



DISCUSSION SERIES ON OLD AGE WELL-BEING IN PAKISTAN

## DISABILITY IN OLD AGE



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# Old Age Well-being in Pakistan: Disability Burden

Jointly organized by Social Protection Resource Centre & Pakistan Alliance for Social Protection (PASP)

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## SPEAKERS

**Dr. Asghar Zaidi**

Vice Chancellor - Government College University, Lahore

**Topic:** *Ageing Health and pensions in Pakistan: An economic and social policy perspective*

**Dr. Akhtar Ali Syed**

Principal Clinical psychologist, Waterford, Ireland

**Topic:** *Protecting the rights of persons with intellectual disability, especially in Old Age*

**Dr. Safdar Sohail**

Executive Director, SPRC & Convener, PASP

**Topic:** *Care of PWDs in Pakistan: How to walk the talk on the rights of PWDs*

**Moderator:**

**Ms. Rabia Javeri Agha**

Federal Secretary, Ministry of Human Rights

*Government of Pakistan*

## Old age well-being in Pakistan - Disability Burden (*Discussion III*)

18th July, 2020

### PURPOSE

Social Protection Resource Centre (SPRC) is a think tank dedicated to promoting universal social protection in Pakistan. Being a premiere think tank dedicated to policy research and advocacy for social protection, SPRC has collaborated for an alliance of like-minded national and international organization under the ambit of Pakistan Alliance for Social Protection (PASP). SPRC has initiated the advocacy related activities in which SPRC Policy Dialogue Series is a key initiative. This series aims to provide quality and knowledge-based insight of eminent professionals and policy advisors on various issues related to social protection. For this purpose, SPRC conducted three rounds of debate on much ignored issue of social protection for persons of old age. The third episode this discussion revolved around issue of old age well-being and disability. Disability is a burden and threat to old age well-being, that's why the discussion is focusing on the protection of rights of persons with their disabilities.

### OVERVIEW AND CONTEXT

Old age is a very relevant issue because it is an inevitable reality for all of us. Unfortunately, old age comes with difficulties because it involves hardship, infirmity, immobility, ill health, mental, dementia and so on. It is crucial therefore in today's day and with Pakistan in particular, that we commit to protect and promote the rights of older people. In Pakistan we have 12.5 million older persons and this places us among the group of top 15 countries that have more than 10 million aged people. The moderator for this discussion Dr. Rabia Javeri Agha said.

So, the debate is of the cost benefit that is taking place in COVID. Utilitarians all over the world are advocating that lockdowns while giving senior citizens an additional five years of life are jeopardizing the economy, the education and the future of the youth of the country. This point was brought up by the former government of the bank of England, "why on earth is our future being put at stake in order to help prolong expectancy of older people? Whose life is not very high in any event."

In all the countries structural changes are happening: demographic change, rural and urban migration and industrialization. Along with this change the intergenerational change is also taking place due to which the younger population is bearing economic pressure.

### SESSION'S PROCEEDINGS

In her introductory remarks Dr. Rabia shared her point of over the topic in context of COVID and changes happening around the world.

Building upon her discussion, Dr. Rabia initiated the debate by raising the issue of cost-benefit of supporting older persons' in disability and the cost benefit between saving the elderly or saving the economy. She also asked the speakers to express their expert views about the COVID situation and what type of protection is required for old age persons in the current scenario.

Dr. Asghar began with sharing a different lens to this debate, by critically unpacking the dichotomy of young vs old. He stated that as we live in the same family, we should not be separating young from the old, especially in the context of Pakistan. So anything that would harm or benefit a family, would impact both the young and the old. We have to think about the family and family includes both young and old and we have to think about how we can maximize protection to the family against the disease and poverty.

The second issue he raised is of the comparison whether to protect ourselves against disease or poverty. The premise of the smart lockdown is exactly on those grounds where you can protect against both with the good efforts. Commenting on the debate in UK highlighted by Dr. Rabia, he said the social practices in UK are of different nature, because of which in UK, the mortality risk became very high in the care homes and there was this call to protect elderly in care homes. We all know care homes are expensive. In our context, we should not be getting into that kind of debate, we should be thinking about finding a way in which we could protect our family both from disease and poverty.

He also pointed out the much less discussed issue of mental frailty in old age. When we talk about disability and when we talk about older persons, we often look at their physical frailty whereas miss out looking at their mental frailty. This is a problem across the age range but it is particularly true for elderly, where the wear and tear of the brain leads to problems linked with Alzheimer's or dementia. He suggested that as a society to understand the challenge of dementia and provide care to those who suffer from it; we need to take discussions on board. He mentioned his upcoming survey on aging and brain health in Pakistan which would be a critical contribution in understanding the prevalence of this problem. Because unless we know the prevalence of this problem, we will not be able to do much about it and what policies we can bring about.

Moreover, he said we shouldn't take old as synonymous to disability. The problem arises in how we define old age, we need to flip the coin and need to think about the opportunity that the people have in the age of 60. Old age group is underprivileged group of the society. We have to go move forward from the way we define old age and concentrate on the rights so they can contribute as resourceful and productive person of the society.

He further said that we should focus on 3 domains:

1. Independence: include basic right of independence to access the basic needs and other essential needs.
2. Participation: basic rights of participation in so many areas.
3. Care: right of basic health care, welfare and those ailments of old age less common in young people.

Next step of the domain is self-fulfillment. They do not perform activities that provide them self-fulfillment because society pushes them back. There are some disabilities which get worse as we get older. He also mentioned about the index which he developed with the help of UNICEF which

is known as active ageing index. He said this index comes from the tradition of Dr. Mehboob Ul Haq.

#### DR. AKHTAR ALI SYED

Responding to a question by Dr. Rabia regarding intellectual disability among senior citizens in times of COVID, Dr. Akhtar suggested that we need to consider how we respond to the needs of people with intellectual disability when they are young. He then explained his experiential knowledge on the subject by sharing his contribution in Ireland back in 2003. To overcome the repetition and replication in policies, the practitioners and psychologists of the time decided that instead of developing a new policy altogether, we just focus on the *UN Convention on the Rights of Persons with Disabilities* (CRPD) for the rights of people with disabilities and developed procedures under the guiding principles of the UN. The policies were then oriented in light of examples from two of the international standard procedures; one was set by the CQL which is the council for quality and leadership and the second was inclusion from European Union. They took article 3 of the convention, right to make their own choices; and article 19, right to living independently and inclusion in the community, as guiding principles for developing procedures. The main focus under the areas is to support and enhance their cognitive potential.

Two main **diagnostic principles** are primarily important; one is **cognitive potential** and the other is their **adaptive skills** because they are two main diagnostic principles on which the intellectual disability or dementia can be diagnosed. Moving on, he suggested that we should not be isolating, youth, childhood and old age as categories when considering intellectual disability, instead we should look at it all as a continuum. Therefore, for any person with intellectual disability, as a psychologist, we think of how we can help this person while ensuring growth processes up and running throughout their lives. For example, early on in childhood, we need intervention to enhance their cognitive potential, because the main issue with intellectual disability is cognitive abilities. To help people in old age we need to work on their cognitive potential throughout their lives. Developing their skills to support them in their old age. So, we don't compartmentalize the old age, young age or childhood, we have an overall approach and we just use the UN convention.

Moreover, he gave his expert opinion about the situation of persons with disability in Pakistan. He said, in Ireland we have choice index for the people living with disability. When people grow older, they are more prone to have mental health problem. He said we are working at micro level and team level. He mentioned that a team level they have people providing care for people with disabilities under their supervision. As psychologist and practitioners, they're providing both support to the persons with mental disabilities and working on them throughout lives. We are working on understanding, how and why these people develop mental health problems and how can we support? If they are facilitated in enhancing their cognitive abilities and the ability to make their own choices during the life-course, then the chances of mental disability are reduced. Unlike Ireland, the older people with disabilities reside with their families as there is no external support system available. Due to these cultural factors there is not much we can do in the short term, however in the long term we need to think of ways to support the families. He also raised the issue of the lack of mechanism for registering the people in Pakistan and emphasized the need for some fundamental work in this regard.

## DR. SAFDAR SOHAIL

In COVID times, the multiplicity of vulnerabilities and risks people in old age are exposed to, becomes a pressing issue that brings us to the question of how social protection interventions should be oriented to deal with these challenges. Dr. Safdar remarked that this is an issue where health, social welfare services and socio-economic conditions, they all enter into creating net vulnerability. Our key question is we must first understand the accumulation of disadvantages which is taking place among older persons in Pakistan. We are trying very hard to segregate accumulation of chronic diseases across the age, if we start from 55 onwards, we can see a very clear link between no pension and high chronic diseases. Another aspect is if we compare with international global average levels, our disease burden and particularly disability burden is much bigger than the global average or in the region. He said we need to look upon the both the kind of disadvantages we are accumulating and the interplay between external determinants. For example, 75% of Pakistani older persons have no social protection or pension. Even if we consider old age pensions for public sector, military and EOBI and the BISP income transfers, we don't have data on this income distribution within the household. How much is spent on the older person and the arbitrage of the head of household to choose between their parents and children.

Coming to the public goods and services, we have poor healthcare delivery, poor provision of social services but the key factor is that in Pakistan we have a fair amount of data and a lot of studies on intergenerational disadvantages which are accumulated downwards. We know that if the parents are poor or uneducated, children would have problems like low abilities, stunting. But what are the intergenerational impacts upwards? If the family is poor, having low education, then what is the impact on the parents? That's where the role of social protection comes in, as the intergenerational disadvantage that the caregiver is producing on the parents in the form of extremely low expenditure. We would be collecting data on that but total evidence says that our expenditure on parents is extremely low. The caregivers due to low educational attainments and ignorance lack basic awareness of old age care, usually they go for the quack care. The aspect which we are looking at is the lack of integration between older person care and disability care.

While acknowledging the laws being brought forward by Ministry of Human Rights for senior citizen and persons with disability, Dr. Safdar emphasized the need for integration among them. The most important problem we have is we don't have scientific assessment of the unmet needs of the older people. We have very simple statistics on the incidence of disease. In Karachi, Dr. Sania Sabswari had this index made back in 2014, but not for the whole country so if we don't even have a fair amount of idea of the unmet needs how can our responses, our policies and then our framework for helping them. In this context we feel at the SPRC and PASP that the framework for the older persons need to be independent of other areas.

- **Social Protection for Older Age People**

Unfortunately, there is no UN conventions on the rights of older persons. Also overtime we have lost a constructive push from the international community for ratification of the conventions and making the laws. There is a need to identify older people as a separate marginalized group and prepare responses for them. However, family as caregiving would remain the key point in Pakistan and we have to take care of the caregivers as well. We believe that government must

consider its responsibility as right of the older people, a minimum social protection and by that we imply coverage in the form of universal pension, minimum social welfare services and essential health services as a responsibility of the state where the regular care is being given by the family which is fine, but family also needs to be strengthened. If there is a chronic disability in the family, the international studies say that the emotional and financial stress on the caregiver is three times higher so we talk about the rights of the caregiver also, which actually in Pakistan is not a much-discussed subject. In UK, since 1970s, they have right for caregivers, they are given holidays, they are given financial support. So, it is not only giving old age pension, it is giving financial support to the severe cases of disability if they are not institutionalized.

Further, he explained that well-being of older is a composite phenomenon where a combination of different interventions is required but the most important one is financial support. We have some experiments in Punjab like they are giving PKR 2000 to the older persons and we are trying to design a survey with them but the global evidence says after getting PKR 2000 their acceptability in the family is far more improved. Right now, we should take them as a marginalized group and deploy resources to identify them and track them in socioeconomic registries and reach out to them with the financial support and then in the medium to long term we should upgrade our health services and disability services. Drawing attention on the reverse phenomenon happening, he mentioned people in 50s have started displaying those infirmities, those characteristics, those inability to work and function properly which in other countries would kick in very late.

## COMMENTS

The webinar was concluded with a question and answer session among the discussants and audience. One of the discussants added that, due to some religious belief only 7% people come to institutions and leave their family even though they are in worst condition. As care giver has all the more stress, there should be policy to give incentives to the family. There should be collaboration between the NGO's which are working on this issue. It was also pointed out that there's a need to come up with a framework and policy for senior citizen rights, so that all the issues of old age persons should be addressed at upstream level. Another discussant stressed upon increasing the knowledge of younger people about the basic care of parents by giving an example. He said our children are not willing to judge that their parents are suffering from the depression or any other mental health. He a study according to which 30% older people live by themselves and majority of them were suffering from clinical depression.