Reflective journal

From the margins

Photo by ADCAP Pakistan

From the margins

"We were just thinking, Anwar, you could take over the role of Ageing and Disability advisor," said Ajeeba K Aslam, our country director.

I had been working as Inclusive Disaster Risk Reduction and Inclusive Community Based Disaster Risk Management coordinator for the last five years. Some days, I would work until I fell asleep. I did this because I really believe in this innovative work. It made me proud when people called me "Mr. Inclusion" at the National Disaster Risk Reduction forum, where I had developed some tools for ensuring the mainstreaming of older people and people with disabilities, for use during risk reduction and risk management.

I discovered that through developing these tools, we were helping to meet the divergent needs of the groups. People and organisations, either government or other humanitarian workers, were able to include these groups in their mainstream work. I had received requests from government institutes like National Institute on Disaster Management and National Disaster Management Authority to provide input into their own tools.

New horizons

But a new horizon opened for me when I got the chance to work in humanitarian response. I realised that lifesaving actions during any disaster are equally as important as longer-term empowerment. But to navigate the lifesaving aspect of the work, preparedness is the fundamental step.

And so I found another way to get my voice heard. I joined people in London for a training – part of the ADCAP programme, which trains Inclusion Advisors to improve age and disability inclusiveness in humanitarian response. Here, people from different organisations and different thematic areas had joined together to talk about how this could work. Most inspiring was the realisation that what we needed to do to include these groups might be different, depending on the culture and context. This was important, because it demonstrated that inclusion needs specific actions that actively involve the people on ground. Meaningful participation needs equal power of decision-making.

Change from within

Immediately after the training, I began to create a sense of urgency within the organisation of the equal importance of mainstreaming the needs of people with disabilities as those of older people. I met with a fear from some individuals that addressing issues related to disability would increase their caseload. In reality though, HelpAge was already working on this issue, as many older people have a disability.

When I started these discussions, I did not think about the financial implications of including people with disabilities. At the start of my assignment, however, many people thought costs would be a considerable barrier – though in reality, most adaptations are not that costly.

Colleagues were asked to take the example of an older person who was a carer, looking after a child with a disability. They were asked to consider how he or she would respond in an emergency and be involved in preparedness. The idea was to bring home how disability might already form part what they were doing – even if it was not something they had originally thought of as part of their responsibility. This approach was intended to help the team think differently. I had learnt from John P. Kotter's story *Our Iceberg is Melting* that

for successful change, you first need to convince your team. In HelpAge International I gained the support of the Country Director, Senior Programme Manager and Senior Operation Manager – so I was now confident that I could influence external environments as well. And so the journey continued.

Challenging our own attitudes

In 2015, I witnessed the earthquake here in Pakistan, seeing people from my office rush out of the building for their lives. At that time, the Ageing and Disability Task Force coordinator, who is visually impaired, was accompanied by his assistant and easily got out of the building. Yet my first thought was – why the assistant didn't just run and leave the coordinator behind? This negative thought helped me to consider and understand his reaction – that it was the habitual practice of the assistant to support the coordinator at every turn. At the time of earthquake, as I see it, the assistant recognised his responsibility to guide his colleague to safety. He turned back and saw that coordinator was still there, and he helped him get out of the room.

This experience highlighted to me how positive attitudes towards older people and people with disabilities need to be built up. It takes time to challenge existing belief systems and build positive attitudes and relationships. I realised I had not seen programmes in humanitarian organisations that work on preparedness for families of people with disabilities. We had not looked into who is caring, and how, despite evacuation for these groups being critical.

In Pakistan, seasonal flooding is a routine disaster, as well as earthquakes. During these floods, people with disabilities generally lose their assistive devices. So the question is, what will be the mechanism to assist these people? We need to establish how the international community can be more responsive and what kind of changes would be required – from family to system level – to put in place an inclusive, affordable and acceptable community structure for all.

Inclusion is often considered a soft field, rather than a tangible issue. Attitudes are critical in the process of inclusion and changing attitudes is a challenge which varies from one culture to another.

I got the chance to work with well-known local and international organisations, to influence their inclusion efforts. When I started speaking to people and providing training, I met different people with different attitudes towards people with disabilities and older people. Some considered themselves more of an expert than me, challenging what I was saying. Some believed nothing new was being said, only different words being used. The attitudes I encountered were a real challenge; often, after I put a great deal of effort into training people, the ideas would be dismissed in just a few words. This happened in the same way, many times.

Ten years invisible

"This is the first time I've been asked about my needs," an 85-year-old man from Sindh, Pakistan told me. I looked at his expression for several seconds and felt the different types of pain there. He was from Tharparkar, a part of Sindh where the majority of people live below poverty line.

"We can barely get one or two times meal a day," he added. I asked the person from the local organisation how long they had been working in the area. He proudly replied that they

had been working for the vulnerable community for more than ten years. Why then, I asked myself, had they never came across this man? Perhaps it was that they hadn't realised, they were not sensitised to the issue, that such groups remained invisible.

I learned from working with older people that when a person gets older, there is definite change in roles and responsibilities. But I observed that there are beliefs held by many – some young, some older, some female, and so on – that their own point of view is not important and others can make better decisions on their behalf.

Sometimes this is due to power dynamics. This phenomenon is sometimes referred to as 'voluntary exclusion', when people internalise their marginalised position and think they have nothing to contribute. Thinking again about that older person in Sindh, I wondered if he volunteered himself for exclusion. I wanted to find out the reason why his voice had not been heard over the last ten years. And to understand how can we work towards ensuring meaningful participation of all vulnerable groups in our work.

There are so many questions to ask when it comes to attitudes, but this includes both the service provider and the individual.

Using the tools

To help motivate staff to take the lead on inclusion, I used two guidance tools: the Core Humanitarian Standards and the Minimum Standards on Age and Disability on Humanitarian Response ("Minimum Standards").

Some people challenged the Minimum Standards, the purpose of which was to provide a guide to field workers on age and disability. Some people voiced concerns that they did not provide the "how" part of the action. I was once asked whilst providing training whether it would be possible to develop a checklist for an overall project cycle, so that it would be easy to tick the boxes and get things done.

However, a checklist is not really an option if you want things to work in the local context. The Disability Creation Process is a well-recognised model to understand the process of disability. The model explains that a person with an impairment is not disabled if the barriers in the environment are removed. This means that the environment itself can make a person enabled or disabled. If you can replace the barriers with facilitators therefore, then you can ensure inclusion.

Both the barriers and facilitators are local, and may differ from one region to another. This means there cannot be one checklist that can be used everywhere, or a formality that needs to be ticked off. There is a critical need to understand the local context, the concepts, the barriers and the facilitators. Localisation will make the process realistic and cost-effective. The Minimum Standards' concepts on inclusion provide a guide to anybody to localise the issues, and therefore make an enabling environment.

Slow process of change

This journey kept going. I didn't give up, despite the fact that my new role was not as 'visible' as the previous one, which produced more visible actions and impacts.

The first training I held that focused specifically on disability was for people working on a four-year project, "RELIEF". As the training began, I learned that some participants did not feel confident in their knowledge of disability, and felt they would probably take some time to achieve the technical expertise needed to include age and disability. Yet other

participants felt they had a greater knowledge than I did, so were not expecting to gain from the experience.

With this varied experience in the room, we adapted the training to find an in-between methodology. The idea was to encourage them in what they were already doing, but also help them improve by using and applying the new knowledge, building on these foundations. For example, if participants were doing an assessment, we asked them to use Washington Group Questions to collect disability focused data for the first time. These questions were used to assess the level of disability and also give guidance on how to communicate with older people and people with disabilities. This provided a great advantage in collecting data – a way to ask about disability in a culture where such a direct question would be difficult. Through this training, the Washington Group Questions were used for the first time in Pakistan.

Pathways to influence

I found other opportunities for influence – such as the chance to work on many project proposals, one of which was a four-year project, funded by the UK Department for International Development. For donors and INGOs, I developed a straightforward and convincing strategy. To ensure that inclusion is always there in your programming; you must acknowledge the proportion of older people and people with disabilities within a population. You also need to consider functional ageing, looking at people's capacities, which may not always correspond with their chronological age.

Firstly, in addressing the proportion of the ages they would need to look at the percentage of any segment of the society in a given population. Globally, the proportion of persons with disabilities is 15 per cent.[1] Some statistics suggest that 38 per cent of older people have a disability.[2] However, depending on data available, either global or national, proportional age should be used in programming. For example, if the percentage of older people is seven per cent, then seven per cent should be budgeted for the specific needs of older people; and a similar approach adopted for other vulnerable groups.

Secondly, the service provider must be aware of the capacities of different people within a community. For example, perhaps the service provider expects all people to be able to wait in line for an hour, or that everybody can carry a 40kg ration. However, they will need to take into account that the capacities and vulnerabilities are different – not everyone may be able to stand for that long, or carry such a heavy load. Cultural norms may differ too, and need to be considered. This concept gave me more focus towards an inclusive process. This was the point from where the real success started in ADCAP.

Growing and growing

The collaboration, networking and working through partnerships helped me to spread the inclusive message quickly. The biggest emergency fund (RAPID) in Pakistan, managed by Concern Worldwide, provides funds to local NGOs. RAPID programme staff were trained and sensitised on the inclusive strategy. "We have worked with a million beneficiaries but never thought about the specific needs and systematic inclusion of these groups," said one RAPID programme director during a training session. The senior management was also on board –

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[1] World Health Organization and The World Bank, *World Report on Disability*, 2011, p29, p44 and p261
[2] World Health Organization and The World Bank, Table 2.1

considering and allocating budget allocation for older people and people with disabilities. They also offered up their projects to test the Minimum Standards.

Around this time, I met the regional learning advisor from DFID's Disasters and Emergencies Preparedness Programme. After her arrival, we started sharing the inclusion approach with partners in this programme who were managing projects similar to ADCAP in Pakistan. The process of sharing is helping to change attitudes and give momentum to the inclusion agenda.

As a result of all this networking, we received a request from Tearfund to train 12 partners in their project. This was a huge achievement for me, because I could see that the organisations fully accepted and understood the value my work was adding. "We did not even know how to ask about disability," said a training participant during a closing ceremony in Hyderabad Sindh, "we felt shy and left many people with disabilities in the belief that their families would need to be the ones to care for them. Today, we realised that communication opportunities are there."

I was proud to see the message spreading so quickly as a result of this collaboration. People at last realised the importance of working with all segments of the society. The momentum was on, we were receiving continuous appreciation from our headquarters, and the team was expanding.

The international stage

I was astonished to receive an unexpected email from my counterpart in Kenya earlier this year. He wrote, "Dear Anwar, owing to the confidence I have in you, I have chosen you to be one of the panelists during the discussion on disability charter [at the international humanitarian conference in Nairobi, Kenya]." This was an honour for me, to be selected as a panelist to speak at the annual conference of the Inter Agency Working Group for Disaster Preparedness in East Africa.

During the conference, we were asked, "Agenda 2030 for sustainable development is all about 'leaving no one behind'. What is your understanding of 'no one' in view of inclusive humanitarian programming?"

The responses from the panel focused on the difference between impairment and disability. With so many issues and concerns, the journey we all are on, and technical organisations' representatives on the panel, I felt sad and overwhelmed. For me, this issue should be something beyond terminologies, something about meaningful participation and empowerment. So, I responded to the question, as follows:

What inclusion means to me

"Thank you very much for giving me the opportunity. Leave no one behind is targeting the most vulnerable people who societies so often miss, for example, older people, people with disabilities, ethnic minorities, children and women. Isn't it about giving voice to those who are furthest behind but who stand to gain the most as we embark the implementation of Agenda 2030?

"I feel there are many realities in this field when we talk about inclusion. I would like to share a few of them here.

"1. **We need to recognise diversity.** *The community we work in, delivering humanitarian response, is diverse. There are older people, people with disabilities, children,*

women, ethnic minorities and, in the cases of complex emergencies, there are internally displaced people and refugees. I have seen organisations working on other segments of the society but not much on older people and people with disabilities. So we need to recognise the importance of every segment. If you want to reach real inclusive programming, the first step is the recognition of every group, over and above your mandate and vision. We usually remain focused on our own vision and mandate and go to the community with our own lens, which should not be the case. Diversity, looking at everyone as equal, also means recognising that the needs of all groups are different from each other.

*"2.   **We need to understand exclusion.** Attitudes are important in ensuring that no one is left behind. There is critical need to understand the concepts of including and involving. A psychologist says that if you tell a young child that what they are doing is always wrong or that something is wrong with them, then this will be reinforced in their behaviour. The young child with a speech impairment may not speak confidently for their rights even once grown up. The concept of voluntary exclusion is now coming up in our humanitarian documentation; when someone starts believing that his or her point of view is not important, they do not speak up for their rights. For me, leave no one behind means ensuring that everyone is speaking. Everyone needs to be empowered to speak for his or her rights, irrespective of age, caste, religion and so on.*

*"3.   **We can take simple, practical steps.** Sometimes it is easy to think that inclusion of older people and people with disabilities needs a lot of extra work. In looking for the complex solutions, we may lose the opportunity of finding easy solutions to include such groups. To leave no one behind, we need to stick to the realities.*

"Now, finally, the Sustainable Development Goals and the Sendai Framework for Action speak of inclusive approaches, taking into consideration all segments of society. As a humanitarian worker, if you ask me to give you a message at this stage, my message would be to recognise diversity. Inclusion of older people is not the job of HelpAge only. Inclusion of people with disabilities is not only the job of Handicap International. As a humanitarian community, this is everyone's job. If we stick to the formula, we will soon see improvement. Thank you."

In the break, I got talking to people who had heard the discussion. They really appreciated the sentiment and told me, "here in this conference, where everybody is thinking about and understanding impairment and disability differently, you were the only one who spoke about meaningful participation, of giving people a voice". This was an honour for me, as including disability into my work was a new chapter in my career.

This journey is not yet an end. It will continue, with many more lessons to learn and challenges to overcome. For me, **humanitarian workers are the duty-bearers, and the affected communities are rights-holders and a family for which we need to take more responsibility. Overlooking the basic and specific needs of any group is against all principles of humanity, impartiality and neutrality**.