling the person concerned the nature of the issues, the outlook about their participation in the workforce and so on, but also supporting the family. These people of course are living with their families, and it is about helpful ways for the family to interact with the person. The expectations are set, not excluding them from the workforce, working on the farm or whatever it might be, but including them in the recovery pathway. It is a mixture of basic psychological, basic social and basic pharmacological interventions. You can deliver those in low-income settings. You can show that they are cost-effective, but what we have not yet done is actually scale that up across whole regions and whole countries.

Professor Groce: To add to that, in addition to allied health professionals or community health workers that can get skills like psychiatry or psychology, many countries have few or no speech therapists, audiologists or the basic allied health professionals, who translate often or can deliver direct services. Probably for the vast majority of interventions you do not need a physician. It would be nice to have one in some cases but, often, to get out there and provide most of the services, if we teach people and include people with the basic community health skills to acquire skills that have something to do with disability or can serve the disabled communities, we can immediately have effect in many of the most resource-poor areas. We are simply not doing that.

People who are trained as nurses, midwives or any number of other mid-level health professionals or community-based professionals receive no information about disability. Often if you talk to them, they will say, "Well, I don't have these skills." In fact, what they do and what we fund in terms of good basic community health services can address, I would say, the vast majority of the issues or at least the initial major blocks to fuller participation and richer, fuller and healthier lives for the people with disabilities who we deal with in developing countries. It is a low-cost, low-tech issue. We need more awareness and commitment, and to build it into general healthcare systems right now.

Dr Shakespeare: I was just struck by the story of the pregnant lady who was a wheelchair user, who turned up to the hospital in a West African country. Before they admitted her, all of the staff stood around and laughed at her and said, "How did you get pregnant? Ha, ha, ha." It is about the supply, but it is also about the human rights emphasis to understand that disabled people have sex, have babies, have arthritis, have cancer. Everything that everybody else does, disabled people do. Health workers are the first people who should realise that, and yet that is not the case.

I did a paper last year about what we know works to train health professionals to be inclusive of disabled people. We still need to do more of that. In this country, we have very good medical schools, as they do in other countries, but we are prioritising in our medical schools ensuring that students understand disability and that disabled people will

present as pregnant, as wanting cancer screening or whatever else it is. Perhaps we can share some of that when we support medical schools in developing countries.

Q100 Mr McCann: Chair, I know we are running out of time, so I will get straight to the point. What are the main benefits or risks with community-based approaches to rehabilitation and mental health care?

Professor Thornicroft: The benefits are you can actually reach a great proportion of the population if you have locally based care. The big problem with mental health is access in that, in many countries, 10% or fewer people are actually getting any treatment at all. Part of it is geographical access. You can actually get out and disperse services and make them available; if the government will invest in them, you can have basic skills on the ground. The risks are that usually mental health is seen as the Cinderella; they are seen as low-tech and less of a priority. Unless you have ongoing funding, you have this invidious situation of short-term external-funded three-year programmes. It is quite a good service, but stops. Another one starts and then stops. You get discontinuity, disillusionment, staff going abroad and so on, so you do not get a platform you can build with, sustain and grow over time.

Professor Groce: Can I just build on that? The benefits far outweigh the risks, and the benefits are you reach many more people and many more individuals and their families if you do this. The risk I see, to echo what was just said, is often when these services are put in at all, either for mental health, for people with disabilities or for rehabilitation, they are done as pilot projects. It is not built into the sustainable fabric of a community health centre or a community ongoing policy or programme, so you get funding for a year or two years.

This is true not only for health, by the way, but for just about anything I can think of about water and sanitation, transportation or anything that has to do with people with disabilities coming through development, not just DFID, but USAID and AusAID. Often they are done as pilot projects and everybody feels great about it. You reach 20, 30, 200 or 300 people, and then it is over, so it needs to be knitted into the ongoing fabric and commitment, because it is both a right and because the term could be "enlightened self-interest". If you do not do it, then the downside, the risk, is that these people will not be served, and their lives and the lives of their families will be the poorer for it.

Dr Shakespeare: I agree with all that. The thing about, say, community psychiatry or rehabilitation is that it is a long-term, complex—not "complex" difficult, but multi-faceted—set of interventions. The risk is that it is not visible. It does not cure people. Well, it can, but largely it is not like, for example, vaccination or mine clearance, or these best buys for development actors, where they go, "Right, I've built that shiny hospital. I've inoculated all those children. We've eliminated polio from India." Those are great; they look good for everybody and you get a lot of kudos for that.

What we are talking about is much cheaper and will help as many people, but it is not visible so easily. It is with a section of the population who are not particularly valued or not valued at all and, also, because it is complex and long term, it is administratively complicated and there is scope for more corruption. Donors fight shy of that. They say, "Give us something easy. Give us something quick. Give us something that looks good

and is a priority." That is so much easier for them than the sorts of things that Graham, Nora and I know work and know reach tens of thousands of people.

Professor Groce: Could I just follow up on that? Let me give you the example of polio. Last year, worldwide, or in 2012, when we have the latest figures from, there was something like 223 people worldwide who got polio, give or take. In Syria there was an outbreak as well and then mass inoculations. We are very close to eliminating polio compared with, say, the late 1980s, 1987-88, when 350,000 people per year got polio. We are down 99%. This year or next year we think that polio will, in fact, be eliminated.

That is great, but 20 million people worldwide—20 million—live with some form of disability acquired by polio. Very soon, there are going to be parties all over the world to help people celebrate eliminating polio. The lives of those 20 million people are just as valuable and, unless we build them into ongoing services, they will be at a disadvantage for decades to come. Tom said it is good to have a shiny "we've eliminated polio", but unless we really think critically about how to integrate people with disabilities into ongoing services, their lives will be the poorer for it and their communities will be the poorer for it. Quite frankly, all of us will be the poorer for it.

Q101 Chair: Perhaps it just brings us down to counting, measuring and collecting data. We have had slightly contradictory evidence. One says, if you do not have the data, you will not get policy to deal with it. Others say data not only costs money but implies that you have to spend money on the people you have acquired from that data. How do you ensure, first of all, that you get on with it while you are collecting the data and, secondly, that data collection does not get in the way? Indeed, governments actually say, "Let's not count them, because that will just create a problem."

Professor Thornicroft: Just to work that out, I have been looking closely at how colleagues in the HIV/AIDS field deal with this. Of course, they have got tremendous funding to support it, but they measure coverage. In each of the relevant recipient countries for the major donors, so it is Global Fund, PEPFAR and Gates, they can say the proportion of people who have HIV or have AIDS, per year, who are getting treated, and then they can compile a league table. They can see changes relative and absolutely. I know colleagues in ministries of health pay a lot of attention to their absolute numbers, but also their position in the league table. That follows the principle that, if you do not measure it, you cannot manage it. In mental health, we do not have those data yet, but I think they are transformative in shaping policy and investment, if you have the right light-touch figures available.

Q102 Chair: DFID is very much focussed on targets and outcomes" "We have reached so many people; we have treated so many people." First of all, is that the right approach? Does it actually deliver results? Is there not a danger that people will effectively fix the statistics by not identifying people or in some other way?

Professor Thornicroft: Just to follow on, it depends who wants the data. Does DFID want it or do the recipient countries want that and which numbers would they act upon? If you like, what is the minimum amount of information that could be gathered that would be truly informative to their investment decisions? Having said that, how do you validate it and make sure they are not sham data? Both are important.

Professor Groce: Just to follow on, we both collect data and we implement programmes for women, for example, or people in rural areas or people in slum communities. We do not make this distinction; in mainstream development terms, we do both, and we assume that we need to collect accurate data to better inform and target, over the course of programmes and policies, so it is not either/or. At a certain point, you probably have more data than you need, but we are far from that point. Even with something like AIDS, where there has been research and data collection for the last two decades, there is still a tremendous emphasis on learning and bringing into the fold new ideas and new approaches based on data.

When we try to distinguish between the two, it is a false dichotomy. The more data that we get, as long as it is data asking good questions about on-the-ground issues, the more we can target, improve programming and policy, and monitor and evaluate what is going on. However, I do not think that should take away from action.

Dr Shakespeare: A lot of people talk about the Washington Group's six questions. They are very useful, because they are quick and dirty disaggregation. When we are delivering services or when we are doing any work, we want to know what proportion of folks that are using this service are disabled, so things like those six questions do that quick, cheap and—I have to say—dirty.

They measure people who have impairments, and what the disability movement says is, "Look, disability emerges from the inter-relation of somebody with an impairment and their environment, and we historically have only measured people with impairment." We have endless headcounts of people with an impairment, people with this, people with that. We should be looking at how many of the new buildings you are building are accessible; how many rehabilitation therapists you are providing; how many of your buses are accessible. When we are researching disability, do not just count disabled people; count disabling barriers. It is possible.

We were involved in the *World report on disability*. I hope very much that WHO, at some point, will do a global status report on disability or maybe the UN system will do a global status report on disability. As Graham said, if you rank different countries to see how well they are doing and, say, Cambodia is doing less well than Thailand or some other neighbouring countries with similar levels of development have different outcomes, they will be spurred to improve. That is the benefit of the Committee on the Rights of Persons with Disabilities. That process has really driven change, not fast enough and not far enough, but people do not like to be named and shamed. They like to know that they are doing what is right. These are generally good people and good parliamentarians. They want to be praised, if we can measure what they are achieving and get comparable data.

The WHO is doing a model disability survey, which is innovative, because it allows you to compare all sorts of people with issues of functioning to look at the role of environmental barriers. Historically, we have said, "We know who disabled people are. They are like an ethnic group or they are like women. They are a separate group." They are not. Disability is a construct. We said they were 15% of the population. That was an intellectual decision, but it was also slightly a political decision. It is about trying to understand a meaningful figure. Actually, many countries say it is 2% or 3% and in Britain it is higher than 15%, and all the rest of it. It is what we make it.

Many people do not want to identify as disabled. In Britain, only about 50% of people with what we might call disabilities identify as disabled people. I do not want to be a social scientist, deconstruct everything and tell you to do more theory, but I do want to say that there are people affected by disability. When we talk about disabled people, disabled people, disabled people, we may make the mistake of thinking that you can go into a community and go, "Right, they are disabled." You cannot. You can generally say who is a woman and who is a man, but you cannot say who is a disabled person and who is not. What matters is how communities are responding to this challenge, the amount of health workers they have, the amount of accessible buses, the accessibility of their health systems and so forth. We can hold people to account on those figures.

Professor Groce: Maybe to just follow up quickly, many people do not identify as disabled but, even if they do not identify themselves as disabled—an older person with poor eyesight may not say, "I have a vision impairment"—that does not mean they will not benefit from the services that you put in place.

Q103 Jeremy Lefroy: Turning now to research programmes, DFID has several disability research programmes and is quite strong on research in a number of areas. One of the questions we always ask is whether this is put into action and what your experience is of the research being put into action, not just with DFID but perhaps more broadly.

Professor Thornicroft: I am involved in a DFID-funded project, which is called PRIME, and this is across five countries in Asia and Africa. This has shown tremendous and really positive support from DFID, both in respect to the research and in capacity-building. An explicit part of this is to develop younger investigators in those countries, who will go on in the future to lead research and then provide evidence to their own governments, in turn. It is deliberately a type of knowledge-transfer exercise, and DFID has been tremendously supportive, so I can speak very highly of that example.

Professor Groce: We have just completed a DFID-funded project on cross-cutting disability and development. We are not quite as far down the road as you folks are, because we are just now coming out with the findings, but we have found that DFID, in the research capacity, has been very helpful and very responsive. The question is how much of what we bring in as research is transferred to the other components of DFID, and some areas of DFID have been more interested and responsive than others. Again, the issue is leadership from the top. If there is interest at the top and senior DFID officials are including more of this and integrating the research findings in DFID programming, that will make a major difference. Could I say one more thing?

Chair: We are running up against colleagues with other engagements, but we just have a couple of more questions.

Professor Groce: Could I say also the interest in integrating disability is important for DFID not only at headquarters levels, but at national levels with in-country programmes. Again, it was mentioned in the previous session. Some DFID offices are very interested; some are not. It is the luck of the draw. Sometimes you will be working in a country where there will be a local DFID person who is great and very interested in disability, and sometimes you will be working in some place where the DFID person may be great, but

they are not interested in disability. It becomes optional on some levels whether they are interested or not.

I would think that one step forward would be more emphasis, not just from London, but also throughout the DFID system, to ensure that this is a priority, because otherwise you are left with an individual often with not well-informed opinions of disability. In some cases, it almost feels charitable: "We'll get around to disabled people once we address other issues." That is like saying, "We'd love to vaccinate all the children in the village, but we only have enough vaccine for the boys. We'll get to the girls as soon as more vaccine shows up." You cannot do that. People with disability have the same rights and, for that reason, it is important that this be, both at headquarters level and at national level, an issue that is really taken up and championed.

Chair: We are working on the assumption that, if DFID has a commitment, that has to be part of the challenge that they are going to take up. We will engage more on that.

Q104 Hugh Bayley: Finally, I would like to put to you the final question put to the last session, which is that we are on that continuum between saying, on the one hand, leave no one behind and, on the other hand, let us have a disability and development policy; would you like to see our report coming down? Dr Shakespeare, you talked about the benefits you could get from building an ageing and disability synergy. You talk about the conceptual difficulty of numbering or categorising who is disabled. 20 years ago, "health for all" was the slogan from the WHO, wasn't it?

Dr Shakespeare: DFID invented it; it is the twin-track strategy. We have to do both. We have to look at DFID's portfolio of work and make sure that it is inclusive of disabled people. There are some small things that could be done, things like physical accessibility of buildings, like they have done with schools. That is fantastic. In the business case, just have a question, so all business cases have to ask, "How has it included disabled people?" There is the information accessibility and these sorts of basic cross-cutting things. It is not elaborate; it is not rocket science to get that right. Then of course some targeted work is needed to understand the specific issues that face disabled people.

As to the balance between the two, if you have your mainstream funding accessible to disabled people and fully inclusive to disabled people, that has to be the biggest change that we could possibly make, but that cannot be at the expense of forgetting that there are some specific needs that DFID is in a position to help countries meet better, like wheelchair provision. I have a wonderful wheelchair provided by my wheelchair service. I have no complaints about that. Only 15% of the people in the world who need wheelchairs have the wheelchairs that they need. Thanks to Chinese manufacturing, you can buy a wheelchair for less than $150. A wheelchair should be like a bicycle and there are bicycles everywhere in developing countries, across Africa, Asia or whatever it is. A wheelchair is not much more complicated than a bicycle. It need not be more expensive. Things like that would make a huge difference to people, so targeted and inclusive.

Professor Groce: I would just echo what Tom said. I cannot emphasise enough, before I came to the UK, for example, how everybody uses a twin-track approach. DFID is already famous in the field for the twin-track approach, which is disability-inclusive and disability-specific. You might as well build on something you are already lauded for around the world, in terms of how you position yourselves. You need maybe to reflect on

your pre-eminence in the field and put the funding in to back the pre-eminence that you have had for many years.

Dr Shakespeare: Sorry to interrupt and to add, with DFID as a champion, the taskforce on disability worked at WHO because it had a high-level champion and it had a low-level agitator, which was me, and obviously representation from different sections. You need to push away at it. Having a policy to be inclusive does not work. Having a champion and having some people pushing away at it will help.

Professor Groce: It is a process.

Q105 Hugh Bayley: Who would you choose as a champion?

Dr Shakespeare: We already have Lynne Featherstone and that is wonderful. I do not understand sufficiently the structure of DFID but, in WHO, we had an Assistant Director General, so that is right, as you know, under the Director General. He chaired the meetings of the task force. When I went to have a meeting with a Director or somebody else, or the Regional Director or whatever, I would say, "My boss is Dr Ala Alwan. He is the ADG and he said … and his boss is the DG and she said..." Of course, in a civil service-type structure, we will meet you and we will do something, because you are going to report back.

Hugh Bayley: It needs to be a minister or a director.

Chair: Ministers come and go. That is the point.

Dr Shakespeare: Well, then a director.

Professor Groce: With seniority.

Professor Thornicroft: I have this image of bicycles with the twin-track and wheelchairs making twin tracks. In terms of mental health, I think it is genuinely cross-cutting. If you think about the post-2015 shifts indicated, mental health intersects with all of those. In fact, not paying attention to mental health actually stops you from achieving all of them. For example, with regard to HIV, TB and malaria in the current MDGs, if you do not pay attention to the fact that people with those conditions are twice as likely to be depressed, and that they are therefore less likely to take their antiretroviral treatment—they are more likely to die—you are actually not going to hit your targets. Similarly, there are complex interactions between poverty and mental illness, so you have to look at both in the round.

Q106 Hugh Bayley: Can I ask one last question? I know you are going to clonk me. To what extent do you deal with mental health by improving housing and improving employability?

Professor Thornicroft: In a profound sense; those are etiological factors that cause mental illness in the first place.

Dr Shakespeare: And war.

Q107 Jeremy Lefroy: I chair the All-Party Group on Malaria and Neglected Tropical Diseases. Now, these neglected tropical diseases are some of the main causes of disability, if you think about things like lymphatic filariasis and so on. There is again so much preventable disability amongst these. In your work, do you have any interaction with the work that is being done on NTDs?

Professor Groce: Yes.

Jeremy Lefroy: That is something that clearly, over the past few years, has come up the agenda but, by their very nature, they have been neglected.

Dr Shakespeare: You did say neglected tropical diseases, yes. Back when I was at WHO, I spent a lot of time going round. Some of these, like Chagas disease, Guinea worm and all the rest of it are associated with lifelong morbidity. What is interesting is, when we measure the impact of those, not just to look at mortality but also to look at morbidity.

Professor Groce: For example river blindness: in some communities everybody above the age of 40 has lost their vision because of river blindness. In those communities, it is not unusual for blindness to be considered a part of the ageing process. It is rethinking a lot of these, and then making provisions if people are affected and have a morbidity. We are not very good at doing that and sometimes we are not very good at bringing them into the disability efficacy fold either and, again, that is where the proper programming and community interventions could make an enormous difference.

Q108 Jeremy Lefroy: I have not seen, and it is a very interesting thing I need to look into, so much link between the work being done on NTDs, which has been very much focussed on the fact that this is a very cost-effective way of treating the 1.2 billion to 1.4 billion people who are susceptible to them. It is often a matter of a dollar a year or less. I have not seen as much made as perhaps one would think of the link between that and disability.

Professor Groce: There could be more. I sit on a WHO committee on NTDs, for example. There could be a lot more, but it is an important area to explore.

Chair: You have seen the Committee has been engaged and this evidence session and the previous evidence session have pointed to quite a lot of very clear recommendations that we can make to DFID. If it wants to act upon them, they will put substance on to the objectives. From the conversation I have had with Lynne Featherstone, I am sure she is committed. She is as aware as anybody that ministers come and go, and she wants to ensure that the Department has a structure to take forward. There will be an election next year and we want to ensure that, if it is built in, it is built in regardless. That is really the objective. We thank you very much indeed. It has been really helpful. If you have any reflections afterwards on anything, where you think you want to add to what you said, amplify or qualify, please feel free to get in touch. Polly here will be happy to engage with you.

Professor Groce: Could I just thank you for holding these sessions? We really appreciate it.

Chair: I think we appreciate that this is an issue where the Committee can make a useful contribution. People like you giving us evidence is a really important part of that.

Dr Shakespeare: It is a very timely moment globally, with the post-MDGs. This is exactly the time to push on this issue.

Chair: Let us hope it follows through. That certainly would be our objective. Thank you very much.