

Transforming Communities for Inclusion

Paper on Intergenerational Solidarity and Inclusion of Older persons with Psychosocial Disabilities

Statement by Waqar Puri, TCI

Introduction

Transforming Communities for Inclusion (TCI) is a global Organization of Persons with Psychosocial Disabilities [an OPD]. TCI forecasts a future in which all human rights and full freedoms of persons with psychosocial disabilities are realized.

Empowered by the extraordinary vision and guidance of the Convention on the Rights of Persons with Disabilities, TCI's purpose is to situate ourselves at the center of the cross-disability movements at the national, regional, subregional and global levels, as a way to reclaim our personhood, our identity, dignity and autonomy, experience our independence and to realize our right to live in the community. Our key allies in this process have been the cross-disability movement.

The world's population is ageing. The population aged 60 years or above is growing at a rate of about 3 per cent per year, and the demographics vary country by country.¹ The proportion of people over the age of 60 years is expected to increase to 21 per cent by 2050.² Therefore it is evident that the intergenerational gap is increasing between the different age groups and creates numerous barriers for social inclusion of the older persons. Such factors could include, communication barriers, technology divide, institutionalization of the older ones, economic barriers, lack of support in the families, isolation, loss of purpose, health issues, homelessness and not participating as useful members of communities.

People with psychosocial disabilities in general continue to experience forced treatments, institutionalization and confinement. Within the mental health system, as stated in several reports and resolutions, they are subjected to cruel, inhuman, degrading and torturous treatments, against their will. Specifically the older persons with psychosocial disabilities are subject to forced institutionalization in the name of old age homes and 'long term care', which are mushrooming in large numbers. They are left there by their families who never return back to enquire about them. They have no access to adequate standard of living and in many low income, developing economies, older persons with psychosocial disabilities are not provided with universal health coverage, therefore they remain dependent on the families and the care takers, who neglect them. Health and general insurance schemes do not have policies for the elderly, so there is a big gap to fill in this area of social protection as well. Record keeping systems do not capture details about this vulnerable population, so we know very little about elderly persons with psychosocial disabilities. During times of humanitarian crisis, especially for the older persons who are living inside institutions, care homes, health facilities, assisted living facilities, etc. the situation is very grave.

The present paper underscores various challenges and barriers faced by older persons with psychosocial disabilities and numerous aspects which restrict their participation in the community on an equal basis to others. In this paper we also highlight that what are the challenges older persons face due to the intergenerational gap in the global south countries of the Asia and Pacific. The paper is also followed by a

¹ United Nations, Department of Economic and Social Affairs, World Population Prospects: The 2017 Revision, Key Findings and Advance Tables, Working Paper No. ESA/P/WP/248 (2017).

² Promoting Inclusion through Social Protection: Report on the World Social Situation 2018 (United Nations publication, Sales No. E.17.IV.2), p. 47.

set of recommendations for governments for bringing solidarity and social inclusion of older persons with psychosocial disabilities.

Issues Faced by Older persons with Psychosocial Disabilities to Live Independently in the Community

With the social systems changing to adapt to the new, post pandemic world, the inter generational gaps between older persons and the younger generations has widened. Earlier processes of social reproduction through physical presence, availability, sharing of knowledge, taking guidance, telling shared stories from the family or the community, heroism during times of adversity, myths and fables and various other aspects of having lived as a family or a community, through multiple generations, have become defunct. This means that precious knowledge and wisdom that could be gathered and archived as the soft wealth of all generations for adaptation and survival, are lost. And the knowledge holders no longer hold this position of dignity and respect, giving way to Google, YouTube, Insta and other such digital resources.

Needless to say, older persons are more often disadvantaged by the digital world. As ecosystems and markets are increasingly digitally wired, and upgraded for sophisticated uses, for older persons to navigate investment options, insurance schemes, retirement investments, housing purchase, travel arrangements, health coverage, pensions, consumer markets, online purchases, banking, bill payments, and so on, has become increasingly complicated and inaccessible. They depend on the younger family members, or other nearby support persons, leaving the door wide open for corrupt practices or financial outcomes that they did not want to see or worse, disqualification by their own family members on grounds of 'incapacity'.

Worse, there are miscommunications, loss of understanding and communication, changes in attitudes intergenerationally, leading to family / community conflict and possible separations. Since the ways of life and learning have changed so much, and changing at extraordinary pace, older persons are not favored as teachers, educators or guides, as before. They lose status and are not involved in family decision making and left out of family life more generally. The older generations, not expecting such devastating changes in their lives, towards their end, did not also save enough having spent their earnings on their wards and families; and having the traditional expectation to be covered for their needs in their older years (earlier known as the 'golden years'.)

In a fast globalizing world, where those in the working age group seek greener pastures outside the country, or the rural youth are moving to nearby cities through large scale migratory processes, the elderly are left behind in their traditional homes, often alone or with ageing relatives. In many parts of the global south, farm labour is hard to come by because of such migratory patterns and the older persons are left to tend to the farms, and all the associated tasks, other than the wellbeing of their families, often also older persons, and community members. In the case of urban areas, travel abroad for study or work is the pattern these days, again with the same effect on older persons. Soon enough, the children start their search for an 'assisted living' place of an institution to provide 'long term care' for their parents or other senior folks. These phenomena are fairly widespread in middle income and high income Asian economies and growing. Organizations such as the World Bank, under the 'care agenda', are already preparing for such eventuality, using the plight of older persons as a way to build more 'long term care facilities'.

Moreover, older persons living with dementia, long-term chronic illnesses and persons with mental, intellectual, multiple and psychosocial disabilities remain at high risk inside such care facilities. Older women with disabilities who are survivors of sexual violence face particular barriers to disclosure and access to justice, resulting in their experiences remaining hidden. When they do report abuse, older

women, in particular women with psychosocial disabilities, may be viewed as poor witnesses owing to memory problems and as mad women.

A Case Study

“Coming from the family of persons with psychosocial disabilities, I would like to share here the story of my grandmother, who has lived with a psychosocial disability. She was a housewife with eight children and had a great life till the age of 50s. But after the 50 years of age, and due to the increasing intergenerational gap and being a woman with psychosocial disability who had lacked so much of family support, her life started to get worse. Due to the lack of understanding of her disability identity and awareness on what supports she may require to live equally in the community and be included in the family and community she had lost a lot of joy, and happiness, which every elderly person envisions and dreams during his or her retired life.

I come from a joint family system where all relatives live nearby, visit routinely at home despite of busy routines etc. In my family system there used to be a lot of influence of other family members and my other relatives in decision making, and therefore there has been a huge influence of family members in decision making related to my grandmothers life. This is the case whether it is her health, food, medicines, participating in cultural events, etc. In the larger family system she was stigmatized, and people in the family used to say that she has been affected by spiritual powers. Children in my joint family system did not used to go to near her and even their mothers used to stop their younger children to meet her as if she was a curse. Not only children but even the ones who were in the age of 30s did not respect her at all.

She was a diabetic patient and a heart patient. Her heart was also to live with her other daughters and sons, if she had gone to live in their homes, she used to plan for a week stay but used be back home in a couple of days only, because of lack of support. She used to experience lack of priority to give her medicines on time, they did not use to bother what nutrition she requires based on her health condition, has she taken a bath or not? She was not allowed to sit in the room where everyone is seated or if a guest has visited because she may not say right things, eating meals without getting proper doses of insulin was one of the very common issues due to which her sugar level used to fall down and many more such issues. At the end, after a couple of days she used to return back home. Many of these practices were only done by the young ones because others had their own priorities and things to do.

Inclusion starts from home, your neighbors and your community, it is important to listen and pay attention to what is required by the older persons. My grandmother used to live with me and I used to be her only support in the family. There is always a need to dialogue, talk to the person and provide support where the person needs it. As a young peer supporter, and as her grandson, I always used to dialogue with her to talk about her priorities and what she requires, support her in making dialogue with other people, visit the health care services with her and not leave her only responsible of her own life, provide support in decision making, discuss together and decide what may work best for her and what may not work best for her, take proper care of the nutrition she takes and ensure her medications are provided to her on time. Many times she used to leave home for a walk or to buy things on her own and because of created awareness inside my small mohalla (Street) and community, she used to receive support in the community by the neighbors, shopkeepers, etc. Many times in winters when she needed sun light, and three to four homes away in our street there is a home where they had a lawn and where the sunlight used to stay for a longer period. Because of created awareness they everyday welcomed her in their garden for enjoying the sunshine, and also offer eatables etc. to make her feel as comfortable as possible.

The element of family and community support is very important for the inclusion of older persons with and without disabilities inside communities and provided with that support only they may be able to access available services in the community and live equally like others.”

Recommendations

States are required to outlaw all forms of age and disability discrimination. All older persons with psychosocial disabilities must be considered and shall be provided with all rights on an equal basis to young people. Any differentiation, exclusion, or restriction based on a person's age or disability, or connected to the intersection of the two grounds, that restricts the rights of older people with psychosocial disabilities should be eliminated.

Laws that prohibit or prevent older people with psychosocial disabilities from receiving services and benefits should be eliminated and states must ensure effective policy making and law reforms to provide equitable and universal access. States shall also take all necessary steps to guarantee that older people with psychosocial disabilities are provided with any reasonable accommodation when and where requested.

No older person with psychosocial disabilities should be institutionalized or sent to old homes for the purpose or in the name of care. States need to bring transformation in the society and ensure support systems and support services in the community. States must ensure full and effective implementation of de-institutionalization guidelines which was adopted by the CRPD Committee in 2022 and dismantle all legal incapacity laws, mental health laws, which take away legal capacity of older persons and older persons with psychosocial disabilities and the right to live independently in the community on an equal basis with others. There must be an increase in the provision of in-home and community support; improve accessibility within the community; provide adequate information and easy to understand information; and ensure access to disability-inclusive social protection system in countries.

States must ensure the effective access of older persons with psychosocial disabilities to a wide range of community-based support services and arrangements inside the community, including personal assistance; support for decision-making; assisted living arrangements; mobility aids; assistive devices and technologies; palliative care; and community services. These support services must be available, accessible, affordable, acceptable and adaptable to all elderly persons and persons with psychosocial disabilities regardless of age and impairment. Support in the community must provide older people with psychosocial disabilities various options and control over those options. When designing and implementing support services, States must ensure participation and dialogue with not only the elderly but also with the young generation for effective implementation of support systems and services in the community. Therefore, all forms of assistance must be given voluntarily and must uphold the rights and dignity of older persons. States must also ensure that older people have the freedom to request, organize and manage their own assistance, including via proactive planning and personalized solutions.

In many low income countries there is no system of social protection schemes and universal health coverage. State parties must ensure that budgets are allocated specifically for all older persons in the country to have access to universal health coverage system and provide them with adequate and required health care as they require. The services available to the elderly must be sensitive to age and disability, making sure the staff is well trained, the services are accessible and reasonable accommodation is available to older persons when and where requested. The information system must be inclusive and easy

to understand as many of the elderly are not educated, they must not be dependent on the young generation to provide them with the information. The system of health care must be accessible and easy to access by all elder people living in the country to access good health on an equal basis to others.

States must ensure food security and right to life for every elderly person living in the community. States must ensure both, economic and physical access to adequate food and dietary requirements despite giving up on other right to life aspects. States must ensure that the older persons are able to maintain and have access to social security programs specifically designed to support the elderly individuals who may face financial constraints or lack access to sufficient food. Such programs can include cash transfers, or food vouchers to be provided to older persons. Create awareness and education in the community to foster community-based support systems that involve neighbors, local organizations, community workers, volunteers, in providing support to the elderly to access adequate food.

States must ensure to overcome the digital divide and ensure equitable access to information, services, opportunities, resources etc. for elderly people in today's digital world. States must promote, develop and implement digital literacy programs specifically designed for elderly people. These programs should cover basic computer skills, internet usage, and online safety. States must promote intergenerational learning experiences by pairing elderly individuals with younger family or community members who can provide one-on-one assistance and guidance to the elderly people. Moreover a key role should be played inside families, communities, workplaces, etc. where the young one's provide assistance, guide and teach their elderly ones on technology. States must ensure access to user-friendly devices and software tailored to the needs of elderly people and consider devices with larger screens, simplified interfaces, and voice-activated controls. Specifically ensure accessibility for elderly people with psychosocial disabilities.